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## *At the Bedside*

# Nine Lessons from Ashley and Her Parents

*Edmund G. Howe*

### ABSTRACT

Parents' love for their child, even a child who has severe impairments, may give them much joy and quality in their life. This is also the case for caregivers of adults with severe cognitive impairments, such as end-stage dementia. How can clinicians work with these parents and caregivers and help them?

In this issue of *The Journal of Clinical Ethics*, in the article "Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability," Lisa Freitag and Joan Liaschenko discuss a decision parents made a decade ago for their daughter, "Ashley," who had a rare condition that left her with a mental age of three months and unable to walk, with no possibility that either would change.<sup>1</sup> Her parents feared that, as Ashley grew, they would not be able to lift and move her, and, when this happened, they would have less time to be with her and love her if they could not easily take her with them. Consequently, when Ashley was six, they asked her doctors to give her estrogen to limit her growth, and they did this for three years.

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At her parents' request, doctors also performed a hysterectomy and removed Ashley's breast buds. I will not discuss interventions that followed. Rather, I will consider the decision to limit Ashley's growth. This decision was especially controversial. After it became known that this was done, some said her parents did this to benefit themselves, and some sent the parents hate mail. Internationally, people asked what the limits of medical intervention for children like Ashley should be. I will not discuss whether the decision to limit Ashley's growth was the right one. The experiences of Ashley and her parents offer important lessons that I will discuss, referring to them as "lessons from Ashley." The lessons also apply to adult patients and their loved ones. These lessons can be implemented now, and should help clinicians to help their patients. I will also present a relatively new tool to do this, which the clinician who introduced it calls the "ethics of finitude."

### NEW INSIGHTS

We constantly make assumptions about who we are. I will explore three assumptions we might alter: our capacity to love, the ethical value we afford to persons who can feel joy without cognition, and the profound loneliness we may sometimes feel but hide. I will discuss the clinical implications of each. It may be an error to speak of "joy," if it is present without cognition or self-reflection. What is the "experience" of emotions without cognition? Even the use of the word "pleasure" is confounding in this context. We might point to indicators suggesting that

infants such as Ashley seem to feel at least a reduction of tension, yet this too may risk reification. We can observe behavior and responses in infants, their smiles and coos. We can read these as indicative of at least pleasure, but joy? Yet, if an infant smiles or even laughs, have we not missed something if we see this as necessarily not joy, but only pleasure?

### **Lesson One: We May Be More Capable of Loving, and Loving Selflessly, than We Know**

One empirical question is whether people, and especially parents, can continue to love another when that person can't reciprocate. This could involve children like Ashley as well as aged persons with end-stage dementia. Of course there are profound distinctions in what loved ones and caregivers feel for persons at the different ends of the life spectrum. For example, we are only beginning to know a child and feel hope for the future, whereas with an aged parent, we have our entire relational history. Nel Noddings, an eminent writer on the ethics of care, believes that even parents can't sustain their love unless they have *some* reciprocity.<sup>2</sup> But Joan Tronto, another expert in this area, states flatly that Noddings is wrong.<sup>3</sup> Who is right? Can Ashley's parents continue to love her? We can wonder what might count as reciprocity. Might, for some parents, the mere survival of their child be enough?

#### *An Answer, Even for an "N" of One*

The question of whether a parent or another—for example, a caregiver of an older person with severe dementia—can continue to love one who cannot reciprocate would seem to be answered by Ashley's case. Her parents seem to have been able to continue to love her fully. Their capacity to continue to love her, although she cannot reciprocate, is not unique. Ashley's parents have communicated with other parents whose children have severe impairments. Ashley's parents did this "privately" to avoid exposing themselves to more hate mail. Other parents have shared with them that they have found that they continue to love their child. It would seem that what these parents intend to convey is that the caring they feel for their child is no less—and is possibly more—than what they would feel for a child who is not impaired. We can ask, though, what is the nature of this love, and is it at all different that love this is returned? These questions speak to our most profound and deepest capacity to care for each other, even to the extent that we would willingly sacrifice ourselves and our own needs for another.

This is not how it is, or should be, for all parents. We differ. Parents who continue to be able to fully love their child who cannot reciprocate may

be the rule more than the exception, and the capacity to love without reciprocity seems not at all limited to parents. An example is a woman whose husband lay unresponsive in what was then believed to be a persistent vegetative state (PVS). (Now we know these patients can have and develop awareness, and thus this term is no longer accurate or accepted.) The wife came to the hospital and stayed by her husband's bedside every day from daybreak to dusk for months. She said she found it meaningful to be with him whether or not he was aware of her presence. The most paradigmatic example of our capacity to love without reciprocity may be, however, that of a mother whose child was born with anencephaly. She went to court to sustain her child's life over clinicians' objections. She succeeded. Her daughter lived on for more than two and a half years.<sup>4</sup>

*Implications for clinicians.* Why might some parents and caregivers have the capacity to love fully without reciprocity? We might ask here, prior to proceeding further, what loving fully might most accurately mean. Does loving fully mean "without reservation"? Or "with all the love that I am capable of"? Or "without distraction or diminishment"? Surely what it means must vary with the individual. And so parents of a child like Ashley should not feel guilty because they do not love as fully as other parents, or as they expect they should.

