

# THE JOURNAL OF CLINICAL ETHICS

VOLUME 28, NUMBER 3

FALL 2017

## ***At the Bedside***

- 177 Nine Lessons from Ashley and Her Parents  
*Edmund G. Howe*

## ***Features***

- 189 Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability  
*Lisa Freitag and Joan Liaschenko*
- 197 How We Become Who We Are: Ashley, Carla, and the Rest of Us  
*Jamie Lindemann Nelson*
- 204 Giving Voice to the Voiceless: The Colorado Response to Unrepresented Patients  
*Deb Bennett-Woods, Jean Abbott, and Jacqueline J. Glover*
- 212 Re-Evaluating the Ethics of Uterine Transplantation  
*Danish Zaidi*
- 217 May Medical Centers Give Nonresident Patients Priority in Scheduling Outpatient Follow-Up Appointments?  
*Armand H. Matheny Antommara*

## ***Cases and Analysis***

- 222 Responding to Moral Distress and Ethical Concerns at the Intersection of Medical Illness and Unmet Mental Health Needs  
*Donna D. McKlindon, Pamela Nathanson, and Chris Feudtner*
- 228 At the Intersection of Faith, Culture, and Family Dynamics: A Complex Case of Refusal of Treatment for Childhood Cancer  
*Amy E. Caruso Brown*
- 236 The Angry Amish Grandfather: Cultural Competence and Empathy: A Case Commentary  
*James L. Benedict*

## ***Research***

- 239 The Ethics of Research in Lower Income Countries: Double Standards Are Not the Problem  
*David S. Wendler*

## ***Perspectives***

- 247 Universal Health Care: The Cost of Being Human  
*Roger Strair*
- 250 Vaccine Exemptions and the Church-State Problem  
*Dena S. Davis*

## ***The Journal of Clinical Ethics***

6 West Washington Street, Suite 302, Hagerstown, Maryland 21740 USA  
240-420-8850 • fax: 240-718-7100      [jce@clinicaethics.com](mailto:jce@clinicaethics.com)

[www.clinicaethics.com](http://www.clinicaethics.com)

### **EDITOR IN CHIEF**

**Edmund G. Howe, MD, JD**

Professor of Psychiatry, Director of Programs in Medical Ethics, Uniformed Services University of the Health Sciences

### **EXECUTIVE EDITOR AND PUBLISHER**

Norman Quist

### **MANAGING EDITOR**

Leslie LeBlanc

### **ASSOCIATE EDITORS**

**Armand H. Matheny Antommara, MD, PhD, FAAP**

Cincinnati Childrens' Hospital

**Jeffrey T. Berger, MD**

Winthrop Hospital

**Arthur L. Caplan, PhD**

New York University Langone Medical Center

**Christine K. Cassel, MD**

American Board of Internal Medicine

**Dena S. Davis, JD, PhD**

Lehigh University

**Arthur R. Derse, MD, JD**

Medical College of Wisconsin

**Nancy Neveloff Dubler, LLB**

New York City Health and Hospitals Corporation

**Ezekiel J. Emanuel, MD, PhD**

University of Pennsylvania

**Joseph J. Fins, MD, MACP**

Weill Cornell Medical College

**Paul Ford, PhD**

Cleveland Clinic

**Rebecca E. Garden, PhD**

State University of New York, Upstate Medical University

**Jodi Halpern, MD, PhD**

University of California, Berkeley

**Albert R. Jonsen, PhD**

University of Washington

**Eric Kodish, MD**

Cleveland Clinic

**Robert J. Levine, MD**

Yale University

**Charles MacKay, PhD**

National Institutes of Health

**Alan Meisel, JD**

University of Pittsburgh

**Christine I. Mitchell, RN, MS**

Children's Hospital of Boston

**Jonathan D. Moreno, PhD**

University of Pennsylvania

**Jamie Lindemann Nelson, PhD**

Michigan State University

**Robert Pearlman, MD, MPH**

Seattle VA Medical Center

**Thaddeus Mason Pope, JD, PhD**

Hamline University School of Law

**Lainie Friedman Ross, MD, PhD**

University of Chicago

**James E. Sabin, MD**

Harvard Pilgrim Health Care and Harvard Medical School

**Mark Siegler, MD**

University of Chicago

**Robert Truog, MD**

Harvard Medical School Childrens Hospital

**William J. Winslade, PhD, JD, PhD**

University of Texas Medical Branch

**The Journal of Clinical Ethics**, ISSN 1046-7890, print and electronic versions.

**The Journal of Clinical Ethics** is a peer-reviewed, refereed journal, indexed in PubMed, Research Alert, and Cumulative Index to Nursing & Allied Health Literature.

**Photocopying:** All rights reserved. No part of this journal may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or by any other information storage and retrieval system without the prior written permission of *The Journal of Clinical Ethics*.

**Note:** *The Journal of Clinical Ethics* does not hold itself responsible for statements made by any contributor. Statements or opinions expressed in *The Journal of Clinical Ethics* reflect the views of the authors. This journal is published as an information and research tool only. The publisher is not rendering legal or medical advice nor is the publisher to be held liable for the accuracy of the information contained herein.

© 2017 by **The Journal of Clinical Ethics**.

Please contact Mary Gesford at 240-420-8850 or [jce@clinicaethics.com](mailto:jce@clinicaethics.com) for assistance with subscriptions.

## *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.

---

**Edmund G. Howe, MD, JD**, is Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland; and Editor in Chief of *The Journal of Clinical Ethics*. The opinions or assertions contained herein are the private views of the authors and are not necessarily those of the AFRRI, USUHS, or the Department of Defense. The funders had no role in study design, data collection, and analysis, decision to publish, or preparation of the manuscript. Conflicts of interest: none.

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 teenage 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 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

I would like to thank N. Quist for his careful reading and most insightful comments and suggestions.

1. L. Freitag and J. Liaschenko, "Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability," in this issue of *JCE*, 28, no. 3 (Fall 2017).

2. N. Noddings, *Caring* (Berkeley, Calif.: University of California Press, 1984), 73-74.

3. "Noddings asserts that caring is not complete unless recognized by the cared-for person, but this position is clearly wrong." J.C. Tronto, "Women and Caring: What Can Feminists Learn About Mortality From Caring?" in *Gender/Body/Knowledge*, ed. A.M. Jaggar and S.R. Bordo (New Brunswick, N.J.: Rutgers University Press, 1989), 172-8, 178.

4. M. Tousignant and B. Miller, "Baby K's Mother Gives Her the Prayer that Many Deny She Has," *Washington Post*, 7 October 1994.

5. R. Nolan, B. Luther, P. Young, and N.A. Murphy, "Differing Perceptions Regarding Quality of Life and Inpatient Treatment Goals for Children with Severe Disabilities," *Academic Pediatrics* 14, no. 6 (2014): 574-80.

6. M-S. Lizotte et al., "Optimizing Empathy and Compassion During End-of-Life Conversations with Parents in Neonatology: Parents' and Providers' Perspectives," 2016 American Society of Bioethics and Humanities meeting, Washington, D.C.

7. K. Evers, "Neurotechnological Assessment of Consciousness Disorders: Five Ethical Imperatives," *Dialogues in Clinical Neuroscience* 18 (2016): 155-62.

8. P. McArthur, "Carried and Held: Getting Good at Being Helped," *International Journal of Feminist Approaches to Bioethics* 5, no. 2 (Fall 2012): 162-9, 164.

9. See J.R. Bach, "The Use of Mechanical Ventilation is Appropriate in Children with Genetically Proven Spinal Muscular Atrophy Type 1: The Motion For," *Paediatric Respiratory Reviews* 9, no.1 (2008): 45-50, and M.M. Ryan, "The Use of Invasive Ventilation is Appropriate in Children with Genetically Proven Spinal Muscular Atrophy Type 1: The Motion Against," *Paediatric Respiratory Reviews* 9, no. 1 (2008): 51-4.

10. A.M. Chung, "Percutaneous Gastrostomy Feeding Tubes in End Stage Dementia: Don't 'Just Do It,'" *Canadian Association of Radiologists Journal* 63, no. 3 supp. (2012): S5-6.

11. I. Brown, *Boy in the Moon: A Father's Journey to Understand His Extraordinary Son* (New York: St. Martin's Griffin, 2009), 156.

12. R.D. Stolorow, "A Phenomenological-Contextual, Existential, and Ethical Perspective on Emotional Trauma," *Psychoanalytic Review* 102, no. 1 (2015): 123-38, 128, 124, 123, 132, 134.

13. K.I. Eisenberger, "The Pain of Social Disconnection: Examining the Shared Neural Underpinnings of Physical and Social Pain," *Nature Reviews/ Neuroscience* 13, no. 6 (2012): 421-34.

14. S. Raz and B.D. Berger, "Social Isolation Increases

Morphine Intake: Behavioral and Psychopharmacological Aspects," *Behavioural Pharmacology* 21, no. 1 (2010): 39-46.

15. J. Lock, "Where Are We? Psychosocial Treatments for Eating Disorders in Children and Adolescents," 2017 American Psychiatric Association meeting, San Diego.

16. D. Zaidi, "Re-Evaluating the Ethics of Uterine Transplantation," in this issue of *JCE*, volume 28, no. 3 (Fall 2017).

17. A. Gawande, "Being Mortal: Medicine and What Matters in the End," 2014, <https://www.youtube.com/watch?v=VDdtAiTrwt4>.

18. For discussion of the need to speak up, see B. Murphy, "To Err is Human. To Speak Up? It Depends, Study Says," *AMA Wire*, 19 June 2017. I would like to thank Norman Quist for referring me to this piece.

19. A.E. Caruso Brown, "At the Intersection of Faith, Culture and Family Dynamics: A Complex Case of Refusal of Treatment for Childhood Cancer," in this issue of *JCE*, volume 28, no. 3 (Fall 2017).

20. W. Laqueur, J.T. Baumel, and J. Tydor, *The Holocaust Encyclopedia* (New Haven, Conn.: Yale University Press, 2001), 346-50.

21. D.B. Kraybill, S.M. Nolt, and D.L. Weaver-Zercher, *Amish Grace* (San Francisco, Calif.: Jossey-Bass, 2007).

22. J. Lindemann Nelson, "How We Become Who We Are: Ashley, Carla, and the Rest of Us," in this issue of *JCE*, volume 28, no. 3 (Fall 2017).

23. K.S. Smith and A.N. Graybiel, "Habit Formation," *Dialogues in Clinical Neuroscience* 18, no. 1 (2016): 33-43; A.M. Graybiel, "Habits, Rituals and the Evaluative Brain," *Annual Review of Neuroscience* 31 (2008): 359-87.

24. M. DeGuzman, "Association of Elevated Reward Prediction Error Response with Weight Gain in Adolescent Anorexia Nervosa," *American Journal of Psychiatry* 174, no. 6 (2017): 557-65.

25. S. Lupkin, "Patient Restraints: Bad Medicine," *Medpage Today*, 2 March 2016.

26. Brown, *Boy in the Moon*, see note 11 above, pp. 156, 224.

27. Stolorow, "A Phenomenological-Contextual," see note 12 above, p. 132.

28. R.B. Carr, "Authentic Solitude: What the Madness of Combat Can Teach Us About Authentically Being-With Our Patients," *International Journal of Psychoanalytic Self Psychology* 9, no. 2 (2014): 115-30, 116.

29. *Ibid.*, 122, 126, 128.

30. M. Straus, "Being There," *Psychotherapy Networker* 41, no. 3 (2017): 40-5, 41.

31. K. Neff, *Self-Compassion* (New York: Harper Collins, 2011), 44, 75, 88-9.

32. M. Krakovsky, "The Self-Compassion Solution," *Scientific American Mind* 28, no. 3 (2017): 65-9, 68.

33. *Ibid.*, 67.

34. Brown, *Boy in the Moon*, see note 11 above, pp. 184-5.

35. McArthur, "Carried and Being Held," see note 8 above, p. 164.

36. Gawande, "Being Mortal," see note 17 above.

## Features

# Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability

*Lisa Freitag and Joan Liaschenko*

### ABSTRACT

The controversy over the so-called Ashley Treatment (AT), a series of medical procedures that inhibited both growth and sexual development in the body of a profoundly intellectually impaired girl, usually centers either on Ashley's rights, including a right to an intact, unaltered body, or on Ashley's parents' rights to make decisions for her. The claim made by her parents, that the procedure would improve their ability to care for her, is often dismissed as inappropriate or, at best, irrelevant. We argue, however, that caregiving is a central issue in the controversy, as Ashley's need for caregiving is a defining characteristic of her life. In this article, we analyze the ethics of the Ashley Treatment within the context of family caregiving. Through the physical and emotional work of caregiving, families participate in the formation and maintenance of personal identity, a process that Hilde Lindemann recently called "holding." We argue that, in an intellectually disabled person such as Ashley, who depends on her family for every aspect of her care, the family's contribution to identity is an essential source of personhood. We believe that the treatment can be justified if it is indeed an instance of appropriate family "holding" for Ashley.

---

**Lisa Freitag, MD**, is a Retired Pediatrician with a Master of Arts Degree in Bioethics from the University of Minnesota Center for Bioethics in Minneapolis. [frei0035@umn.edu](mailto:frei0035@umn.edu)

**Joan Liaschenko, PhD, RN, FAAN**, is a Professor at the Center for Bioethics and at the School of Nursing at the University of Minnesota. [jlisch@umn.edu](mailto:jlisch@umn.edu)

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

### BACKGROUND

In 2004, the parents of a six-year-old, profoundly intellectually delayed girl requested from doctors at Seattle Children's Hospital a series of procedures for their daughter, Ashley, that they felt would help them manage her long-term care. None of the procedures was new, but the constellation of medical interventions in a multiply disabled child was unprecedented. Doctors, in consultation with ethicists, agreed with the parents, and the procedures were done.

Both parents and doctors, believing that they had developed a procedure that might benefit other families with similar caregiving burdens, were willing to make the process public. The parents began a blog, and the doctors published an analysis of the growth attenuation aspect of the procedure in the *Archives of Pediatric and Adolescent Medicine*.<sup>1</sup> Both expected controversy, but were stunned at the explosion of responses, many of which were deeply negative.

The girl came to be known as Ashley X, and the set of interventions called the Ashley Treatment. The treatment was comprised of several procedures whose intent was to limit her eventual body size. First were two simultaneous surgical procedures: removal of breast buds and hysterectomy. The final procedure was the administration of high-dose es-

trogen to cause early fusion of bone growth plates, effectively attenuating her growth. The stated medical reason for the surgery was to abate the unknown long-term risk of high-dose estrogen, including the possibility of rapid breast enlargement, severe uterine bleeding, and an undetermined risk of breast cancer. The medical risk/benefit ratio of the triple procedure has been much discussed elsewhere,<sup>2</sup> and we feel the evidence is, so far, insufficient to either support or oppose the procedure on medical grounds.

Additional benefits to Ashley of the three procedures, stated by her family and doctors, included preventing the discomfort of menstruation, avoiding difficulty in positioning that might result from large breasts, and completely ending the possibility of pregnancy. To her caregivers, however, the largest benefit was that keeping Ashley small would make it possible to continue their caregiving, as they had done since birth, in their home.<sup>3</sup> The most important part of this was the ability to physically hold and carry Ashley, easing the burden of caregiving for both Ashley and her parents. We believe that growth attenuation in support of family caregiving is perhaps the most significant aspect of the procedure, although it has taken the least importance in the ensuing discussions.

With the complexity of this case and its numerous divergent ramifications, it is difficult to discuss the AT as a whole. The different components of the procedure have different implications, both legal and ethical. The initial article defending the procedure defended the ethical implications and medical risk of only the growth attenuation phase of the procedure. The inclusion of hysterectomy in the AT also adds the factor of involuntary sterilization, and the legality of this without a court order has been questioned.<sup>4</sup> There have been objections to the use of surgery to address a nonmedical problem,<sup>5</sup> discussions of the meaning of altering a “natural” child’s body,<sup>6</sup> and even controversy over the possibility of surgical pain.<sup>7</sup> Others, speaking for the disability community, question the undesirability of “stunting” normal growth, preventing the achievement of a sexually mature body, and “infantilizing” Ashley’s body.<sup>8</sup>

The discussion has also questioned Ashley’s parents’ right to decide for the procedure. Parents are, of course, called on to make medical and surgical decisions for their children who are incapable of consent. However, some believe that, in obtaining the procedure, Ashley’s parents exceeded their authority and caused her actual harm, particularly by an infringement of her right to her own healthy,

intact body.<sup>9</sup> Whether the procedure is seen as a net burden or net benefit—whether it was something that was “done to” Ashley, or “done for” her—is integral in deciding if the procedure was in Ashley’s best interest. That the procedure was done at least partially in order to ease her parents’ caregiving, for some, constitutes a further wrong,<sup>10</sup> despite claims that the procedure has likely also made life easier for Ashley.

The ethical controversy over the AT persists in the pages of pediatric, ethics, and disability studies journals. Although there are many supporters, the hospital no longer offers the procedures. The parents shield their faces online, and screen all potential members of the chat room the father still runs. Ashley, meanwhile, has never developmentally exceeded two months old, and remains completely unaware of the controversy.

Our evaluation will center not on the medical burdens or benefits, or an analysis of parental rights, but on a different aspect of the procedure: the way in which it contributes to, or detracts from, Ashley’s identity. We will describe the ways in which Ashley’s identity and personhood are constructed in the context of family caregiving. We maintain that allowing the family to continue to hold her physically also supports their holding her in personhood as a valued, though profoundly intellectually disabled, individual.

#### PHYSICAL HOLDING AND EARLY FORMATION OF IDENTITY

Ashley’s parents’ stated intent in seeking the procedures was to keep her small, so that they would be able to continue to hold and carry her. Ashley was, and continues to be, non-ambulatory, and, at age six, it was already beginning to be difficult to move her. Her parents were expected to perform routine caregiving tasks such as bathing and diapering. They also wanted to be able to carry her with them, so that she could continue to be physically present for family activities. They were able to envision a time when Ashley’s size would prevent her from being included in some activities, as well as a time when they would be physically unable to care for her.

There is some disagreement as to the importance of Ashley’s parents’ ability to hold and carry her. Detractors of the AT have indicated that the desire to keep her small is largely for the parents’ own benefit. It has been suggested that the procedure was done merely “for the convenience of her carers.”<sup>11</sup> Ouellette affirms the seeming selfishness of this ben-

efit: “Ashley’s parents had much to gain by changing Ashley’s body. Simply put, their lives would be made better if they modified Ashley. They would be relieved of the burden of caring for a profoundly needy adult-sized being.”<sup>12</sup> It is indeed true that the burden of caring for Ashley might be eased somewhat by keeping her small, but caring for her will never be trivial.

It is also true that there are other ways in which the parents’ caregiving burden might be relieved somewhat. A lift could be employed to move Ashley’s body from bed to wheelchair, for example. But is this truly a better option for Ashley? Few would deny that there is an intimacy in physical holding and carrying. We carry infants in our arms, or in slings that keep them near our own bodies, and no one doubts that this contact benefits the infant as well as the parent. Psychoanalytic theories support our view that the physical contact inherent in caregiving is essential, not just in meeting bodily needs, but in laying the groundwork for psychological development.

According to the psychoanalyst D.W. Winnecott, physical holding—defined as all parts of meeting the needs of an infant, including, but not limited to, actual cradling in the mother’s arms—is an integral part of the maternal-child bond. He writes that the formation of a rudimentary sense of self begins within the physical contact that is necessary for care. In the earliest, infantile stage of development, dependency is so complete that the infant can perceive no separation, either physically or emotionally, between mother/caregiver and self.<sup>13</sup> So, in this stage, an infant’s selfhood is derived from the caregiver. In psychoanalytic theory, a stable holding relationship in this stage is essential, and is the basis upon which individual selfhood is formed.

The need for physical holding in the context of caregiving declines as we grow up, but does not go away. Park MacArthur, who developed a form of late-onset muscular dystrophy, wrote about her father’s assistance with transfers, which were at that point done without mechanical assistance. She states, at age 26, “This caring labor is also affirming. Because it resembles a hug, the lift that allows a caregiver to transfer . . . me from one seat to another makes the caring aspects of assistance tangible—the lift literally looks like an expression of love.”<sup>14</sup> This sort of contact is not present in a mechanical lift. We maintain that, for Ashley as well, there is a benefit and a beauty in being physically held and carried.

Ashley will likely remain totally dependent on others to meet all of her bodily and psychological needs. She likely will remain in the infantile psy-

chological state, without the ability to develop a sense of her own separate self. In this early developmental state, her sense of self will continue to be derived from her parent’s holding. Her family, through the caregiving process, can sustain her in personhood by holding her physically.

### HOLDING IN PERSONHOOD

Physical holding begins the process of emotional development and identity formation. Families not only hold a physical place for a child to grow in personhood, they also hold an emotional place, an identity for a child’s personality to form around. For Ashley, who cannot actively uphold her own identity, the identity provided for her by her family is of the utmost importance.

Lindemann has recently proposed that one of the important functions of families is “holding” an identity for each of their members. According to Lindemann, families provide, essentially from birth, a ready-made identity, which will become the basis for each individual’s unique personhood. It is with this initial identity that a family member’s personhood is established. The “holding” becomes a mutual, interactive process as a child develops and begins to participate in the process by expressing her or his own self and desires, and accepting or rejecting the identity the family has given him or her. The identity is constructed from narrative, essentially a collaborative storytelling effort, as members share experiences and repeat them to each other. Together, the network of narratives about the family creates and upholds each other’s identities and calls new members into personhood.<sup>15</sup>

This network can sustain its members through difficult times, such as when a family member’s personal identity is threatened by serious illness or dementia. A family can “hold” members with Alzheimer’s, for example, by remembering for them what they did, how they lived, and who they were, preserving their identity even though they can no longer participate in the process. Lindemann calls this “the practice of holding the individual in personhood,” and it is done “by constructing or maintaining an identity for her when she cannot, or can no longer, do it for herself.”<sup>16</sup> The family’s holding supports both maintaining an identity and upholding personhood.

Creating and holding an identity for a typical infant is perhaps more difficult than maintaining an adult in an identity that is fading or being threatened. An infant cannot express as much as an adult, although parents report that each infant can indeed

express a unique personality from birth. An infant, however, cannot remember and tell stories for herself or others, at least initially. The infant's narrative therefore is constructed by others, and told from a third-person point of view. It is formed around very little data; a smile, a cry, a reaction to a toy, the timing and content of first words. Over time, the child's story can be honed and refined, as the child becomes an active participant in the stories told by and about her or him.

A child such as Ashley poses an even more difficult problem. Ashley cannot and likely will never be able to participate in more than a minimal way in the construction of her own identity. However, this does not prevent the formation of an identity by her caregivers. Indeed, one of the main points of Lindemann's theories is that personhood can be constructed, by families or other close social groups, for a human being who is never able to participate in the process. Lindemann claims that this account of identity formation as a social practice "allows for the possibility that a personal identity could be constructed from a purely third-person perspective."<sup>17</sup> This practice can be performed by a family or any other close social group.

Lindemann's observations of the role of family in identity formation were formed in part from the care of a sibling who, much like Ashley, had a profound intellectual disability. Her sister, Carla, had hydrocephaly and never developed the ability to express herself. She could not swallow, or smile, or speak. Lindemann points out that Carla did not meet the philosophical definition of personhood. Carla was not self-aware or capable of rational self-expression. She could not express, nor did she likely have, second-order desires. Nor did she possess an autobiographical narrative; she could not participate in the telling of her own story.

Carl Elliott has pointed out that there is a good bit of ambiguity in the way in which modern philosophy and ethics talk about such profoundly impaired children. Carla, and others with profound intellectual disability, fill none of the criteria usually used to distinguish persons, and never will. Yet, our gut feeling is that Carla is a person, and that is how we think, talk, and write about her. We call her "she" and not "it," and give her a name rather than a number.<sup>18</sup> According to Lindemann, this social practice of habitually thinking about, interacting with, and caring for Carla in the same way that persons are treated identifies her in personhood. By recognizing and responding to her as a person, her family members engaged in the "social practice of personhood."<sup>19</sup>

Like Carla, Ashley does not meet the philosophical definition of personhood. She will never develop moral agency; the available medical facts indicate that she will never function above the level of an infant. However, neither Ashley's nor Carla's personhood has ever really been in contention. Both the detractors and supporters of the AT seem to agree that Ashley is a person, if not a fully competent, decisional one. The ethical discussions about Ashley assume that she is a person, but rarely examine the source of that personhood. We do not wish to question Ashley's personhood here. We want instead to focus on the ways in which that personhood is derived and bestowed upon her by her caregivers.

We agree with Lindemann that the identity, and therefore personhood, of Carla was derived from the "third-person" narratives constructed around her. Lindemann, and her parents and siblings, wove Carla into the story of their family, even though Carla could participate only minimally in the process. Carla's identity was thus "constructed entirely from the third-person point of view. We who were her family, along with friends, neighbors, and the many health professionals she encountered in her short life, gave her all the identity she had."<sup>20</sup> They envisioned her and treated her as a daughter, sibling, or even playmate, creating a narrative for her. In this way they constructed and held for her an identity as a person.

Ashley's family has also given her an identity, and is holding her in personhood by that identity. She has been given the role in her family story of valued daughter and sibling. As it was for Carla, this is the source of her personhood. Ashley's family has an additional burden, or joy, in that her story is much longer than Carla's. Carla died at age 18 months, and her family's "holding" continues only in memory. Ashley's family has cared for her and held her in personhood for 20 years now.

#### CREATION OF IDENTITY AND CAREGIVING

We have stated that personhood is constructed in part through the cooperative, narrative work of a family or social group, and that this process can be performed for a human being who cannot participate in it. We wish now to discuss how the narratives essential for holding an infant in personhood are created by, and told in, the context of caregiving.

We turn to Lindemann again for a description of how the social practice of identity construction is done by the families of profoundly intellectually disabled children. Lindemann states that, for the

process of narrative construction of personhood to work, there must be at least some response from the individual. She believes that a family cannot hold in personhood an infant who is anencephalic or in a persistent vegetative state, in which the absence of any higher brain activity precludes the possibility of reaction. However, Carla was given her identity as daughter and sister at (or before) birth. That identity grew to include not only her diagnosis, but also other stories about her, that were based upon very minimal reactions. We believe that Lindemann, in requiring some response, has underestimated both her own ability to interpret cues from Carla and the narrative creativity of many parents.

All infants must be constantly monitored to provide for their bodily needs, and the information received from the infant is never complete. Much of the parental response is based on supposition (“it’s been three hours, the baby must be hungry”) and physical evidence (“time for a new diaper”). From this data, parents begin to form an idea of who their infant is becoming. For Carla, also, most of the family narratives, like those told about any infant, revolved around the basic activities of feeding, bathing, carrying, and comforting.

Parents caring for intellectually disabled children frequently engage in a somewhat inventive process of determining a response to care, even if no response is present. 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. Carla did not really provide much feedback. It was likely from the close monitoring required for meeting her bodily needs that Lindemann and her family based their ideas about her personality.

Likely Ashley’s family also began to “hold” her before birth, by giving her a place in the family as a daughter and sibling. Perhaps they had to alter those stories, adjust their hopes and expectations for her, as they learned of her diagnosis. Likely they have formed opinions about her personality, or at least her temperament, based on their observations of what she seems to like, or what seems to cause her discomfort, or what she seems to respond to. Certainly they have to interact with her physically: give her feedings, change her, bathe her, and move her from room to room. Her identity would have to be constructed largely from her reactions to this care given to her body.

Ashley can tell us what she wants through her response to care, and only in the most basic way, crying or seeming comfortable. She can tell us who she is only through the interpretations her caregiv-

ers form around those responses. Since she will remain verbally noncommunicative, the only way to interpret her identity/personhood is through the physical act of caregiving. Her family holds her in personhood through meeting her physical needs.

Through the enormous and ongoing task of caregiving, the parents of intellectually disabled children become inextricably bound with the lives of their children. If a child can never take over the process of identity formation, the parents become life-long interpreters of their child’s needs and personhood. As they enact this social practice of identity construction, parent-caregivers are responsible for creating the narrative of their child’s life.<sup>21</sup> Thus, claims that they make about their child’s needs and personality should not be taken lightly. Their children are called into and sustained in personhood almost entirely by the fact of their care.

