

Edmund G. Howe, "Treating Children Maximally: Practical Applications," *The Journal of Clinical Ethics* 30, no. 3 (Fall 2019): 171-82.

At the Bedside

Treating Children Maximally: Practical Applications

Edmund G. Howe

ABSTRACT

Lainie Friedman Ross suggests that clinicians increase our efforts to meet children's most basic needs in several ways. These include prioritizing, to a greater extent, children's present and future feelings; placing greater decisional weight on other family members' needs; spotting earlier threats from surrogate decision makers so that we can better prevent these threatened harms; and finding ways to intervene earlier so that we can allow parental surrogate decision makers to remain in this role. I offer some practical ways in which Ross's ideas might be applied.

In this issue of *The Journal of Clinical Ethics*, Lainie Friedman Ross, in "Better than Best (Interest Standard) in Pediatric Decision Making" suggests five ground-breaking ways that we may treat children better than we presently do.¹ Ross suggests that we shift our priorities to meet the most basic needs of children, that we give

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their current feelings and future feelings increased moral weight, that we do more to include their parents, and that we hone our perceptions of parents as surrogate decision makers, to benefit children as much as we can. Ross's article is at the edge of the field in many respects. The decisions she addresses are among the most ethically challenging in medicine, especially when children are seriously ill and even dying. I will focus on these issues in my introduction to this issue of the journal, and particularly discuss how to approach these issues.

I will do this in three sections. In the first section I will discuss children's greatest needs, especially when they are seriously ill and dying: for parents and clinicians to be honest with the children, when that's what children want; for parents and clinicians to ask children what they want most; and, to the degree possible, for parents and clinicians to find a way to provide what children say they most want. None of these endeavors will be straightforward.

In the second section of this article, I will discuss how we can help parents to be better surrogate decision makers. Our efforts may make the difference in whether parents can continue to serve in this role. Specifically, I will consider parents who, when under stress, tend to meet their own needs rather than their child's needs; parents who give up when their child's needs prove too demanding; and parents who are lit-

erally unable to see that their child's needs and wants are different from their own.

In the third section, I will discuss children whose needs and wants are outside Ross's primary discussion. These needs and wants are addressed to a greater extent by Erica K. Salter in her commentary on Ross's article, in this issue of *JCE*, "When Better Isn't Good Enough: Commentary on Ross's 'Better than Best (Interest Standard) in Pediatric Decision Making.'" ² Building on some of Salter's concerns, I will consider children who are not able to think or feel, or who are somewhat aware, but it may not be possible to know. For example, a child may have profound brain damage as a result of a motor vehicle accident. The child may be in what we have called in the past a "vegetative state," or VS, but now refer to as an "unresponsive wakefulness syndrome," ³ or be minimally conscious. ⁴ Or a child may not have awareness at present, but may develop it later as the child's brain begins to heal. ⁵ Salter presents a case that considers what we should do for such children: a new question, in its infancy.

Ross's and Salter's articles, and the other commentaries on Ross's proposals published in this issue of *JCE*, move our thinking forward. ⁶ As Ross states (and I will suggest repeatedly), whatever we do, we must share our efforts to help these children as much as we can by working with their parents. This will often be our greatest challenge, because these parents almost always are, and will remain, far more important to their child than we will ever be.

WHAT DOES A CHILD, ESPECIALLY ONE WHO IS DYING, NEED MOST?

Ross states that we should meet children's most basic needs. She refers to John Rawls's view that these needs, or "primary goods," are "things which it is supposed a rational man wants, whatever else he wants." ⁷ For a child, and especially for a child who is dying, three needs are especially important: for parents and clinicians to be honest with the child; for the child to say what she or he most wants; and for the child to have what he or she wants, if possible. I will discuss each of these in turn.

Parents and Clinicians Should Be Honest

If clinicians are not honest with a child, they risk losing the child's trust. Without this trust, a

child may lose numerous important benefits; for example, the child may miss experiencing joy and meaning with family members during their last times together.

The possibility that a child and parents can find joy and meaning with each other, even when all of them know that the child is dying, may seem surprising and implausible. How could they possibly feel joy and meaning when the child has only a short time to live? In one sense it seems paradoxical. Yet it happens, possibly because all of them refuse to allow the death that they face to dictate their present, and/or because they want to make the most of their last moments together. In any case, since the possibility exists, it is critically important for parents and clinicians to be honest, when the child wants this. Doing so allows optimal outcomes. Further, it is important, in its own right, to respect children. This is depicted compellingly, using empirical findings, by Myra Bluebond-Langner in her book, *The Private Worlds of Dying Children*. ⁸ Her rare, deep insights will fuel much of the following discussion. ⁹

Bluebond-Langner reports that dying children often adopt a pattern of interaction with parents and clinicians marked by "mutual pretense"—when parents and clinicians are not honest with the child that she or he is dying. This starts when the child detects, from a parent or clinician, that the child is not supposed to know, much less discuss, that she or he is dying. Bluebond-Langner relates that parents and clinicians, for their part, guard ceaselessly against allowing any "leak" of information to the child that the child is dying, from the moment the child enters the hospital. Parents and clinicians somehow signal—consciously or unconsciously—that they don't want to, or are unwilling to, talk with the child about her or his illness. ¹⁰ A child can detect these signals and can comply with the pretense. Then all parties "practice mutual pretense to the end." ¹¹