We can't know why some people are able to love without reciprocity, but it may be in part because doing so gives profound meaning to their life, caring for a person who could not live or possibly even thrive without them. (Here, I mean "thrive" in the sense that the person cared for seems, for the most part, to experience mostly pleasure.) I will consider later how being able to recognize that such meaning may be the most important need in a person's life may affect clinicians' treatment decisions. This may be particularly valuable to clinicians should they tend to underestimate the quality of life that a child with impairments and their parents can experience.<sup>5</sup> This quality of life may be different, but still may be profound. Such awareness can change how we practice at the beginning and at the end of patients' lives, as the examples that follow illustrate.

*Practices with children.* Pregnant women may know that their fetus has a lethal illness and will die shortly after birth. Many may still want to carry to term so that they can have precious moments with their baby before the baby dies.<sup>6</sup> In the past, some clinicians discouraged these mothers from having a live birth, and in many cases the results were strongly negative. Some mothers complied and had an abortion; others did not. All may have felt deep resentment. In response to their experiences, some

parents formed support groups to help parents during pregnancy and afterwards. Their experiences and, in some cases, their lifelong, positive memories show the varied and profound connections we can have with others—especially our children. These profound connections come from who you are, and who I am, and who we are together. It is all that only I can give you—and you me.

Clinicians may come to know better how meaningful raising a child like Ashley can be, and become better able to imagine how meaningful it might be for parents carrying a child with a lethal illness. Knowing this, clinicians may support rather than discourage parents from continuing a pregnancy, if this is what the parents want. Exploring the clinical implications of Ashley's parents' experience may change our attitudes. For example, we may want to end a child's life over the parents' objection because we believe that maintaining the child's life is futile. We may strongly convey this to the parents. In response, the parents may feel isolated and alone, even when, as in the case of the mother of the child with anencephaly, they are able to keep their child alive. Knowing about Ashley's parents' experience, and having some understanding of it on an emotional level, may help us to be more supportive of parents.

Knowledge of Ashley's parents' experience may even affect clinical policy. There are now, for example, protocols guiding clinicians on how to allocate scarce drugs to children with rare cancers. One criterion for allocating a scarce drug, in some protocols, is whether the child has siblings whose best interests may be in competition with the interests of the sick child. The interests of siblings are considered in these protocols because, if the ill child survives the protocol, there may be less attention paid to the needs of her or his siblings and this may cause them harm. Siblings may, however, love their sister or brother who has cancer as much or more than their parents, as much or more than they would love a sister or brother who is not sick. Thus, clinicians working through criteria for allocation in these sorts of drug protocols may want to reconsider the criterion that an ill sibling may negatively affect brothers and sisters. Rather, clinicians might now see siblings' interests as being more varied and complex, since they may gain from the child's treatment, rather than being harmed.

*Implications for adults.* A more nuanced awareness may change our attitudes toward patients who are at the end of their lives. For example, there are patients like the husband discussed earlier, who are in a PVS-like state. It is now known that they may, to some degree, think, feel, and relate.<sup>7</sup> A patient's loved ones may adamantly want the patient to stay

alive and for clinicians to repeatedly test to see if the patient has developed awareness, so that, if the patient has, communication may be possible. If we are aware that some people are able to love without reciprocity, we may respect loved ones' feelings to a greater extent than we would otherwise, and may strive more, if possible, to meet loved ones' requests.

We may change how we see patients of all types whose care appears to be futile. We may come to see that some patients retain sufficient reasons to live that we didn't perceive before. I will discuss this profound and far-reaching effect in the next section, as it involves not only parents' and caregivers' capacity to love, but the possibility that patients may be able to positively experience life. Such a change in attitude may affect how we counsel patients. I recall a grandmother who, due to her illness, had to literally live in the hospital to receive the daily medical treatments she needed. Her family, taking turns, visited her the hours she was awake, every day. One clinician asked her whether she knew she could stop the treatments, which would end her life, but would "free" her many relatives, so they could "go on" with their lives. Hearing this, the woman stopped her meds the next day and shortly thereafter died.

A lesson here—not from Ashley—is that before we convey information like this, we should always, unambiguously, state our intentions. In cases like that of the woman who stopped her meds, we should state that we are not at all saying what the patient *should* do, but, rather, that we intend *only* to ensure that the patient is informed about the possible options available. In regard to this woman, I fear she inferred that the clinician was suggesting that she *should* end her life, even though her family members found tremendous meaning in being able to visit with her. Perhaps this could be, then, a lesson from Ashley: that we should not be as concerned that patients' loved ones necessarily would rather be "free" than to continue to be with the patient. I suspect that this clinician lacked such an awareness. With this new awareness, we may try to keep some patients alive longer, when, before Ashley, we might have regarded continuing care as futile. Like Ashley, our patients may retain quality in their lives and may give their loved ones' lives unique meaning that their loved ones could get in no other way.

### **Lesson Two: We Should Value the Lives of People with Severe Impairments More than We Do Now**

A second lesson from Ashley that logically follows from the first is that if Ashley's parents, and parents like them, value their child as much or more than other parents it might be that we should, at least in some contexts, value patients who are as

severely impaired as Ashley more than we do now. One indication of the degree to which our society values impaired children may be the extent to which we are willing to give these children equal access to transplant organs. It may indicate how much we value the lives of severely impaired adults, such as those with dementia, as well. A second indication of how we value these patients may be the extent to which we are willing to allocate the resources necessary to increase the quality of their lives. Some patients may have the capacity to experience joy, even with little or no capacity for cognition. We may, as a result of Ashley, want to re-examine what moral weight we assign to meeting the needs of these children and adults.