We wish to note that there is another set of narratives told about Ashley, the story told by the decade-long academic discourse about her. This narrative clearly also establishes her in personhood by thought and attitude. However, the participants in the discussion do not have any actual contact with Ashley, and have constituted her as a generalized other, rather than as a particular person. It should be noted that the identity thus constructed for her has no contribution from Ashley, unlike the one given to her by her parents.

### THE PILLOW ANGEL

The creation and maintenance of identity through caregiving is certainly a moral act, particularly if there is minimal participation from the person being cared for. Lindemann agrees that family holding can be done well or badly. We believe that disagreement about the proper identity for Ashley is at the core of much of the arguments over the AT. The accusations of infantilization, denying sexuality, and stunting growth are essentially arguments for a different identity for Ashley than the one her parents have given her. The parents stand accused of forming Ashley’s body into their image of her as an infant, thus enforcing a wrong identity for her.

It is clear that Ashley’s family does not consider her merely as a body to be hauled around, kept clean, and fed. In attitude and treatment, she is treated as a person, both as an individual to be cared for and as an integral part of her family. The responsiveness inherent in good caregiving will enforce her identity as a person to be included in activities, and whose desires, if discernible, are very important. Her parents report that Ashley is seemingly happy, lay-

ing motionless on her pillow as the activity of her family revolves around her. This is the identity in which they have chosen to hold her.

Ashley's family describes her as their "pillow angel," a title that is still used on the public portion of their website. This identity, presumably repeated in family stories, implies that she is, at the very least, a cherished member of the family. The addition of the word "angel" implies a kind of holiness or innocence, although we do not know if her family intends a religious meaning here. They may mean merely that she never gets into trouble, not surprising as she is unable to move. She certainly is cherished.

However, it is true that the family also identifies her as an infant. By asking for the surgery, they requested that her body be made more in keeping with her mind, which would never advance developmentally out of infancy. No one, that we know of, has criticized her family for identifying Ashley as an angel, but there have been many objections to their treating her as a perpetual infant. Indeed, the image of Ashley being carried helpless from room to room on her pillow implies an eternal infancy. However, the ongoing necessity of bathing, feeding, and diapering her, as well as the level of emotional attentiveness she needs, is similar to the caregiving required by infants.

In asking for the AT procedures, Ashley's parents asked her doctors to reform her body in line with the care that she needs and that they are providing. By questioning their judgement, we also question the identity they have given her through this care. We have to ask, then, if holding Ashley in an identity as an infant is inappropriate for her, and if altering her body to hold her physically and emotionally in that identity constitutes a wrong.

Lindemann admits that identities can indeed be constructed inappropriately. A family who "holds well" will preserve an identity while allowing each of the individual members of the family to find their own way. They will, perhaps, hold an open future for a child, so that the child has the widest possible identities to choose from when she or he is able to do so.<sup>22</sup> A family that "holds badly" will forget or fail to acknowledge its members or, worse, enforce its own agenda for its' members' identities. They can restrict their child's future autonomy by making desirable choices impossible, or insisting on or refusing to recognize certain qualities.

Few families are totally correct in the identity they bestow upon their child. We don't usually question the identity that parents have given their child, but we do expect children to be able to refute it, to

some extent, as they mature and begin to tell their own story. If Ashley's family has constructed an inappropriate identity for her, she will never be able to refute it. If, by consenting to the AT, her parents do force her to remain in a static and inappropriate identity, that would be a great wrong. We maintain, however, that the identity of a perpetual infant is not inappropriate for Ashley.

It is true that her parents have not held open for her the possibility of becoming a full-grown, sexual woman. This is indeed an immense loss, but, along with many other privileges of adulthood, it was not taken from her by the surgery. The circumstances of her birth had already made many futures impossible. At the time of the surgery, she did not suck or swallow, did not say any words, and had minimal spontaneous movement. Her best possible developmental outcome did not allow for the emergence of the ability to take care of her own body, nor the ability to recognize her physical losses.

Some commenters on the procedure fear that Ashley's development might eventually become more advanced than anyone could predict at age six. There is an idea that she will some day come to miss those things that the surgery stole from her, particularly sexual maturity and fertility. Those who suggest this are seemingly unaware of the consequences of profound intellectual disability. Even if she makes unexpected developmental progress, it is likely that she will remain totally dependent on her caregivers. There is no possible developmental outcome that would allow Ashley the maturity to engage in consensual sexual activity. If her parents came to a fertility clinic requesting that she be artificially inseminated in order to bear them a grandchild, we would find that ethically outrageous.

Some of the detractors feel that holding Ashley as an eternal infant will ultimately result in holding her back from any development at all. The lack of ability to mature sexually is felt to contribute to that inability to mature emotionally. However, proper family holding allows for the possibility of change. In being responsive to her bodily needs, the family must monitor her emotional moods, and thus will become aware of any change in attitude or preferences. Holding her well will not hold her back from all change. In fact, attentiveness to her physical needs will lead to the recognition of any change in personality she might express.

Ashley's parents have not limited her future or her identity in any way by having the procedure done. Her impairments had already done that. Essentially the growth attenuation and surgery merely formed Ashley's body in keeping with the only iden-

tity her parents could give her. She will continue to need to be cared for as an infant, although she is, in fact, a good deal larger than a baby, despite the growth attenuation. By having the surgery, Ashley's parents insured that it will be possible to continue to care for her. Assuring her continued care is perhaps the only way they can guard her future. She is, and will remain, their pillow angel, a personality constructed through the responsive meeting of her bodily needs.

The reality of Ashley's disability is that she must be cared for as an infant; she will continue to require feeding, bathing, diapering, and comforting. As part of that caregiving, her parents will interact with her and respond to her moods, while attending to her physical needs. She will also quite probably remain at an infantile level of psychologic development, in which she benefits from the intimacy of close physical holding. Because of the surgery, she can for now continue to be held in personhood and identity as a cherished member of a family.

Being held in an identity as an infant is not inappropriate for Ashley. It is likely that it is impossible to hold her in any other way.

### CONCLUSIONS

Ashley represents a level of disability rarely acknowledged in medical or ethical literature, but unfortunately not unheard of in pediatric medicine. Ian Brown, the father of a severely intellectually and physically disabled boy, says of his son and others like him, "Until twenty years ago, children this medically complex didn't exist. They didn't survive. High-tech medicine has created a new strain of human beings who require superhuman care. Society has yet to acknowledge this reality, especially at a practical level."<sup>23</sup> Perhaps it is no surprise that there is controversy over the proper way to envision a person such as Ashley. She may well be a new type of person, one we are just beginning to see value in, and care for.

Ashley's parents, and those of similarly disabled children, understand what it means to care for a child who will remain intellectually an infant. Through caring for profoundly delayed children as cherished persons, these parents establish for their children an identity and a life narrative. Since much of the story of Ashley's life is encompassed in the act of bodily caregiving, the way in which she is cared for is central, not only to her physical comfort, but to her psychological well-being.

Within the act of caregiving, Ashley's family is holding her in personhood and identity. Because she

will never be able to participate in her story or object to its contents, the identity thus formed can never be confirmed or refuted. This does not mean that her identity is static, however. Holding well includes being responsive to changing needs and potential for growth.

It is possible that the debate over the Ashley procedure can be reframed as a debate about who, exactly, we envision Ashley to be. Perhaps Ashley has been given one identity by her parents, and an utterly different one in the ongoing discussions about her. We maintain that, because of the relationship between Ashley and her parents as responsive caregivers, the identity they have given her takes precedence. We must be careful not to impose our own identities on Ashley and her body.

We believe that the identity constructed by Ashley's family, as an eternal infant and beloved pillow angel, is not inappropriate for her. By allowing her parents to choose the growth attenuation and surgery, we have not only eased the burden of caregiving, but validated her family in holding her well. We support the procedure because it was done in accordance with an appropriate identity constructed by her caregivers.

### NOTES

1. 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 and Adolescent Medicine* 160 (2006): 1013-7.

2. *Ibid.*; J.W. Jordan, "Reshaping the 'Pillow Angel': Plastic bodies and the rhetoric of normal surgical solutions," *Quarterly Journal of Speech* 95, no. 1 (2009): 20-42; D. Sobsey, "Cutting edge treatment: Pain and surgery in the Ashley X case," *Intellectual Disabilities Bulletin* 37, no. 1 (2009): 63-90.

3. D.S. Diekema and N. Fost, "Ashley revisited: A response to the critics," *American Journal of Bioethics* 10, no. 1 (2010): 30-44.

4. J. Lantos, "It's Not the Growth Attenuation, It's the Sterilization!" *American Journal of Bioethics* 10, no. 1 (2010): 45-60.

5. Jordan, "Reshaping the 'Pillow Angel,'" see note 2 above.

6. G.E. Kaebnick, "It's against nature," *Hastings Center Report* 39, no. 1 (2009): 24-6.

7. Sobsey, "Cutting edge treatment," see note 2 above.

8. A. Asch and A. Stubblefield, "Growth Attenuation: Good Intentions, Bad Decision," *American Journal of Bioethics* 10, no. 1 (2010): 46-8, S. Goering, "Revisiting the relevance of the social model of disability," *American Journal of Bioethics* 10, no. 1 (2010): 54-5; E. Kittay, "Forever Small: The strange case of Ashley X," *Hypatia* 26, no. 3 (2011): 610-31, C.L. Marcus, "Only Half the Story," *Archives of Pediatric Medicine* 161 (June 2007): 616.

9. S.D. Edwards, "The Ashley treatment: A step too far, on not far enough?" *Journal of Medical Ethics* 34 (2008): 341-3. A.R. Ouellette, "Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley Case," *Houston Journal of Health Law and Policy* (2008): 207-44. B.S. Wilfond, P.S. Stevens, C. Korfiatis, and D.S. Diekema, "Navigating growth attenuation in children with profound disabilities: Children's interests, family decision-making, and community concerns," *Hastings Center Report* 40, no. 6 (2010): 27-40.

10. Edwards, "The Ashley treatment," see note 9 above; M. Liao, J. Savulescu, and M. Sheehan, "The Ashley Treatment: Best interests, convenience, and parental decision-making," *Hastings Center Report* 37, no. 2 (March-April, 2007): 16-20.

11. Edwards, "The Ashley treatment," see note 9 above..

12. Ouelette, "Growth Attenuation," see note 9 above.

13. D.W. Winnicott, "The theory of the parent-infant relationship," *International Journal of Psycho-Analysis* (1 January 1960): 585-95.

14. P. MacArthur, "Carried and held: Getting good at being helped," *International Journal of Feminist Approaches to Bioethics* 5, no. 2 (2012): 162-9.

15. H. Lindemann, *Holding and Letting Go: The Social Practice of Personal Identities* (New York: Oxford University Press, 2014).

16. *Ibid.*, 3.

17. *Ibid.*, 22.

18. C. Elliott, "Attitudes, souls, and persons: Children with severe neurological impairment," *Mental Retardation and Developmental Disabilities Research Reviews* 9 (2003): 16-20.

19. Lindemann, *Holding and Letting Go*, see note 15 above, p.16.

20. *Ibid.*, 8.

21. L. Freitag, *Extreme Caregiving: The Moral Work of Raising Children with Special Needs* (New York: Oxford University Press, 2017).

22. J. Feinberg, "The Child's Right to an Open Future," in *Whose Child? Children's Rights, Parental Authority, and State power*, ed. W. Aiken and H. LaFollette (Totowa, N.J.: Rowman and Littlefield, 1980).

23. I. Brown, *The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son* (New York: St. Martin's Press, 2011), 95-6.

# How We Become Who We Are: Ashley, Carla, and the Rest of Us

*Jamie Lindemann Nelson*

## ABSTRACT

Lisa Freitag and Joan Liaschenko's thoughtful and important article goes directly to the under-examined heart of Ashley's case, namely to what sustains her in a habitable and intelligible identity. Though quite sympathetic with their conclusion and line of argument, I try to trouble their proceedings a bit, largely by wondering how having a specific such identity, out of several that may be in-principle available, matters to someone with Ashley's cognitive scope. I do this not simply to be contrary, but because their article also seems to me to raise issues in the ethics of bioethics—in particular, what I call the dilemma of ethical endeavor: How ought one publicly pursue deeply important and complex issues, the very raising of which may offend interlocutors who indeed have grounds for resentment. Making a habit of second guessing oneself may be part of the answer.

## INTRODUCTION: DOING ETHICS— SOME MORAL COSTS AND CAUTIONS

Writing about ethical issues is a vexed enterprise in ways that we who work these vineyards seldom

---

**Jamie Lindemann Nelson, PhD**, is Professor of Philosophy at Michigan State University in East Lansing. For extended periods from the mid-1980s through late 2016, she was the partner of a bioethicist extensively discussed in this article, Hilde Lindemann, with whom she has also collaborated on a number of research projects. [jlnelson@msu.edu](mailto:jlnelson@msu.edu)

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

acknowledge explicitly. Consider, for example, the costs of failure. In other intellectual endeavors, the chief cost of failure would seem epistemic, theoretical—you might well bring it about that those attending to your work leave the exchange with new confusions and fewer true beliefs than they arrived with, should they be taken in by your plausible, persuasive, sincere, and yet fallacious reasoning. It's also possible that the very power of your sound reasoning might perversely encourage them to dig all the more into their own errors. Even if we believe both that the more reasonable and well-justified beliefs will out over time, and that all defensible methods must include public disputation, people who care about getting things right should care as well about the costs that may be incurred by their failure,

Yet if worries about failure in our efforts to get clear about the structure of the world deserve more attention than they generally get, the issues we face as moral thinkers are even more fraught. If we get things wrong in this domain, we not only degrade our own and possibly other people's sets of beliefs, but we lend our authority to bad behavior and may even court corrupting characters as well.

This is not something that I am charging Lisa Freitag and Joan Liaschenko with being in any particular danger of doing.<sup>1</sup> I rather think their thoughtful and sensitive return to the controversies surrounding the interventions that "Ashley" underwent over a decade ago elevates the preservation of Ash-

ley's identity to a central place in our deliberations, which is just where it ought to be. Further, in the end I accept their permissive conclusion, despite some worries about whether their use of identity can do quite all of the heavy lifting they think it does. I have had roughly this kind of view of the matter, for roughly their reasons, since first I learned about Ashley's situation a decade or so ago. Given that, it seems unlikely that my exposure to their article will erode my character further. Nor am I particularly worried in this respect about you, dear colleague. Readers of *JCE* are typically keen professionals who have a sense of their peril and can take steps to avoid it. No, what concerns and at the same time excites me about their piece is that, by topic, timing, and treatment, it foregrounds these under-considered issues in the ethics of bioethics, as it helps us to understand more fully just who Ashley is, and what is required for her to be so.

### Doing Bioethics in Fear and Trembling

Should conscientious bioethicists worry, not merely about the possibilities of inadvertently persuading people of conclusions that are erroneous—the costs of failure—but of causing unintended though foreseeable harms simply as a result of raising and pursuing certain issues in certain ways—the costs of endeavor?<sup>2</sup>

Imagine, if you can, that there has been a poor relationship between bioethics and another community of scholars whose work involves social groups who have been, variously and seriously, stigmatized, marginalized, and otherwise harmed. Imagine further that the disaffected community has reason to believe that the reasoning and pertinent conclusions of many bioethicists are marred by the same kinds of morally indefensible attitudes and practices that are at the bottom of this ill treatment generally—a particular source of resentment, as surely better might be expected of people who think about ethics for a living. Now, suppose still further that some bioethicists find a well-motivated and exciting new take on an old and betimes bitterly contentious issue whose re-awakening might, contrary to intent but predictably, deepen the divide between these groups, and cause some people significant distress.

Should we ever find ourselves facing such a situation, how, if at all, should it bear on what we write about, and how we write about it?

This is a question I raise but do not pretend to settle, although I'll have something more to say toward the close of this commentary. I will, however, try to illustrate my concern throughout by infusing my attention to Freitag and Liaschenko with a sort

of second-order self-suspicion, a sort of modesty that is focused not so much on the results of my thinking about Ashley with our authors, but on what is taken to be appropriate as a form of thought itself. This attitude is not a panacea, even when skillfully employed; still, I wish to recommend it to my fellow workers in this field. For even given the painstaking care in analysis and argument characteristic of bioethics, and our resultant confidence in the soundness of our conclusions, some issues justly trigger special worries about whether we can count on our characteristic ways of going on to detect all the reasons that bear on the issue, and reliably recognize and rectify our missteps.

Reasoning about Ashley ought to inspire just that kind of modesty—certainly for bioethicists like myself who are only starting to have experience of what living with even mild disability is like. Why, given what has long seemed to me to be a defensible justification to hand for Ashley's treatment, have so many esteemed colleagues, and particularly those who by experience, scholarship, or both, are alert to the circumstances faced by people with disabilities, seen the matter so differently?<sup>3</sup> Having already confessed my admiration for their article, sympathy for its approach, and approval of its conclusion, I shall try to think through Freitag and Liaschenko's work in ways that give a reasonably full run to countervailing concerns that emerge from disabilities-sensitive perspectives, as I understand them.

### HOLDING ASHLEY

As Freitag and Liaschenko note, the Ashley Treatment is often depicted as though it is a matter of subjecting a highly vulnerable person to surgical and hormonal treatment to benefit third parties—namely, to ease her caregivers' responsibilities, which will become increasingly challenging as she grows. Accordingly, one way of understanding the Ashley issue is to see it as a matter of what some moral theorists, with apologies to Samuel Scheffler, might call "parent-centered prerogatives."<sup>4</sup> These are considerations that purport to justify reducing the stringency of certain standing moral notions. For Scheffler, the relevant standing norm is utilitarian, but the prerogatives idea is more commodious than that. It could well modulate the force of, for example, doing no harm, putting patients' interests first, honoring patients' autonomy—those norms thought to be partially constitutive of the healthcare provider/care recipient relationship, in order to protect care-providers' interests. The incipient justification for Ashley's interventions here is that healthcare pro-

professionals were authorized by her parents, operating within the range of their parent-centered—or perhaps better, family-centered—prerogatives, as bolstered by a reasonable belief that Ashley herself would benefit from the procedure in medical ways.

In arguing for their permissive conclusion, Freitag and Liaschenko set aside such considerations of medical benefit and parental prerogatives, or perhaps, subsume them in considerations of the role of families in identity constitution and maintenance. I'm a bit dubious that this part of their strategy is altogether well advised. While it can be plausibly argued that none of these norms are either strictly observed nor strictly obligatory, unless pretty exhaustively further specified, neither are they mere pious pretense—whatever the appropriate range of parent-centered prerogatives, they can't be allowed to set countervailing patients' interests at zero. So the size of the risks to which Ashley has been subjected, the intensity and duration of discomfort or pain she suffered, are surely pertinent in determining whether what was done to her was defensible. As such, it is just slightly unsettling that Freitag and Liaschenko seem a bit insouciant about such matters, as when they write: "The medical risk/benefit ratio of the triple procedure has been much discussed elsewhere, and we feel the evidence is so far insufficient to either support or oppose the procedure on medical grounds." Their point, surely, is to remain agnostic about whether not having to, for example, experience menstrual distress or risk cancer in organs she will never use is worth whatever risks Ashley ran, or whatever pain she suffered; fair enough. Their stress is on the role of these interventions in securing Ashley a respect-worthy and coherent identity via these interventions. Yet might there not have been other habitable identities on offer for her, that did not require she undergo whatever her treatment cost her in terms of pain or risk?

This question puts the nature and value of what our authors see as Ashley's chief, nonmedical benefit on the table. Stunting Ashley's growth, preventing her sexual maturation, looks as though her parents, doctors, and nurses are making common cause with her disabling condition. They are mirroring its impact on Ashley's cognitive life with a similarly wide-ranging assault on her corporality, to steer her from one identity—a cognitively disabled adult—to another—a simulacrum of an infant—simply in order to make it easier for her parents to continue to care for her.

A good part of the burden Freitag and Liaschenko carry in their article is to challenge precisely this movement of thought. Here, they are far from insou-

ciant, but keen and resourceful. They enlist Hilde Lindemann's work on the role of social relationships in forming and sustaining individual identities, which includes a philosophical motivation for the common and crucial intuition that Ashley is one of us, a person, despite a permanent inability to conceive of herself in such terms.

### **What Personal Identities Are Made of**

Lindemann's interest is in personal identities as they involve how we understand ourselves and are understood by others, as contrasted with questions concerning how things of our sort persist over time and through change.<sup>5</sup> Much of the construction work is done not by us, but rather for us—we both piece ourselves together, and are pieced together by others. As Freitag and Liaschenko understand this process, its initial raw materials are typically provided chiefly by the results of the careful attention our bonded intimates pay to small and subtle hints and clues we provide as infants. Lindemann herself, however, emphasizes its social character—that identities are constructed out of "tissues of stories and story fragments,"<sup>6</sup> drawn largely from stock narrative plot lines available from one's culture.

The notion that personal identities are narrative in form is common enough—recall, as influential illustrations, Alastair MacIntyre's argument in *After Virtue* that, when it comes to making sense of people the kind of "deductive-nomological" explanations used in science are no improvement over ordinary, intensional explanations of human behavior that draw on the teleological structure of stories,<sup>7</sup> or Margaret Walker's argument in *Moral Understandings* that narrative provides the vehicle for expressing how persons relate to time.<sup>8</sup> While Lindemann accepts these views, her own reason for promoting a narrative perspective flows more from the content than the structure of a personal identity. Her argument for the narrative character of personal identities is itself narratively structured: throughout *Holding and Letting Go* she uses her gifts as a creative writer to tell compelling stories about both fictive and real people, that show how ubiquitous is the practice of drawing on culturally available narratives as we strive to make sense of other people, and of ourselves as well.

Lindemann also insists that there are limits imposed by this rough world on what can be achieved through our story telling: for example, for an effort to build a personal identity not to misfire, its target must have a human form, and have at least some form of subjective awareness. These constraints have been subject to some controversy even among those

broadly sympathetic with her overall view, although the effort to mark out some boundaries on what narrative can contribute to our form of life surely makes sense.

In broad terms, and acknowledging differences in emphasis, this is the conception that undergirds Freitag and Liaschenko's bid for how we should understand Ashley and what made her famous treatment defensible. She didn't go under the knife primarily to avoid periods and pregnancy, nor merely to make things easier for her parents, who denied her natural maturity because they were reluctant to accept the mounting challenges of caring for her as she grew into her own version of adulthood. Rather, her parents unflinchingly accepted the constraints that the world imposed on Ashley and creatively worked within them to sustain their daughter's identity within her intimate circle. The physical interventions made it much easier—perhaps even possible—for her 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. If the treatment is alleged to infantilize her, the reply is that no identity foreign or distasteful to her is being imposed—she can continue to be her family's sweet little pillow angel for the rest of her life.

That this isn't a fantastic and perhaps disturbing image is supported by Lindemann's account of how our personal identities in general require other people to sustain them, the practice that she has dubbed "holding" in personhood. In the poignant chapter from *Holding and Letting Go* that serves as a touchstone for Freitag and Liaschenko's position, Lindemann describes how the distinctive personhood of her own cognitively disabled sister was crafted by her family. She provides a lovely and affecting vignette about the six-year old Hilde deciding that Carla, clearly uncomfortably warm, needed her mother, and, ever so carefully, lifting her sister out of her crib, and carrying her down a flight of steps brought her to Mrs. Lindemann, who reacted with what might be called veiled consternation. In this glimpse into the Lindemann story, we get a sense of the interlinked attitudes and practices that marked Carla as one of the family.

It's important to Lindemann, and to Freitag and Liaschenko, too, that the conferral of personhood on Carla and Ashley not be understood as a mere *façon de parler*. It is the real deal we are talking about here—which implies that a person's own contribution to who and what they are is not essential; this in turn raises questions about who has authority to narrate the identity of such people.

No challenges to the identity-constituting narratives enfolding Carla or Ashley could be expected to arise from their own point of view. Yet they well might from other, third-person perspectives. What prevents stories of the child as an oppressed victim, rather than a cherished daughter, from becoming the stuff of Ashley's identity, particularly if we accept Lindemann's stress on the socially available narrative matrix of our identities, rather than seeing our identities as formed from idiosyncratic details known to few other than one's intimates?

Lindemann's constraints of physical form and subjective content are not designed on their own to adjudicate contesting stories pressed from other third-person perspectives. Freitag and Liaschenko gently remonstrate with Lindemann about these constraints, suggesting in effect they are too strong, that she undercuts the power of her own insight.

Yet it isn't clear to me that, Freitag and Liaschenko fully appreciate the challenge constituted by other identity-constituting narratives that might be available to Ashley. Their stress on intimate particularities as the stuff of identity-constituting narratives suggests a way of answering the threat of the alternative identity on offer from relatively remote sources—the remote sources simply don't know as much about the bare bones of Ashley's narrative. Still, the significance to Ashley herself of those details is unclear, particularly if another narrative might allow her to sidestep significant surgery. There may be more direct ways to vindicate the importance of the family Ashley has, contrasted with others who may desire to claim her.<sup>9</sup>

Despite reservations about specific formulations, Freitag and Liaschenko seem to agree with Lindemann, that the possible identities that their intimates may construct on behalf of those unable to participate in the fashioning of their own identities are not malleable in any direction that may take a family's—or anyone else's—fancy. A good part of their point is that Ashley's surgical and hormonal treatments are not so much revisions of her identity as they are its confirmation; "infantilization" is a disrespectful mélange of practices and attitude as directed to those who are not infants. But infancy is not itself an abject condition, and an infant, cognitively, volitionally, and socially, is what Ashley is, and almost surely, what she ever shall be. Further, there is no reason to believe that any of this registers with her, at all. Where is the disrespect?

### Respect and Reasons

Ensuring that Ashley can continue as part of her family of origin strikes me as a very good thing. It

confirms her as a daughter, as a sister—statuses that are deeply human. It allows her progenitors to remain her parents, her mom and dad, carrying for her as moms and dads do for their most vulnerable children. It may increase the odds that she will experience care that is not merely competent, but exacting, for at least many years to come.

Yet there are those who are greatly troubled by the thought of Ashley remaining fixed in her pillow angel identity for decades yet to come, who see in her treatment another instance of nonconsensual power operating in the lives of people with disabilities for the primary benefit of others than themselves. If they think the goods of family life were substantially diminished or even silenced by what was done for it to continue, I'm not convinced that all the resources needed to reply effectively can be found in the way our authors deploy Lindemann's account of the narrative conditions of personal identity.

It can't, for example, be enough to point out that Ashley, while fully a person and therefore vulnerable to dignitary offenses, surely doesn't resent her treatment. Ashley has a strong moral claim to be well cared for. Yet the distinction between good care provided by the touch of her parents' loving hands, as opposed to good care provided via a competently used lift, while, as noted in the text, is extremely significant to Park McArthur, may not be salient to a person like Ashley at all. In addition to suffering from muscular dystrophy, McArthur is a visual artist and feminist aesthetician with graduate degrees, award-winning installations, and publications in significant intellectual journals to her credit.<sup>10</sup>

Further, while Donald Winnicott may well be spot-on in identifying parental touch as a crucial requisite for infants with developmental potential, the importance of parental touch must be differently understood for someone like Ashley, whose developmental path is so atypical.

If we are going to find a place from which to argue successfully about whose account ought prevail, we may need other aspects of Lindemann's thought to help us out. Chief among these, I suspect, will be some of the corollaries for families and for healthcare of her insistence on the deeply social character of selves: for example, her view that families typically play particularly crucial roles in forming and sustaining our identities, and her idea that family caregiving typically operates according to different and quite defensible moral norms, than those involved in the provision of professional healthcare. We may also need a good answer to a question that may not get an explicit reply in Lindemann's text.

### **Why Being Held in Your Identity Matters—Even When it Doesn't Matter to You**

In addition to crediting the good faith and reasonableness of her parents' belief that the treatment will make life easier and safer in the long run for Ashley, we ought to consider that the importance to Ashley's parents of the particular style of loving caregiving they provide to their daughter is worthy of our respect, even if it may not be experientially significant to Ashley herself. Considering the impact of caregiving on caregivers, and allowing treatment decisions to be influenced by it is not a common understanding of the moral defaults in healthcare. But Ashley's primary caregivers are not healthcare professionals. They are her family, and there is surely something to be said for allowing them to make determinations that will allow the family and its members, not only to endure, but to flourish, with Ashley at its heart. Given the role of this particular family in providing loving care to their daughter while maintaining her in a respect-worthy identity, their claim to represent her interests in seeking medicine's help in continuing to provide such care deserves sympathetic attention.