Bluebond-Langner reports that a child almost always knows that he or she is dying before death becomes imminent. Stacey Springer, a clinician who has spent three decades caring for dying children, agrees; she puts the percentage of children who know that they are dying before they are told at a remarkable 98 percent. ¹² Bluebond-Langner considers this still "more remarkable" because the children learn this in a situation in which "the parents and the staff unconsciously conspired to keep them in painless

ignorance.”¹³ The challenge for parents and clinicians is to avoid evoking such a mutual pretense that leaves a child, parents, and clinicians all emotionally isolated. Rather, clinicians and parents should be open with the child about his or her condition, if and when the child indicates that this is what he or she wants. Bluebond-Langner gives guidance on when and how parents can do this with clinicians, if that is what the parents want to do. She suggests that using “the same rule of thumb that is applied when deciding what to tell children about sex: Tell them only what they want to know, what they are asking about, and on their own terms.”¹⁴

Parents may not want to do this. They may believe that doing so will ruin the quality of their child’s remaining life. Ideally, we might discuss the risk of mutual pretense with parents well in advance. Then, if and when the time comes that a child wants to know more, parents will have thought through what they want to say. To begin, we can initially validate parents’ concerns about talking with their child about the child’s condition. We can affirm with parents that such a discussion may cause great pain to the child, but that mutual pretense is worse.

Beyond this, we should give parents the opportunity to share information with their child before anyone else does. If at all possible, we should not share information with a child before we consult parents. If a child asks us about his or her condition before we have talked with the parents about it, we are faced with the difficult decision of whether to equivocate or to be honest. Any sort of equivocation suggests the need for mutual pretense, against which Bluebond-Langner so rightly rails. We can say to the child, with the best intentions, that we want his or her parents to be present, but this may convey the truth—that the child is dying. Accordingly, we can discuss with parents this risk, too, and as early on as possible.

In general, younger children want parents with them when they first hear their diagnosis or prognosis. They feel afraid and apprehensive. Respect for their autonomy must be tempered with concern for their emotional needs. Thus, the default should be that children receive information from parents and clinicians together.

Autonomy

An equally hard task for us may be to persuade parents to ask their child what the child

wants. It is important to all of us to be able to say what we want. Being asked and being able to express what we want allows us to be included in decision making, whether or not we end up being able to get what we want. Thus, before they ask a child what he or she wants, parents should share with the child that they love the child and want to provide whatever the child wants, but it may happen, to their sorrow and regret, that they may not be able to provide what their child wants. There is only one first chance for parents to get this tone right, and how they say this will color all conversations that follow.

Materials are now available to help children express their advance directives. The pamphlet “Voicing My Choices” is one example, modelled after “Five Wishes,” an advance directive pamphlet for adults.¹⁵ Here is a sampling of the choices that the advance directive for children offers:

If I am in pain, I would like:

- My doctor to give me enough medicine to relieve my pain, even if that means I will not be awake enough to interact with my friends or family. . . .

How I would like to be supported so I don’t feel alone:

- Please always ask me before visiting. . . .

How I want to be comforted. . . .

My favorite music/food is: _____

The kinds of books, stories, or readings I like, are: _____

_____

I would like:

- To be buried
 An open casket A closed casket
 To be cremated. . . .

This is how I would like to share my belongings:

Clothes: _____

Pets: _____

Games: _____

The person I would feel most comfortable going through my belongings is: _____

How Far to Go

Once parents or clinicians ask a child what he or she wants, the next hard task is to decide how to respond to the child’s requests. What a child wants may go beyond what parents or clinicians may expect. My favorite example is one that children quite often request—and get—a visit with a pet. Dogs have been admitted, for example, even to children in an intensive care unit.¹⁶ Another example that is probably not uncommon is the high school senior who, although

dying, wanted to go to her prom, more than anything else. She went and she came back feeling thrilled.¹⁷ But parents and clinicians may (not illogically) regard such requests as trivial, relative to the reality that the child is dying. After first validating this logic, we should inform parents that although these requests may seem illogical, they may be all-important to the child.

It may be even more perplexing to parents that their children, although dying, may care more about others than themselves. For example, the children's advance directive pamphlet, *Voicing My Choices*, asks what a child what she or he would want "If people are very upset or crying." One child said that if her parents were there, she would want them to leave the room.¹⁸ We can't know why she said this, but perhaps she cared as much or more for her parents' needs as for her own. It may be that she knew that seeing their hurt, she would hurt too. In either case, her concern, in part, was for someone else. Ross notes this; she writes, "It is also not clear to what extent a child has other-regarding interests in addition to self-regarding interests, at what ages these may develop."¹⁹ Age is a factor that underlies all of the concerns noted here. Clearly, the emotional maturity of children who are even the same age may vary greatly.

Meeting Children's Needs Now

Ross urges us, through her discussion and the case she relates, to place due weight on children's present and future feelings. In her article in this issue of *JCE*, Erica K. Salter highlights this contribution of Ross's, saying that she allows parents to incorporate into their decision-making process "a broader array of interests beyond just the physical interests of the child in question (for example, siblings' interests, spiritual interests, the family's interests)" and thus to make decisions that involve interfamilial trade-offs.²⁰

The "broader array" of interests that Ross encourages us to meet may indirectly benefit most dying children, and may directly benefit most other children. When the needs of family members are met, they may become more emotionally available to a sick child. Ross recognizes that most family members are interdependent, and so she avoids a common mistake: of seeing a sick child's needs as predominantly intrapsychic (that is, in the child's mind), which can lead to seeing a sick child's needs as being in conflict with the needs of others. Ross relates a case

that epitomizes this, in which an ethics committee broke precedent in its recommendation regarding a child's medical need for assistance from her younger sister.