#### *The Value of Being Able to Feel and Express Joy*

Children like Ashley, with even great cognitive impairments, may, as best we can tell, still experience joy. The benefit these children experience may far outweigh the burden, especially when they are the recipients of love from their parents, as Ashley is. Their parents may feel that the joy that their child can experience to be sufficient to make the child's life as valuable as their own. The following two examples are illustrative. One child, like Ashley, could neither talk nor walk. She could, though, bang a toy on the floor. Her siblings found a way to make this into a game with her. They played the game together, to the delight of all. Another child could neither talk nor walk. His siblings were all girls and older. They found that they could set him at the bottom of a stairway in their house, and come down the stairs in weird costumes. He would shriek with delight, and so would they. He died from his disorder before he was 10 years old. His siblings all later chose careers in which they could help children like him. They viewed wanting to do this as his legacy. This path may not be uncommon for siblings of a child with impairments. Siblings, in my experience, seem to have a sense of what is most important to them in their lives more clearly than many of their peers. If this impression is true, I suspect their deeper awareness may be due in large part to the joy and its meaning they experienced from being with their sibling. The joy children with impairments and persons with dementia give to others may move us—and the greater society—to provide more equal access to transplant organs and other scarce resources. Clearly, this may require taking a scarce resource from someone else. When this might be justifiable requires comprehensive review and wide representation.

The meaning and happiness these children can give to others may go beyond what the others, usually their parents, could experience in any other way.

This rationale may raise a potential ethical problem: these children may be viewed as a means to others' happiness, as opposed to seeing them as ends in themselves. It may be ethically warranted to more greatly value children and their needs due to what they can give to others, notwithstanding this objection. If we, as a society, value these children and older persons who lack cognition more than we do now—more as Ashley's parents value her—what might we do differently?

#### *Clinical Implications*

If our society placed greater value on children like Ashley, we still might not provide them greater access to transplant organs, but we might provide them greater access to other resources. Even if our society provided all of these children with more of the physical resources they need, some may still need growth-limiting treatment to do best. An example would be to provide a lift to all such children. A lift may be seen as a basic need, as it may enable children to interact to a greater extent with those closest to them. Park McArthur, a sculptor and installation artist, relates how, over time, she needed help from her parents to move from her bedside to a chair, due to muscular dystrophy. She uses a lift, and describes it in a positive way: it is "affirming" and seems like "a hug." It makes "the caring of assistance tangible . . . the lift literally looks like an expression of love."<sup>8</sup> McArthur is capable of meaningful reflection and enjoys it, but Ashley might find it painful to be alone. Not having access to a lift might create a very bad time for her. It would be ideal if all parents of impaired children would do whatever it takes to have the child with them every waking moment. This is unlikely. But the needs of children like Ashley, with a greater need for company, may be more likely to be met if the child is physically small.

We may make different treatment choices, regardless of any societal change, as a result of knowing about Ashley. For example, I remember the case of a child who was severely impaired, but who enjoyed school. Her health precipitously declined. Only surgery could save her life, but whether it would do so was uncertain. If she survived the surgery, she might be more impaired. Her surgeons decided not to operate, and she died. Some members of the medical staff felt they should have operated, because if the child had survived, she still would have been able to enjoy going to school, as she had prior to surgery, and thus would experience pleasure. In sum, they thought the benefits would overwhelmingly outweigh the burdens. This girl had parents who were devoted to her, like Ashley's parents. It is possible that the girl's surgeons might have



made a different decision if they had had a greater awareness of how a child like Ashley may be able to thrive, with dedicated parents. Knowing about Ashley and her parents might enable us to imagine better outcomes for such a child when we make decisions about ending treatment, within the standards of our practice.

Here is an example from my own experience. A toddler had Werdnig-Hoffman's disease, a genetic disorder that causes ever-ascending muscle paralysis. It is like amyotrophic lateral sclerosis (ALS—Lou Gehrig's disease) in adults, but occurs in infants. The children usually die by about age two.<sup>9</sup> This toddler came to the hospital with pneumonia. She acquired the infection because her lungs were already weak. She got well in the hospital with antibiotics. The staff were concerned: What should be done if she came in again, and at that future point her lungs were so weak that she needed to be on a respirator? Should they start a her on a respirator? Pediatric respiratory specialists were brought in. They concurred that the girl's clinicians should *not* start her on a respirator, because, they believed, the harms would outweigh the benefits: she would not understand why her parents were hurting her; she would not be able to enjoy her parents' hugs; she would suffer from frequent tracheal suctioning. I went to the girl's hospital room after the ethics committee's decision, and was surprised and moved by what I found. From the hall, I heard the family loudly sharing hilarious joy, even though her parents knew that she wouldn't be with them much longer. The ethics committee did not imagine this. I asked myself whether I should try to reconvene the committee, but did not. Her parents did not bring her back to this hospital. They knew that the staff would not do all that they could to extend her life.

This second lesson from Ashley suggests that, under exceptional circumstances, as exemplified by this case, we may want to make exceptions to our usual practices. We may want to make some—even if rare—decisions not based on solely a patient's *category*. In this case, this category would be two-year-olds on respirators. As in this case, there could be rare exceptions to "the rule." The benefit-burden ratio for some patients might be seen as reversed.