Yet if we allow the tethers between Ashley's experiential good and justifying surgical and medical interventions to loosen, it seems that we may need to allow other considerations than those concerning her family to have a look in, too. In emphasizing how identities are formed out of fragments of "stock plots," rather than idiosyncratic details, Lindemann is supported by the idea that our intelligibility to ourselves and to others is more readily secured if at least a good deal of the semantic resources used for the job are widely familiar. At least in principle, however, this must be a reciprocal process—we find in the general library of narrative themes the resources to understand who we are, and we then work in our own distinctive elements, a few of which may sometimes become both sufficiently distinctive and sufficiently celebrated—or excoriated—to attract the attention of others and win a place for themselves in the storehouse of stories.

One of the distinguishing features of Ashley's story is that it introduces new and unsettling elements to a common story, a new variation on themes available to disabled people: a surgically shaped pillow angel, whose body is medically adjusted not in response to her own most deeply felt yearnings for a coherent identity, but to suit the desires of others. Particularly given the tragic history of nondisabled people making free with the bodies of people with disabilities, resistance to the spread of this narrative seems not only reasonable, but required.

This is just where I want to return explicitly to the theme of the ethics of bioethics in general, and to the ethics of endeavors in particular. It's been a decade and more since Ashley underwent her treatment; is it really a good idea to return to it now, when nothing seems practically pressing about the case or any offshoots, and when dredging it up again may cause more people with disabilities to feel again unheard and hurt, and more disabilities scholars to feel yet further alienated by mainstream bioethics? There surely needs to be a reason for running such risks, that goes beyond the opportunity to insert a bright new idea into the literature.

But here's just where I think Freitag and Liaschenko have made a substantial and worthy contribution by drawing the connections between Ashley, Carla, and Lindemann's work. Lindemann provides a way of thinking about personhood and personal identity that allows Ashley and Carla, and so many others like them, to count robustly and univocally as persons, despite lacking the kinds of complex subjectivities that allow them to understand and have views about their situations—considerations that are criterial for personhood in so many philosophical theories. In Lindemann's more naturalized account, the work of identity formation and maintenance as it involves people with profound cognitive disability is no more the heteronymous imposition of an alien will in their lives than it is in anyone's; rather, it seems part of the work that's necessary to bring it about that one might speak with sense about Ashley and Carla's having the kind of dignity that makes these concerns pertinent at all.

I don't wish to deny that growth attenuation and sterilization are, at first face, very disquieting, as is the notion of a person living on for decades, yet always held in her earliest identity. Yet one of the lessons that mainstream bioethics, and mainstream society in general can learn, if we will but be taught, from the witness of people with disabilities and the work of disabilities studies scholars, is that the human form is express and admirable in many different incarnations. It might be useful, in my view, for work such as is attempted by Freitag and Liaschenko to note and feature such affinities with the views expressed by those involved in the disability community, as they attempt to reawaken debate on such a deeply fraught matter.

Of course, I have not the slightest wish to discourage the pursuit or the publication of deeply thoughtful and creative research—quite the contrary. Yet everyone tempted to weigh in ought to do so in the awareness that, among its other effects, their work may help shape such variations on the stock

plots that allow us to envisage and enact new forms of identity; whether the Ashley Treatment was or was not justified may, at day's end, be influenced by which understandings of identity in general, and of her identity in particular, get the most uptake. In their public performances, bioethicists and disabilities scholars may do more than argue for one or another such conception—they may help bring about what they warn against, replenishing the stock of stories with the story of Ashley: either a cautionary story of parental indolence, that marred the natural character of a child's body, or a laudatory story of parental creativity that sustains a child's identity while it expands our sense of the ways the human form can have beauty and dignity. Who Ashley ultimately is may remain an open question—something else she shares with many of the rest of us.

#### CODA: HOLDING CARLA

I conclude with a short memory of a walk I once took through an autumn graveyard in St. Peters, Minnesota, roughly 30 years ago. I was with the woman who would become the author of *Holding and Letting Go*, and we were looking for the resting place of her sister. Memory is an odd thing; I remember how poignant that walk felt, and, almost incredibly, I am pretty sure I remember what I was wearing. What I can't quite remember is whether we ever found Carla; if pressed, I'd have to say that I don't think we did. Not that it really matters; it was in the looking that we continued to affirm who Carla was, and to hold her in that identity, despite her then being 35 years gone, and no more able to understand what we were about than she was when her six-year old sister gently scooped her from her crib, and so carefully carried her down the steep stairs to their mother.<sup>11</sup>

#### NOTES

1. L. Freitag and J. Liaschenko, "Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability," in this issue of *JCE*, 28, no. 3 (Fall 2017).

2. I'm aware that my handling of the ethical problem involved in failing at and even attempting ethical argument is couched in a cognitivist idiom, but it seems to me that the same issues arise for any noncognitivist meta-ethics that accommodates the notion that some ethical positions are more satisfactory than others, and that ethical reasoning can be worthwhile, as a means of sorting sheep from goats. I further assume that the vast majority of bioethicists accept meta-ethical views that are so accommodating. Translation from my idiom to your favorite non-

cognitivist jargon should be straightforward.

3. I have particularly in mind here many of the writers cited in Freitag and Liaschenko, note 8, in particular: Adrienne Asch, Sara Goering, and Eva Kittay, from whose work I have learned a good deal, though not, I expect, as much as any of these scholars think I ought to have.

4. See Samuel Scheffler, *The Rejection of Consequentialism: A Philosophical Investigation of the Considerations Underlying Rival Moral Conceptions*, 2nd ed. (New York: Oxford University Press, 1994).

5. To use a distinction introduced into the literature by Marya Schechtman, Lindemann offers an answer to the *characterization* question, as opposed to the *reidentification* question. See M. Schechtman, *The Constitution of Selves* (Ithaca, N.Y.: Cornell University Press, 2007).

6. H. Lindemann, *Holding and Letting Go: The Social Practice of Personal Identities* (New York: Oxford University Press, 2014).

7. A. MacIntyre, *After Virtue: A Study in Moral Theory*, 3rd ed. (Notre Dame, Ind.: University of Notre Dame Press, 2007).

8. M.U. Walker, *Moral Understandings: A Feminist Study in Ethics*, 2nd ed. (New York: Oxford University Press, 2007).

9. At a meeting at the Hastings Center on prenatal screening held in the mid-nineties, I well remember the passion with which a disabilities studies scholar, herself a woman with disabilities spoke of aborting fetuses as a result of finding them to have anomalies that would give rise to disabilities. "These are *our* children," she said.

10. "Park McArthur," [https://en.wikipedia.org/wiki/Park\\_McArthur](https://en.wikipedia.org/wiki/Park_McArthur).

11. This article is a contribution to the work of the Project on Responsibilities in Change/The International Research Consortium on the Ethics of Families in Health and Social Care ([www.familyethics.net](http://www.familyethics.net)) funded by the Netherlands Organization for Scientific Research (NWO). Many of its themes are discussed in more depth in my contribution to *Social Lives, Personal Identities: Essays in Honor of Hilde Lindemann*, currently in preparation.

# Giving Voice to the Voiceless: The Colorado Response to Unrepresented Patients

*Deb Bennett-Woods, Jean Abbott, and Jacqueline J. Glover*

## ABSTRACT

Medical decision making on behalf of unrepresented patients is one of the most challenging ethical issues faced in clinical practice. The legal environment surrounding these patients is equally complex. This article describes the efforts of a small coalition of interested healthcare professionals to address the issue in Colorado. A brief history of the effort is presented, along with discussion of the legal, ethical, practical, and political dimensions that arose in Colorado's effort to address decision making for unrepresented patients through an extension of the existing Colorado Medical Treatment Decision Act (CRS 15-18).<sup>1</sup> A discussion of lessons learned in the process is included.

## INTRODUCTION

“Unrepresented patient” is one of many terms used to describe a class of persons for whom the capacity to make medical decisions is absent or substantially impaired. “Unbefriended,” “adult orphan,” and “patient alone” also refer to this singularly vulnerable group of people who lack power or voice in representing themselves when confronting

medical decisions requiring informed consent. The lack of family, friends, or other social connections to make medical decisions can lead to delays in diagnostic procedures or treatment, prolonged or overly aggressive treatment, or extended placement in an acute care setting or other highly restricted environment. Such conditions come with associated clinical risks and threats to patients' finances, housing, and psychological well-being. The patients are among the most at risk in the healthcare system.<sup>1</sup>

Statistics on the number of such patients in various settings of the healthcare system are scarce, yet there is general agreement that it is growing.<sup>2</sup> Both the elderly and the chronically ill populations are increasing in number, with many of these individuals having outlived or been estranged from family and friends. Added to this are homeless persons, the mentally ill, and intellectually or developmentally disabled persons who do not have a guardian or other representation.

Current statutory solutions vary widely across the United States. The fact that there is no widely agreed upon standard for addressing decisions for unrepresented patients further increases the overall vulnerability of this population. In 2016, the American Bar Association Commission on Law and Aging reported that slightly less than half of the U.S. states have a comprehensive healthcare decision act that allows a range of decision makers including relatives, close friends, and clergy. Hawaii, Illinois, Kentucky, and Montana are examples of states with a comprehensive act. A few other states address proxy decision makers in focused statutes such as those on do-not-resuscitate (DNR) orders (Georgia), living

---

**Deb Bennett-Woods, EdD**, is Professor Emerita and Faculty at Regis University in Denver, Colorado. [dbennett@regis.edu](mailto:dbennett@regis.edu)

**Jean Abbott, MD, MH**, is Professor Emerita and Faculty at the Center for Bioethics and the Humanities, University of Colorado Anschutz Medical Campus, in Aurora, Colorado. [jabbott49@gmail.com](mailto:jabbott49@gmail.com)

**Jacqueline J. Glover, PhD**, is a Professor at the Center for Bioethics and the Humanities, University of Colorado Anschutz Medical Campus. [Jackie.Glover@ucdenver.edu](mailto:Jackie.Glover@ucdenver.edu)

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

wills (Iowa) or informed consent (North Dakota). South Dakota is an example of a state with a separate surrogate consent act. In most cases, these acts and statutes are silent beyond providing a common list or hierarchy of surrogates and assume someone will be found. West Virginia and the District of Columbia explicitly prohibit healthcare providers or facility employees from acting as a surrogate decision maker. Florida's statute allows the appointment of a licensed clinical social worker by a bioethics committee. However, most states with a comprehensive healthcare decision act that goes beyond the standard list of surrogate candidates have utilized physicians in the role of proxy decision maker. The most common approach authorizes the attending physician in consultation with an ethics committee or second physician (Alabama, Alaska, Arizona, New York, Oregon, Tennessee, and Texas).<sup>3</sup>

### PROXY DECISION MAKING IN COLORADO

Colorado has efficiently addressed a wide scope of issues related to medical decisions in the Colorado Medical Treatment Decision Act.<sup>4</sup> Section 18.5 of this act, entitled "Proxy decision makers for medical treatment authorized," specifically addresses surrogate decision making for incapacitated patients who lack a medical durable power of attorney or relevant advance directive. Developed during the 1980s in response to social changes that included the HIV epidemic and an aging population, the Colorado law accurately anticipated the need to create a flexible framework from which to draw potential surrogate decision makers. Rather than default to a specified hierarchy of familial surrogate candidates, the Colorado statute allows a broad range of interested parties (including not only family but close friends) to agree on a decision maker best able to represent the values and interests of the patient. In most cases, this approach is very helpful in identifying an appropriate decision maker.

Unfortunately, the Colorado statute failed to address the possibility that no interested party could be found, leaving facilities and healthcare providers with few options for timely medical decision making. In addition, Colorado lacks a guardianship system that can accommodate the nature and timing of medical decision making. In Colorado, the most common source of volunteer guardians has a waiting list of several months to a year or more. There is no system of public guardianship. The general guardianship process in the courts ranges from weeks at minimum to months or even well over a year. In addition, this process assumes that a willing candidate for a permanent guardian can be found

and is comfortable making medical decisions. Adult Protective Services is statutorily limited in applying as an interested person and, in most counties, will rarely act as a medical proxy.

### Colorado Collaborative for Unrepresented Patients

After a decade or more of general discussion among the Colorado healthcare ethics community, a coalition formed, calling itself the Colorado Collaborative for Unrepresented Patients (CCUP). The CCUP consisted of a small and loosely affiliated group of interested healthcare professionals, led primarily by representatives of two university ethics centers in the greater Denver area and the Colorado Healthcare Ethics Forum (CHEF). CHEF is a unique volunteer organization composed of a diverse membership of Colorado's ethics community, whose mission is to provide a forum for discussion and education for ethics committee members and other interested professionals. The formation of the CCUP launched a five-year odyssey that ultimately resulted in passage of a state statute addressing unrepresented patients. However, the path itself was not at all direct and reflects the complexity of the issue.

The initial intent of members of the CCUP was to research and write a white paper that explored existing approaches to the issue of unrepresented patients with the hope to eventually enable the creation of a network of qualified, volunteer proxy medical decision makers in Colorado. Known barriers included the lack of an ongoing supply of willing volunteers and no reliable or sustainable means of creating a community-based infrastructure to support the recruitment, training, and appointment of volunteers. The general options explored included private guardians, public guardians, attending physicians, other clinicians/individuals, and members of institutional and external committees.

As the white paper began to take shape, the CCUP team became aware of an initiative by a Denver probate judge to address the general issue of public guardianship. The team approached the judge with the specific problem of short-term medical decision making as a unique dimension of the larger issue of public guardianship. A member of the CCUP was invited to serve on a judicial task force charged with investigating and proposing a workable approach to public guardianship in Colorado. The Public Guardian Advisory Committee (PGAC) produced two well-researched reports in 2014.<sup>5</sup> The first report recommended establishment of an office of public guardianship and the second report proposed a pilot project to better define the necessary scope and likely costs. Given the problems of prior volunteer approaches, the CCUP's draft white paper was

eventually revised to support the PGAC's recommendation to establish an office of public guardianship with special provisions for medical proxy decision makers. The white paper was released in July 2014 and appended to the PGAC's second report to emphasize the unique challenge of medical decision making in the absence of a proxy.<sup>6</sup> Unfortunately, the political landscape in Colorado was such that the PGAC's recommendations did not go forward.

### A LEGISLATIVE APPROACH

With no workable community-based options and no promise of public guardianship in the near future, the CCUP went back to the drawing board and began considering legislative options. With the help and advice of an extraordinary lobbyist, who assisted our efforts on a *pro bono* basis throughout the process, we approached a member of the Colorado House of Representatives who had a known interest in both healthcare and guardianship. Having obtained his support, and with the help of a healthcare attorney familiar with the existing statutes involving both medical decision making and guardianship, HB 16-1011: Concerning Medical Decisions for Unrepresented Patients began to take shape in the fall of 2015. The goals of the proposed legislation were to:

- Address the oversight in the existing Colorado proxy statute that did not make allowance for situations in which no willing proxy can be found.
- Improve the timeliness and quality of medical decision making and placement for unrepresented patients.
- Provide transparency and a legal framework that limits professional liability and reduces the risk of unilateral decision making by physicians.
- Raise the community standard for decision making through the appropriate involvement of an ethics committee.
- Reduce moral distress among members of care teams as they experience care delays for these patients.

### Stakeholder Process

The stakeholder process began well before the legislation was drafted, with presentations and feedback sessions starting in early 2015 that proposed using physicians as proxies of last resort. Presentations were made at the annual CHEF conference and at invited sessions to an array of interested stakeholder groups. By December, a stakeholder list had been developed that included representatives of the state medical society and hospital association, indi-

vidual healthcare providers and facilities, the long-term care community, the disability community, state government (including adult protective services), the legal community, liability carriers, other professional associations, the senior lobby, and various miscellaneous other parties. Representatives of the legal community included the state bar association, with specific engagement by sections involved in elder law and guardianship, the state's association of trial attorneys, and a number of individual attorneys who specialize in health law. Professional associations included several medical specialties, nursing, social work, and chaplaincy.

The initial draft of the legislation proposed a basic modification to the existing proxy statute that allowed healthcare facilities to create a process by which an attending physician, on a voluntary basis, could serve as an interim proxy decision maker of last resort with mandatory ethics committee involvement. This draft was initially distributed to stakeholders in late November and December 2015. All the work with stakeholders up to this point suggested there was general support for legislative action, including formal support from the state medical society, and very little in the way of stated opposition. The primary concerns expressed up to that point involved dual professional roles and conflicts of interest, and the potential that the bill would become caught up in negative press and push back from advocates who opposed other legislative initiatives involving assisted death, personhood, and abortion.

Once the draft bill was circulated and formally introduced, the CCUP team did not expect the sudden level of stakeholders' opposition that arose. The first surprise was the strength of the response by the disability community; their concerns ranged from a perceived lack of due process to the historical experience of bias and devaluation of their lives by healthcare providers. Also not anticipated was strong opposition from the state's largest physician liability carrier, which directly led to an initial reversal of the medical society's position and opposition from the state hospital association. Active support from individual healthcare providers and facilities did not materialize to a meaningful extent and, in fact, resistance was encountered from the legal departments of several hospital systems. Finally, the CCUP team quickly found themselves caught in the middle of long-standing tensions between the liability carrier and Colorado's trial attorneys.

Thus, stakeholder negotiations continued throughout the legislative session and beyond. The challenges that arose in both the stakeholder process and the subsequent legislative process were

variously legal, ethical, political, and practical in nature. Given the complexity of the issues, it was not surprising to find a great deal of crossover between these four dimensions.

### **The Legal Dimensions**

The legal dimensions of HB 16-1101 were largely focused on deep-seated and opposing views between the Colorado Trial Lawyers Association (CTLA) and the primary medical professional liability insurance carrier for Colorado physicians regarding liability language in the proposed statute. This dispute then extended to many of the acute care facilities and hospital systems. Representatives of CTLA were concerned that the statute went too far in limiting the liability of healthcare providers and the rights of patients to file suit. The liability carrier insisted that facilities and healthcare providers willing to act on behalf of patients should be protected, so long as decisions are made in accordance with the statute.

The position of the CCUP team was that nothing in the proposed statute protected either physicians or facilities from legal action based on medical negligence or malpractice. Furthermore, the team argued that the current situation, in which physicians either delayed treatment decisions or made them unilaterally, was already fraught with potential liability. Nonetheless, attempting to garner agreement on the specific language within one brief section of the bill proved to be perhaps the greatest challenge faced. It resulted in numerous behind-the-scenes negotiations, competing versions of language, and specific clarifications of intent.

The other legal concerns raised by a variety of stakeholders involved the issues of dual roles and potential conflicts of interest in having the attending physician also act as the proxy decision maker. Inconsistencies in current Colorado statute served to confuse the issue. For example, while paid caregivers, including long term care administrators, are specifically prohibited from petitioning to also be a patient's or resident's guardian, the proxy decision maker section of the Colorado Medical Treatment Decision Act was silent on the potential role of healthcare providers as proxy medical decision makers.<sup>7</sup> On the other hand, the proxy statute did appear to explicitly prohibit Adult Protective Services from petitioning as an interested person for purposes of becoming a proxy medical decision maker despite the fact that Adult Protective Services could accept appointment as a guardian.<sup>8</sup> In addition, the guardianship statutes restricted the ability of direct service healthcare providers, including long term care administrators, from applying as guardians. Competing interpretations of existing law there-

fore raised questions about the legal status of any healthcare provider willing to serve in the role of proxy decision maker.

Colorado's primary medical professional liability insurance carrier also argued against the bill based on dual roles. The initial bill allowed for appointment of the attending physician as a proxy, and the early debate over both liability language and conflicts of interest was resolved, in part, by agreeing to use a different willing physician, who is not clinically involved in the treatment of the unrepresented patient, as the physician proxy. This change initially satisfied not just the trial attorneys, but also helped address the concerns of other stakeholders, including disabilities advocates.

However, the liability carrier eventually took issue with the use of a second physician, claiming that it created additional confusion with respect to liability standards and dual roles. The carrier argued that a physician providing a medical opinion as a consultant is held to the higher standard of a medical expert, or what a reasonable physician would recommend under the same circumstances. Under normal circumstances, a proxy decision maker would be held to the lower standard of ordinary negligence, which simply requires acting with the same degree of care as any other prudent person. In the case of HB 16-1101, the carrier argued that a physician acting as an interested person in the role of proxy might still be held to the higher standard even though, in that role, the physician would not be covered under a professional liability policy. Therefore, the conclusion of the carrier, as stated in its testimony during the first committee hearing, was that it would actively discourage physicians from acting in this capacity.

Related concerns over dual roles and conflicts of interest involved the imposition of a physician's values on the patient and potential pressure from the facility to make decisions based on financial factors. Although several parties shared this concern, the liability carrier was particularly strident in its insistence that a physician could not reasonably wear both hats. Throughout the process, the position of the CCUP team was that the potential for conflict of interest was already inevitable, and that the present situation, in which no proxy is appointed, carried a greater potential for unchecked conflicts of interest, given the lack of formal oversight and transparency. The team argued that safeguards in the bill, including an independent capacity assessment, mandatory ethics committee involvement, and a second medical opinion in end-of-life decisions, lent transparency and provided assurance that a multidisciplinary viewpoint, already accustomed to ne-

gotiating values-driven decisions, is in place. The team claimed that there are substantially more protections in this process than the average proxy process involving a distant or estranged relative who may have little insight into the patient's wishes. The CCUP team made the case that the current hesitation to make decisions (in order to limit liability) represented as great a conflict of interest as decisions made on the basis of direct financial factors.

### **The Ethical Dimensions**

The proposed legislation attempted to address a number of ethical dimensions relevant to this patient population. The primary challenge for medical decision making when a patient lacks a voice is how best to discern and honor the patient's values and those choices the patient would make if capable of fully informed and autonomous decision making. However, this is not the only ethical challenge. Unrepresented patients raise issues of preventing needless or avoidable harm, determining best interests, and achieving social justice, all of which were addressed at some level by the proposed legislation.

Respecting patients' autonomy, even when using a patient-appointed proxy, is challenging, since there is evidence that proxy choices do not reflect patients' preferences as much as 30 percent of the time.<sup>9</sup> No process can completely guarantee that the decisions made will be consistent with what an unrepresented patient might want; however, the participation of a multidisciplinary ethics committee can support the process by ensuring that patients are involved to the extent that they can be, that any existing collateral evidence of values is considered, and that bias is minimized by providing diverse perspectives to advocate for the patient.

The high potential for overtreatment, undertreatment, delayed treatment, and the risks associated with extended and inappropriate placement raise complex questions of patients' best interests and avoidable harm. For all practical purposes, delaying medically indicated urgent or elective procedures due to the lack of a proxy *is* a medical decision, as is continued aggressive treatment that the care team might not otherwise recommend to a capacitated patient or a proxy. Both situations offer the potential for increased suffering and for actions not fully in line with a patient's best interests or even optimal standards of care. When a patient's best interests are not evident, or it is difficult to weigh potential harms, shared decision making using an ethics committee can facilitate thoughtful deliberation and representation of a range of viewpoints.

Perhaps the most pressing ethical aspect of caring for unrepresented patients is their sheer vulner-

ability. Patients who lack capacity or who suffer from diminished capacity and who do not have representation are totally powerless and dependent on the care team for their medical well-being.<sup>10</sup> Many of these patients are the targets of negative assumptions and social biases regarding the elderly, the physically disabled, the intellectually or developmentally disabled, the mentally ill, the homeless, undocumented immigrants, and others. They often lack the means or opportunity to assure fair and equitable treatment or to appeal decisions made on their behalf. By mandating the involvement of an ethics committee, the legislation introduced a new level of protection based on the transparency of the decision-making process and a multidisciplinary effort to seek the patient's voice.

### **The Practical Dimensions**

A number of practical concerns were raised by individuals and institutions during the process of negotiating the legislation. While most of the stakeholders' and legislators' questions were logistical in nature (and too detailed to address in the statute), the conversation itself was instrumental in developing shared understanding, support for the legislation, and then, later, a process to develop implementation guidelines. These issues included, among others, due diligence in attempting to locate a proxy, the qualifications and education of a physician proxy, the termination of a physician proxy's responsibility, decision-making capacity assessments, an ethics committee's role and the extent of its involvement, and the possible lack of availability of an ethics committee in rural hospitals or other non-hospital facilities.

A good example of the practical issues encountered was the question of whether advance practice nurses could also serve as medical proxy decision makers under the statute. As a stakeholder in our process, the Colorado Nurses Association was supportive of an expanded definition of medical proxy, particularly in rural areas where there is a serious shortage of healthcare providers. While the CCUP team had no objection to the addition of advance practice nurses for practical purposes, it was strongly advised not to amend the bill in this direction due to current political realities related to other legislation and debate regarding scope of practice.

Of primary importance in addressing the many practical dimensions was the recognition that different settings were going to have different resources and different needs, so there was a strong effort to keep the statute itself as broad as possible in terms of specific requirements. The intent was to allow facilities to develop policies and procedures that met

the intent of the statute that were suited to each facility's unique context. The CCUP team's stated commitment to assist in the development of more specific implementation guidelines following passage of the bill was particularly helpful in preventing the process from getting bogged down with these issues.

### **The Political Dimensions**

The political dimensions reflected a combination of the legal, ethical, and practical aspects earlier. In particular, the legal concerns and subsequent lobbying efforts of both CTLA and the liability carrier became a primary political barrier to passage of the statute. In addition, there were challenges associated with competing priorities during this specific legislative session. There were a number of health-care related bills with significant fiscal implications that diverted attention from the efforts on behalf of the unrepresented. As mentioned earlier, political dynamics around scope of practice prevented the addition of advance practice nurses as proxy decision makers. In addition, and of particular concern, was HB 16-1054: "Concerning end of life options for individuals with a terminal illness," which we recognized could easily become negatively conflated with our bill by opponents of the assisted death initiative, including our stakeholders in the disabilities community.

More generally, the legislative effort was hampered by the relative obscurity of the issue. Although their numbers are increasing, these patients make up a small percentage of inpatient admissions. Aside from anecdotal case summaries, there are no systematic data documenting the number of patients and the relative costs or clinical outcomes of these patients as a class. There are no family members or friends to raise alarms, and many of our stakeholders proved unwilling to publicly advocate for these patients. On the positive side, the bill addressed an obvious shortcoming in existing statute, and did so in a manner that involved no fiscal impact. In addition, its use remained voluntary and at the discretion of both healthcare facilities and physicians.

### **THE LEGISLATIVE PROCESS**

As HB 16-1101 was altered to accommodate stakeholders' concerns, the CCUP team, the lobbyist, and our sponsors prepared for hearings in the Colorado House of Representatives. Prior to the first hearing in the house, and based on intensive meetings with stakeholders, the bill was revised to add an independent medical capacity assessment. In addition, language around the role of ethics commit-

tees was strengthened to require their agreement with significant medical decisions on behalf of a patient. Later in the process, the term "agreement" was changed to "consensus." Efforts to negotiate liability language that was acceptable to both the trial lawyers and the liability carrier failed.

The initial hearing of the bill in the Colorado House Committee on Health, Insurance, and Environment was unexpectedly contentious. We had been advised that the house would be the easier of the two state legislative bodies to approach, yet that proved not to be the case. In a hearing lasting nearly three hours, representatives of the trial attorneys and the liability carrier were called upon and challenged to defend their opposition to the bill. In addition, several amendments offered by committee members, relating mostly to end-of-life decisions, were introduced, debated, and defeated. One amendment, requiring facilities without an ethics committee to obtain an ethics consultation from another facility did pass. The bill eventually passed the committee on a vote of seven to six, along party lines.