Ross urges us to place greater relative weight on the feelings of children than we generally have in the past. Doing this may increase the difficulty of making treatment decisions, because feelings are harder to quantify than the majority of medical gains, which typically are assigned greater moral weight than feelings are. It is possible to discuss feelings in a meaningful way. Feelings may prevail over our thoughts or more cognitive wants when they are in conflict.

The following real case illustrates how making such decisions may be extraordinarily painful. Parents may have to choose between the length of their child's life and its quality. Parents may favor quantity of life when a child is younger, and the quality of a child's life as the child becomes older. These decisions are emotionally and ethically excruciating.

An adolescent girl who was dying had a younger brother with profound special needs. She knew that as she was dying, her physical appearance would quickly deteriorate. She feared her brother would notice the changes in her appearance and not understand what was happening, and be emotionally scarred for the rest of his life. Thus she requested to be allowed to die earlier, before marked physical deterioration began. Her parents respected her request.²¹ This girl's decision exemplifies how dear the price of respecting a child's feelings may be. When a dying child's preference makes ethical sense, we should support the child's choice, even when parents will not seriously consider it. We must be prepared to explain to parents why a child should be allowed to prioritize her or his preferences that are based on feelings over living slightly longer.

A few reasons to do this seem outstanding. First, a child's needs and wants are important in their own right, and respecting them respects the child. As the number of medical options that can be offered to a child decrease, greater priority should be accorded to respecting the child's needs and wants. As Ross says, parents' "responsibilities develop from the fact that children are persons and like all persons are deserving of respect. . . ."²² Second, giving priority to what a child wants may cause the child to deeply appreciate his or her parents in a way that might not be possible otherwise. This especially may

be the case when the child knows that the parents' support of his or her needs and wants goes against what the parents want. We can tell parents that their memories may be "sweetened" by doing this; remembering their child's deep appreciation for their support may later soften the agony of their loss. This should be seen as a secondary beneficial effect. In these situations, the child's needs should predominate.

Meeting Children's Needs in the Future

Ross extends the importance of considering children's feelings in the future. In the case of the young girl who needed a donation from her sister, a decisive factor in the ethics committee's recommendation may have been the benefit the donating child would reap from being able to live with her sister over subsequent years. Ross says, referring to this ground-breaking criterion, "Thus, the potential psychosocial benefits were very important, even if the benefits might not be appreciated by the donor for years to come. The sisters had been a constant presence in each other's lives and had a healthy intimate relationship."²³

There are innumerable contexts in which we already routinely take children's future feelings into account. For example, we do this whenever we work with parents to plan for the future of child who, in adulthood, probably will not be able to live independently.²⁴

I would like to end this section by providing a formula that may be helpful to parents and clinicians when making a decision like the agonizing one involving the adolescent patient who wanted to die prematurely. This example involves an adult patient, and is a real case that came before a hospice ethics committee, of which I was a member. An elderly woman was bedridden. An adult son was her only relative and her beloved, only companion. Her hospice doctor believed that, for medical reasons, the woman should be placed in a nursing home, even though this was against her wishes. The doctor thought that someone should be available around the clock in case the woman needed emergency medical care, although she had no disorder that would make this likely. The woman lived for nightly visits with her son, who spent hours with her every night. The nursing home was hours away, and her son would be able to visit her only on weekends if she moved.

Let's "do the math." On a scale of 1 to 3, with a score of 3 being the highest, medically

meeting the woman's needs by moving her to a nursing home might warrant a score of 3. Allowing her to stay in her home would warrant a medical benefit rating of 2. But a rating of the quality of life the woman would experience if she saw her son every night, rather than only on weekends, would be 2, while the quality of life of moving to the nursing home and not seeing her son every night would be 0. Thus, the net gain of staying at home would have a score of 4, surpassing the score of 3 of moving to a nursing home. This kind of scoring is not scientific, but can help to prevent patients' quality of life being overridden by conventional medical rationales and thus overlooked. The hospice ethics committee looked at the importance of the patient's quality of life in this way. The patient stayed in her home as she and her son most wanted.

HELPING PARENTS TO BE BETTER SURROGATE DECISION MAKERS

Ross cites the view expressed by Buchanan and Brock in their 1998 book, *Deciding for Others: The Ethics of Surrogate Decision Making*, that parents should not be a child's surrogate decision maker under three conditions: (1) the parents have abused or neglected their child, (2) the parents' conflicts of interest are too great, or (3) the parents aren't sufficiently competent.²⁵ Ross seeks to increase the protection of children and suggests that, as clinicians, we intervene before parents fall short in decision making. We should intervene not only when parents fail to meet their child's basic needs, but also "when parents or other adult members of society fail to protect a child from threats to his or her basic interests."

To further protect children, Ross suggests prophylactic interventions that may help parents to continue as their child's surrogate decision maker. This may be a less harsh way to reduce potential threats to the safety of children. "Under the model of constrained parental autonomy," Ross writes, "parents have broad discretion, but there are cases in which third-party evaluation and oversight are appropriate, even if it is decided that no intervention is necessary."

In this section I will discuss how Ross's interventions might best be applied. I will focus on how clinicians might use "appropriate oversight" to prevent the intervention of a third party to remove parents from serving as their child's

surrogate decision maker. Such an intervention might prove devastating to a dying child. I will review Buchanan and Brock's three prohibitions—parental abuse and neglect, great conflicts of interest, and a lack of adequate competence—as they may occur in less pronounced forms. That is, I will consider each prohibition as it may occur to an insufficient degree to warrant formal third-party intervention, but in sufficient degree that a parental surrogate would insufficiently benefit a child. As clinicians, we may be able to help the child fare better.