We could also consider making exceptions like this for adults who have severe dementia or a life-ending condition. We might, for example, give adults with even end-stage dementia a gastrostomy tube when they can no longer eat, although generally this is held to be medically contraindicated.<sup>10</sup> Likewise, we might make a rare decision to give life-extending kidney dialysis to a patient who is dying. These interventions, although generally contraindicated,

might be made, based on the exceptional joy and love a patient shares with others. We might even consider not writing a do-not-resuscitate order for a patient because, if the patient was among the few who would survive cardiopulmonary resuscitation, the few hours or days gained with loved ones might be worth it. Presumably, it would be family members who would initiate the discussion. But they may be confused and burdened by the emotionally tortured experience, and not initiate a discussion—and later they might wonder whether they should have done more, asked for more, or demanded more.

These considerations may include a troubling inequity. In making an exception, we may favor patients who are more fortunate than others—those who have someone who loves them to an exceptional degree. The result could be profound: life versus death, even for a short time. Making an exception based on good fortune furthers and increases inequity. Still, it may be warranted to vary from usual practice when patients are exceptionally loved. It may further, for all, the greatest good.

### **Lesson Three: Patients May Suffer More from Loneliness than We Know**

A third lesson is that it is possible to better infer when a patient feels isolated and alone than we do now. Loneliness may be one of the most painful emotions. Support from another person may relieve it, most profoundly. Thus there is much that can be done. Ian Brown is the father of a child who has a rare condition that includes severe cognitive impairment, altered facial structures, and fishlike skin. Brown is open in sharing his feelings and the feelings of other parents like him whom he knows. He relates that parents almost invariably envy other parents who have a child who is not so impaired. They may feel "the hyperbolic sense of isolation that can make a father or mother believe he or she is the only one to whom this or that is happening."<sup>11</sup>

Ashley's parents may have felt even more isolated for an additional reason—the hate that others expressed toward them in letters. Whether or not this is the case for our patients, our awareness that these things could be possible should move us to try to be more observant. Once we can see these things, we can try to do whatever we can in response.

### *Seeing When Patients Feel Isolated*

The experience of isolation is described by Robert D. Stolorow, a psychoanalyst, who felt "deadened and broken" after his wife died. He says that he experienced an "unbridgeable gulf" that separated him "forever" from his friends and colleagues.<sup>12</sup> He came to see this estrangement and isolation as com-

mon after such trauma. He refers to this human vulnerability as “*the unbearable embeddedness of being*” that we all have in common. As a result of this experience he came to consider it most important for clinicians help people in this state. He believes that to do this, seeing an “ethics of finitude” may help. We must “face up to our finitude and the finitude of all those we love.” Giving credit to the French philosopher Jacques Derrida, Stolorow provides this example: when we look a friend in the eye, we know that one of us will die before the other will. With this awareness, Stolorow says, we can focus on the common end that we share with all others, despite how we differ. This can, he says, enable us to bridge whatever separation we may feel, so that we can “dwell emotionally” with others.

Later, I will discuss how this tool may help us to reach even those patients we dislike. I describe Stolorow’s source of insight to illustrate the profundity of the loneliness we may be likely to miss. To “dwell emotionally” with others, as Stolorow writes, we must first detect others’ loneliness. We may tend, though, not to see it, or to deny it when we do. This may be because seeing such loneliness is painful. Even when we see it, we may fear that there is nothing we can do to help. This in some ways is true, and knowing it is important. Stolorow’s description of an “unbridgeable gulf” conveys this. But Stolorow also notes that we *are* able to help. How we can help will be explained shortly. Before that, I would like to explore how loneliness may exist and remain hidden, for example, in patients who sign out of the hospital against medical advice. An entire ward staff may see these patients as pariahs. Another example is patients who have been raped, but can’t make themselves heard. The circumstances of the assault may be such that they can’t go to court. Because they can’t, others to whom they might tell their ordeal may doubt their credibility.

A third and last example is one in which I was involved and, to my discredit, in which I used massive denial. During a counselling session, a patient related how she had locked the family liquor cabinet to protect her teenaged son, who had a history of violent and reckless behavior while drinking. He became enraged at her. She said that he had never harmed her, but now feared that he would. She said that that night, under her bed sheet, she would have her cell phone pre-dialed to 911 in one hand and a can of pepper spray in the other. I nodded, as if I understood. I did not. I heard her words, but not her fear. I hardly registered the terror she felt at this time. The son didn’t try to harm her that evening, but I still wince, recalling my total failure to sense the depth of her pain at that time.

Ashley’s third lesson is to recognize and to empathize with this kind of pain and then to act.

#### *How to Act When Patients Feel Isolated*

When patients feel isolated, the task is, if possible, to help them connect with others, if this is at all what they want. Or, when there are no “others,” to make a connection with patients ourselves. It may be counterintuitive to believe we can do this as clinicians, but even just a moment of a felt connection can go a long way. Even in animal research, the gains from connecting with others can be strong. The comfort of having a connection with another has been found to offset the lure of highly addicting drugs.<sup>13</sup>

When possible, it is optimal to connect patients with others in similar situations. People best cope when they have access to someone knowledgeable, who is going through what they are experiencing, who has gone through what they are experiencing and fully recovered. The two interventions with patients I will focus on will be connections with family members—by far be the best—and, in their absence, a connection with us, their clinicians.