The initial passage of the bill through committee brought the stakeholders back to the table. The primary issue remained liability, with stakeholders' efforts to include liability protections for physicians, facilities, and even members of ethics committees. Detailed requests for revision were received from several stakeholders, and a compromise version of the bill was crafted based on what we and our sponsor were willing to take forward. The most significant revision, proposed by CTLA, was to change the proxy-of-last-resort from the attending physician to a physician who is not involved in the treatment of the patient and appointed by the attending physician, with ethics committee approval. At the request of the liability carrier, a detailed list of the points at which a proxy's responsibilities terminated was added. In response to the concerns expressed by house committee members, language protecting against euthanasia that was consistent with other Colorado statute was added. Also, consistent with other existing Colorado statute, a second clinical opinion in end-of-life decisions was added. Finally, new liability language specifying a good faith standard for the physician acting as a proxy, specifying that the attending physician remains responsible for negligent acts or omissions in rendering care, was adopted. Through continued work with representatives of the disabilities community, we were able to make the above changes that enabled them to fully support the bill.

The substantially amended bill was introduced on the floor of the house, passed on a second and third reading, with a single technical amendment

on a vote of 40 to 25, with 18 cosponsors, and was referred to the Colorado Senate. Passage into the senate garnered yet another round of meetings with stakeholders. In particular, the liability carrier remained generally opposed to the bill, requesting that we return to having the attending physician serve as proxy and expressing continued concerns regarding untested liability, legal standards, and conflict of interest. Its position continued to be that it would instruct clients not to use the statute if it passed, rendering it virtually useless. The ensuing discussion was substantive and valuable, but a decision was made not to change the bill at that point and further requested amendments were not accepted.

Upon arrival in the senate, it was discovered that the bill was slated to be “killed” without an initial hearing. However, our lobbyist succeeded in turning the ship and located a senate sponsor on the Health and Human Services Committee. Despite testimony against the bill by the liability carrier, the bill received a favorable initial hearing and was passed unanimously, with one minor technical amendment to the floor. Here, it should be noted, further conversation with the liability carrier and the state hospital association did eventually result in support for the bill. The bill went on to pass the senate on third reading by a 33 to one bipartisan vote, and a successful concurrence vote back in the Colorado House of Representatives. The governor signed it into law on 18 May 2016.<sup>11</sup>

### IMPLEMENTATION

The statutory language of HB 16-1101 became law on 5 August 2016, and healthcare providers across the state began the process of implementation. To effect our goal of ensuring a more standardized and consistent approach to unrepresented patients, the CCUP engaged stakeholders to facilitate the development of a guidelines document to assist facilities in developing internal policies and procedures consistent with the statute. Active participation by numerous stakeholders, including the liability carrier and state hospital association, was of great value. The first version of the guidelines was released in November of 2016, and, as of this writing, the statute is in active use by at least a subset of healthcare providers and facilities.

### LESSONS LEARNED

The importance of a strong and broadly targeted stakeholder process cannot be understated. Earlier engagement with several key stakeholders could have avoided some of the initial opposition. For

example, we did not adequately include patient advocacy organizations, such as those in the disabilities community, until an early draft of the bill was circulated in late November 2015. Although key representatives from the disabilities community did ultimately support the bill, the initial response was negative, and we belatedly discovered that the entire process would have benefitted from their active engagement and advice during the initial drafting of the bill. Likewise, efforts earlier in the year to engage the state’s medical society and the state’s hospital association, among other key stakeholders, were not successful, with both organizations advising us to come back in the fall once the bill was drafted. However, it was not until the bill was introduced that serious objections were raised by these and other organizations. Key stakeholders then insisted that another full year was needed to work out the details, although it was unclear how another year would guarantee compromise once the immediate pressure of the legislative session was removed. While successful in our response to work very hard to keep bringing stakeholders back to a sense of urgency on the issue by emphasizing the negative impacts of further delay on patients and healthcare providers, it was clear that we had missed an opportunity to create momentum with specific stakeholders earlier in the process.

Another key lesson was the power of lawyers and liability carriers to dominate opinions. The CCUP team underestimated the extent and speed with which the liability carrier and the trial lawyers’ association could shift the positions of other stakeholders. Because we focused initially on the healthcare provider community, who we felt had a stake in the issue second only to the patients themselves, we neglected to fully consider nonhealthcare provider stakeholders such as the liability carriers and other members of the legal community, who exerted great influence over both healthcare providers and legislators.

Finally, the team’s perspective came from our experience at the bedside with direct healthcare providers, social workers, chaplains, and others from the Colorado healthcare ethics community who experienced firsthand the problems of “doing right” for this vulnerable group of patients. While ethics committees are often the venue in which these cases play out, the committees were not necessarily effective in communicating the issue and our legislative efforts to the top of their organizations. Therefore, there was little engagement from healthcare leaders, particularly from the hospitals, who deferred to their legal departments and the state hospital association. As noted previously, the extent to which

hospital legal departments took issue with the proposed statute was something that perhaps should have been anticipated, but was not.

On the positive side, our team learned very quickly the importance of patients' stories and proactive efforts to educate stakeholders and legislators. As is common with legislation, the issues are complex, and many of the decision makers will be marginally (if at all) familiar with the context and details of an issue. We created three documents that proved invaluable as the process unfolded. The first was a two-page (front and back) document entitled *Stories from the Bedside*, that presented eight actual patient cases to illustrate the range of potential circumstances and consequences of under treatment, over treatment, and improper placement for these patients. The second was a single page fact sheet presenting two brief cases, the definition of an unrepresented patient, an outline of the scope of the problem, and a request for legislative action. The third document, entitled *Questions and Response*, was more lengthy, and posed 25 questions, based largely on existing feedback from stakeholders, that anticipated legal, ethical, and practical concerns. The document detailed answers that addressed each concern in relation to the proposed statute. This last document also provided our team with consistent language to use when addressing stakeholders and providing testimony. Taken together, these documents provided stakeholders and, most importantly, legislators with information and detailed answers to relevant questions that may or may not have been addressed via testimony.

The final lesson was clearly the importance of collaboration and compromise. Although some of the compromises made the statute more cumbersome, the final legislation absolutely benefitted from most of the revisions negotiated throughout the process. Likewise, the process itself generated a community of stakeholders, both individual and institutional, that had previously not worked together on such an issue. It is easy to foresee these groups more easily coming together on similar issues in the future. For example, our team efforts contributed to a renewed legislative focus on the issue of public guardianship, which is now being addressed in the in the 2017 legislative session, and has brought many of the former stakeholders back together.

#### NOTES

1. T.M. Pope, "Making medical decisions for patients without surrogates," *New England Journal of Medicine* 369 (2013): 21-3; D.B. White, J.R. Curtis, B. Lo, and J.M. Luce, "Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and

surrogate decision-makers," *Critical Care Medicine* 34 (2006): 2053-9; B.D. Weiss, E.A. Berman, and D.L. Howe, "Medical decision-making for older adults without family," *Journal of the American Geriatric Society* 60 (2012): 2144-50.

2. T.M. Pope and T. Seller, "Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients without Surrogates (Part 1)," *The Journal of Clinical Ethics* 23 (Spring 2012): 84-96; Weiss, Berman, and Howe, "Medical decision-making," see note 1 above; White, Curtis, Lo, and Luce, "Decisions to limit," see note 1 above; T.M. Pope, "Legal Briefing: Adult Orphans and the Unbefriended: Making Medical Decisions for Unrepresented Patients without Surrogates (Part 2)," *The Journal of Clinical Ethics* 26, no. 2 (Summer 2015): 180-8.

3. American Bar Association Commission on Law and Aging, "Default surrogate consent statutes," 2016, [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2014\\_default\\_surrogate\\_consent\\_statutes\\_authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes_authcheckdam.pdf); E. Wood, "If there is no advance directive or guardian, who makes medical treatment choices?" *Bifocal* 37, no. 1 (2015): 10-1, [https://www.americanbar.org/content/dam/aba/publications/bifocal/BIFOCALSept-Oct2015\\_authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/publications/bifocal/BIFOCALSept-Oct2015_authcheckdam.pdf).

4. Colorado Revised Statutes, Title 15, Article 18, "Medical Treatment Decision Act," and Title 15, Article 18.5, "Proxy decision-makers for medical treatment and surrogate decision-makers for health care benefit decision," <http://www.lexisnexis.com/hottopics/Colorado/>.

5. Office of Public Guardianship Advisory Committee (OPGAC), "Recommendations for a Pilot Program: The Public Guardianship Advisory Committee's Report to the Chief Justice of the Colorado Supreme Court," 2014, [http://www.courts.state.co.us/userfiles/file/Court\\_Probation/Supreme\\_Court/Committees/Public\\_Guardian/Office\\_of\\_Public\\_Guardianship\\_Final\\_Report\\_and\\_Recommendations\\_July312.pdf](http://www.courts.state.co.us/userfiles/file/Court_Probation/Supreme_Court/Committees/Public_Guardian/Office_of_Public_Guardianship_Final_Report_and_Recommendations_July312.pdf); OPGAC, "Office of Public Guardianship Advisory Committee Recommendations: The Public Guardianship Advisory Committee's Report to the Chief Justice of the Colorado Supreme Court," 2014, [http://www.courtscolorado.org/repository/Inside\\_Bar/Trust\\_Estate/Trial\\_Procedure/2014\\_Office%20of%20Public%20Guardianship%20-%20Final%20Report%20\(2\).pdf](http://www.courtscolorado.org/repository/Inside_Bar/Trust_Estate/Trial_Procedure/2014_Office%20of%20Public%20Guardianship%20-%20Final%20Report%20(2).pdf).

6. CCUP, "Addressing Gaps in Healthcare Decision Making for Unrepresented Adults: A Proposal for the Inclusion of a Public Healthcare Guardian in the Office of Public Guardianship," 2014, <http://www.coloradoethicsforum.org/resources.html>.

7. Colorado Revised Statutes, Title 15, Article 14: Probate, Trusts, and Fiduciaries § 15-14-413-(5), (6a) and (6)(b).

8. Colorado Revised Statutes, Title 15-18.5-103(8).

9. D.I. Shalowitz, E. Garrett-Mayer, and D. Wendler, "The accuracy of surrogate decision makers: A systematic review," *Archives of Internal Medicine* 166 (2006): 493-7.

10. D.B. White et al., "Life support for patients without a surrogate decision maker: Who decides?" *Annals of Internal Medicine* 147 (2007): 34-40.

11. Colorado HB 16-1101, "Concerning medical decisions for unrepresented patients." For a review of the legislation and the legislative process: <https://legiscan.com/CO/text/HB1101/2016>.

# Re-Evaluating the Ethics of Uterine Transplantation

*Danish Zaidi*

## ABSTRACT

In February 2016, the Cleveland Clinic initiated the first attempt at cadaveric uterine transplantation (UTx) in the United States. The transplantation was ultimately unsuccessful, but it opened doors for further research on both live and cadaveric UTx. While initial strides toward successful transplantation have been made, questions persist on the ethics of UTx: whether the uterus is a vital organ, whether we should prioritize live or cadaveric options, and how the procedure should be covered by health insurance. If we agree that the goal of the medical profession is both to treat and improve quality of life, then the question of whether or not infertility is considered a disease becomes inconsequential in the discussion. As such, the medical enterprise should move forward with research in UTx. In doing so, considering the ethical implications of UTx remains essential—and we must remember to pair innovation with regulation.

Two years ago, Mats Brännström at the University of Gothenburg in Sweden reported the first successful live birth following uterine transplantation. A 61-year-old woman who had been postmeno-

pausal for seven years had donated a uterus to a vetted recipient. The pregnancy suffered from no complications until gestational week 31, day five, when the woman who received the transplant was admitted for pre-eclampsia, and a healthy baby boy, named Vincent, was delivered by cesarean section, with normal weight and Apgar scores.<sup>1</sup> In the following month, Brännström reported two additional successful live births, this time without pre-eclampsia.

While the long-term implications of uterine transplant for Baby Vincents and their mothers remain unknown, the work that Swedish researchers have done is impressive. For those who suffer from absolute uterine factor infertility (AUI), the Swedish researchers have opened a door to an alternative to adoption or gestational surrogacy. (It is worth noting that gestational surrogacy is banned in Sweden and other parts of the world, unlike in the U.S.<sup>2</sup>). Moving forward, Brännström's team hopes to reduce surgery time and risk using three-dimensional mapping for advanced planning and using robotic assistance.<sup>3</sup> Given this, one can assume that researchers will continue to innovate and improve the uterine transplant procedure to the extent that it gains “alternative” rather than “experimental” status.

As the U.S. now looks to experiment with the possibility of UTx, many relevant ethical considerations have been raised that have kept deliberative conversations ongoing. In particular, three points are

---

**Danish Zaidi, MTS, MBE**, is a Doctor of Medicine Candidate at Wake Forest School of Medicine in Winston-Salem, North Carolina; is an Alumni Affiliate of the Harvard Medical School Center for Bioethics in Boston; and is Vice Chair of the American Medical Association, Medical Student Section, Committee on Bioethics and Humanities. [dzaidi@wakehealth.edu](mailto:dzaidi@wakehealth.edu)

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

worth focusing on: (1) the medical necessity of UTx when considering the vitality of the uterus, (2) the issue of live versus cadaveric donation in UTx, and, finally, (3) the question of funding streams for these transplants. This article offers a brief overview of the aforementioned ethical considerations and concludes by arguing that the U.S.—as a leader in medical research—should move forward with UTx, to set a regulatory model that can be adopted/emulated by countries that similarly offer this transplant procedure.

## IDENTIFYING THE STAKEHOLDERS

### Patients

Within the U.S., of approximately 62 million women of reproductive age, almost 9.5 million suffer from uterine factor infertility (UFI), and seven million suffer from absolute UFI.<sup>4</sup> UTx offers these women an alternative to adoption or gestational surrogacy. It allows a genetic link between parent and child (not possible through adoption), and offers some of the physical and psychological aspects of pregnancy and childbearing that are lost in gestational surrogacy.<sup>5</sup> To those who identify UFI as a “diseased state,” a transplant would be a step toward a “treatment” for infertility, although it cannot be seen as a “cure,” as UTx would still require assisted reproductive technologies (ART) through in-vitro fertilization (IVF) and—more importantly—a transplanted uterus would need to be removed after a given number of pregnancies to reduce the long-term side-effects of immunosuppressive medications.<sup>6</sup> Some of the obvious harms to a patient who receives a transplant would include (1) repeated surgeries: a cesarean section to deliver each child, and at the completion of childbearing, a hysterectomy; (2) the side-effects of immunosuppressive medication, which would subside upon removal of the uterus (the same cannot be said for other, nonvital transplants like the hand and face that require lifelong immunosuppression); and (3) the possible psychological harms of feeling obligation, indifference, or guilt at sharing another’s organ and—by association—that person’s reproductive identity.<sup>7</sup>

### Donor

A donor faces more risks in donating a uterus than she would for other organs due to the greater duration (roughly 10 hours) it takes to procure the organ.<sup>8</sup> Risks similarly seen in hysterectomy would be characteristic of live donors, including bleeding, infection, damage to the urinary tract or bowel, and/or adverse reactions to anesthesia.<sup>9</sup> There are also

potential risks for coercion, especially in the context of related donors.<sup>10</sup> This can be avoided through altruistic donation.

### Fetus and Potential Child

Medical risks to the potential child are, as yet, unknown. However, before the successful birth of Baby Vincent, Brännström posited that immunosuppressive medications could potentially lead to prematurity and the risk of the newborn being small for gestational age (SGA), both contributing factors to neonatal death.<sup>11</sup> However, the subsequent successful pregnancies indicate that, with proper prenatal care, immunosuppressive medications should not cause uncontrollable complications during pregnancy. Some have pointed to the aforementioned medical harms in forming an argument similar to arguments against ART: one is better off not having been born, given the medical risks of UTx and ART. Others find this line of reasoning weak, unconvinced that “existence” is a harm done upon an agent.<sup>12</sup>

### Third Parties

There are also relevant, nonclinical parties who have a stake in this discussion: partners, doctors, and funders. Partners of recipients—despite the stress of planning for and waiting during transplantation—have reportedly responded positively in psychological follow ups by Brännström’s team, grateful to the recipient and for their relationship.<sup>13</sup> Medicine also has much to benefit from UTx: the procedure will continue to push ART forward, and also (if funding for UTx remains private) be a considerable source of revenue. This leads to the final stakeholder: funders. If health-maintenance organizations (HMOs) decide that infertility is indeed a disease, and medical experts can point to UTx as a treatment option, it will present significant costs to funders. Funding could be paid with taxpayers’ dollars; in this scenario, debate would open on whether UTx would be a cost-effective means to treat infertility.

## THE “VITALITY” OF THE UTERUS

Within the Montreal Criteria for the Ethical Feasibility of Uterine Transplantation, one of the clinical ethical points made against the practice of UTx is that—unlike the heart, liver, or kidneys—the uterus is a “non-vital organ” that is not physiologically necessary for life.<sup>14</sup> This is the starting point for an interesting conversation, because it raises important questions: (1) What are the doctor’s professional role and obligations? (2) Do we accept infertility as a disease? and (3) How do we define vital

organs? These questions are a basis for how institutions could evaluate requests for UTx.

The foundational question is, in this context, what does the professional role of the medical enterprise entail? And, relatedly, how does that play out in the obligations we owe our patients? Is the role of the physician simply to treat disease or is it also to improve the quality of life? These are tricky questions. Some may immediately point to palliative care as a compassionate example of physicians who are not (solely) focused on treating disease. In this field of medicine, the ultimate goal of the physician is to minimize pain and improve quality of life.<sup>15</sup> But the questions are more complicated when debating the necessity of elective cosmetic medical procedures performed by plastic surgeons. This specialty also improves patients' quality of life, even with, as Eric Swanson termed it, its "commercialized underbelly."<sup>16</sup> In both instances, disease is not the primary concern: in palliative care, disease is no longer being treated, and, in plastic surgery, there may be no disease to treat. Despite the lack of disease, both fields have credibility in the medical arena. This implies that, within medicine, the primary goal of treatment is complemented by a secondary goal, to improve the quality of life. The acceptance of "non-vital" transplants like that of the hand and face further support the notion that the transplant enterprise has multiple goals (saving but also improving lives).<sup>17</sup> If we accept this premise, we need not move further in argument: UTx improves the quality of life of infertile women who express a desire to become pregnant.

Some would still argue that quality of life should not be a concern within medicine; as such, treating disease becomes the sole goal. This leads to the following question: How do we define disease, and does infertility fall under that category or not? A disease is any disorder of the human body that produces signs and symptoms that are generally replicated across patients. The World Health Organization (WHO) defines infertility as "a disease of the reproductive system defined by the failure to achieve clinical pregnancy after 12 months or more of regular unprotected sexual intercourse."<sup>18</sup> Whatever the causation—UFI, cancer, and so on—infertility is a disorder that has recognizable symptoms across patients; and, given expert opinion of its status as a disease, it demands treatment.

Some may rush to argue that a uterus is not a "vital organ"—but what makes an organ vital? The uterus is not necessary to individual survival. Generally, the transplant community has sought to uphold a commitment to save lives; and, on the sur-

face, UTx does not do so.<sup>19</sup> A counterclaim is that one of the vital functions of the female body is to reproduce; without this, humanity would cease to exist. From a Darwinian standpoint, the organ is vital for "fitness" and the survival of the species.

Furthermore, with advances in technology, one could make the case that some organs are losing their "vitality." For example, there have been cases in which patients have lived on dialysis for 20 to 30 years; does this lead us to conclude that kidneys are no longer vital to human function?<sup>20</sup> No. The point of medicine is to help make our patients whole; to restore their body to a proper, nondisease state of function in which they can perform all the functions of their species and sex.

### LIVE OR CADAVERIC TRANSPLANTS?

Brännström and his team have put forth medically relevant and pragmatic reasons to argue in favor of live transplantation, at least in this early stage of UTx.<sup>21</sup> Not only does live donation allow proper planning with donor and recipient, it also allows logistical flexibility leading up to, and during, the procedure. From a clinical standpoint, the viability of the organ is greater in live donation, with minimal ischemia and improved graft survival due to minimal systemic inflammation.<sup>22</sup>

Those in favor of deceased or cadaveric donation offer both clinical and ethical arguments. In pointing to an unsuccessful instance of UTx in Saudi Arabia, it has been reported that the length of vasculature used was insufficient to supply blood to the uterus.<sup>23</sup> It would be impossible to excise a vessel graft that is the preferred length from a live donor, but from a living donor, the abdominal aorta and vena cava could be integrated into the graft.<sup>24</sup> But beyond the science, proponents of deceased donation also argue on several ethical fronts. For one, they claim that deceased donation can avoid instances of coercion and manipulation, by both family members and/or researchers (for example, organ harvesting).<sup>25</sup> More interestingly, proponents of deceased donation find that harm to a donor is justified in common transplant cases like the living donation of kidney, liver, bone marrow, *et cetera*. But, given the early stages of UTx, the unfavorable harm to benefit ratio does not (yet) ethically justify live donation.<sup>26</sup>

### WHO PAYS?

As UTx grows more promising, the question of who funds such an expensive procedure becomes

more pressing. Some critics of public funding refuse the WHO's definition of infertility as a disease, instead arguing that it is an impediment to those who have a certain "desire."<sup>27</sup> Relatedly, some question whether fertility is mislabeled as a disease, and argue instead that it is more of a social wrong. Similar to ideas of racial superiority, height, *et cetera*; this line of reasoning finds that there is nothing fundamentally wrong with infertility; it is a social problem that has come to be seen as a disease.<sup>28</sup> These arguments seek to dispel the view that infertility is a disease; if it is so defined, public funds and/or HMOs would not have to pay for UTx.

Still others argue that, while infertility is indeed a biological disease, there are appropriate alternatives that are cheaper and less risky. They argue that, rather than spend research and public dollars on UTx, efforts should be made to improve adoption laws and gestational surrogacy regulations; community engagement initiatives should seek to downplay the emphasis that society has placed on genetic relatedness.<sup>29</sup> However, there is an inconsistency in this line of reasoning; that is, surrogacy is practiced for the very reason of genetically related offspring.

Moreover, proponents of public funding for UTx have argued that, while UTx may not be necessary, there are other medically elective treatments that are funded either publicly or through HMOs, and that UTx should be treated no differently than these other elective treatments.<sup>30</sup> A final point related to cost is that it remains unclear whether "commercial surrogacy arrangements" in some countries are cheaper than UTx.<sup>31</sup> It may cost as much—or be even more expensive—for a family to opt for gestational surrogacy. (The high price of gestational surrogacy within countries like the U.S. has led to the growth of an international surrogacy market, as seen in countries like India).

Much of the ethical deliberation, up till now, has taken place in Europe, where most countries have public healthcare systems. In the U.S., the question of funding is more complicated, as governmental healthcare coverage is complemented by private health insurance. It will be interesting to see how HMOs will react to advances in UTx, given that most of them fund infertility treatments like IVF (but rarely gestational surrogacy)—although this is inconsistent across state lines.<sup>32</sup> But transplant procedures to address infertility are picking up steam; and with the U.S. Department of Defense negotiating funding for penis transplantation for wounded veterans, it will not be long until the spotlight shines even brighter on UTx and how it will be funded in the U.S.<sup>33</sup>

## CONCLUSION

Uterine transplantation is an exciting reality in the field of obstetrics and gynecology, offering for the first time an opportunity for infertile women to gestate their own child. Research across the world, particularly in Sweden, has opened the door to this procedure. The world now looks to the U.S. and other countries to see further innovation in UTx. But we should not fail to pair "innovation" with "regulation," to think not just of the science behind a procedure, but the complexities associated with its implementation and bringing it to scale. This review sought to give a condensed (but not exhaustive) primer on the ethical considerations surrounding UTx, from an understanding of infertility as a disease, to the ethics of live versus cadaveric donors, to the pragmatics of funding streams. As the global medical community moves to lead the next charge in UTx research, obstetricians and gynecologists, researchers, and bioethicists ought also to lead in the conversation on the regulation and implementation of UTx.

## NOTES

1. M. Brännström, "The Swedish Uterus Transplantation Project: The Story behind the Swedish Uterus Transplantation Project," *Acta Obstetrica et Gynecologica Scandinavia* 94, no. 7 (2015): 675-9.
2. L. Johannesson et al., "The Future of Human Uterus Transplantation," *Women's Health* 10, no. 4 (2014): 455-67.
3. Brännström, "The Swedish Uterus Transplantation Project," see note 1 above.
4. K.S. Arora and V. Blake, "Uterus Transplantation: Ethical and Regulatory Challenges," *Journal of Medical Ethics* 40, no. 6 (2014): 396-400; G. Del Priore et al., "Uterine Transplantation—A Real Possibility? The Indianapolis Consensus," *Human Reproduction* 28, no. 2 (2013): 288-91.
5. *Ibid.*
6. M. Brännström et al., "Livebirth after Uterus Transplantation," *Lancet* 386, no. 9968 (2015): 607-16; B.M. Dickens, "Legal and Ethical Issues of Uterus Transplantation," *International Journal of Gynaecology & Obstetrics* 133, no. 1 (2016): 125-8; R. M. Farrell and T. Falcone, "Uterine Transplant: New Medical and Ethical Considerations," *Lancet* 385, no. 9968 (2015): 581-2.
7. R. Catsanos, W. Rogers, and M. Lotz, "The Ethics of Uterus Transplantation," *Bioethics* 27, no. 2 (2013): 65-73; Arora and Blake, "Uterus Transplantation," see note 4 above.
8. Brännström et al., "Livebirth after Uterus Transplantation," see note 6 above; Farrell and Falcone, "Uterine Transplant," see note 6 above.
9. Arora and Blake, "Uterus Transplantation," see note

4 above.

10. Catsanos, Rogers, and Lotz, "The Ethics of Uterus Transplantation," see note 7 above.

11. M. Brännström et al., "Uterus Transplantation—Substantial Progress in Research but Not Yet Ready for the Clinic," *Middle East Fertility Society Journal* 12, no. 2 (2007): 86-95.

12. G. Bahadur, "Death and Conception," *Human Reproduction* 17, no. 10 (2002): 2769-75; J.A. Robertson, "Emerging Paradigms in Bioethics: Posthumous Reproduction," *Indiana Law Journal* 69 (1994): 1027-65; Arora and Blake, "Uterus Transplantation," see note 4 above.

13. S. Järholm et al., "Uterus Transplantation Trial: Psychological Evaluation of Recipients and Partners during the Post-Transplantation Year," *Fertility and Sterility* 104, no. 4 (2015): 1010-5.

14. A. Lefkowitz, M. Edwards, and J. Balayla, "The Montreal Criteria for the Ethical Feasibility of Uterine Transplantation," *Transplant International* 25, no. 4 (2012): 439-47.

15. E. van der Vinne, "The Ultimate Goal of Disease Management: Improved Quality of Life by Patient Centric Care," *International Journal of Integrated Care* 10, no. 9 (2009): e89.

16. E. Swanson, "The Commercialization of Plastic Surgery," *Aesthetic Surgery Journal* 33, no. 7 (2013): 1065-8.

17. G.J. Agich, "Extension of Organ Transplantation: Some Ethical Considerations," *Mount Sinai Journal of Medicine* 70, no. 3 (2003): 141-7.

18. F. Zegers-Hochschild et al., "International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) revised glossary of ART Terminology, 2009," *Fertility and Sterility* 92, no. 5 (2009): 1520-4.

19. Agich, "Extension of Organ Transplantation," see note 17 above.

20. J. Heaf, A.H. Nielsen, and H.P. Hansen, "Long-term Haemodialysis Survival," *Clinical Kidney Journal* 5, no. 2 (2012): 168-9.

21. M. Brännström et al., "First Clinical Uterus Transplantation Trial: A Six-Month Report," *Fertility and Sterility* 101, no. 5 (2014): 1228-36.

22. M. Brännström, "Uterus Transplantation," *Current Opinion in Organ Transplantation* 20, no. 6 (2015): 621-8; Johannesson et al., "The Future of Human Uterus Transplantation," see note 2 above.

23. N. Williams, "Should Deceased Donation be Morally Preferred in Uterine Transplantation Trials?" *Bioethics* 30, no. 6 (July 2016): 415-24.

24. A. Nair et al., "Uterus Transplant: Evidence and Ethics," *Annals of New York Academy of Science* 1127 (2008): 83-91; G. Del Priore and D. K. Gudipudi, "Promise of Uterine Transplant—Myth or a Reality?" *Maturitas* 77, no. 1 (2014): 20-3.