In some cases, our early intervention may reduce the likelihood of a threatened harm before parents enact it. This may allow parents to remain their child's surrogate decision makers. Parents who are removed as surrogates may want to serve in that role, and, as a result feel embittered and become distant from their child. Thus, if these parents are helped to safely serve as surrogates, their child may benefit. If, despite the exceptional interventions I will suggest, parents continue to threaten the safety of their child, we will still be able to quickly intervene.

Parents Who Go Too Far

Parents may abuse or neglect their child in ways that are not legally reportable, paradoxically, because they love the child. They may, for example, abuse the child, because in their effort to do for their child the best that they can, they may simply go too far or be too rigid. I will now give examples.

Abuse and Neglect

Parents may go too far by spanking a child too hard or too often. (Or, many would say, at all.) They may do this because they believe it is the best way to parent. To them, their logic seems irrefutable. They may reason that this is how their parents raised them: "See how I turned out. Am I not living proof of this method?" The same kind of "loving motivation" may underlie emotional abuse, although in this case the problem may be that the parents are too rigid. Some parents, for instance, hound their high school aged child to study from the moment the child comes home from school until the child goes to sleep, so that the child will get better grades and get into a better college. They allow their child no time to take a break and refuel. Under these circumstances, children may "crack" and end up needing to be hospitalized. They may even take

their own life. Encouraging children to do well in school is, in moderation, most likely optimal. But what parents who hound their children like this may miss is how their children may come to believe that they only have value to the degree that they can perform. These children may have no sense of worth or belief that their parents value them for themselves. They may then, without warning, end their lives.²⁶

Narcissistic Parents

Why might parents act in these ways? One possibility is that they are narcissistic. By this I mean they may go too far or are too rigid with their child because they seek to meet their own needs, rather than the needs of others, without knowing that they are doing so. Narcissism is only one of many characteristics that may cause parents to be suboptimal surrogates for their child. My purpose in using this example is to present a specific intervention that we can use to benefit children and parents. There are many initiatives we can imagine and pursue proactively, rather than passively observe what parents do, and then find it is too late to stop or undo what has been done. Should an intervention eliminate or reduce potential risk to a child, it may allow parents to remain their child's surrogate decision maker, which may be what the child and parents most want.

Warning Parents

What might we do, using the example of narcissistic parents? A first step is to not label parents, to the degree possible, as "narcissistic." To the degree that we permit ourselves to label parents in this way, it will cause us to see parents as "other," and impaired, and that will show. A second step is to alert parents to the pitfalls that may lie before them, depending on the choices they make. As clinicians, we may be in a better position to see this than they do. We should consider doing this at the first sign that parents may pose a threat to their child. Anyone, when under stress, including those who may be more narcissistic, may attend more to their own needs than to the needs of others.²⁷ If we can let parents know, early on, that we are "with" them, and give them advance "inside" warning of what may occur, depending on the choices they make, it may reduce their stress and provide them with the information they need to make different decisions, the kinds of decisions most parents want to make.

As a second step, we could give parents an example of the type of choice that could be seen as placing a child at risk. Ross presents the example of the French infant, Charlie Gard. We could go further and describe the type of case that resulted in a parent being denied custody of her child: Cassandra C., a patient in her late teens, had cancer and had a good chance of surviving, with treatment. Cassandra refused treatment, and her mother supported her. The courts removed Cassandra from her mother's custody.²⁸

We can also share cases of when parents' unusual requests were successful, for example the case of Ashley X, a young girl with severe intellectual disabilities whose parents sought to stop her growth and sexual development via therapy and surgery, to make it easier for family members to care for her at home.²⁹ We could also describe a case that Ross cites at the end of her article in this issue of *JCE*, in which an ethics committee recommended that a younger sibling be allowed to donate to an older sibling.³⁰ We may be able to help parents to avoid the involvement of a third party when parents' actions appear to pose a threat to the safety of their child—as well as to avoid the possible sanctions that third-party involvement might bring.

There is evidence that such assistance can help. But, as psychiatrists Glen Gabbard and Holly Crisp (who are widely recognized as experts in working with narcissistic patients) note, it may be necessary to use a “2 by 4 approach” to get through to narcissistic individuals.³¹ (They describe this approach as using bold confrontation to symbolically “bop” patients in the head to get their attention.) In these difficult situations, we are clearly not parents' therapists, but we may still usefully inform them of limits, without implying that we are in any way trying to change them.

Conflicts of Interest

A critical concern when a parental conflict of interest exists is how it can affect them emotionally. When torn by conflict, they may make different decisions than they otherwise would. When parents feel conflicted, for whatever reason, they may make decisions that are different than they usually would for their child, and these different decisions may be less beneficial for their child. I will now consider why parents may be inadequate decision makers. For illustrative purposes, I will look at a specific group

of parents as a paradigm. Then I will provide a specific intervention that we could consider in coming up with our own possible interventions.

Conflicts of Interest

We all have conflicts of interest, but when parents have a child who is dying, these conflicts may be much worse. Such conflicts of interest may impair parents' freedom to make choices, in the emotional turmoil caused by the conflict. This may impair parents' capacity to make the best decisions for their child. This could occur in response to any number of severe stresses. The stresses may be external or internal. As clinicians, then, we might take the initiative to inquire about and seek to reduce parents' stresses, including seeking to help with external and internal sources of conflict.