*Involving family members.* Ideally, clinicians may help family members connect with patients. This may be ideal, because typically family members have had prior years together with patients. Family members also may want to help patients more than anyone else does. Family members may often be able to connect with patients when others can’t. On psychiatric wards, for example, patients who feel threatened may sometimes back into a corner, feeling ready to attack. A spouse, sibling, or mother may arrive, and immediately calm them. The likely gain to patients by involving family members is exemplified by a new practice a leading hospital has taken to treat patients with anorexia nervosa—a disorder that frequently proves lethal. In the past, parents often were largely excluded from patients’ wards, since it was felt that they could add to the patients’ problems. Now, in this hospital, however, parents are welcome and can stay through the night if they want. The staff teaches parents how to treat patients, and parents then take over this role. The belief underlying this is that the gains patients make in the hospital will continue once they go home. Otherwise, it is feared that their gains won’t generalize from the hospital to their home, and it will be only a matter of time until they relapse.<sup>14</sup>

Family members often rise to such challenges. I think here particularly of a transgender girl who was miserable as a teen until she made this change. Her relationship with her father, with whom she lived alone, had been miserable. When she made this change, she had difficulty making a social transi-

tion. Her father saw this, changed abruptly, and became her sole—but adequate—source of support until she fared better. The point here is that we should not prematurely underestimate the capacity of family members. Like Ashley's parents and caregivers of patients with dementia, family members may be among those who are able to love greatly without reciprocity. Frequently, however, even patients who get on well with their family members will say, "But I don't want to trouble them." Often I tell patients that their family members may dearly value an opportunity to help them, and that this may give meaning in their lives that they would not and could not get in any other way.<sup>15</sup>

*Involving oneself.* As a last resort, we can seek to relieve patients' isolation ourselves. Just being there and responding based on how we feel, even if only for a few short moments, may help. Here is an example. A patient came to see me the same day her grandmother died. She had done all she could to help other family members who were grieving this loss. With me, she cried. She said she wanted to show me a last video she had made of her grandmother on her cell phone. I moved my chair next to hers and we watched. When the video came to an end, I stayed beside her as we talked, as opposed to moving my chair back where it had been. It seemed to echo a strange, silent closeness at the time between the patient and me. I recall wondering how long I should stay sitting in my chair next to her and talking. Later, the time seemed right, and I moved away. Such an effort isn't possible during emergencies; it is, however, something all clinicians, including ethics consultants, can do.

We can do this with patients who are less competent, as the following example shows. An older female patient with a history of an immobilizing depression was admitted to the hospital from her home, due to a lack of self-care. She lived alone. She had not been taking in food or fluids, moving, or bathing. She would speak reluctantly, if prompted, but refused intravenous (IV) fluids and bathing. She would say in a whisper, "No, I don't want it," and then withdraw as if in some kind of daze. After this had gone on several days, "ethics" was called, because the nurses were concerned. They wanted the patient declared incompetent, with the idea that an IV could then be placed. The ethics consultant, a nurse, went to the patient, turned down the bright lights, sat next to her on the bed, and began to speak with her in a soft, low voice, and explained why an IV was necessary. This consultant also took the patient's hand and stroked it where the IV would be placed, explaining that this would be the IV site. She said, too, that it might be uncomfortable, but

was necessary. The patient did not take her hand away and continued to let the consultant stroke it. The consultant asked the patient whether she was afraid, and said that she would *stay* by the patient when the IV was placed. The patient answered "no," but didn't say anything else, and didn't pull her hand away. Another nurse came in the room with the IV equipment and placed the IV while the consultant sat with her. The patient didn't indicate verbally or nonverbally that this was not OK. After she received nutrition and felt better, she agreed to take her meds, and began then to recover.

### ETHICAL PRIORITIES WE MIGHT ALTER

Ashley's parents choose to put Ashley's quality of life above all else. They chose to do what others hadn't done. This next section will discuss this specific priority, patients' quality of life, and other, additional ethical priorities. The lessons from Ashley and her parents may suggest what we should do.

#### Lesson Four: Give Priority to Patients' Quality of Life

Ashley's parents sought to give her the maximal quality of life they could, both early and later on in her life. A second article in this issue of *JCE* addresses the question of the priority clinicians should give to patients' quality of life. In "Re-Evaluating the Ethics of Uterine Transplantation," Danish M. Zaidi asks whether clinicians should comply with a woman's request for a uterine transplant when she wants to be able to bear her own child.<sup>16</sup> He answers, unequivocally, "yes." He states that an "ultimate goal" of a physician is to improve patients' quality of life, and uterine transplantation does this. As is often the case in questions involving reproduction, the mother in this case had other options. Parents who can't have their own biologically related offspring without medical help, for example, may usually adopt. This mother could have her own biological child if she wanted to, possibly by hiring a surrogate mother. Why then should we comply with such requests? The answer is like Ashley's parents' answer: to enhance the patient's quality of life.

Ashley's parents chose to request treatments to limit her size, in spite of the harms the treatments posed to her and to themselves. The exceptional insight her parents offer us is that Ashley's quality of life, and anyone's quality of life, may depend mostly on what we *feel*, and this may or may not be wholly rational. What people feel may determine what means the most to them in life. Thus, clinicians should prioritize this, if they can, even when there might be significant cons.

An example of this is shared by the eminent surgeon Atul Gawande.<sup>17</sup> This story involves his daughter's piano teacher. The teacher was dying of cancer and found that what she most wanted to do was to continue to teach piano as long as she could. This required her clinician to give her just the right frequency and dosage of pain medication, to relieve her pain enough to enable her to teach, but not too much, since this would sedate her so that she couldn't teach. Her clinician did this, and she continued to teach, including Gawande's daughter, until shortly before she died. This extra effort to titrate her medication to enhance her quality of life in this way provides a model of what we should strive to do with all of our patients.