25. Williams, "Should Deceased Donation be Morally Preferred in Uterine Transplantation Trials?" see note 23 above; Dickens, "Legal and Ethical Issues of Uterus Transplantation," see note 6 above.

26. Williams, "Should Deceased Donation be Morally

Preferred in Uterine Transplantation Trials?" see note 23 above.

27. S. Wilkinson and N.J. Williams, "Should Uterus Transplants be Publicly Funded?" *Journal of Medical Ethics* 42, no. 9 (September 2016): 559-65; A. Griel, J. McQuillan, and K. Slauson-Bevins, "The Social Construction of Infertility," *Social Compass* 5, no. 8 (2011): 736-46.

28. G. Becker and R.D. Nachtigall, "Eager for Medicalisation: The Social Production of Infertility as a Disease," *Sociology of Health & Illness* 14, no. 4 (1992): 456-71; Wilkinson and Williams, "Should Uterus Transplants be Publicly Funded?" see note 27 above.

29. G. Becker and R.D. Nachtigall, "'Born to Be a Mother': The Cultural Construction of Risk in Infertility Treatment in the U.S.," *Social Science & Medicine* 39, no. 4 (1994): 507-18; M. Lotz, "Commentary on Nicola Williams and Stephen Wilkinson: 'Should Uterus Transplants Be Publicly Funded?'" *Journal of Medical Ethics* 42, no.9 (September 2016): 570.

30. A. Alghrani, "Yes, Uterus Transplants Should be Publicly Funded!" *Journal of Medical Ethics* 42, no. 9 (September 2016): 566-7.

31. J. Balayla, "Public Funding of Uterine Transplantation," *Journal of Medical Ethics* 42, no. 9 (September 2016): 568-9.

32. M.A. Reynolds et al., "Does Insurance Coverage Decrease the Risk for Multiple Births Associated with Assisted Reproductive Technology?" *Fertility and Sterility* 80, no. 1 (2003): 16-23.

33. M. Cohn, "Hopkins Makes the Case for Penis Transplants," *Baltimore Sun*, 26 February 2016.

# May Medical Centers Give Nonresident Patients Priority in Scheduling Outpatient Follow-Up Appointments?

*Armand H. Matheny Antommara*

## ABSTRACT

Many academic medical centers are seeking to attract patients from outside their historical catchment areas for economic and programmatic reasons, and patients are traveling for treatment that is unavailable, of poorer quality, or more expensive at home. Treatment of these patients raises a number of ethical issues including whether they may be given priority in scheduling outpatient follow-up appointments in order to reduce the period of time they are away from home. Granting them priority is potentially unjust because medical treatment is generally allocated based on medical need and resource utilization, and then on a first-come, first-served basis. While it is difficult to compare the opportunity cost of waiting for an appointment to different patients, nonresident patients incur higher expenditures for travel, room, and board than resident patients. Giving them priority in scheduling to reduce these costs may be justifiable. Preferentially scheduling nonresident patients may also indirectly benefit resident patients consistent with Rawls's difference principle. This potential justification, however, rests on several empirical claims that should be demonstrated. In addition to reducing resident patients' waiting times, medical centers should not prioritize nonresident patients over resident patients with more urgent medical needs. There is, there-

fore, a limited and circumscribed justification for prioritizing nonresident patients in scheduling follow-up appointments.

## INTRODUCTION

With increasing financial pressures on academic medical centers, some have sought to recruit patients from outside their historical catchment areas. Some of these patients live beyond a reasonable commuting distance from the institution and require local accommodations. Being away from home is an issue for these patients and those paying their expenses due to the personal and financial costs, and the question arises whether it is ethically acceptable to expedite outpatient follow-up appointments to facilitate their return home. This question can be analyzed in terms of justice, and useful analogies may be drawn with concierge medicine and the treatment of very important persons (VIPs). The formal principle of justice is based on treating similar cases similarly. Potential criteria for what makes patients similar or different include medical need and resource utilization; status; opportunity costs; and the costs of travel, room, and board. The allocation of healthcare resources is typically based on patients' medical need and resource utilization. Patients with similar need and utilization are then generally treated on a first-come, first-served basis. While concierge practices may provide patients within the

---

**Armand H. Matheny Antommara, MD, PhD**, is Director of the Ethics Center and Lee Ault Carter Chair of Pediatric Ethics at Cincinnati Children's Hospital Medical Center, in Cincinnati, Ohio. [armand.antommara@cchmc.org](mailto:armand.antommara@cchmc.org)

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

practice greater access to providers than other practice models, these benefits do not typically extend beyond the practice itself. At times, however, different treatment in some respects is justified in order to treat patients similarly in other, ethically relevant respects. For example, additional effort may be required to protect celebrities' confidentiality. While status and opportunity costs are not ethically relevant to scheduling, a potentially relevant consideration is the increased travel, room, and board costs nonresident patients incur. In addition to the formal principle of justice, there are a number of substantive principles. Unequal treatment may also be justified by Rawls's difference principle; privileging nonresident patients in scheduling may indirectly benefit resident patients. This empirical claim should be verified. The difference principle, however, does not justify prioritizing nonresident patients over resident patients with more urgent medical needs. Therefore, while there are some potential justifications for giving nonresident patients priority in scheduling outpatient follow-up appointments, they are limited in their scope and force.

### BACKGROUND

Given the economic downturn, uncertain reimbursement environment, and increased competition, some academic medical centers in the United States have sought to diversify and strengthen their sources of income. One potential mechanism is recruiting patients, either domestic or foreign, from outside of their traditional catchment areas. This article will refer to these patients as nonresident. (Residency is independent of citizenship.) These individuals may seek treatment that is unavailable, higher quality, or lower cost than in their local community. In addition to increasing facilities' patient volume, these patients are attractive to medical centers because their treatment is typically reimbursed at a higher rate than Medicare or Medicaid through self-pay, commercial insurance, or government sponsorship. Medical centers may also seek wealthy patients as potential donors. Recruiting patients from new catchment areas may also support the institutions' education and research missions.<sup>1</sup>

Treating such patients may generate additional issues for medical centers. They may need to provide interpretation services and develop their staff's cultural competence. They may also need to facilitate lodging and provide appropriate dietary choices. Care of patients from other cultures may also raise ethical issues, such as requests for careproviders of a particular gender or differences in informed consent or end-of-life care.<sup>2</sup>

One prosaic ethical issue that has arisen in the treatment of nonresident patients relates to the scheduling of appointments. Nonresident patients may be away from home for significant lengths of time, hundreds of days. During some of this time, the patients may have been discharged from the hospital and be living in the local community awaiting outpatient follow-up. It may not be possible to schedule these follow-up appointments prior to the patient's arrival, and outpatient clinics may have significant waiting times, weeks or months, for appointments. The issue has arisen whether it is ethically acceptable to schedule nonresident patients sooner than resident patients. (Note that this particular response is not an effort to reduce waiting times in general, which would benefit both resident and nonresident patients.<sup>3</sup>) This issue is most appropriately analyzed in terms of justice.

### FORMAL JUSTICE

Justice does not require treating everyone the same. Rather it requires treating similar cases similarly. The crucial question is what are the ethically relevant similarities and differences.<sup>4</sup> Medical care in the U.S. is generally or ideally allocated based on medical need and resource utilization and then on a first-come, first-served basis. (It should be acknowledged that many individuals' access to healthcare is constrained by their ability to pay.)

### Medical Need and Resource Utilization

*Primary care.* In the primary care setting, even within concierge practices, appointments are typically based on medical need and then on a first-come, first-served basis. Careproviders typically have fixed-length appointment slots and assign different categories of patients different numbers of slots. Categories may include sick, well, and new patients. Careproviders may also have access rules that specify how available slots may be assigned. They may, for example, reserve a certain number of sick visits that cannot be scheduled more than one day in advance in order to accommodate urgent needs. (Clinics may also accommodate excess demand by double-booking patients or extending service hours.) Each category of visit is generally scheduled on a first-come, first-served basis: the first caller has the first choice among available appointments. Scheduling specialty care is more complex because it generally involves different length appointment slots and a higher percentage of urgent patients.<sup>5</sup>

Some careproviders have developed a practice model called various names including retainer, concierge, boutique, and luxury primary care, in which

patients pay an annual fee for greater access. The annual fee is typically \$2,000 to \$4,000. (A practice may also bill patients' insurance. Some insurance plans, however, prohibit balance billing or charging access fees.) This source of revenue allows careproviders to have smaller panels of patients: approximately one-third fewer. Careproviders offer amenities or special services such as longer appointments, house or office calls, and accompanying patients to specialists or procedures. The practices typically provide patients with 24-hour-a-day, seven-day-a-week access via telephone or email.<sup>6</sup> Analysts contend that, while patients receive additional services, they do not necessarily receive a higher quality or standard of care.<sup>7</sup> Data regarding resource utilization and health outcomes in retainer practices compared to conventional practices are lacking.

Some have criticized this model for reducing access<sup>8</sup> or unjustly creating two tiers of healthcare.<sup>9</sup> Within this system, however, patients are treated similarly in the allocation of appointments. Patients generally do not receive similar amenities when they see a specialist or are hospitalized.<sup>10</sup> (For the purposes of this discussion, executive physical programs—corporate-sponsored examinations for top executives at referral centers<sup>11</sup>—are more like domestic medical tourism than retainer medicine, because they involve generalist and specialty care, but do not provide patient-centered, comprehensive primary care.)

*Emergency care.* In acute and emergency care, patients are generally triaged based on medical need and resource utilization. Most triage systems utilize five, rather than three or four, levels.<sup>12</sup> The most commonly used triage system in the U.S. is the Emergency Severity Index (ESI). The highest level, Level 1, are patients who require immediate lifesaving interventions, and the second highest level, Level 2, are patients who are in high-risk situations; are confused, lethargic, or disoriented; or in severe pain or distress. Levels 3, 4, and 5 are differentiated on the basis of how many different resources—laboratory and radiographic studies, treatments, specialty consultations, and procedures—patients need. Level 3 patients, who require many different resources, can be increased to Level 2 if their vital signs are in the “danger zone.”<sup>13</sup> ESI has been shown to be both reliable and valid.<sup>14</sup> (Military and disaster triage systems differ from emergency triage by including a category for patients who will die even with treatment, and by potentially prioritizing individuals who are essential to the war effort or to the common good.)<sup>15</sup>

Level 1 patients are seen before Level 2 patients, and Level 2 patients are seen before Level 3, 4, and 5 patients. Level 3, 4, and 5 patients are generally

tracked to the appropriate level of service and then are seen on a first-come, first-served basis. In triage in the emergency department, need and resource utilization are the relevant criteria, and patients with the same level of need and resource utilization are treated similarly.

### **Security and Confidentiality**

While medical treatment in the U.S. is predominantly allocated based on medical need and resource utilization, there are other potential criteria for allocating treatment. An example of just, although potentially different, treatment is modifying treatment based on the need to protect patients' security or confidentiality. The confidentiality of all patients should be protected. To provide the same level of protection, some patients may, however, be treated differently. There may be more interest in politicians' or celebrities' medical information, and special actions, such as placing them in a private area or treating them under a pseudonym, may be necessary to provide the same level of protection.<sup>16</sup> Note that being placed in a private area, such as a treatment room, does not mean being treated sooner.<sup>17</sup>

### **Status and Opportunity Cost**

An example of potentially unjust treatment is the preferential treatment some VIPs (very important persons) receive in emergency departments. VIPs may include not only celebrities and political leaders, but also individuals who are influential within the healthcare organization, such as board members and their families.<sup>18</sup> Schenkenberg, Kochenour, and Botkin reinterpret the I in VIP as *influential*, to include anyone whose clinical or personal characteristics produce a significant alteration in the clinical approach.<sup>19</sup> It is an open question whether this different medical treatment represents higher quality of care. Some have raised the concern that being treated by the department chair or being spared uncomfortable or complex procedures may produce worse outcomes.<sup>20</sup>

Empirical data suggest that VIPs are frequently treated sooner than other patients in emergency departments.<sup>21</sup> Diekema, among others, argues that this is unjust because social status is not a morally relevant criterion. He contends that while individuals who have contributed to society deserve benefits, VIPs generally have already received benefits, and that these benefits should not extend to healthcare because the healthcare system was largely developed through public funds.<sup>22</sup>

A second possible justification for seeing VIPs sooner is the opportunity cost incurred by waiting; the cost of alternatives foregone by waiting. Some

individuals' time may be much more valuable than others' and they may, therefore, bear a greater cost waiting. An engineer's hourly wage, for example, is substantially higher than a cashier's. It is not, however, clear that this is an ethically relevant criterion. The economic or social effect of the lost income may be more significant to an hourly, minimum wage employee who has no or limited financial reserves. This individual may also not have paid time off, have limited childcare resources, and/or risk losing his/her job as a result of missing work.<sup>23</sup>

### **Travel, Room, and Board**

Consideration of opportunity costs suggests another, potentially relevant consideration: the additional expenses nonresident patients incur while waiting. Martin, for example, argues, "International patients' medical care must be expedited because of the time invested and expense incurred when they travel to the United States."<sup>24</sup> Individuals who travel for healthcare typically must pay for lodging in the destination community in addition to maintaining their home. They also experience increased per diem costs for food and other amenities. If they were to go home and come back for an appointment, they would experience additional transportation costs. (These expenses may be paid for by a sponsoring agency that nonetheless has an interest in reducing these costs.) There are also nonmonetary costs, including being in a foreign culture and away from family and friends. These are costs that local residents do not incur. It may be reasonable to attempt to reduce these costs by decreasing waiting times.

It is important to note that this argument justifies reducing wait times for follow-up appointments, but not for the initial evaluation. In addition, while some institutions attempt to facilitate scheduling multiple appointments on a single day, this service is generally available to all patients.

A potential counter argument is that these patients elected to travel for medical treatment, and the additional costs should have been considered in their decision; because they were voluntarily accepted, they are not unjust. This argument would have more force if reduced cost were patients' primary decision-making criterion. It holds less force when the treatment sought is not available in a patient's home location or is only available at substantially lower quality.

### **THE DIFFERENCE PRINCIPLE**

Some individuals argue that facilitating the treatment of wealthy, influential, or nonresident patients benefits other patients: the economic resources that

these patients generate can be used to treat other patients.<sup>25</sup> This claim is potentially consistent with Rawls's difference principle.<sup>26</sup> Rawls contends that basic liberties should be equally distributed among persons, but the distribution of income and wealth may be unequal under certain conditions. He argues that social and economic inequalities "must be to the greatest benefit of the least advantaged members of society."<sup>27</sup> (It should be noted that Rawls limits the application of his principles to the basic structure of society.)

An appeal to the difference principle is based on a number of empirical claims that should be verified. One is that decreasing nonresident patients' waiting times will increase the number of nonresident patients. A second is that treating nonresident patients generates additional revenue. While these patients' treatment may be paid for at a higher than average rate, their treatment may involve additional costs.<sup>28</sup> For example, it may require hiring additional medical interpreters. It would be important to be clear that there is a positive net financial benefit.

It would also be important to verify that the additional revenue is utilized in a way that benefits other patients. This may not be the case in a publicly traded healthcare organization where additional revenue is returned to investors. A further issue is whether the patients who are benefited must be the same patients whose appointments were delayed, and whether the benefit must be in kind. The simplest arrangement would be to use the increased revenue to decrease waiting times.

Some commentators argue that preferential treatment is not justified because other patients are harmed in the form of inconvenience, discomfort, and worse outcomes from delayed treatment.<sup>29</sup> The difference principle, however, requires that the inequalities benefit the least advantaged, making them better off than an equal distribution. An analogy might be drawn to Rawls's serial or lexical ordering of his principles; basic liberties cannot be violated to produce social and economic benefits.<sup>30</sup> In the case of scheduling follow-up appointments, medical need should have priority over residence status. It would be inappropriate to give priority in scheduling a nonresident patient's non-urgent, follow-up appointment over a resident patient's urgent appointment.

### **CONCLUSIONS**

With changes in healthcare, medical centers are attempting to diversify their sources of revenue, including recruiting domestic and foreign patients from outside of their local community. There are

pressures to treat these patients differently, including giving them priority in scheduling outpatient follow-up appointments. Access to healthcare is generally based initially on medical need and resource utilization, and then on order of presentation. Giving some patients preference over others based on their status or opportunity cost is unjust. Reducing nonresident patients' travel, room, and board costs may, however, be a reasonable consideration. Unequal treatment may be justified by the difference principle, but only in cases of similar medical need. The increased revenue generated should be verified and used to improve resident patients' access.

#### ACKNOWLEDGMENTS

I would like to thank Jennifer E. deSante-Bertkau, MD, MBE, and Kathryn L. Weise, MD, MA, for their comments on an earlier draft of this article.

#### NOTES

1. J.J. Hutchins, "Bringing International Patients to American Hospitals: The Johns Hopkins Perspective," *Managed Care Quarterly* 6, no. 3 (Summer 1998): 22-7; D.R. Martin, "Challenges and Opportunities in the Care of International Patients: Clinical and Health Services Issues for Academic Medical Centers," *Academic Medicine* 81, no. 2 (February 2006): 189-92; M.D. Fottler et al., "Can Inbound and Domestic Medical Tourism Improve Your Bottom Line? Identifying the Potential of a U.S. Tourism Market," *Journal of Healthcare Management* 59, no. 1 (January/February 2014): 49-63.

2. Hutchins, "Bringing International Patients to American Hospitals," see note 1 above; Martin, "Challenges and Opportunities," see note 1 above; S.C. Foster, "Practitioner Application," *Journal of Healthcare Management* 59, no. 1 (January/February 2014): 63-4.

3. Hutchins, "Bringing International Patients to American Hospitals," see note 1 above.

4. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 6th ed. (New York: Oxford University Press, 2009): 242.

5. D. Gupta and D. Denton, "Appointment Scheduling in Health Care: Challenges and Opportunities," *IIE Transactions* 40, no. 9 (2008): 800-9.

6. J. Kirkpatrick, "Concierge Medicine Gaining Ground: Competition Forces Medical Center into 'Boutique' Business," *Physician Executive* 28, no. 5 (September-October 2002): 24-6; G.C. Alexander, J. Kurlander, and M.K. Wynia, "Physicians in Retainer ('Concierge') Practice: A National Survey of Physician, Patient, and Practice Characteristics," *Journal of General Internal Medicine* 20, no. 12 (December 2005): 1079-83.

7. D.J. Lucier et al., "Academic Retainer Medicine: An Innovative Business Model for Cross-Subsidizing Primary Care," *Academic Medicine* 85, no. 6 (June 2010): 959-64.

8. T.A. Brennan, "Luxury Primary Care—Market In-

novation or Threat to Access," *New England Journal of Medicine* 346, no. 15 (11 April 2002): 1165-8.

9. M. Donohoe, "Luxury Primary Care, Academic Medical Centers, and the Erosion of Science and Professional Ethics," *Journal of General Internal Medicine* 19, no. 1 (January 2004): 90-4. Cf., T.S. Huddle and R.M. Centor, "Retainer Medicine: An Ethically Legitimate Form of Practice That Can Improve Primary Care," *Annals of Internal Medicine* 155, no. 9 (1 November 2011): 633-5.

10. Brennan, "Luxury Primary Care," see note 8 above.

11. C. Connolly, "Healers Go for the Well-Heeled," *Washington Post*, 28 May 2002.

12. G. FitzGerald, G.A. Jelinek, D. Scott, and M.F. Gerdtz, "Emergency Department Triage Revisited," *Emergency Medicine Journal* 27, no. 2 (February 2010): 86-92.

13. "Appendix B. ESI Triage Algorithm, v. 4." <http://www.esitriage.org/algorithm.asp?LastClicked=algorithm>.

14. N.A. Green et al., "Emergency Severity Index Version 4: A Valid and Reliable Tool in Pediatric Emergency Department Triage," *Pediatric Emergency Care* 28, no. 8 (August 2012): 753-7.

15. G.R. Winslow, *Triage and Justice: The Ethics of Rationing Life-Saving Medical Resources*, (Berkeley, Calif.: University of California Press, 1982).

16. M.S. Smith and R.F. Shesser, "The Emergency Care of the VIP Patient," *New England Journal of Medicine* 319, no. 21 (24 November 1998): 1421-3; D.S. Diekema, "The Preferential Treatment of VIPs in the Emergency Department," *American Journal of Emergency Medicine* 14, no. 2 (March 1996): 226-9.

17. Diekema, "The Preferential Treatment of VIPs," see note 16 above.

18. Smith and Shesser, "The Emergency Care of the VIP Patient," see note 16 above.

19. T. Schenkenberg, N.K. Kochenour, and J.R. Botkin, "Ethical Consideration in Clinical Care of the 'VIP,'" *The Journal of Clinical Ethics* 18, no. 1 (Spring 2007): 56-63.

20. Smith and Shesser, "The Emergency Care of the VIP Patient," see note 16 above.; J.A. Guzman, M. Sasidhar, and J.K. Stoller, "Caring for VIPs: Nine Principles," *Cleveland Clinic Journal of Medicine* 78, no. 2 (February 2011): 90-4.

21. A.J. Smally et al., "Treatment of VIPs," *Annals of Emergency Medicine* 58, no. 4 (October 2011): 397-8.

22. Diekema, "The Preferential Treatment of VIPs," see note 16 above.

23. Donohoe, "Luxury Primary Care," see note 9 above.

24. Martin, "Challenges and Opportunities," see note 1 above, 190.

25. Ibid.

26. J. Rawls, *A Theory of Justice* (Cambridge, U.K.: Belknap Press, 1971); J. Rawls, *Political Liberalism* (New York: Columbia University Press, 1993).

27. Rawls, *Political Liberalism*, see note 26 above, p. 291.

28. Hutchins, "Bringing International Patients to American Hospitals," see note 1 above.

29. Diekema, "The Preferential Treatment of VIPs," see note 16 above; see note 19 above.

30. See note 26 above.

## *Cases and Analysis*

# Responding to Moral Distress and Ethical Concerns at the Intersection of Medical Illness and Unmet Mental Health Needs

*Donna D. McKlindon, Pamela Nathanson, and Chris Feudtner*

### ABSTRACT

Some of the most difficult clinical ethics consultations involve patients who have both medical and mental health needs, as these cases can result in considerable moral distress on the part of the bedside staff. In this article we examine the issues that such consultations raise through the illustrative example of a particular case: several years ago our ethics consultation service received a request from a critical care attending physician who was considering a rarely performed psychosurgical intervention to address intractable and life-threatening agitation and aggression in an adolescent patient for whom standard treatments had proven unsuccessful. We consider strategies that may be useful in addressing not only the ethical dilemmas or the clinical problems, but also the emotional, social, and moral distress that arise in delivering care in such complex cases, in which standard routine practices of care

have been exhausted. In addition, we explore the processes that led to this situation and suggest ways to promote early recognition and intervention for similar cases in the future.

### INTRODUCTION

Ethical dilemmas are woven into the everyday fabric of pediatric healthcare. Among the most challenging cases are those involving patients who have both medical and mental health needs. These complex cases can generate feelings of moral distress within the healthcare team.

The concept of moral distress, as applied to nurses, was first described by Jameton in 1984, as the psychological disequilibrium that occurs when health professionals know, or believe they know, the ethically appropriate course of action to take, but are unable to carry it out because of obstacles that are present.<sup>1</sup> Contributors to moral distress have been identified as institutional constraints and their impact on nurses' ability to advocate for patients; the inability to influence medical decisions related to patients' pain and suffering; and a lack of recognition of one's expertise within the hospital power hierarchy.<sup>2</sup> Under these types of circumstances, acting in a manner that is contrary to personal and professional values undermines the individual nurse's integrity and authenticity as a person.<sup>3</sup> While much of the early literature focused on moral distress as

---

**Donna D. McKlindon, MSN PMHCNS-BC**, is Associate Director of the Department of Medical Ethics at the Children's Hospital of Philadelphia. [mcklindon@email.chop.edu](mailto:mcklindon@email.chop.edu)

**Pamela Nathanson, MBE**, is the Policy and Program Coordinator in the Department of Medical Ethics at the Children's Hospital of Philadelphia.

**Chris Feudtner, MD PhD MPH**, is the Director of the Department of Medical Ethics at the Children's Hospital of Philadelphia and is a Professor in the Department of Pediatrics and the Department of Medical Ethics and Health Policy at the Perelman School of Medicine, University of Pennsylvania, in Philadelphia.

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

experienced by nurses, the concepts and their underpinnings have application for all healthcare providers.

By definition, complex care situations involving challenging medical and behavioral health needs beg the services of many consultants, including mental health professionals and ethics consultants. The practice of consultation routinely employed in healthcare settings may vary based upon a number of factors, including the nature of the consultation, the composition and skill set of the consult team, the specific request, and the level of urgency (real or perceived), as well as the culture of the organization. The process and outcome of any specific case can be greatly affected by who is asked to consult and how the consultation is managed.

In this article we will consider the intersection of ethical dilemmas and unmet mental health needs in principle and application. Utilizing a specific, complex case example to ground the discussion, we will examine the intertwined nature of these two issues, identifying the guiding principles, standards of practice, and skill sets recommended for addressing complex care cases.

### THE CASE

Myles (a pseudonym) was a mid-adolescent male with severe intellectual disability and multiple complex medical and behavioral health conditions, including the need for a tracheostomy and ventilatory support. He had experienced numerous lengthy hospitalizations in several tertiary care pediatric hospitals during his lifetime. Guardianship and medical decision making had been assumed by the state several years prior to this hospitalization, and a guardian *ad litem* was appointed at that time. Myles had lived in several residential facilities, and immediately prior to this hospitalization was living in a small group home that had demonstrated an ability to manage his behavioral and stable medical needs.

For his most recent admission, Myles presented to the hospital with increasing respiratory distress requiring ongoing ventilatory support. The admitting diagnosis was respiratory distress and autism with aggression toward others and self-injurious behaviors. Care was provided on a unit where most of the children are mechanically ventilated. A primary focus of the unit is the education of families in anticipation of discharge of the child to home or to a long-term care facility, and, of note, the unit staff did not have training or experiential expertise in addressing severe behavioral health concerns.

Myles was nonverbal with very minimal sign language capacity. He had an estimated IQ of 20. He was ambulatory and enjoyed interactive activities such as blowing bubbles and water play, liked to be sung to, and had several favorite videos. Myles received physical therapy, occupational therapy, respiratory therapy, and child life services. Behavioral health services were provided by the state, and included weekly visits by a behavioralist and in-hospital observation for four hours per day, four times per week, provided by a state-funded therapeutic staff support worker.

Myles had an extensive history of mental health concerns. Both prior to and during this hospitalization, he had frequent episodes of agitation, self-injurious behavior, and aggression toward others, resulting in the use of behavioral management restraints and sedating medications. Hospital policy allowed the use of restraints under these circumstances; but less restrictive measures must have been exhausted prior to their use. Several medications had been tried in an attempt to address Myles's care needs, including his sleep cycle, agitation, and aggression, all with insufficient success. Following extensive consultation with the psychiatry service, the team determined that no additional medication options were available.

The medical team had identified three major goals of care for Myles: (1) medical stabilization, (2) behavior management in order to provide for the safety of the patient and staff and to minimize or eliminate potential injuries, and (3) optimization of the care environment by arranging for appropriate disposition to a facility able to manage Myles's medical and behavioral health needs.

### INITIAL ASSESSMENT BY A PSYCHIATRIC MENTAL HEALTH ADVANCE PRACTICE NURSE

Early in Myles's hospitalization, a psychiatric-mental health advance practice nurse (PMH-APN) responded to a request to review the use of behavioral management restraints for aggressive behavior and threat to self and others. As a member of the restraint and seclusion committee, the PMH-APN was responsible for oversight and review of all uses of behavioral management restraints, and in this capacity provided ongoing education and communication regarding restraint episodes to staff and unit leadership. In addition, the PMH-APN was asked to provide support and guidance to the staff who were caring for Myles related to addressing the complex care needs of the patient and accompanying staff distress.