Our ability to help with external conflicts may be limited. One example of this is financial strain. We may be able to help parents find some means of financial relief, but this may well lie outside our reach. In contrast, we may be able to help with internal turmoil. The degree to which we can help to quell parents' emotional distress, for example, may go well beyond what seems logical. The paradigm I will use to illustrate this is not that of parents of a child who is dying, but of parents of a child with severe autism. The specific emotion we might seek to help to relieve for these parents is guilt.

Overwhelmed Parents

Parents who have children with severe autism may feel overwhelmed, especially initially. Over time, they may find having and caring for such children most rewarding. Parents' initial stresses may include finding the best care for their child. Here I rely principally on information provided by psychiatrist Ilana Slaff, who presented at the annual meeting of the American Psychiatric Association just a few months ago.³² She not only specializes in this area; she has two brothers and a daughter, Talia, with severe autism. Thus she has personally experienced what she writes about.

She has experienced extreme external conflicts. For example, she experienced great frustration in trying to find centers and experts that could offer her daughter Talia the best care. She calls the painful process that parents of children with autism go through “autism lotto.”³³ For example, a school she hoped Talia could attend had 70 applicants for seven openings. Many of

these parents experience the pain of feeling isolated. As clinicians, we could expend the extra effort of helping parents network with others who have worked through similar conflicts. We may need to make a special effort to learn that parents are going through such experiences; we may need to ask them what they are going through. We may be able to help them contact other parents who will help them better know what to expect. This may prepare them for obstacles they may encounter and leave them feeling that they have an ally.

Our primary opportunity to help parents may lie in areas that are emotional and internal. Parents may feel overwhelmed and, over time, give up. This might be the case when they seem to be seeking less than optimal care for their child, and be why and when they need our help. Here are two examples of when parents need our help. The second is the worst of the two.

In the first example, parents may be advised to ignore their child's crying when comforting the child would reinforce a maladaptive behavior, and make it harder to reverse the maladaptive behavior after each comforting. For example, parents who hug a child whenever she or he has an explosive temper tantrum may seem to be rewarding this behavior with a comforting hug, so that it persists. But not hugging their child at this time may evoke a profound sense of guilt. The long-term effect of parents comforting a child with such a maladaptive behavior may be much more negative than we can imagine. The behavior may result in the child having to live in an institution, rather than living with parents at home, as the child would want as he or she get older. (This is an example illustrating what Ross recommends regarding attending to a child's future feelings.) Another example is Slaff's severely autistic daughter Talia. Slaff relates that, at one time, she was afraid of being home alone with Talia. But Slaff was able to get Talia the help that she needed, making it possible for Talia to continue to live at home. Slaff feels this result is "priceless."³⁴

But as noted above, when the parents do not hug a child when the child seems most upset, this may evoke feelings of guilt. Over time, these feelings may overwhelm them as much as any other stress, external or internal, would.

But such stress and guilt may pale relative to a second example of when parents need our help. Some children may need aversive shocks to curb their maladaptive behavior if they are to

reverse their downward course and do better. This may involve, for example, parents placing a bracelet that administers shocks to their child's arm and triggering a shock from the bracelet when necessary. As would be expected, this intervention is controversial.³⁵ It may be necessary, however, to maximally benefit these children over the long run. This possibility raises an ethical issue neither Ross nor I address—potential conflicts for children in the shorter and the longer run, and how they may best be resolved.

The example I presented earlier of the adolescent who wanted to end her life sooner to benefit her younger brother raises this question. The longer run gain that was achieved in this case may have been slight, but the example indicates more broadly the importance of a child's quality of life in the shorter run. In the case of the bracelets that administer shocks, parents may feel extraordinarily painful guilt. This raises again the paradigmatic question how we might best intervene, as clinicians.

Assuaging Parents' Guilt

Not hugging a child, much less shocking a child, may go against what parents believe is right and may cause great feelings of guilt. Yet they may feel as much guilt if they don't, because if they don't, it may steer their child toward a future that none of them want.³⁶ We may be able to help relieve parents' pain by sharing that it is likely they will feel guilt no matter what they choose to do. We can do this prior to discussing a possible intervention because, by doing this, we put first what may be the greatest obstacle for parents in doing for their child what she or he needs. We can inquire about how parents feel about a recommended intervention as the parents begin it, and as they proceed.

Doing this takes extra time. It takes no more time than speaking a few sentences, and despite being brief, doing so may go far to alert parents about issues they may not know they will face. We can soften our guidance by asking parents if they want to hear what we would say before we say it. We may make this choice for parents easier by adding that they may not want to hear about possible complications because this may make their decisions harder. We can also normalize their possible guilt by noting that this is what others feel, and we may help further by connecting that feeling such guilt is a result of how much they care. This is true.

It is possible that parents who are very narcissistic may not feel such guilt, although they may carry out difficult interventions, such as the two described above, for the purpose of benefiting themselves.

Competency

I will not discuss the usual criteria for competence. As now practiced, these criteria are well established and no doubt will continue to be applied as they are now.³⁷ There is, however, another way that parents may, although they love their child, make suboptimal surrogate decisions, although they are not so suboptimal that they are legally actionable.

Parents may be unable to imagine that what their child most wants may be different from what the parents most want. This is referred to medically as an inability to adequately mentalize.³⁸ As discussed earlier, it is most important for a child to be able to express his or her own wants and, if possible, for parents and/or clinicians to fulfill them. For parents and clinicians to be able to accomplish this, however, it may be necessary for them to place themselves “in the child’s shoes” to a sufficient degree.

If parents are limited in their ability to mentalize, they may be unwilling to provide what they can, and should, for their child. Parents need to be able to mentalize to make the best possible surrogate decisions. If they cannot do this, it may have a negative effect on their relationship with their child. Bluebond-Langner notes that dying children “need to have their parents with them,”³⁹ and children whose parents are unable to mentalize may suffer when they do not get what they want when dying, and also feel emotionally abandoned by their parents.