Accordingly, I ask all of the medical students I teach what they, knowing of *this* clinician's extra effort, would do if the same need occurred with a patient they were seeing, and their attending or resident was unwilling to go the extra mile. And then I add a touch of insult to the "injury": I ask them what they would do if and after the attending or resident told them, "You must learn to accept your limitations. You can't rescue everyone!" because I am told that this happens. Some of the medical students say they would not do anything. They may say something like, "after all, the attending or resident should know better than I do."<sup>18</sup> Other students state, however, that they *would* share that it is their and Gawande's belief that clinicians *should* go this far, and, if the attending or resident won't agree, the student would go "higher," to the head of the service. I tell all of the students who are considering this question that, to me, the students who say they would speak up are my heroes. Why? Because the fourth lesson that Ashley teaches us is that we should seek to provide our patients with the best quality of life that we can, and our doing this, like Ashley's parents have done for her, is perhaps more important than anything else in the practice of medicine.

#### **Lesson Five: Put Patients above Principles**

It is possible that our commitment to ethical principles may blind us from seeing what our patients really need most. Information about what patients most need can come only from them. Ashley's parents put what they believed were Ashley's greatest needs above the principles that had previously been given the highest priority. They violated, for example, Ashley's bodily integrity by limiting her growth. Her parents and her clinicians violated what some see as what is "natural." Another article in this issue of *JCE* involves putting patients' needs over ethical principles, an article by Amy E. Caruso Brown, "At the Intersection of Faith, Culture, and

Family Dynamics: A Complex Case of Refusal of Treatment for Childhood Cancer."<sup>19</sup> Brown relates a case in which the elder of an Amish family, based on his beliefs, says he is willing to allow his three-year-old grandson to die, even though the toddler could live, with surgery. The child's clinicians, understandably, fear and oppose this outcome. The ethical principle that they prioritize may be seen as similar to a principle that often underlies our society's approach to the children of Jehovah's Witnesses: children should be able to choose death only after they have reached an age at which they can make a choice for themselves.

But being able to follow one's religious beliefs may be the greatest need patients have. Here are a few examples. It is perhaps less well known that, during World War II, Nazis imprisoned German Jehovah's Witnesses in concentration camps. The imprisoned Jehovah's Witnesses were told they could go free if they renounced their religion, submitted to the Nazis, and supported the German military. They refused. An estimated 1,200 died while imprisoned; 250 were executed.<sup>20</sup> More recently, Amish beliefs became better known when they collectively forgave a man who shot 10 Amish schoolgirls in October 2006. Five of the girls died. The capacity of the Amish community to forgive is, to many, astounding. Members of the Amish community teach their children to forgive early on.<sup>21</sup>

The fifth lesson we may learn from Ashley is that sacrificing ethical principles may be necessary to best meet patients' needs. In Ashley's case, this included giving her estrogen. For other patients and their loved ones, this may mean that we accept their religious beliefs. The conflict between upholding a critical ethical principle and accepting a patient's or loved one's opposition may be greatest when we treat patients from a different culture. Excruciating examples of this may occur when we are committed to gender equality but practice in cultures where that priority is not valued. For instance, small medical clinics have been set up in a rural areas in other countries where men are more valued than women. At one such clinic, there was only one male surgeon. The head of the local community informed the clinic staff that the community would bring only men to the clinic, because they did not believe in exposing women to the presence of men, even in this context. Since the staff had received notice from the local community that it discriminated against its own female population, perhaps their devotion to the principle of gender equality should have prevailed, and they should have stated they would only treat patients under the condition that the patients seen include women. In other instances—for ex-



ample, when we do not receive prior notice of an unethical practice—we may need to give up an ethical principle that is important to us to be able to meet our patients' needs. Here is another example, from a clinic established by a U.S. medical team in another culture. A family brought in a young woman who needed surgery. Her father said that he would not admit her unless she would have a female surgeon. The staff had heard of a similar scenario at a nearby clinic. That patient's father also would allow only a female surgeon. The only surgeon there was male, but no one informed the father before the surgery. Afterwards, the surgeon, who believed in the importance of telling the truth, told the father he had operated on the daughter. On the way home from the clinic, she was thrown to her death from the family car. Knowing of that incident, the current surgeon chose, along with the rest of the staff, to lie. They said a female nurse performed the daughter's surgery. As far as they know, she survived. These clinicians greatly valued truth-telling, but chose to sacrifice that principle to save their patient's life.

The lesson from Ashley here is that, in some cases, abandoning an ethical principle may be necessary to meet a patient's need. Ashley's clinicians, like Ashley's parents, went against previously accepted ethical principles to do what they thought would be best for Ashley.