The assessment completed by the PMH-APN identified the following six areas of concern:

1. Patient behavior management (agitation/aggression): Myles's aggression/self-injurious behaviors had resulted in multiple episodes of restraint to protect himself and others. Staff characterized his agitation and aggression as being unpredictable in nature and difficult to anticipate, as it was not easy to identify and/or read his cues. As a result, Myles had no consistent behavior management plan in place, and the strategies employed by the staff to communicate with him were not effective. Finally, Myles had an extremely disrupted wake/sleep cycle that was not amenable to medication management.
2. Staff's response to and interactions with the patient: Frequent restraint use and staff injury led to a great potential for moral distress and post-traumatic stress disorder responses among staff. Some staff were frightened of the patient, and, if they were injured while providing care, had difficulty returning to care in any capacity as a direct care provider or as an assistant. The behavioral healthcare needs of the patient exceeded the skill set of the staff and conflicted with the primary focus of the care setting.
3. Optimization of the care setting: The care team needed to develop an appropriate plan of care involving collaboration between psychiatry, psychology, nursing, and critical care medicine, with a focus on a consistent plan of care and approach.
4. Disposition: Myles was considered to be medically stable, even though he was ventilator dependent. The inpatient care team agreed that an acute care hospital was not an optimal care environment for this adolescent, but the team had difficulty finding a facility that could adequately provide for both the patient's medical and behavioral care needs.
5. Organizational oversight: Systems level considerations included safety risks, length of stay, availability of and access to resources, and a complicated plan for continued care after discharge.
6. Advocacy: Myles was a ward of the state with an assigned guardian *ad litem*. Because he had no family present, the staff caring for Myles served as his only on-site advocates, and therefore felt a heightened level of responsibility for his care.

Through this assessment, the PMH-APN highlighted many important aspects of care and organizational

concerns that needed to be addressed. The overriding sense of moral distress on behalf of the care providers who were directly caring for Myles was palpable and certainly took its toll.

#### **GROWING MORAL DISTRESS WHEN PROBLEMS WERE INEFFECTIVELY MANAGED**

As the length of Myles's hospitalization stretched from weeks into months, several members of the healthcare team who provided care for Myles reported a growing sense of moral distress. A perceived lack of response on the part of the medical team, the hospital administration, and the behavioral health and child welfare agencies of the state, coupled with an inability to improve the care of the patient, manifested itself in part as a sense of helplessness among the staff. In the face of continued agitation and aggression and with no identified long-term plan of care, the staff's frustration grew.

The experience of moral distress—which typically also includes elements of personal emotional distress and the social stress of feeling either neglected by or in conflict with other members of the clinical care team—can have a great impact at the individual, team, and organizational level. An ethics consultant who is not experienced with or attuned to moral distress can potentially overlook this important aspect of consultation. In this case, the staff experienced moral distress related to perceived violations of duties, feelings of powerlessness to affect day-to-day care, lack of appropriate resources, safety concerns for the staff and patient, and the inability to establish an appropriate locus of care. The staff who cared for Myles believed that they knew what he needed, but felt powerless to make it happen.

Several members of the physician staff requested the exploration of psychosurgery (anterior cingulotomy) as an option for Myles to manage his agitation/aggression, thus perhaps broadening his options for placement. (Anterior cingulotomy, rarely used in the pediatric population, is a psychosurgery used to treat chronic pain, depression, and obsessive-compulsive disorder. The surgery involves disconnecting the thalamic and posterior frontal regions of the brain and damages the anterior cingulate region.) By proposing this unusual use of psychosurgery, the requesting physicians underscored the extreme nature of the care situation and the frustration level of the entire care team.

While not all of the ethical dilemmas or feelings of moral distress that arise from such cases result in ethics consultation requests, the way in which

these situations are defined and navigated can profoundly influence the experience of a patient and family, as well as of a staff.

### THE ETHICS CONSULTATION

In the absence of an independent patient advocate with an ongoing presence in the hospital, a specific request for an ethics consultation came from physician members of the healthcare team, as the proposed psychosurgery represented an extreme, rarely implemented intervention with little evidence of a successful outcome. The process of consultation revealed the team's perception that the organization had not appropriately addressed the needs of this very complicated patient and of the staff caring for him. This sense of organizational inertia and ineptitude, as experienced by the healthcare team, led to a call for extreme measures in what was considered an extreme circumstance.

The questions posed during the ethics consultation included: (1) What is the right thing to do for this patient? Have we exhausted all options? Is psychosurgery an ethically permissible consideration? (2) How can Myles's best interests be protected? Who is responsible? How will his rights be maintained? (3) Is this an appropriate allocation of resources? This question applied both to the proposed surgical intervention as well as to planning for continued medical care after discharge. At the time of the request for the ethics consultation, Myles had been in the hospital for the better part of a year.

The PMH-APN involved with this case was also a member of the Ethics Consult Service (ECS). She was thus in a unique position as the ethics consultant to recognize and clarify the potential ethical dilemmas posed, understand the behavioral health needs of the patient, and assess the level and sources of moral distress experienced by the staff. In addition, the ECS brought to the discussion a neutral and objective ability to see the big picture, assess the available resources, and draw attention to the needs of the patient as well as those of the staff.

The ethics consultation involved mapping the case through detailed descriptions of past and present treatment interventions. Careful analysis revealed several unexplored or underdeveloped possibilities, which in turn had remained in the shadows because the care team was overwhelmed by the day-to-day care of the patient and did not have the optimal skill set, knowledge, or clinical experience required to access all of the potential resources to help think through and respond to the clinical challenges. The resulting recommendation

from the ECS was that psychosurgery was not the only option remaining, and, therefore, until other options were vetted and tried, discussion of the ethical considerations specific to psychosurgery should be tabled.

The ethics consultation and the involvement of the ECS occurred well into the patient's hospitalization, and the mere act of requesting a consultation served to greatly increase organizational attention to the case. As a result of the increased attention and additional skills and experience brought to the table, several additional resources were committed to the care of the patient, many of which came about in response to the questions raised regarding protection of Myles's best interest and the appropriate allocation of resources. Additional interventions that had previously been overlooked included: (1) assessment by autism experts with identification of a plan of care; (2) a request for clinical expertise in a behavioral approach to care, resulting in plans to contract for consistent, trained, and competent behavioral support from an outside agency; (3) mobilization of internal and external resources aimed at facilitating the patient's discharge from the hospital (although a care facility had been identified early in the patient's hospital stay, the process of transition had been complex and slow); and (4) reinforced efforts to maintain engagement with the appointed guardian *ad litem* regarding decision making for Myles.

### INTERSECTION BETWEEN ETHICS AND MENTAL HEALTH

The notion that combined mental health and ethics skills, education, and preparation can contribute positively to the process and outcome of ethics consultation is not new. Calvin P. Leeman described, through a case example, the need for ethics consultants to have training in the recognition of psychiatric issues and in interpersonal skills.<sup>4</sup> He recommended that these skills could be taught by psychiatrists, and also argued that psychiatric consultants themselves needed sufficient training in clinical ethics to recognize the ethical dimensions of many of their cases and to serve effectively on ethics committees and ethics consultation services. He suggested that psychiatric consultants should help other participants to develop greater psychological awareness and skills. Leeman stated that "the overall goal should be a comprehensive approach to patient care in which both psychiatric issues and ethical concerns are recognized and addressed."<sup>5</sup> Leeman concluded, therefore, that the most highly

effective consultants need to be versed in both ethics and psychiatry, so as not to miss a need for consultation that surely belongs in one of these domains.

In her 1993 article, "Keeping Moral Space Open: New Images of Ethics Consulting," Margaret Urban Walker stated, "the moral expertise of clinical ethicists is not a question of mastering codelike theories and lawlike principles. Rather, ethicists are architects of moral space within the healthcare setting, as well as mediators in the conversations taking place within that space."<sup>6</sup> She went on to say, "the ethicist's special responsibility is to keep open, accessible, and active (and if necessary to create and design with others) those moral-reflective spaces in institutional life where a sound and shared process of deliberation and negotiation can go on."<sup>7</sup> Similar responsibilities can be ascribed to mental health consultants, who aim to create an opportunity for open, reflective dialogue. In Myles's case, by creating space and time for discussion through the process of ethics consultation, the team was able to examine additional options and revisit previously discarded options in a calm and intentional manner. Mental health and ethics consultants working in collaboration may draw attention to perceived organizational gaps in care by creating a space for these difficult conversations and for care planning.

### THE DENOUEMENT

With organizational acknowledgment of and response to this patient's unique care needs, and a renewed commitment to identifying the most appropriate locus of care, a multidisciplinary team, supported by ethics consultation and mental health resources, was able to identify a long-term care facility with resources and supports for Myles's medical and behavioral health needs and to prepare for his transition. His discharge took place approximately six weeks after the ethics consultation meeting.

### GENERAL LESSONS LEARNED AND FUTURE PRO-ACTIVE STRATEGIES

This case prompted reflection by the individual staff members involved, the care delivery team as a whole, and the broader organization. The questions at each level were the same: What have we learned as a result of caring for this patient? and What can be done differently in the future?

Consultants, whether from mental health, ethics, or both, would benefit from being attuned to the potential intersection between these roles. In complex consultations, a consultant often serves in a

dual role, responding to the staff's needs in addition to the needs of the patient and family. One strategy would be for a consultant to specifically name the moral distress exhibited by the staff, perhaps by incorporating a moral distress assessment tool, such as the one developed by Mary C. Corley and colleagues.<sup>8</sup> This assessment tool, potentially coupled with an ethical environment inventory such as the one developed by Charlotte McDaniel,<sup>9</sup> could prove useful in quantifying and documenting a staff's response, thus enabling consultants from both mental health and ethics to recognize and attend to these concerns promptly. Additionally, the use of these tools would help to create a framework for ethics consultation and the organization of the proposed interventions.

A review of the literature indicates that when careproviders perceive that there are ethical issues that they feel powerless to address, an open dialogue among patients, careproviders, and administrative personnel is warranted. Complex care situations, such as the case described here, that involve medical and psychiatric aspects of care and potential ethical dilemmas, are often accompanied by the experience of moral distress. Ethics consultations can often help patients and careproviders think through alternative strategies, utilizing an open and creative approach. An ethics consultation, provided by an individual who is skilled in medical ethics and mental healthcare, is one way to bring patients, family members, and members of the healthcare team to the table and open up a dialogue, creating the space and time to explore potential options to address the needs of all involved.

Interdisciplinary education and collegial practice are two strategies that have been identified to decrease moral distress. They represent a commitment to seek common ground, garner mutual respect for individual roles, and promote discussion of meaningful ways to communicate and collaborate effectively about the ethical problems each group identifies.<sup>10</sup> Moving to increased collegiality and shared practice models may help alleviate moral distress by increasing a sense of shared responsibility and professional satisfaction. Recurring instances of moral distress can indicate underlying systemic problems of poor communication, inadequate collaboration, and perceived powerlessness, all of which must be addressed to develop and sustain a healthy work environment.<sup>11</sup> Incorporating these strategies into everyday practice is an important first step in preventing or alleviating moral distress.

Staff are often reluctant to request an ethics consult.<sup>12</sup> In this case, ultimately the suggestion of an

“extreme intervention” prompted a request for consultation. For this patient, who did not have an active advocate other than the staff, and whose care team expressed concern about their lack of expertise in behavioral health and who felt thwarted by early attempts to involve outside resources, a reluctance to request additional consultation may have reflected and exaggerated their sense of isolation and vulnerability. Ultimately, engaging an outside consultation prompted an additional review of the case at multiple levels of the institution. In retrospect, having a lower threshold for revealing the challenges in delivering care and asking for assistance may have resulted in attention being paid to this case and the mobilization of adequate resources, which may have expedited a move to an appropriate locus of care.

In follow-up discussions, the team who cared for Myles chose to use this case as a learning experience. The action of committing to regularly scheduled interdisciplinary care team meetings provided a natural forum for increased dialogue. By continuing to meet after Myles was discharged, the team was able to develop a realistic plan of care and identify adequately trained, contracted behavioral health staff in anticipation of his subsequent hospitalizations. In a more generalized way, the plan developed for Myles could serve as a template for early recognition and response to other complex care situations that involve patients with co-morbidities of medical and behavioral health needs throughout the organization. Such an approach would wisely include pro-active attention to the staff’s needs. To this end, inclusion of a PMH-APN or another individual skilled in mental health and ethics in such planning would be beneficial.

Through collaboration, well-positioned and accessible mental health and ethics consultants could utilize their skills and strengths to improve care for patients and families, and in doing so uncover and address hidden moral distress. While moral distress cannot be eliminated, a systematic approach to assessment can develop new ways to respond to ethical conflict. When instituted on a regular basis, early recognition of and attention to moral distress goes a long way to support the development and maintenance of a healthy work environment, and to positively impact the care of patients and their families.

#### PRIVACY STATEMENT

Informed consent for permission to publish this case could not be obtained. Some details have been altered to protect the privacy of the patient.

#### NOTES

1. A. Jameton, *Nursing Practice: The Ethical Issues* (Englewood Cliffs, N.J.: Prentice Hall, 1984).
2. D.M. Huffman and L. Rittenmeyer, “How Professional Nurses Working in Hospital Environments Experience Moral Distress: A Systematic Review,” *Critical Care Nurse Clinics of North America* 24, no. 1 (2012): 91-100.
3. C.H. Rushton, “Defining and Addressing Moral Distress: Tools for Critical Care Nursing Leaders,” *AACN Advanced Critical Care* 17, no. 2 (2006): 161-8.
4. C.P. Leeman, “Ethics Consultation Masking Psychiatric Issues in Medicine,” *Archives of Internal Medicine* 155 (1995): 1715-7.
5. *Ibid.*, 1717.
6. M.U. Walker, “Keeping Moral Space Open: New Images of Ethics Consulting,” *Hastings Center Report* 23, no. 2 (March-April 1993): 33-40.
7. *Ibid.*, 38.
8. M.C. Corley, R.K. Elswick, R.M. Gorman, and T. Clor, “Development and Evaluation of a Moral Distress Scale,” *Journal of Advanced Nursing* 33, no. 2 (2001): 250-6.
9. C. McDaniel, “Ethical Environments: Reports of Practicing Nurses,” *Nursing Clinics of North America* 33, no. 2 (1998): 363-72.
10. C.M. Ulrich, A.B. Hamric, and C. Grady, “Moral Distress: A Growing Problem in the Health Professions?” *Hastings Center Report* 40, no. 1 (January-February 2010): 20-2.
11. E.A. Epstein and A.B. Hamric, “Moral Distress, Moral Residue, and the Crescendo Effect,” *The Journal of Clinical Ethics* 20, no. 4 (Winter 2009): 330-42.
12. E.J. Gordon and A.B. Hamric, “The Courage to Stand Up: The Cultural Politics of Nurses’ Access to Ethics Consultation,” *The Journal of Clinical Ethics* 17, no. 3 (Fall 2006): 231-54.

# At the Intersection of Faith, Culture, and Family Dynamics: A Complex Case of Refusal of Treatment for Childhood Cancer

*Amy E. Caruso Brown*

## ABSTRACT

Refusing treatment for potentially curable childhood cancers engenders much discussion and debate. I present a case in which the competent parents of a young Amish child with acute myeloid leukemia deferred authority for decision making to the child's maternal grandfather, who was vocal in his opposition to treatment. I analyze three related concerns that distinguish this case from other accounts of refused treatment.

First, I place deference to grandparents as decision makers in the context of surrogate decision making more generally.

Second, the maternal grandfather's ardent refusal of treatment and his rationale appeared to be inconsistent with the beliefs expressed by other family members and by members of the same Amish community, leading members of the medical team to question whether refusal of treatment should be treated differently when it appears to be based on the idiosyncratic beliefs of an individual rather than on community-wide values.

Third, the medical team perceived tension and dissension between the nonverbal behavior of some family members and the verbal statements made by the maternal grandfather, leading the team to question the parents' true wishes and debate how to weigh nonverbal and indirect forms of communication.

Finally, building upon the conclusions of these queries, I explore whether, if the child's prognosis was less favorable or if he were to relapse later, the maternal grandfather should have been permitted to drive a decision to refuse further treatment.

## CASE PRESENTATION

A three-year-old Amish child presented to the emergency department with a one-week history of fever, rhinorrhea, and decreased appetite, accompanied by his 24-year-old father, his maternal grandfather, and his paternal grandfather. His primary caregiver, his 23-year-old mother, was at home recovering from an illness. On examination, the child was noted to be pale and lethargic, with a profoundly enlarged liver and spleen. Blood tests revealed that his white blood cell count exceeded 100,000 cells/microliter (normal range is five to 15,000); 66 percent were blast (leukemia) cells. He was subsequently admitted for evaluation and treatment of presumed leukemia.

Upon the child's arrival on the inpatient unit, the attending physician discussed the probable diagnosis and necessary additional testing with the father and grandfathers. The initial plan presented to the family included a bone marrow aspirate and biopsy, a diagnostic lumbar puncture with administration of intrathecal chemotherapy, and placement of a tunneled central venous catheter to facilitate

treatment with systemic chemotherapy. The family members were told that specific treatment options and prognosis would be dependent on the type of leukemia identified by the additional testing. The maternal grandfather immediately raised concerns regarding the child's quality of life during therapy, as well as the costs of such treatment, which would be borne by the community, and he expressed doubt regarding whether to treat the child at all. He stated that he wanted to involve other family members and elders from the community. At this point, the physician encouraged the involvement of additional family members and requested that the family meet with an ethics consultant.

The following afternoon, the family provided consent for the procedures after flow cytometric testing confirmed the diagnosis. The patient's father and grandfathers again met with the attending physician, joined by two members of the ethics consultation service. The physician explained that the recommended standard therapy involved four cycles of intensive inpatient chemotherapy and that the child's prognosis would depend on cytogenetic testing, as well as on his response to the first cycle of chemotherapy. Specifically, the family was told that the boy's chance of cure could be as low as 20 percent or as high as 80 percent, and that further information would help determine the prognosis. Prior to the meeting, the medical team had reached a consensus that initial chemotherapy was indisputably in the child's best interests; however, the team also agreed that it was important to fully understand the family's values and beliefs and to obtain their buy-in, if at all possible.

During this meeting, the young father was extremely quiet and spoke only during introductions. Shortly after, the patient was escorted to the preoperative area, and the grandfathers encouraged the father to accompany his son, while they continued the discussion with the physician and ethics consultants. The maternal grandfather took the lead in explaining his interpretation of his family's faith and culture. From his perspective, he said, it would not be a tragedy if his grandson died in childhood, but instead it would be the will of God, sparing the child from ever falling into sin. The paternal grandfather, who had been silent, became tearful. The maternal grandfather went on to share his perspectives on the freedom of religion, as described in the U.S. Constitution, and his belief that it enshrined the right to refuse treatment for his grandson. Eventually, the stories of several other family and community members who were treated unsuccessfully for cancer emerged from this dialogue.<sup>1</sup> In one relative's case,

the treatment that the family had felt pressured to accept was later described as "futile" by another physician, a statement that both devastated and frustrated her kin.

The maternal grandfather requested a day to consider the information provided and to discuss the situation with his community. In pursuit of the goal of establishing therapeutic rapport, the team agreed to his request. Given the degree of hyperleukocytosis, which placed the child at increasing risk of a fatal stroke or pulmonary edema, they felt that a longer delay was not medically safe for the boy. When the maternal grandfather asked what would happen if they decided to refuse therapy, the attending physician gently explained that she would need to take legal action to protect the child and compel treatment; however, she emphasized that if the patient had features suggesting high-risk or difficult-to-treat disease, they would revisit the possibility of foregoing curative treatment in favor of comfort care only.

The following day, the family consented to chemotherapy and the child began treatment. The family members at the bedside varied, including combinations of his mother, father, and both sets of grandparents. The careproviders noted that the family seemed to follow a strict hierarchy, in which the eldest male relative present in the room would answer and ask all questions. The patient's grandmothers only spoke when no men were present, and the patient's mother only spoke when she was alone with her son and a healthcare provider.

Both the medical team and the family seemed to feel that an acceptable compromise had been reached. The child would receive one cycle of chemotherapy according to the standard of care, but would receive further cycles only if his prognosis proved favorable. Practically, this allowed his care to move forward immediately, yet it left many ethical concerns unresolved. As the first doses of chemotherapy were administered, the maternal grandfather shared that he had prayed for the child to die during the previous night, in order to spare them all the ordeal of treatment.

## CASE ANALYSIS

While all involved awaited additional test results, questions arose regarding the medical, ethical, and legal options if the child's prognosis was poor. Some of these were familiar ethical questions regarding the roles of risk and uncertainty in determining thresholds for intervention by the state. Among the members of the pediatric oncology team

and the pediatric residents, an energetic debate took place: What probability of cure was sufficiently high to compel a family to accept treatment for a young child over the objections of family? Responses varied dramatically, with some careproviders arguing that a 20 percent chance of survival was a chance that every child was entitled to have, regardless of a family's personal, religious, or cultural beliefs, while others felt that a 50 percent chance of survival was also a 50 percent chance of a child dying in circumstances that violated a family's deepest values. This is consistent with the lack of a demonstrated consensus in the published literature on refused treatments. I acknowledge these questions, but they are not the primary focus of the analysis, as they have been extensively explored elsewhere.

This case stood apart from other accounts of refused treatment in pediatric oncology because of the particular dilemma that arose from the parents' conscious and consistent deferral of decision-making authority to the maternal grandfather, a practice that diverges considerably from the mainstream American approach to child rearing and decision making for children.

This analysis will explore three related concerns. First, I place deference to grandparents as decision makers in the context of surrogate decision making more generally, asking whether it is permissible for a grandfather to refuse treatment on behalf of his grandchild. Second, the medical team perceived tension and dissension between the nonverbal behavior of some family members and the verbal statements articulated by the maternal grandfather, leading the team to question the parents' true wishes and to debate how to weigh nonverbal and indirect forms of communication. Third, the maternal grandfather's ardent refusal of treatment and his rationale appeared inconsistent with the beliefs expressed by other family members and by members of the same Amish community, which raised questions of whether refusal of treatment should be treated differently when it appears to be based on the idiosyncratic beliefs of an individual, rather than on the values shared by the patient's community. Finally, building on answers to these queries, I conclude with a consideration of whether, if the child's prognosis were unfavorable or if he were to later relapse, the maternal grandfather should be allowed to drive a decision to refuse further treatment.

### **Parental Deference of Decision-Making Authority to Grandparents**

In this case, the decision that treatment was obligatory was rooted in the ambiguity of the child's

prognosis. Unlike other prominent cases that have been subject to scholarly analysis and media attention, the child's prognosis at the time of the diagnosis could not be determined without further information, including his response to initial treatment.<sup>2</sup> Discussions amongst the team indicated a substantial "gray zone" of disagreement regarding the ethics of legally compelling treatment in the face of an uncertain prognosis. Depending on certain prognostic factors, the child might have had as little as a 20 percent chance of survival, at which point many of the medical team members stated a reluctance to request intervention by the state. When all of the prognostic information was available, four weeks into treatment, the child's likelihood of survival was thought to be closer to 80 percent, a threshold at which most, but not all, of his careproviders felt that treatment was obligatory. Highly personalized and specific prognostic information is an increasingly common feature of pediatric oncology care; therefore, this aspect of the case is likely to be a feature in future conflicts regarding the refusal of treatment.<sup>3</sup>

Had this patient been shown to have a high-risk disease up front, or were he to relapse in the future, his best chance of cure would rely on a bone marrow transplant, which would entail greater medical expense, geographic separation for the family, and a potential for physical pain, life-threatening complications, and lifelong adverse effects.<sup>4</sup> If a bone marrow transplant was necessary to achieve a cure, should the family—with their belief that a short, good life was better than a longer one with more suffering, even temporary suffering, and their concerns about expense and geographic separation—be obligated to proceed with such an intervention? Should the maternal grandfather be allowed to drive a decision to forego treatment at that point?

In the United States, parents generally have the legal authority to make medical decisions for their child.<sup>5</sup> This surrogate decision-making authority is grounded in several assumptions: that (1) parents are likely to know their child best and therefore are best positioned to make decisions in their child's best interests, (2) parents are best positioned to weigh the potentially competing interests of other family members against the interests of their child,<sup>6</sup> (3) parents are typically the most invested in any potential outcome, and (4) parents should be allowed to raise their child in accordance with their values, beliefs, and customs. This encourages a level of investment in the patient's family that would be forsaken if their autonomy were circumscribed too greatly.<sup>7</sup>

The language of surrogate decision making in Western medicine tends to be highly individualis-

tic.<sup>8</sup> Standards for making decisions for an incapacitated adult typically presume that a surrogate will act as the patient would have wanted, or, when what the patient would have wanted is unknown, in the patient's best interests.<sup>9</sup> Among the Amish, the best interests of all children—to be raised within a community that values hard work, interdependence, and self-sufficiency, and that is separate from the corrupting influences of the modern and materialistic world—outweigh the individual interests of one child.<sup>10</sup> From the perspective of the patient's maternal grandfather, this would be true even should the "interests" of the child in question become a matter of life and death.<sup>11</sup>

Grandparents who do not have legal guardianship of a child do not have any legal rights to make major medical decisions for their grandchildren in the U.S., and they certainly cannot overrule the decision of a parent, except in specific circumstances involving legal guardianship.<sup>12</sup> However, in some families, grandparents may demonstrate all of the qualities that identify parents as optimal surrogate decision makers. Within the context of the Amish community, some grandparents may have a better understanding of the potential impact of extraordinarily costly treatment on their community and a deeper appreciation for the proposed treatment, compared with young parents with limited exposure to the non-Amish world. Grandparents' greater life experience may equip them to better appreciate the benefits and burdens of treatment in the context of community resources, traditions, and faith. Certainly no law prohibits parents from voluntarily consulting or even deferring their decision-making authority to a child's grandparents or another relative.

Exceptions and limitations to parental—and, by extension, *grandparental*—authority vary from state to state in the U.S., but they have typically allowed for adolescent patients to make their own decisions in matters of sexual, reproductive, or mental health and substance abuse, and for the state to intervene when parents' decisions (or lack thereof) would be very likely to cause substantial or irreparable harm to a child's health.<sup>13</sup> The accepted thresholds for state intervention in the U.S. have varied widely, with little consensus between physicians, hospitals, courts, and states, except at the extremes.<sup>14</sup> For example, in *Newmark v. Williams*, the Supreme Court of Delaware ruled in favor of allowing the parents of a three-year-old boy with Burkitt lymphoma to decline treatment that would have given him a 40 percent chance of survival.<sup>15</sup> This decision was based in part on an exemption for "spiritual treatment" in the state's child abuse and neglect statutes, and in

part on the 60 percent chance that the treatment would cause debilitating side-effects yet fail to effect a cure.<sup>16</sup> While some states have repealed such exemptions or "religious shield" laws, others remain in place.<sup>17</sup>

### **Tension Between Verbal and Nonverbal Communication**

In this case, the first indication that statements made by the boy's maternal grandfather might not represent the beliefs of other family members came during a meeting between the family, attending physician, and ethics consultants. The maternal grandfather exuded serene conviction: he was verbally and physically unwavering. Yet when he stated firmly that he did not see early death as tragic, the child's paternal grandfather began to cry silently, leading those present to wonder if he fully shared his kin's views.

As the first cycle of chemotherapy progressed, the pediatric oncologists, residents, nurses, and support staff slowly built rapport with the patient and his family. Many staff observed that neither parent, when encountered alone at the patient's bedside during treatment, ever spontaneously voiced an objection to treatment. In hindsight, no careprovider could recall a conversation with any relative, other than the maternal grandfather, regarding refusal of treatment, although most acknowledged that they did not deliberately raise the subject themselves.

Like most Amish families, this family did not purchase medical insurance or accept governmental assistance. When caring for other families who pay for treatment out of pocket for these reasons, the team was accustomed to articulating the specific rationale for each test and intervention, allowing the family to consider the cost relative to potential benefit. It was therefore surprising that these types of conversations never occurred with this child's parents. Neither his mother nor his father questioned the day-to-day recommendations of the medical team, even when these included additional tests or other interventions to ameliorate adverse effects. Some team members interpreted the absence of this behavior to be further evidence that the parents did not agree with the maternal grandfather.