What can we do, beyond what we would normally do, to help parents be better surrogates? We can help them see their child’s wants that are different from their own. There are numerous ways to do this. All involve in one way or another trying to nudge parents to be able to see and then be able to accept their child’s different wants, and the importance of these wants to the child.

Here is one intervention to help patients better mentalize. Psychotherapists cut out paper shapes of the soles of another person’s shoes. The patients are then asked to place their feet on the paper simulation of the other’s shoes. The

footprints are a physical aid to the patients to help them feel what it might be like for another person to have a different perspective.⁴⁰

Again, while children’s clinicians are not therapists, we may be able to present to parents what we believe are—or may be—their child’s different thoughts in any number of ways, without suggesting that we are trying to change them.⁴¹ We need to go as far as we can to try to help parents to see what they may not be able to see without this help. Otherwise, a child’s greatest needs may go unmet. This may go well beyond what we generally might do, but that this is beyond our usual practice, and also clearly paternalistic, should not deter us. To present alternative views of a child to her or his parents most successfully, we may want to contextualize what we will say before we say it, in the hope that what we will say will then be more acceptable to the parents. We can say, for example, that often what a child, and particularly a child who is dying, most wants lies outside what parents would expect, and their wants may sometimes lie outside logic. We can point out the likely deleterious effect of denying a request that could be granted, and the effect on their relationship with their child, and the exceptional importance of granting the request if these are the last days they will have together with their child.

The adolescent girl who wanted to die prematurely for her brother’s sake may be a useful example to offer. We can share this example and ask parents who are unwilling to consider their child’s wants how they think this teenager would have fared if her parents had denied her request.

“UNRESPONSIVE BUT WAKEFUL” OR MINIMALLY CONSCIOUS STATES

As noted above, Erica Salter expands on Ross’s article in this issue of *JCE*. Salter refers to the case of Ashley X, reinforcing and further deepening Ross’s emphasis on the importance of children’s present and future feelings. Salter adds to Ross’s analysis the challenges posed by a child such as Baby Bonnie. Shortly after birth, Baby Bonnie’s doctors predicted that, due to severe prenatal injury to her central nervous system, the infant would have a shortened life span, be functionally quadriplegic, continue to have significant respiratory distress, and have profound intellectual disability. It was unlikely that she would develop beyond the mental age of one year. Salter reports that Baby Bonnie did not in-

teract much with her surroundings, “although she does seem to find comfort in head rubs.” I include this quote to put into greater focus the core question raised by the baby’s medical condition: the degree to which she may be suffering. Do the benefits of continued life, such as her apparent pleasure at being touched, outweigh the burdens? Is this enough, we could ask, to, on her behalf, continue to keep her alive in this state? We also can ask, who should decide this?

A well-known, often ethically optimal approach to take when reasonable people continue to disagree is to change the question from what we should do, to who should decide. Here there may be an easier answer, and more of us may be likely to agree on this. Salter comments in response to this question of “who?” that Baby Bonnie’s parents felt unsure about what they should do, and her clinicians were divided as well. Salter relates a suggestion made by John Lantos, that when physicians disagree, it may make the most sense to let the child’s parents decide, so long as there is one doctor who supports their decision.⁴² This means of resolution contrasts with the decision reached in regard to the infant Charlie Gard.⁴³ Lantos’s approach could be questioned regarding its arbitrariness, in that what is decided may depend on the clinician who happens to be present at the time. Further, Lantos’s suggestion doesn’t include the views of other clinicians such as nurses, whose views may be just as important. Ross’s approach avoids these concerns.

There is, however, a clinical category of children who are similar to Baby Bonnie, but who may be even worse-off, making the questions they raise even more taxing. These are children who are in what used to be called a vegetative state (VS), or what is now called an unresponsive wakeful state, as may come about, for instance, after a terrible car accident. Alternatively, these children may be in a minimally conscious state. Like Baby Bonnie, they may be suffering, depending on how we would wish to define suffering. Finally, even children who are in an unresponsive wakeful state, in which they can’t think or feel, may come to acquire some minimal consciousness over time.⁴⁴

A horrifying first possibility we can imagine is that these children may be feeling pain without our knowing this.⁴⁵ Their pain could be emotional as well as physical. Their experience may differ from that of similarly affected adults,

since adults, if they are aware, may fathom the nature of the state they are in, much like some patients who are in a locked-in state. Some of these patients have recovered and told us what they felt. Adults who have or who develop basic awareness may be in less or more pain than they were before, or would be without it. In regard to this question, experts disagree.⁴⁶

Children who have basic awareness or who, for the first time gain it, may understand what they are experiencing to a lesser extent than adults do (if at all). Relative to adults, they may lack the life experience to be able to make sense of what they are experiencing. They could feel hopelessly and endlessly confused, and/or perhaps experience only an ongoing, panicked state. Whether this occurs might depend on the age of the child. Given this, two dilemmas might be what we should do for these children, and who should decide what should be done. It may be that decisions for these children should be made in a way that is unique. If, for example, the net likely suffering of a child cannot be known, there may be no basis to decide when and whether the child should be kept alive or allowed to die. It might be, in this situation, that the parents should be able to decide the outcome, whether or not there is a clinician who agrees with them.⁴⁷

CONCLUSION

Ross has suggested that we increase our efforts to meet children’s most basic needs in several ways. These include prioritizing to a greater extent children’s present and future feelings, placing greater decisional weight on other family members’ needs, spotting earlier threats from surrogate decision makers so that we can better prevent these threatened harms from taking place, and finding ways to intervene earlier so that we can allow surrogate decision makers to remain in this role. I have offered some ways in which her ideas might be applied.