### **Lesson Six: Be Wary of Too Strong, All-or-None, Instant Ethical Judgments**

This sixth lesson also applies to the prior two lessons. That is, to be able to consider giving greatest value to patients' quality of life or to whether patients' needs should prevail over ethical principles, we must be open to considering these as possibilities. This may not be the case. In this issue of *JCE*, Jamie Lindemann Nelson, in "How We Become Who We Are: Ashley, Carla, and the Rest of Us," comments on the article by Freitag and Liaschenko: "The physical interventions made it much easier—perhaps even possible—for [Ashley] to stay who she is, cherished by and enmeshed within her family. She can receive their loving care every day, conveyed through their tender touches."<sup>22</sup>

As mentioned above, Ashley's parents received hate mail. Should we find ourselves feeling strong negative feelings toward a patient or family, our feelings may prevent us from seeing that there may be competing values at stake. This happened, I believe, in the following case, which created possibly the most contentious ethics committee meeting I have ever experienced. A girl in her early teens, severely cognitively impaired, appeared to greatly enjoy her life with parents like Ashley's, until she began to

menstruate. When this occurred, she was terrified in response to seeing her own blood. When her parents sought to bathe her, she then became terrified of them, too. One possible remedy suggested was a hysterectomy. Some ethics committee members saw this as heinous, as literally evil, because they saw this to be, in principle, just like what Nazis had done: sterilizing cognitively impaired women. This young woman's parents, like Ashley's parents, however, were seeking only to love her. As it turned out, the young woman was eventually placed on long-acting birth control hormones.

One empirical possibility may add to a concern that clinicians may lack the capacity to remain morally open, despite an absolute need to remain open in our work. That is, the brain may, at times, function like a recording, set automatically on one particular loop. Once set off, a loop may be unresponsive to new data that come in.<sup>23</sup> This may be, some believe, what happens in anorexia nervosa and some addictions.<sup>24</sup> The need to not eat or to have a drug may be ever present and so compelling that this cognitive loop cannot be resisted. If this is so, this automatic circuitry may function even more widely: it might be set off within us by certain ethical problems. When we respond to an ethical question that comes to our attention with exceptionally strong, all-or-none, and immediate ethical judgments, we may be experiencing something like this, and, not knowing this is happening, we may not be able to weigh these problems as we must.

There are also several clinical contexts in which this automaticity seems plausible. It could be the case, for instance, whenever we feel even the slightest degree of contempt. There are several possible examples. Some clinicians still tell patients, for example, with a hint of nonverbal derision, that the patients' bodily symptoms are "all in your head." We may feel and convey such contempt also when patients have emotionally caused seizures, as opposed to seizures caused by a physically altered structure within their brain.

This automaticity may occur any time we overreact to patients whom we believe are "not cooperating." We may then, for example, prematurely use restraints, even though other, kinder responses may succeed if we had shown patience.<sup>25</sup> Further, our possibly automatic response emotions may be triggered by intense feelings such as helplessness. Under circumstances such as those described above, we may feel less sure regarding what we can and should do, and this may set off such nonthinking responses. The lesson from Ashley here, then, applied most widely, is to be wary when we respond to an ethical or innovative clinical suggestion with

an especially intense and immediate “no.” Like the persons who sent hate mail to Ashley’s parents, we may miss truths we should see.

### HELPING PATIENTS WITH WHAT WE LEARN

Ian Brown, the father whom I introduced earlier, reports not only the envy and isolation to which he and other parents of impaired children are prone. He also reports that they may feel deep guilt and may wish for their child, and even themselves, to die. The parents who are “most pained,” he says, are the ones who feel guilty. We are, of course, exceptionally prone to guilt, both rational and irrational, for what we’ve done and, perhaps even more so, *haven’t* done. Brown says that he has wished for the death of his child, and for himself. “One of my secret death fantasies,” he relates, was to “take him high up into the mountains . . . and lie down in a snowbank and end it, quietly, hypothermically.”<sup>26</sup> In the same way, Ashley’s parents may have felt guilt about what they did, whether or not what they did was what was best for her. They may not acknowledge, or be able to acknowledge, a feeling of guilt, due to the external and internal pressures they face to convince others—and themselves—that what they did was right. We may be most helpful when we see these parents. If, however, we feel hatred toward the parents, it is unlikely that we will be able to help. What should we do if we feel this way?

#### Lesson Seven: Appreciate Parents and Patients

We must be able to appreciate and respect patients to be able to help them. How can we do this if they hate them? Stolorow, due to his feelings of isolation that I discussed earlier, came to want to help people who feel as isolated as he did. He writes that to do this requires facing up to our own finitude, “but also to the finitude of all those we love.”<sup>27</sup> Russell Carr, a psychoanalyst, shares specifically how he did this, when he abhorred what a patient had done. The patient had committed atrocities during a war. Carr writes, “Combat is ugly . . . I agree with anyone who recoils from it. I have too. But how then do we help the combat veteran sitting in front of us, or any patient who has done something we can’t tolerate, such as hearing of atrocities that we never had before?” Carr first identified and then showed the patient how vulnerable Carr himself was. He told the patient he felt helpless. He said his pain, too, was overwhelming. He then said, “I don’t know what to do about it. . . . This was a spontaneous, authentic response from me.”<sup>28</sup>

Carr’s response was, in a way, somewhat similar to what I experienced and how I responded when

I sat next to the patient whose grandmother just had died (although that patient had not done anything horrible). Like Stolorow and Carr, I believe that if we can respond authentically to patients, we are most likely to break new ground, even with those patients whose actions we may deplore. Carr states, “Stolorow’s descriptions of authentic solitude have shown me how we are obliged to not run away. . . . Showing our own vulnerabilities and limits in those moments maintains a human relatedness.”<sup>29</sup> Sharing his own vulnerability with his patient the soldier enabled Carr and the patient to be “vulnerable together.” The soldier became to Carr no longer “a killing machine,” and Carr was no longer “the invulnerable therapist with no reactions to his experiences.” Carr says, “We were simply two men, trying to make sense together of combat and our human existence.”