The team noted that the parents were quick to reach out to and support other families on the pediatric oncology service, suggesting questions to ask and inquiring about the other children's diagnoses and treatment. This active engagement with hospital life seemed to suggest a growing investment in the hospital community, and, by extension, their child's place in it. At home, neighbors helped the

family to contact a naturopathic practitioner in an adjacent state who recommended several vitamin and herbal supplements to manage the potentially adverse effects of therapy.<sup>18</sup> The parents willingly provided the supplements to the oncology pharmacist to research and examine prior to administration. The child's father seemed intrigued by Western biomedicine and even occasionally stood outside the conference room where weekly "grand rounds" were held, listening to the lectures.

The patient had favorable cytogenetic features and an excellent response to the first cycle of chemotherapy, with no minimal residual disease detectable in his bone marrow. Three additional cycles of chemotherapy were therefore administered, in accordance with the initial compromise. The maternal grandfather never attempted to interfere with the administration of care, but he continued to spontaneously raise the subject of refusing further treatment during his visits to his grandson's bedside. He expounded on the personal, religious, and cultural reasons he would have chosen not to treat the child and argued against legal and ethical perspectives that favored treatment. His declamations left little doubt that the initial acquiescence to treatment was primarily motivated by recognition of legal consequences and a desire to avoid the involvement of Child Protective Services.

By the end of therapy, the parents, paternal grandparents, and maternal grandmother had begun to frequently express their gratitude to the staff and their trust in the primary oncologist. However, they never publicly disagreed with the maternal grandfather, and all family members had many private opportunities to speak with the medical team.

#### **Personal, Family, Cultural, and Religious Beliefs: Are All Beliefs Created Equal?**

Compelled medical treatment may be experienced by the members of a minority community as a "threat to, or violation of, their chosen way of life by the outside world" that may be transmitted to their children in form of fear, anxiety, and chronic stress; some adults and children may, however, be "relieved to be compelled to do things their religion precludes them from doing voluntarily."<sup>19</sup> The possibility that this child's parents belonged in that latter group contributed greatly to the emotional and moral distress experienced by the medical staff.

The maternal grandfather's beliefs, although articulate and impassioned, did not appear wholly representative of the beliefs of other Amish families treated at the same institution, who were typically willing to accept treatment for childhood cancer,

even in the presence of uncertainty, unfamiliarity, and at times skepticism toward Western medicine, and despite serious concerns about the costs of care.<sup>20</sup>

With regard to the potential financial burdens on farming communities of limited resources, the perspectives of the staff were mixed. Many of the staff who were involved in this case expressed admiration for the interdependent way of life found in Amish communities and questioned the morality of compelling the community to place one child's needs above the needs of all of the others. Other staff expressed frustration, and argued that this approach was inherently flawed, since the patient would have qualified for Medicaid if the community had chosen to participate in state and federal assistance programs.<sup>21</sup> The impact of a single child's resource-intensive medical care on the resources available to care for other children was not something that could be reliably assessed. The staff never felt that the boy's family believed that treating him would result in other children going without food, clothing, or shelter, would force other parents in the community to forego seeking medical attention, or would seriously disrupt the integrity of the community by limiting available resources.

Furthermore, while other Amish may share the maternal grandfather's belief that death before the age of sin guarantees salvation, they generally place emphasis on the idea that "those who worship God, obey the church, provide for family and community will enjoy salvation."<sup>22</sup> Neither individual and institutional experience nor a review of the literature produced any support for the idea that the death of a child would not be grieved as a loss for an Amish parent.<sup>23</sup>

If the boy's family had chosen to forego treatment, and the moral validity of their decision was rooted in respect for the Amish community and the value of protecting that way of life, would the medical team have been obligated to advocate for more involvement from the community? Would that obligation have been greater if it became apparent that the maternal grandfather's interpretation of his religious beliefs was idiosyncratic? The maternal grandfather initially requested that the ethics consultants meet with community elders, but he later changed his mind, and the proposed meeting did not go forward. This was a lost opportunity to directly address the question of whether treating *this* child for cancer was counter to Amish values and would jeopardize the Amish way of life. Theologian Daniel Sulmasy has written persuasively that faith derived from organized religion is, by definition, public (in

the sense of communal) and not private, stating, “judging the authenticity of families’ claims” requires “examining such claims in light of . . . the person’s own religious tradition.”<sup>24</sup>

It must be noted that no member of this patient’s family ever argued for the merits of spiritual or faith healing or of complementary and alternative therapies alone, another typical feature of previously published accounts of refused treatment in this context. Instead, speaking for everyone involved, the maternal grandfather explained that the members of the community accepted that God’s will would be done, regardless of their decisions and interventions, that they accepted that God’s will might be the patient’s death, and that they would therefore prefer to avoid the perceived harms to both the patient, in terms of side-effects from intensive chemotherapy, and to their community, in terms of shared financial burden.<sup>25</sup>

### **In the “Gray Zone”: Who Should Decide What to Do?**

The juxtaposition of (1) the maternal grandfather’s observed status as the most senior and respected figure in the family, with (2) the child’s parents’ apparently growing acceptance of Western biomedicine, and (3) and the sense that treatment was *not* incompatible with the Amish way of life, created tension for the treating medical team. Many staff felt intuitively that, in the event of the progression of the child’s disease or relapse, his parents would be inclined to treat the child more aggressively. When asked, however, the patient’s mother always deferred to her husband, who in turn expressed the desire to consult their families—who naturally included the maternal grandfather—before making a major decision. As the maternal grandfather remained the only person whose beliefs were clearly articulated, the staff were aware that he would most likely refuse further treatment, especially treatment that would be more intensive and possibly less effective.<sup>26</sup>

The family’s nonverbal behavior and indirect statements suggested possible discord between the legal decision makers, the parents, and the *de facto* decision maker, the maternal grandfather. For the medical team, this was an ethical issue with an inevitable affective component. When they contemplated the realistic chance of relapse and the possible outcomes, the idea of allowing a child to die, when his mother might want to give him a chance to live, was devastating. Yet it also could not be assumed that the hierarchy of the family and community had been forced on the parents, when it might

very well be a feature of their culture that they embraced.

Nonverbal communication is not typically given much weight in guidelines regarding informed consent. It is, however, a crucial part of how patients, families, and healthcare providers interact, and often nonverbal behavior is the only indication careproviders receive that consent is truly voluntary and free of coercion. In this case, careful study of nonverbal cues and indirect statements yielded paradoxical outcomes: the parents seemed to both favor treatment of their child and to accept the maternal grandfather’s role in decision making.

### **DISCUSSION**

The apparently positive outcome at the time of this analysis was certainly enhanced by the dedication, patience, and care shown by the staff. This patience may be particularly important to Amish families, who may approach a new physician with a sense of “wariness about providing too much information to someone of the world, no matter how well intentioned.”<sup>27</sup> However, it is important to consider what was learned, as it sheds light on what could be done better, both in the event of this patient’s relapse and in similar future cases.<sup>28</sup>

This situation could have benefitted from more intentional communication about decision-making roles and responsibilities with all of those involved. It was unclear whether the patient’s mother had ever explicitly been *asked* about her desired role in decision making or her preferences regarding her father’s role in decision making for her son. In the crucial first 72 hours after the child was admitted to the hospital, no attempts were made to contact the mother at home, and her lack of involvement was accepted at face value, as a nonnegotiable, practical matter. Equally concerning, the patient’s father was likewise never taken aside to privately confirm his wishes regarding how decisions were to be made. His compliance with his father-in-law’s suggestion that he accompany his son to the operating room during the initial ethics consultation was accepted as proof of his desire to have one or both of the child’s grandfathers acting as his surrogate.

Eliciting with certainty whether the parents, particularly the patient’s mother, had voluntarily granted the maternal grandfather this authority was a perplexing task. In many healthcare situations, a dichotomy is observed between a patient’s verbal statements and his or her behavior: careproviders recognize that a person’s interests and preferences may be conveyed through actions and behaviors.

Over time, the team had many more opportunities to observe the mother's interactions with her son. The ethics of care in this situation seemed to demand special consideration of the mother's obvious love and devotion to her child—particularly as her voice was the least heard.<sup>29</sup>

Although both grandfathers were present for the initial discussion, the maternal grandfather was much more loquacious and assertive. This may have reflected his seniority, being older than the paternal grandfather, or the esteem with which he was held by his community, but it was likely also a function of his personality and temperament.<sup>30</sup> Some of the discomfort felt by team members might have been ameliorated if they had better understood the family's private processes for making decisions. Direct engagement with the community's elders might also have helped to address the concerns of the staff that the maternal grandfather's outspokenness was silencing a mother and father who truly did want to optimize their son's chances for survival.

### CONCLUSIONS

This case illustrates the challenges of fully comprehending the complexity of values, beliefs, culture, and interpersonal dynamics when faced with a child who needs urgent treatment. It argues against the expectation of quick resolutions after initial ethics consultations: only over the course of several months was the team able to truly appreciate the scope of opinions within the family and the place of those opinions within the larger Amish community. In all interactions with patients, but especially those for whom the stakes are highest, it is crucial that nonverbal information be assessed and considered alongside the spoken word.

### ACKNOWLEDGMENTS

The author wishes to thank Cynthia Morrow, MD, MPH, for her thoughtful critique of this article, and Lauren Hall Mutrie, MD, MSc, and Ann S. Botash, MD, for their editorial support. She is also grateful to Alexandra Kolenovd, MD, PhD, for providing invaluable opportunities to discuss this case with healthcare professionals in Central Europe.

### PRIVACY OF PATIENTS AND THIRD PARTIES

The above case has been stripped of all identifying information of involved parties, and non-essential details have been fictionalized or left vague to further protect privacy interests. Written informed consent was not obtained.

### NOTES

1. The maternal grandfather described an experience that justified his mistrust of Western physicians. In the aforementioned case, a young woman in the family collapsed at home and was eventually resuscitated and admitted to an intensive care unit. Despite severe anoxic brain injury sustained during the resuscitation efforts, she was maintained on cardiovascular support medications and mechanical ventilation for several days before the family was told that they should discontinue treatment. According to the maternal grandfather, the physician who finally gave this recommendation told them that the interventions were known to have been futile upon her admission. The grandfather therefore felt that the family had been deliberately misled about the possibility of recovery, and that their beliefs, as well as their financial circumstances, had been knowingly disrespected.

2. L.F. Ross, "Against the Tide: Arguments Against Respecting a Minor's Refusal of Efficacious Life-Saving Treatment," *Cambridge Quarterly of Healthcare Ethics* 18, no. 3 (2009): 302-15; Z. Williams, "When the Physician Says You Have to Get the Shot, but Mommy Says No: The Cases of Taige Mueller and Daniel Hauser, and How the State May Force Parents to Accept Unwanted Medical Treatment for their Children," *Indiana Health Law Review* 8 (2011): 199; D.M. Miller, "Legal Matters: Protecting the Right to Choose CAM Over Conventional Medicine: The Case of Daniel, Colleen, and Anthony Hauser," *Alternative and Complimentary Therapies* 15, no. 5 (2009): 261-6; M. McCoy, "Autonomy, Consent, and Medical Paternalism: Legal Issues in Medical Intervention," *Journal of Alternative and Complementary Medicine* 14, no. 6 (2008): 785-92; D.P. Olsen, "Unwanted Treatment," *American Journal of Nursing* 107, no. 9 (2007): 51-3.

3. C. Bachas et al., "High-Frequency Type I/II Mutational Shifts between Diagnosis and Relapse Are Associated with Outcome in Pediatric AML: Implications for Personalized Medicine," *Blood* 116, no. 15 (2010): 2752-8; L.A. Garraway, J. Verweij, and K.V. Ballman, "Precision Oncology: An Overview," *Journal of Clinical Oncology* 31, no. 15 (2013): 1803-5.

4. G.J.L. Kaspers, "Pediatric Acute Myeloid Leukemia," *Expert Review of Anticancer Therapy* 12, no. 3 (2012): 405-13.

5. L.M. Kopelman, "The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness," *Journal of Medicine and Philosophy* 22, no. 3 (1997): 271-89.

6. E.K. Salter, "Deciding for a Child: A Comprehensive Analysis of the Best Interest Standard," *Theoretical Medicine and Bioethics* 33, no. 3 (2012): 179-98.

7. D. Diekema, "Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention," *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 243-64.

8. A. Ho, "Relational Autonomy or Undue Pressure? Family's Role in Medical Decision Making," *Scandinavian Journal of Caring Sciences* 22, no. 1 (2008): 128-35.

9. J.T. Berger, E.G. DeRenzo, and J. Schwartz, "Surro-

gate Decision Making: Reconciling Ethical Theory and Clinical Practice,” *Annals of Internal Medicine* 149, no. 1 (2008): 48-53.

10. C. Mills, “The Child’s Right to an Open Future?” *Journal of Social Philosophy* 34, no. 4 (2003): 499-509.

11. It is worth noting that most sources cite relatively low rates (5 percent) of departure from the Amish community, in contrast to studies of other religious minority groups such as the Jehovah’s Witnesses, in which two-thirds of children leave the church in adulthood, so it is reasonable to conclude that the patient would eventually grow to share some of all of these values, although perhaps not his grandfather’s more extreme theological views. T.J. Meyers, “The Old Order Amish: To Remain in the Faith or to Leave,” *Mennonite Quarterly Review* 68, no. 3 (1994): 378-95; Pew Forum on Religion and Public Life, “U.S. Religious Landscape Survey: Religious Affiliation: Diverse and Dynamic,” February 2008, <http://www.pewforum.org/files/2013/05/report-religious-landscape-study-full.pdf>.

12. In 2007 in Washington State, a 14-year-old boy refused blood transfusions during treatment for curable cancer on the basis of his religious beliefs as a Jehovah’s Witness. His aunt and legal guardian supported his decision, while his biological parents opposed it. The court upheld his right to refuse, and he died.

See note 2 above; E.B. Brandt, “De Facto Custodians: A Response to the Needs of Informal Kin Caregivers?” *Family Law Quarterly* 38, no. 2 (2004): 291-314.

13. M.A. McCabe, “Involving Children and Adolescents in Medical Decision Making: Developmental and Clinical Considerations,” *Journal of Pediatric Psychology* 21, no. 4 (1996): 505-16.

14. J.D. Hord et al., “Do Parents Have the Right to Refuse Standard Treatment for their Child with Favorable-Prognosis Cancer? Ethical and Legal Concerns,” *Journal of Clinical Oncology* 24, no. 34 (2006): 5454-6.

15. *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991).

16. *Ibid.*

17. H. Hall, “Faith Healing: Religious Freedom vs. Child Protection,” *Skeptical Inquirer* 38, no. 4 (July-August 2014), [http://www.csicop.org/si/show/faith\\_healing\\_religious\\_freedom\\_vs\\_child\\_protection](http://www.csicop.org/si/show/faith_healing_religious_freedom_vs_child_protection).

18. This surprised the medical staff; however, the use of complementary and alternative medicines, including vitamins and other supplements labeled “natural,” has been reported elsewhere to be common among the Amish. S.M. Weyer et al., “A Look Into the Amish Culture: What Should We Learn?” *Journal of Transcultural Nursing* 14, no. 2 (2003): 139-45.

19. J.G. Dwyer, “Spiritual Treatment Exemptions to Child Medical Neglect Laws: What We Outsiders Should Think,” *Notre Dame Law Review* 76, no. 147 (2000): 147-77.

20. J.F. Henderson and R.D. Anbar, “Care for Amish and Mennonite Children with Cystic Fibrosis: A Case Series,” *BMC Pediatrics* 9, no. 1 (2009): 1.

21. C.E. Adams and M.B. Leverland, “The Effects of Religious Beliefs on the Health Care Practices of the Amish,” *Nurse Practitioner* 11, no. 3 (1986): 58-63.

22. D.J. O’Neil, “Explaining the Amish,” *International Journal of Social Economics* 24, no. 10 (1997): 1132-9.

23. This discrepancy underlines the importance of avoiding assumptions based on previous experience with families from the same culture or on readings and popular media coverage about the culture, since individuals from the same religious or ethnic background often do have unique interpretations of their culture and beliefs. L. Wiener, D.G. McConnell, L. Latella, and E. Ludi, “Cultural and Religious Considerations in Pediatric Palliative Care,” *Palliative and Supportive Care* 11, no. 1 (2013): 47-67.

24. D.P. Sulmasy, “Distinguishing Denial from Authentic Faith in Miracles: A Clinical-Pastoral Approach,” *Southern Medical Journal* 100, no. 12 (2007): 1268-72.

25. See note 2 above.

26. Kaspers, “Pediatric Acute Myeloid Leukemia,” see note 4 above.

27. L.L. Graham and J.A. Cates, “Health Care and Sequestered Cultures: A Perspective from the Old Order Amish,” *Journal of Multicultural Nursing & Health* 12, no. 3 (2006): 60.

28. Kaspers, “Pediatric Acute Myeloid Leukemia,” see note 4 above.

29. R. Tong, “The Ethics of Care: A Feminist Virtue Ethics of Care for Healthcare Practitioners,” *Journal of Medicine and Philosophy* 23, no. 2 (1998): 131-52.

30. Graham and Cates, “Health Care and Sequestered Cultures,” see note 27 above.

# The Angry Amish Grandfather: Cultural Competence and Empathy: A Case Commentary

*James L. Benedict*

## ABSTRACT

Crosscultural encounters are common in the delivery of healthcare, and cultural differences may contribute to misunderstandings and ethical conflict. Encounters between members of the Amish ethno-religious group and modern, science-based healthcare providers hold a high potential for misunderstanding and conflict because the Amish stridently maintain a countercultural outlook and they approach such encounters with suspicion and anxiety. This commentary on the case presented by Amy E. Caruso Brown, MD,<sup>1</sup> involving a grandfather's resistance to treating a child with leukemia commends this physician for successfully managing the case and deriving important insights from reflection upon it. It argues, however, that the level of conflict most likely would have been reduced if the care team had made more of an effort to listen to the grandfather and acknowledge the emotional trauma he had suffered.

In modern, culturally diverse societies, cross-cultural encounters in healthcare are inevitable. In the vast majority of such encounters, the provision and reception of appropriate care occurs without incident. In a small percentage of such encounters, however, cultural differences lead to misunderstandings, hurt feelings, and occasionally outright con-

flict. In the late 1970s and early 1980s, recognition of the potential for cultural differences to lead to conflict or to otherwise interfere with the provision of healthcare led to the development of an emphasis on cultural competence. This emphasis has since become a basic element in the training of healthcare providers, especially nurses.<sup>2</sup> Its value to healthcare ethics consultants and committees has also been promoted in the literature.<sup>3</sup>

The case presented by Amy E. Caruso Brown is an excellent example of ethical conflict in which cultural differences between healthcare providers and the patient and his family appear to play a major role. Brown and her colleagues are to be commended for their successful management of this case, both medically and ethically, which ultimately led to a good outcome. Brown is also to be commended for taking advantage of the opportunity to reflect upon and share the case in order to gain understanding that may be useful in future encounters with Amish patients.

The Amish are the most widely known of a number of ethno-religious groups which may be classified as "Plain Anabaptists." Plain Anabaptists share several salient characteristics, including plain dress, resistance to some forms of modern technology, close community ties, and conscious efforts to remain separate from the non-Plain Anabaptist world.<sup>4</sup> Plain Anabaptists are found throughout North America, with concentrations in certain regions, including

---

**James L. Benedict, PhD**, is a Scholar in Residence at the Center for Healthcare Ethics at Duquesne University in Pittsburgh, Pennsylvania. [benedictj@duq.edu](mailto:benedictj@duq.edu)

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

upstate New York, Pennsylvania, Ohio, and Indiana.<sup>5</sup> There are actually more than 40 distinct groups that identify as Amish, with a total population of around 300,000. All trace their heritage back to early Mennonites in Germany and Switzerland during the 16th century. The Amish are the descendants of those Mennonites who followed a leader known as Jakob Ammann in the late 17th century. On the whole, they tended to be more resistant to inculturation than other Mennonites. Today, the degree of Amish resistance to the larger culture and its technologies range along a spectrum, from the most resistant Schwartzentruber Amish to the far more open Beachy Amish.<sup>6</sup>

As evidenced by this case, the Amish are not opposed to seeking modern, scientifically based medical treatment. However, they often do so only after availing themselves of other options, including various forms of complementary and alternative medicine (CAM) and faith healing.<sup>7</sup> It is not unusual, therefore, for Amish patients to be quite ill or injured when they first seek treatment from a physician or hospital. It is also not uncommon for Amish to express or exhibit reluctance toward or outright refusal of recommended tests or treatments, especially those that are expensive or that have only a slim chance of success.<sup>8</sup>

In this case, the reluctance to pursue treatment for a three-year-old Amish boy who presented with symptoms of acute myeloid leukemia raised strong ethical concerns among the medical staff. Refusal of treatment for pediatric patients is one of the most common triggers of ethical conflict involving the Amish, and similar scenarios have appeared previously in ethics literature.<sup>9</sup> What distinguishes this case, as Brown notes, is the seemingly unprovoked and ardent adversarial position taken early on in the encounter by the maternal grandfather of the patient. Brown and her team were right to conclude that this was an atypical reaction and to suspect that it was idiosyncratic, not cultural in its origin.<sup>10</sup>

Brown's analysis also explored questions around the deferment of decision-making authority to a grandparent and the suspicion by some of the treatment team that the child's parents and other family members might have been sending nonverbal signals indicating disagreement with the maternal grandfather. As acknowledged in Brown's case analysis, any competent adult may defer decision-making authority to another competent adult. This is ideally done explicitly and documented. In this instance, the lack of overt objections seems to have served as sufficient evidence of a willingness to defer.

With regard to the possibility that other family members were sending nonverbal signals of disagreement, one should be cautious about reaching such a conclusion and especially cautious about acting upon it. First, the situation is obviously ripe for members of the care team to project their own feelings onto members of the Amish family. Second, cultural barriers can make the interpretation of nonverbal communication quite difficult. Finally, a desire for the child to receive treatment and respect for the authority of an elder in the family can co-exist as first and second order desires.<sup>11</sup> In Amish culture, which encourages an attitude of *gelassenheit*,<sup>12</sup> or surrender to authority within the community, it is conceivable that one might *wish* for the child to receive treatment but nonetheless *will* compliance with the decision of the grandfather.

Brown reached a number of sound conclusions about what might have been done differently and what may be learned from the case. She noted that the failure to pursue the grandfather's initial request to involve community elders in a discussion was a "lost opportunity." If, as suspected, the reaction of the grandfather was idiosyncratic rather than a genuine expression of cultural values, a meeting with the elders would have provided the opportunity not only to determine this, but also to help persuade the grandfather to be more cooperative. Brown also came to recognize that "more intentional communication" might have been beneficial and acknowledged the need for patience on the part of careproviders in order to build trust.

In particular, such patience might have manifested itself in a willingness to listen to and accept the maternal grandfather as someone who was still suffering from his own prior emotional trauma. Ethics must always include a sincere effort to see the situation from another's point of view. The grandfather believed that he and his community had been harmed and disrespected<sup>13</sup> in a previous encounter with science-based healthcare, and this may indeed have occurred. The scenario described in the first endnote of Brown's article, in which a woman from this community was resuscitated and placed on life support for a week without reasonable hope for meaningful recovery, is troubling and not implausible. One should be able to empathize with the grandfather's fear that similarly futile treatment might be forced upon his family. A willingness to listen, to acknowledge the unfairness of the prior situation (at least as the grandfather describes it), and to reassure the grandfather that he and his community are respected, may have lessened the anxiety all around.

So we may add to Brown's list of valuable insights from this case the following: when we meet with an unexpected, highly emotional reaction, either in the delivery of healthcare or in the course of ordinary life, most often there is a story lurking in the background. If one wishes to keep the reaction from developing into full-blown conflict, it is useful to develop the skills necessary to coax out the story, listen non-defensively, and respond with appropriate empathy. In the end, this case may have been less about a conflict between values than it was about a need to recognize and respond to the grandfather's suffering.

#### NOTES

1. A.E.C. Brown, "At the Intersection of Faith, Culture, and Family Dynamics: A Complex Case of Refusal of Treatment for Childhood Cancer," in this issue of *JCE*, 28, no. 3 (Fall 2017).
2. For an account of the development of the field of cultural competence in healthcare, see S. Saha, M.C. Beach, and L.A. Cooper, "Patient Centeredness, Cultural Competence and Healthcare Quality," *Journal of the National Medical Association* 100, no. 11 (November 2008): 1278-80.
3. B. Gray, "Clinical Ethics, Cultural Competence and the Importance of Dialogue: A Case Study," *Journal of Clinical Research and Bioethics* 7 (2016): 256; J.J. Voight, "Cultural Competency—The Caregiver Connection," *Bioethics Forum* 19, no. 1/2 (2003): 17-23; D.F. Pacquiao, "Ethics and Cultural Diversity: A Framework for Decision-Making," *Bioethics Forum* 17, no. 3/4 (2001): 12-7.
4. L. Graham and J.A. Cates, "Health Care and Sequestered Cultures: A Perspective from the Old Order Amish," *Journal of Multicultural Nursing and Health* 12, no. 3 (2006): 60-3; J.A. Brewer and N.M. Bonalumi, "Cultural Diversity in the Emergency Department: Health Care Beliefs and Practices among the Pennsylvania Amish," *Journal of Emergency Nursing* 21, no. 6 (1995): 495; C. Dellasega, J.E. Hupcey, and K. Fisher, "Culturalizing Health Care for a Culturally Diverse Population: The Amish," *Clinical Excellence for Nurse Practitioners* 3, no. 1 (1999): 10.
5. C. Anderson, "Who are the Plain Anabaptists? What Are the Plain Anabaptists?" *Journal of Amish and Plain Anabaptist Studies* 1, no. 1 (2013): 26-71; C. Anderson and J.F. Donnermeyer, "Where Are the Plain Anabaptists?" *Journal of Amish and Plain Anabaptist Studies* 1, no. 1 (2013): 20.
6. J.A. Gates, *Serving the Amish: A Cultural Guide for Professionals* (Baltimore: Johns Hopkins University Press, 2014), 5-10.
7. D. Garrett-Wright, M.S. Jones, and M.E. Main, "Anabaptist Community Members' Perceptions and Preferences Related to Healthcare," *Journal of Amish and Plain Anabaptists Studies* 4, no. 2 (2016): 193-4; Brewer and Bonalumi, "Cultural Diversity," see note 4, p. 495.
8. S.M. Weyer et al., "A Look into the Amish Culture: What Should We Learn?" *Journal of Transcultural Nursing* 14, no. 2 (2003): 143.
9. A.H.M. Antommaria et al., "Two Infants, Same Prognosis, Different Parental Preferences," *Pediatrics* 135, no. 5 (2015): 918-23; E.A. Gibson, "Caring for a Critically Ill Amish Newborn," *Journal of Transcultural Nursing* 19, no. 4 (2008): 371-4; E. Wright Clayton and E. Kodish, "Baby Aaron and the Elders: A Case Study," *Hastings Center Report* 29, no. 5 (1999): 20-1.
10. M.J. Banks and R.J. Benchot state, "[The Amish] tend to avoid abusive, violent, boisterous or threatening words." "Unique Aspects of Nursing Care for Amish Children," *MCN: The American Journal of Maternal Child Nursing*, 26, no. 4 (2001): 192; Dellasega, Hupcey, and Fisher, "Culturalizing Health Care," see note 4 above, p. 12.
11. See Harry Frankfurt, "Freedom of the Will and the Concept of a Person," in *The Importance of What We Care About: Philosophical Essays* (Cambridge, U.K.: Cambridge University Press, 1988), 11-25.
12. For a description of *gelassenheit*, see D. Kraybill, *The Riddle of Amish Culture* (Baltimore: Johns Hopkins University Press, 1989), 99-100.
13. Concern for respect is a main theme in one study of Plain Anabaptist attitudes regarding healthcare. See Garrett-Wright, Jones, and Main, "Anabaptist Community Members' Perceptions," see note 7 above, pp. 194-5; Weyer et al., "A Look into the Amish Culture," see note 8 above, p. 144.