Ross’s endeavors may be seen as focused on minimizing harm to children, and the practical applications I have emphasized in this article may further these positive results. The practical applications I have described here may be paternalistic, yet they are appropriate and warranted, and not coercive. As Ross says in her response to comments on her major article, “Physicians who motivate, or attempt to persuade their patients to make a reasonable health-

care decision, are acting within the scope of the doctor-patient (surrogate) relationship. . . .”⁴⁸ This is my intent.

Salter’s primary motivation in writing about Baby Bonnie is another view of Rawls’—that we should first help those who are worst-off. These children should remain a focus of our attention so that we can do the best for them that we can. Our core goal as we treat children should be to work with their parents, as allies. Parents mean more to their children than we ever will. This is likely to be the case even if the parents spanked their children or made them study too much; felt overwhelmed and gave up on them; or are wholly unable to appreciate that their children’s needs and wants are greatly different from their own. This especially may be the case when these children are dying. Ross says this best: “The central factor is intimacy.”⁴⁹

EXPRESSION OF APPRECIATION

I would like to thank Norman Quist for pointing out numerous critical points that added nuance and balance to this article.

NOTES

1. L.F. Ross, “Better than Best (Interest Standard) in Pediatric Decision Making,” in this issue of *The Journal of Clinical Ethics*, volume 30, number 3, Fall 2019.

2. E.K. Salter, “When Better Isn’t Good Enough: Commentary on Ross’s ‘Better than Best (Interest Standard) in Pediatric Decision Making,’” in this issue of *The Journal of Clinical Ethics*, volume 30, number 3, Fall 2019.

3. C. Koch, “How to Make a Consciousness Meter,” *Scientific American* 317, no. 5 (November 2017): 28-33.

4. J.J. Fins and M.S. Wright, “Rights Language and Disorders of Consciousness: a Call for Advocacy,” *Brain Injury* 32, no.5 (2018): 670-4.

5. Koch, “How to Make a Consciousness Meter,” see note 3 above.

6. The articles that appear in this issue of *The Journal of Clinical Ethics* that comment on Lainie Friedman Ross’s “Better than Best (Interest Standard) in Pediatric Decision Making,” are: D.M. Hester, “Offering the ‘Reasonable Interests Standard’ in Response to Ross’s Analysis of the Best Interests Standard,” Mark Christopher Navin and Jason Adam Wasserman, “Guidance and Intervention Principles in Pediatrics: The Need for Pluralism” D.S. Diekema, “Decision Making on Behalf of Children: Understanding the Role of the Harm Principle”; E.K. Salter, “When Better Isn’t Good Enough: Commentary on Ross’s ‘Better than Best (Interest Standard) in Pediatric Decision Making’”; E.

Paquette, “Constrained Parental Autonomy and the Interests of Children in Non-Intimate Families”; J.C. Bester, “The Best Interest Standard Is the Best We Have: Why the Harm Principle and Constrained Parental Autonomy Cannot Replace the Best Interest Standard in Pediatric Ethics”; N. Quist, “Pediatric Decision Making: Ross, Rawls, and Getting Children and Families Right.”

7. J. Rawls, *A Theory of Justice* (New York: Cambridge University Press, 1971), 82.

8. M. Bluebond-Langner, *The Private Worlds of Dying Children* (Princeton, N.J.: Princeton University Press, 1978). Her findings are based on interviews she conducted with many children who were dying from leukemia.

9. Stacey Springer, a careprovider who has spent three decades caring for dying children, says that if there is only one book careproviders of children should read, Bluebond-Langner’s is it. Ibid. S. Springer, “Ethical Considerations in Pediatric Palliative Care,” presentation at the 2019 Medical Ethics Symposium, Walter Reed National Military Medical Center, Bethesda, Md., 6 June 2019.

10. Bluebond-Langner, *The Private Worlds of Dying Children*, see note 4 above, p. 201.

11. Ibid., 299.

12. Springer, “Ethical Considerations in Pediatric Palliative Care,” see note 5 above.

13. Bluebond-Langner, *The Private Worlds of Dying Children*, see note 4 above, p. 165.

14. Ibid.

15. U.S. Department of Health & Human Services, National Institutes of Health, National Institute of Mental Health, National Cancer Institute, “Voicing My Choices: A Planning Guide for Adolescents & Young Adults,” <https://fivewishes.org/docs/default-source/Samples/vmc-sample.pdf?sfvrsn=4>.

16. Springer, “Ethical Considerations in Pediatric Palliative Care,” see note 9 above.

17. Ibid.

18. Ibid.

19. Ross, “Better than Best,” see note 1 above.

20. Salter, “When Better Isn’t Good Enough,” see note 2 above.

21. Springer, “Ethical Considerations in Pediatric Palliative Care,” see note 9 above.

22. Ross, “Better than Best,” see note 1 above.

23. Ibid.

24. K. Williams, D. Wargowski, J. Eickhoff, and E. Wald, “Disparities in Health Supervision for Children With Down Syndrome,” *Clinical Pediatrics* 56, no. 14 (December 2017): 1319-27.

25. A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (New York: Cambridge University Press, 1989).

26. I.I. Galynker et al., “Imminent Suicide Risk Assessment in High-Risk Individuals Denying Suicidal Ideation or Intent,” presentation at the Annual Meeting of the American Psychiatric Association, 19 May 2019, San Francisco; I. Galynker, *The*

Suicidal Crisis (New York: Oxford University Press, 2017).