The seventh lesson from Ashley is that if we hate a patient, we can, possibly, and perhaps should, try to overcome it. As Stolorow and Carr say, seeing that we have experiences in common, particularly death, may be most helpful in this effort. Our patients may, of course, make this more difficult. They may sense our negative responses to what they have done and then react with hostility. Or they may simply not want to “connect” with us. We should still be reluctant to abandon them. The endeavor of one clinician, a therapist, to overcome the barriers that one of her patients created is illustrative; it took her time and repeated efforts. She writes, “James barely acknowledged me during his first visit, acting like he was on a forced death march. . . .” She gently acknowledged how, for him, all of this “must suck.” They then began to play the card game Rummy 5000. This playing together occupied several sessions before the patient would speak to her.<sup>30</sup>

#### Lesson Eight: Teach Self-Compassion

The feelings of guilt, the desire for their child to die, and even a wish for their own death that some parents experience may move us to ask what we might do to help these parents the most. An answer I would like to suggest is that we may alert parents to approaches that are collectively called self-compassion: several ways that people can become better able to care for themselves. Here are three self-practices that are based on empirical studies. (1) Be kind to oneself, especially at difficult times. (2) Learn to better distance oneself from one’s suffering. (3) Do not see one’s own suffering as unique. A key researcher on the use of this approach, Kristen Neff, provides exercises to help learn these skills.<sup>31</sup> For example, one chapter in her book, *Letting Go of Our Self-Definitions by Identifying Our Interconnected-*

ness, echoes Stolorow's and Carr's approaches, and helps us use it. In her book, Neff uses this imagery: "Imagine a red cardinal bird flying across a clear blue sky. . . . The bird might start doing crazy loops . . . but the sky is still there unperturbed. . . . When we identify with the sky rather than with the bird . . . we can stay calm and centered." "People who learn self-compassion are reported to do better than those who raise their self-esteem by other means."<sup>32</sup> This approach has been found to be particularly helpful for parents who have a child with autism.<sup>33</sup>

### **Lesson Nine: Help Patients Look to their Futures, Maybe**

Ashley's parents were concerned for her future. This is a common concern for such parents. But the future is also often viewed with great dread. Brown gives this example in regard to himself and his son: "as much as I think about getting through the day with Walker, I think more about the future. Who will care for Walker after we are dead? . . . I knew how much work Walker required, and how impossible it was for . . . even four people to care for him adequately. . . ."<sup>34</sup> This view is echoed by McArthur, the young woman with muscular dystrophy, who reports that the challenges her future posed for her parents caused them "a great deal of grief and anxiety."<sup>35</sup> This dread, grief, and anxiety may stem from concerns about who will take care of a child if the parents die first. Children like Ashley may have siblings who could care for them. Parents may fear, and not unreasonably, that this would be most disruptive to the siblings and their own families. What are the implications of this information for us?

If parents are willing, it might be best for them to discuss the future early on. I think in this regard of a couple who didn't do this, but, fortunately, tragedy was averted. The parents had a child with severe autism. As he became older, he was able to climb out of an upstairs window at home. His parents put bars on every window, but, to protect their son from himself, one parent stayed up every hour of the night, every night. They almost divorced when they came to disagree on whether or not they should place their son in an institution. They finally did, and he felt better there, and they, perhaps for this reason, did well as a couple and individually. They might have fared better, and earlier, if they had discussed the future earlier on.

This same lesson from Ashley applies to impaired adults. I think again of Atul Gawande, who suggests that we ask ourselves, in regard to every patient we see, whether we would be surprised to learn that the patient died during the next year. If we would not be surprised, Gawande suggests that

we should seek to initiate a discussion of the patient's future plans. Gawande recommends asking, "What would you want if you were to become worse?" and "What would you want if you were to become frail?"<sup>36</sup> This suggestion may sharpen our timing for asking patients whether they have or want to write an advance directive. Bringing up the future may help our patients a great deal, because they may want to make plans but find it much too painful to do end-of-life planning on their own. These discussions may be particularly important for parents who have a child like Ashley. Few parents of a child like Ashley have *not* found that they need help in advocating for the resources that they and their child need.

We should, however, let parents and the caregivers of patients of all ages determine if and when they want to discuss the future. Some may find these discussions to be "too much" at first, although they may later change their mind. Some may need to use the psychological defense of denial to a greater extent. These people would enjoy the present more by leaving what could occur to the future, and by confronting it only if and when problems later occur. This may be, for many, adaptive. Who knows whether Ashley's parents would be able to love her even more than they do now if they had focused to a greater extent on what might happen in the future. Such as receiving hate mail.

### **CONCLUSION**

The experiences of Ashley and her parents may present several helpful lessons for us, including the risk of underestimating parents' and caregivers' capacity to love without reciprocity, the need to give priority to what is most meaningful to patients and their loved ones, and how to help patients and loved ones to the greatest extent by alerting them to the gains that can be had from self-compassion. A key question left standing is whether parents, with our help, should give children like Ashley growth-limiting hormones.

What is not at issue is that, whether or not parents do this, their love for their child may give them much quality in their life. Freitag and Liaschenko, in spelling this out and bringing it to our attention, make a point that surpasses all others in their article: that a parent can form a complex relationship based on such minimal clues as eyes opened or closed, the appearance of discomfort, or even the timing of bowel movements. Parents may be able to do this regardless of the size of their child. Caregivers of full-bodied adults with conditions like end-stage dementia may be able to do this as well.

NOTES

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