27. Tunney and Ziegler describe four ways parents may make surrogate decisions for their child: they may: (1) do what they think they would themselves want, (2) do what they think their child would want, (3) do what they would want but not know they are doing this because they are unknowingly projecting their own wants on their child as if they were the child, and (4) do what they want for themselves. Only the last, Tunney and Ziegler believe, is necessarily problematic; this last, solely self-centered motivation should exclude parents. R.J. Tunney and F.V. Ziegler, "Toward a Psychology of Surrogate Decision Making," *Perspectives on Psychological Science* 10, no. 6 (November 2015): 880-885, 883. What kind of parent might those in the last group be? It would likely include parents who are sociopathic and thus more prone to make choices only for themselves. Even then, there may be some who still care for their child, and we may not know who they are unless and until they threaten to do their child harm. If, however, parents are "merely" highly narcissistic or in other ways only more prone to make decisions solely for themselves, that they are unsuitable as surrogate decision makers may be much less clearly the case, because they may, despite these traits, when less stressed, make good decisions for their child. But when they are stressed, this may not be the case. G.O. Gabbard and H. Crisp, *Narcissism and Its Discontents: Diagnostic Dilemmas and Treatment Strategies With Narcissistic Patients* (Washington, D.C.: American Psychiatric Association, 2018), 35. Narcissistic parents, then, may be paradigmatic and only one of all such other kinds of parents who may be suboptimal, but may still make good decisions for their child. That these parents may go "either way" makes clear the absolute importance that we spell out what criteria pose a sufficient threat to necessitate clinicians taking action—basic needs, or as Rawls says, primary good—such that if parents' decisions do not meet these needs, clinicians should act. These would be the next two steps needed to further implement Ross's more general requirements. I thank Norman Quist for pointing out these next most critical needs.

28. E.G. Howe, "When Adolescents May Die," *The Journal of Clinical Ethics* 30, no. 2 (Summer 2019):77-88.

29. Salter, "When Better Isn't Good Enough," see note 2 above; D.F. Gunther and D.S. Diekema, "Attenuating Growth in Children With Profound Developmental Disability: A New Approach to an Old Dilemma," *Archives of Pediatric Adolescent Medicine* 160, no. 10 (October 2006): 1013-7.

30. Ross, "Better than Best," see note 1 above.

31. Gabbard and Crisp, *Narcissism and Its Discontents*, see note 27 above, p. 131.

32. I. M. Slaff and J. Russell, "My Personal and Professional Journey Through Autism: Update on Autism Treatment Through the Lifespan," presentation

at the American Psychiatric Association Annual Meeting, San Francisco, Calif., 21 May 2019. I. Slaff, *Don't Medicate—Educate!//One Family, Three Cases of Autism, Safe Treatment for Dangerous Behavior* (Fresh Meadows, N.Y.: Ilana Slaff Medical PLLC, 2017).

33. Slaff, *Don't Medicate*, *ibid.*, 72.

34. *Ibid.*, 68.

35. These unwanted self-injurious behaviors have included, for example, eye-poking that resulted in the detachment of a child's retina. *Ibid.*, 89.

36. In one study of patients with autism and self-injurious behavior, 86 percent of cases showed a 90 percent or greater suppression of this behavior, and 100 percent showed improvement in one to 10 days. Slaff, *Don't Medicate*, see note 32 above, p. 15.

37. P.S. Applebaum, "Assessment of Patients' Competence to Consent to Treatment," *New England Journal of Medicine* 357, no. 18 (1 November 2007): 1834-40.

38. E. Asen and N. Midgley, *Handbook of Mentalizing in Mental Health Practice*, 2nd ed., ed. A. Bateman and P. Fonagy (Washington, D.C.: American Psychiatric Association, 2019).

39. Bluebond-Langner, *The Private Worlds of Dying Children*, see note 4 above, p. 235.

40. Asen and Midgley, "Working with Families," in *Handbook of Mentalizing*, see note note 38 above.

41. S. Edfern, "Parenting and Foster Care," in *Handbook of Mentalizing*, see note 38 above, pp. 265-80, 72.

42. J.D. Lantos, "The tragic case of Charlie Gard," *JAMA Pediatrics* 171, no. 10 (2017): 935-6.

43. "Who is Charlie Gard, what is the disease he suffered from and what happened in the court case?" *Telegraph*, 31 July 2017, <https://www.telegraph.co.uk/news/0/charlie-gard-mitochondrial-disease-suffers-legal-battle/>.

44. Fins and Wright, "Rights Language," see note 4 above.

45. Upward of 40 percent of minimally conscious patients are mischaracterized as vegetative. *Ibid.*, 671. Individuals in a vegetative and minimally conscious state are vulnerable to misdiagnosis and denials of care. *Ibid.*, 670. Most minimally conscious patients may have an inability to call out for relief and there is an absence of adequate metrics to assess the pain of this vulnerable population. *Ibid.*, 672.

46. The benefits of increased cognitive awareness must be weighed against the harm of being more cognizant of one's situation. M. Lanoix, "Where Angels Fear to Tread: Proxy Consent and Novel Technologies," *Brain Injury* 24, no. 11 (2010):1336-42, 1339.

47. Slaff, *Don't Medicate*, see note 32 above, p. 189.

48. L.F. Ross, "In Further Defense of 'Better than Best (Interest),' " in this issue of *The Journal of Clinical Ethics*, volume 30, number 3, Fall 2019.

49. *Ibid.*