**Research**

# The Ethics of Research in Lower Income Countries: Double Standards Are Not the Problem

*David S. Wendler*

## ABSTRACT

Discussion of the ethics of clinical trials in lower income countries has been dominated by concern over double standards. Most prominently, clinical trials of interventions that are less effective than the worldwide best treatment methods typically are not permitted in higher income countries. Commentators conclude that permitting such trials in lower income countries involves an ethical double standard. Despite significant attention to this concern, and its influence over prominent guidelines for research in lower income countries, there has been little analysis of what constitutes an ethical double standard in clinical research. The present article attempts to address this gap in the literature. This analysis finds that ethical double standards involve a kind of disrespect, and yields a three-step decision procedure for evaluating when trials of less than the worldwide best methods raise this concern. Application of this procedure reveals that permitting these trials in lower income countries rarely involves an ethical double standard. Instead, the real challenge is determining when clinical trials of interventions that are less effective than the worldwide best represent a permissible and effective response to differences in access to

healthcare between higher income and lower income countries. To protect research subjects, without blocking clinical trials that have the potential to improve health in lower income countries, research review committees and other stakeholders should focus on this issue, not on ethical double standards.

Clinical trials of interventions and medications that are less effective than the best interventions and medications that are available worldwide (hereafter referred to as the worldwide best methods) raise important ethical concerns and have been the subject of significant debate, especially when the clinical trials are funded by entities in higher income countries and are conducted in lower income countries.<sup>1</sup> Proponents argue that trials to assess less than the worldwide best methods have the potential to improve health in lower income countries and, thereby, reduce health disparities between lower income and higher income countries.<sup>2</sup> Critics respond that such trials are not permitted in higher income countries. They conclude that the trials are unethical,<sup>3</sup> and they should not be permitted in lower income countries either.<sup>4</sup>

Despite the importance of this debate, and the fact that it is now entering its third decade, there is still no analysis in the literature of what constitutes an ethical double standard in clinical research. As a result, it is unclear which trials should be permitted and which trials should be prohibited. The present article attempts to address this gap in the

---

**David S. Wendler, PhD**, is Head of the Section on Research Ethics in the Department of Bioethics, National Institutes of Health Clinical Center, Bethesda, Maryland. [dwendler@nih.gov](mailto:dwendler@nih.gov)

The present work was funded by intramural research funds of the NIH Clinical Center. The views expressed are the author's own. They do not represent the position or policy of the NIH, the Public Health Service, or the Department of Health and Human Services. ©2017 by *The Journal of Clinical Ethics*. All rights reserved.

literature by providing an analysis of ethical double standards and using it to identify those factors that are relevant to assessing when permitting a trial using less than worldwide best methods involves an ethical double standard. This analysis yields a three-step decision procedure, which suggests that clinical trials in lower income countries rarely raise concern over ethical double standards. This analysis further suggests that disagreement over the appropriateness of clinical trials that use less than worldwide best methods traces to a related but distinct issue. It traces to disagreement over whether permitting these trials represents a permissible and effective response to differences in access to healthcare between higher income and lower income countries.

Evaluation of this distinct concern requires stakeholders to answer three questions that are obscured by a focus on ethical double standards. First, is conducting the trial consistent with the obligations of those involved? As we shall see, the answer to this question frequently depends on who is sponsoring the study. Second, will permitting the trial be counterproductive in the sense of leading to worse healthcare in the long run for the affected communities? Third, will permitting the trial increase the potential for abusive research? To protect research subjects without blocking appropriate studies that have the potential to reduce health disparities between higher income and lower income countries, research review committees, guidelines, and other stakeholders should focus on these questions, not on ethical double standards.

## BACKGROUND

The ethics of clinical trials that use less than the worldwide best methods gained attention in 1997.<sup>5</sup> At the time, the 076 regimen (also known as “long-course” azidothymidine/zidovudine—AZT) was known to be effective at reducing vertical transmission of human immunodeficiency virus (HIV) from mother to child.<sup>6</sup> However, there was concern that this regimen might not be feasible and affordable in lower income countries, leading investigators to a series of trials that compared a truncated version of the 076 regimen (so-called “short-course” AZT) to placebo.<sup>7</sup>

Proponents argued that testing a potentially feasible and affordable regimen offered significant potential benefits to mothers and infants in lower income countries who otherwise had little to no access to effective interventions. Nonetheless, this study design would not have been permitted in

higher income countries, where pregnant women had access to the 076 regimen. Critics concluded that permitting these trials in lower income countries, but not in higher income countries, involved an ethical double standard.<sup>8</sup> Twenty years later, this charge continues to influence discussion of the ethics of clinical trials in lower income countries. Most prominently, the revision process that led to the current version of the *World Medical Association Declaration of Helsinki* (hereafter, the *Declaration of Helsinki*) included significant debate over when trials using less than the best methods should be permitted in lower income countries.<sup>9</sup> An expert conference, convened by the World Medical Association in Sao Paulo, Brazil, in 2011, to settle this debate, led to a preliminary proposal to allow these trials in limited circumstances (disclaimer: I was a participant at this conference).<sup>10</sup> This proposal was later dropped in response to objections that permitting trials of less than the best methods in lower income countries involves an ethical double standard. The *Declaration of Helsinki* thus directs physicians and other stakeholders to conduct trials using less than the best methods only when the research subjects are not exposed to any “additional risks of serious or irreversible harm as a result of not receiving the best proven intervention.”<sup>11</sup> The *CIOMS* (Council of the International Organizations of Medical Sciences) *International Ethical Guidelines for Health Related Research Involving Humans* (hereafter, the *CIOMS Guidelines*) similarly allow use of less than the best methods only when “delaying or withholding the established effective intervention will result in no more than a minor increase above minimal risk to the participant.”<sup>12</sup>

These requirements block essentially all clinical trials on interventions and medications that are less effective than the worldwide best, including trials that have the potential to reduce health disparities between higher income and lower income countries. To evaluate whether this prohibition is justified, it will be helpful to consider an example that is unrelated to the HIV trials.

## LESS THAN THE WORLDWIDE BEST CHEMOTHERAPY

Stem cell transplantation is the worldwide best treatment for many leukemia patients.<sup>13</sup> Stem cell transplantation also costs several hundred thousand dollars per patient, far beyond the means of many lower income countries. With this in mind, imagine that an investigator develops an experimental combination of medications that were used to treat leu-

kemia in higher income countries before the advent of stem cell transplantation. While this combination almost certainly will not be as effective as transplantation, it may be more effective than the treatments currently available for most leukemia patients in lower income countries. Moreover, because the drugs are no longer on patent, the combination would be affordable.

Because the proposed chemotherapy combination is likely to be more effective than the treatments that are currently available to individuals in lower income countries, these individuals would be better off enrolling in the chemotherapy trial than pursuing the standard care that is available to them. At the same time, these individuals would face a higher risk of death in the chemotherapy study than they would face if they received transplantation. Clinical trials to evaluate this experimental combination thus would violate the *Declaration of Helsinki's* requirement to use less than the best methods only when subjects do not face any additional risks of serious harm compared to the risks they would face with the best intervention. These clinical trials would also violate the *CIOMS Guidelines*, which allow trials of less than the best methods only when the trials pose no more than a minor increase over minimal risk compared to the worldwide best treatments. Should the chemotherapy trial be prohibited, despite its potential to benefit participants, on the grounds that permitting it would involve an ethical double standard?

### ETHICAL DOUBLE STANDARDS

The potential for ethical double standards arises when individuals (or groups) are treated differently. Of course, differential treatment is often permissible, sometimes even obligatory. Imposing a fine on one individual, but not another, does not constitute an ethical double standard when the two have behaved differently in relevant ways. Similarly, with respect to clinical trials, it can be ethically appropriate to permit a trial in one place or population but prohibit it in another. For example, it would be permissible to conduct a study involving a bovine-derived drug in the United States, but to prohibit such a trial in Hindu communities in India. The difference in the permissibility of the trial would be justified by the differences in the fundamental values of the two populations.<sup>14</sup> Put differently, differential treatment at the level of a specific trial is the result of a uniform application of the principle that clinical trials should be conducted in ways that respect the fundamental values of the host communities.

As this example highlights, differential treatment raises the potential for ethical double standards only when some individuals are treated less well, despite their being similar in relevant respects. And one might argue that unjustified differential treatment involves an ethical double standard in all such cases, including when differential treatment traces to purely random behavior on the part of the agent in question. For example, one might regard as an ethical double standard randomly fining some individuals but not others. Granting this theoretical possibility, ethical double standards are especially troubling when some individuals are treated less well because they are regarded as inferior or less deserving. Fining one individual but not another is especially troubling when the differential treatment traces to the fact that the fined individual belongs to a socially disparaged group. This analysis suggests that ethical double standards involve unjustified worse treatment that represents a particular kind of disrespect, namely, treating some individuals (or groups) worse because they are regarded as inferior or less deserving than other, similarly situated individuals (or groups).

Appeals to ethical double standards are used to condemn certain behaviors by pointing out that an agent behaved inconsistently across relevantly similar cases. This is distinct from a claim that the treatment of the disparaged group, considered in isolation, violates an ethical constraint on the agent's behavior. Imagine, for example, that the agent in the previous example is not permitted to fine anyone. In that case, one can condemn the agent's behavior by pointing out that the agent is not permitted to issue fines. This criticism does not cite differential treatment, hence, it does not involve an appeal to ethical double standards.

Similarly, one might condemn clinical trials in lower income countries that use less than the best methods, not by an appeal to ethical double standards, but by arguing that researchers have an obligation to provide the best methods to their subjects. Consider the following passage in the *CIOMS Guidelines*: "In general, studies must be designed to generate sound scientific information without delaying or withholding established effective interventions from participants. Researchers and sponsors may deviate from this default rule when withholding such interventions is methodologically necessary and exposes participants to no more than a minor increase above minimal risk."<sup>15</sup> If researchers do have a general obligation to provide research participants with the best available methods, all studies that use less than the best methods would be

unethical. In that case, one could condemn these trials without citing the inconsistency of prohibiting the trials in higher income countries. This inconsistency might add to the ethical concern, but it would not represent the primary problem with these trials, namely, that they are inconsistent with the investigators' obligations.

"Appropriate respect" is typically regarded as a behavioral side constraint, in the sense that disrespect is not permitted, even when the consequences are otherwise acceptable. To see this, imagine I teach clinical investigators that they should treat research participants in lower income countries with disrespect, but only when some good may come of it, and when doing so does not pose serious risks. This would be odd. Respect for research participants is mandatory in all cases; it is not something that can be justified when it benefits others and the risks are low. Notice, however, that the *Declaration of Helsinki* and the *CIOMS Guidelines* allow trials that use less than the best methods when the risks to subjects are sufficiently low. This approach would be odd in the same way if such trials involved an ethical double standard. In that case, the guidelines for appropriate behavior on the part of researchers would be claiming that disrespect of individuals in lower income countries can be acceptable when the risks to them are not too great. The assumption that these guidelines do not condone disrespect, even when it poses low risks, suggests that opposition to these trials may not trace to concern over ethical double standards. We will pursue, and, I shall argue, ultimately confirm this suggestion.

### DECISION PROCEDURE

I have argued that ethical double standards represent a particular kind of disrespect, one in which some individuals are treated worse because they are considered to be inferior or less deserving than other, similarly situated individuals. On this analysis, whether permitting a trial of less than the best methods in a lower income country involves an ethical double standard depends on three questions. Taken together, they provide a decision procedure that research review committees (and other stakeholders) can use to evaluate the potential for ethical double standards (see figure 1).

First, are there ethically relevant differences between conducting the trial in lower income versus higher income countries? Second, does one or more of the ethically relevant differences support differential treatment? Third, do the ethically relevant differences together justify permitting the trial in lower

income but not in higher income countries? If the answer to any of these questions is "no," permitting the trial raises concern over an ethical double standard. In addition, as I have argued above, the potential for an ethical double standard is especially concerning when it is based on the view, or seems to convey the view, that individuals in lower income countries do not deserve the worldwide best methods. To illustrate this approach, we shall consider how it applies to the proposed combination chemotherapy study described earlier.

#### Step 1

Stem cell transplantation is feasible and affordable in higher income countries, but not in lower income countries. Hence, the study of a low-cost chemotherapy combination therapy has potential value for lower income countries, but not for higher income countries. Furthermore, research subjects in lower income countries would not receive stem cell transplantation if the low-cost trial was not conducted. Thus, enrollment in the trial does not make the participants worse-off than they would be, absent the trial. This suggests that there are ethically relevant differences between conducting the trial in lower income versus higher income countries.

#### Step 2

The assessment of the chemotherapy combination therapy has significant potential value for lower income countries, but not for higher income countries. This provides a strong reason to permit the trial in lower income countries, but not in higher income countries. Specifically, value for the host community or population is widely endorsed as an important ethical consideration that argues in favor of permitting a trial.

#### Step 3

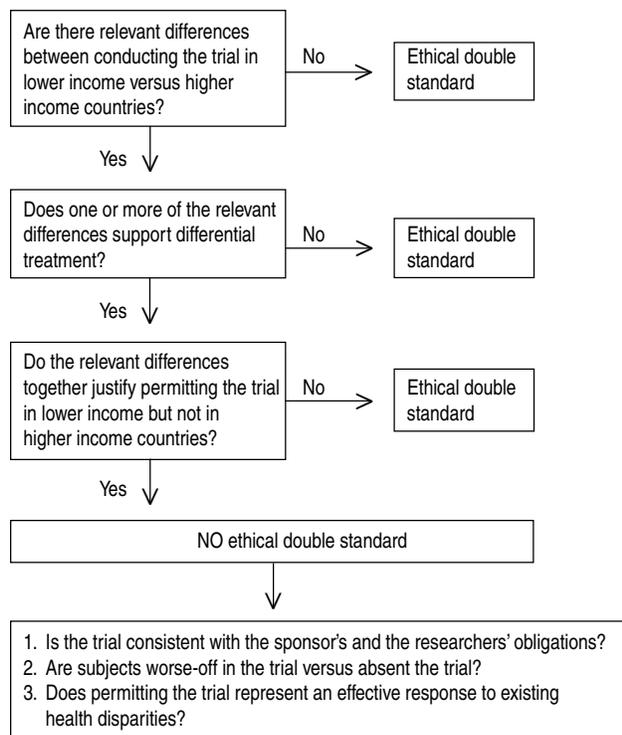
Because some ethical considerations support a trial does not establish that it should be permitted in lower income countries. We still need to determine whether there are any other ethically relevant considerations that conflict with differential treatment. In theory, this question can be difficult to answer, because it can be difficult to determine whether one has taken into account all of the relevant ethical considerations. In addition, the justification for the trial is that individuals in lower income countries are worse-off in the sense of not having access to the worldwide best methods. This raises concern that conduct of the trial is based on the belief that individuals in these countries do not merit the best methods. Explicitly permitting such trials may be

perceived as unseemly, because they may be seen as calling attention to the fact that individuals in lower income countries are worse-off than those in higher income countries.

One way to address these concerns in practice is to consider whether it would be acceptable, if similar circumstances obtained, to conduct the proposed study in a higher income country.<sup>16</sup> This approach offers a way to assess whether ethically relevant considerations are being inadvertently ignored. By removing the potentially disparaged characteristic of being from a lower income country, this approach offers a way to help ensure that permitting a trial does not reflect the belief that those in lower income countries are less deserving.

### WOULD THE TRIAL BE ACCEPTABLE IN HIGHER INCOME COUNTRIES?

Imagine that some leukemia patients in a higher income country do not have health insurance and cannot afford stem cell transplantation. To make the cases parallel, imagine that the population's poverty and lack of access to effective healthcare is due, in part, to historical discrimination and injustice.



**FIGURE 1.** When does permitting a trial of less than the best methods in a lower income country, but not in higher income countries, constitute an ethical double standard?

Finally, imagine that the company that controls the treatments used in stem cell transplantation declines, without justification, to offer the treatments to members of the population at a price they can afford.

In this setting, it seems unethical for this company to conduct a trial of the low-cost chemotherapy combination therapy. Arguably, the company should offer the best treatment methods at a cost that these individuals can afford (or the government should provide stem cell transplantation to patients who need it). This conclusion highlights an important point. Because circumstances might justify a study of less than the best methods does not imply that such trials are acceptable no matter who conducts them: one also needs to assess whether the proposed sponsor has an obligation to provide the population in question with the best treatment methods.

Now imagine that this situation continues for years, despite concerted efforts by a nonprofit organization to force the company or government to provide the best treatment. Recognizing the enduring nature of the situation, and that many patients who need treatment are not receiving it, the nonprofit proposes to test the experimental combination therapy. In this case, the trial does not involve an ethical double standard, because there is an ethically relevant difference between this population and most leukemia patients in the U.S., namely, access to stem cell transplantation. The nonprofit clearly is not saying that the affected population does not deserve the best treatment methods for leukemia. In other words, the differential treatment is not an instance of disrespect. Instead, the nonprofit continues to regard the current circumstances as ethically inappropriate. Its goal is to help the population by the means available.

### ETHICAL DOUBLE STANDARDS ARE NOT THE ISSUE

In the hypothetical case above, potential participants had no access to transplantation. This lack of access represents an important ethical difference that supports conducting a trial of the low-cost chemotherapy combination therapy in this population, but not in others. In addition, the fact that the population did not have access to transplantation implies that enrollment in the trial was consistent with their prospective interests, in the sense that the risk/benefit profile of enrolling in the study was at least as favorable as the available alternatives. Of course, enrollment in the trial may turn out, on balance, to be harmful to one or more of the participants. None-

theless, enrolling in the trial was prospectively in the participants' interests. This suggests that trials of less-effective interventions should be permitted only when subjects who enroll will not be made prospectively worse-off than they would have been, absent the trial. The low-cost chemotherapy example thus suggests that allowing trials of less than the best methods does not constitute an ethical double standard when there are differences in access to effective treatments that might be at least partially addressed by the trial, and enrollment does not make participants prospectively worse-off.<sup>17</sup>

Trials of less-effective interventions typically are not of value for higher income populations who already have access to the worldwide best interventions. Instead, the value of the trial involves the possibility of providing disadvantaged populations with some effective treatment and at least reducing health disparities. Furthermore, if the population does not have access to the worldwide best methods, provision of less-effective methods often will satisfy the condition of not making subjects prospectively worse-off. It follows that the design of many, perhaps most, trials of less than the best methods in lower income countries do not raise concern over the potential for ethical double standards. Whether these trials are permissible then depends on whether those involved have an obligation to provide host communities with the worldwide best methods. When the investigators and the funders do not have an obligation to provide the best treatment methods, the trials can be ethically appropriate.

This conclusion is not based on claims that critics question or reject. It is based on the claim that whether a study is relevant to the health needs of a host community and whether enrollment makes subjects prospectively worse-off are important ethical considerations. Almost all commentators and guidelines, including those skeptical of clinical trials using less than the best methods, endorse these claims. For example, the *CIOMS Guidelines*, which preclude most trials of less than the best methods, state that clinical trials in low-resource settings must be "responsive to the health needs or priorities of the communities or populations where the research will be conducted."<sup>18</sup> Similarly, in an article questioning the appropriateness of the HIV vertical transmission trials, Glantz and colleagues argue that "research is, by definition, designed to create generalizable knowledge, and is only legitimate in a developing country if its purpose is to create generalizable knowledge that will benefit the citizens of that country."<sup>19</sup> One more example: Shapiro and Meslin, who led a U.S. bioethics commission that assessed the

ethics of research in lower income countries, argue that clinical trials sponsored by higher income countries and conducted in lower income countries should provide participants who have life-threatening illnesses with the best care available anywhere in the world. They also claim that these trials "should be limited to those that are responsive to the host country's health needs. If the intervention being tested is not likely to be affordable in the host country or if the healthcare infrastructure cannot support its proper distribution and use, it is unethical to ask persons in that country to participate in the research."<sup>20</sup>

Even opponents to conducting such research in lower income countries regard the relevance of the research to the host community as ethically vital to clinical trials. This provides further evidence that their opposition to trials using less than the best methods does not trace to the potential for ethical double standards. It does not trace to the claim that there are no ethically relevant differences between the host communities and higher income countries that can justify permitting the trials in the former but not in the latter. To the contrary, these commentators and guidelines stipulate that clinical trials must be responsive to the host communities' health needs and priorities. What then explains the intense and enduring disagreement? Why do commentators insist on provision of the worldwide best methods to research participants in lower income countries if this very stipulation renders many trials inconsistent with their own ethical principles?

#### THE ACTUAL POINTS OF DEBATE

As noted previously, some commentators claim that researchers have a general obligation to provide all research participants with the best treatment methods that are available anywhere. While this claim would provide clear and strong opposition to trials of less than the best treatment methods, without any appeal to ethical double standards, it is implausible. Even clinicians from higher income countries who work in lower income countries do not have an obligation to provide the best treatment methods to all of their patients. Unless one thinks that researchers have greater obligations in this regard than clinicians do, it follows that researchers do not have a general obligation to provide research participants with the worldwide best methods.

This conclusion needs to be distinguished from the claim that certain parties may have obligations to provide research participants with the best available treatment methods. In the previous example, it

was suggested that the company that controls the treatment might have been obligated to provide stem cell transplantation to all patients who need it. If that is the case, the company that controls the treatment should not be permitted to conduct a trial of a lesser intervention. The first challenge in evaluating the ethical acceptability of trials that use less than the best methods, then, is determining whether permitting these trials is consistent with the obligations of the specific funders and/or researchers.

Second, research studies of less than the best methods can be justified when they offer important benefit to the host population. To make sure that this condition is satisfied, research review committees should not merely consider whether the trial represents an advance on the *status quo*; they should also consider the long-term consequences of allowing the trial. In some cases, permitting trials that assess second-best interventions may reduce pressure to eliminate the underlying disparities altogether.<sup>21</sup> In the example above, could the nonprofit have used its resources to pressure the government to provide stem cell transplantation to leukemia patients? Or might it have been able to pressure the company that controls the treatment to lower its prices to the point that the best treatment is affordable to the patients? The answers to these questions will depend on each case and circumstances. Hence, rather than adopting a blanket approach and blocking all trials of less than the worldwide best interventions, research review committees and other stakeholders should permit such trials only after determining that the existing circumstances are unlikely to be remedied in the foreseeable future.

To consider a specific example, one critic of trials in lower income countries that use less than the best methods argues that the trials are based on the assumption that the circumstances of the subjects may be problematic, but require “no outside effort to improve care and protection beyond what is locally available.” The author goes on to argue that these trials display “indifference to harm and neglect, ignoring the deprivations they confront and failing to exercise the social virtues of palliating destitution of their research subjects.”<sup>22</sup> The author is right to be concerned with the extent to which such trials are appropriately responding to the needs of local populations. When the trials are not responding appropriately, or when there is an available alternative response that would benefit local populations more, the trials should not be permitted.

Third, insisting that all research studies use the best treatment methods offers important protection for research subjects. It essentially ensures that sub-

jects will not be made worse-off by enrolling in research studies. This suggests that permitting trials that involve less than the best treatment methods in lower income countries may increase the chances that unacceptable trials are approved as well. To take an analogous case, the requirement that research subjects must provide their own informed consent to participate in research—that is, are decisionally capable adults—offers important protection to participants. But this requirement also has the potential to block valuable research that will benefit those who cannot consent for themselves, such as research needed to improve healthcare for children. Recognizing this dilemma, most regulations permit research that involves children, but also adopt additional requirements to block abusive studies. The regulations establish a default of enrolling individuals who can consent, and allow research that involves children only when: enrolling children is necessary, the study is valuable, and the risks are acceptable. Research review committees should similarly adopt a default of requiring clinical trials to use the worldwide best interventions. Nonetheless, they should permit trials of less than the best methods when the funders/sponsors/investigators do not have an obligation to provide the best treatment methods, the trials offer important value for the host community, and enrollment will not make the research subjects prospectively worse-off.

## SUMMARY

Intense disagreement over when it can be appropriate to conduct clinical trials of less than the worldwide best methods in lower income countries is now entering its third decade. Critics argue that these studies are unethical on the grounds that permitting them involves an ethical double standard. This article argues that studies of less than the worldwide best methods in lower income countries rarely raise concerns over ethical double standards. This conclusion suggests that stakeholders should focus instead on three questions that are obscured by a focus on ethical double standards. First, is conducting the trial in question consistent with the obligations of those involved? Second, will permitting the trial be counterproductive in the sense of leading to worse healthcare in the long run for the affected communities? Third, will permitting the trial increase the potential for abusive research? This approach offers the potential to protect research participants without unnecessarily blocking clinical trials that benefit them and their communities and, thereby, reduce existing disparities in health be-

tween higher income and lower income communities and countries.

#### ACKNOWLEDGMENTS

Thanks to Joe Millum, PhD, NIH; Luke Gelinias, PhD, NIH; Seema Shah, JD, NIH; and Alan Wertheimer, PhD, NIH, for their helpful comments on previous versions of the manuscript.

#### NOTES

1. Nuffield Council on Bioethics, *The Ethics of Research Related to Health Care in Developing Countries* (London: Nuffield Council on Bioethics, 2002).

2. H. Varmus and D. Satcher, "Ethical Complexities of Conducting Research in Developing Countries," *New England Journal of Medicine* 337 (1997): 1003-5.

3. M. Angell, "The Ethics of Clinical Research in the Third World," *New England Journal of Medicine* 337 (1997): 847-9.

4. K.J. Rothman and K.B. Michael, "For and Against: Declaration of Helsinki Should be Strengthened," *BMJ* 321 (2000): 442-5.

5. R.A. Crouch and J.D. Arras, "AZT Trials and Tribulations," *Hastings Center Report* 28 (1998): 26-34.

6. E.M. Connor et al., "Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment," *New England Journal of Medicine* 331 (1994): 1173-80.

7. P. Lurie and S.M. Wolfe, "Unethical Trials of Interventions to Reduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries," *New England Journal of Medicine* 337 (1997): 853-6.

8. *Ibid.*

9. *World Medical Association Declaration of Helsinki—Ethical Principles for Medical Research Involving Human Subjects*, 2013: paragraph 33, <http://www.wma.net/en/30publications/10policies/b3/>.

10. T. Kuroyanagi and M. Ishii, "Declaration of Helsinki Expert Conference on the Ethics of Placebo Control in Clinical Trials—Comments on the Reasonable Availability Approach," *Japanese Medical Association Journal* 54 (2011): 346-50.

11. *Declaration of Helsinki*, see note 9 above.

12. *Council of the International Organizations of Medical Sciences, International Ethical Guidelines for Health-related Research Involving Humans*, 2016, <http://cioms.ch/ethical-guidelines-2016/WEB-CIOMS-EthicalGuidelines.pdf>.

13. Medline Plus, "Stem Cell Transplant," <http://www.nlm.nih.gov/medlineplus/ency/article/003009.htm>.

14. A. Wertheimer, *Rethinking the Ethics of Clinical Research: Widening the Lens* (Oxford: Oxford University Press, 2010).

15. *CIOMS Guidelines*, see note 12 above, p. 15.

16. R.J. Kim, "Correspondence: Ethics of Placebo-Controlled Trials of Zidovudine to Prevent the Perinatal Transmission of HIV in the Third World," *New England Jour-*

*nal of Medicine* 338 (1998): 838; A.J. London, "The Ambiguity and the Exigency: Clarifying 'Standard of Care' Arguments in International Research," *Journal of Medicine and Philosophy* 25 (2000): 379-97.

17. D. Wendler, E.J. Emanuel, and R.K. Lie, "The Standard of Care Debate: Can Research in Developing Countries be Both Ethical and Responsive to Those Countries' Health Needs?" *American Journal of Public Health* 94 (2004): 923-8.

18. *CIOMS Guidelines*, see note 12 above, p. 3.

19. L.H. Glantz, G.J. Annas, M.A. Grodin, and W.K. Mariner, "Research in Developing Countries: Taking 'Benefit' Seriously," *Hastings Center Report* 28 (1998): 38-2.

20. H.T. Shapiro and E.M. Meslin, "Ethical Issues in the Design and Conduct of Clinical Trials in Developing Countries," *New England Journal of Medicine* 345 (2001): 39-2.

21. U. Schuklenk and R.E. Ashcroft, "Affordable Access to Essential Medication in Developing Countries: Conflicts Between Ethical and Economic Imperatives," *Journal of Medicine and Philosophy* 27 (2002): 179-95.

22. M.H. Kottow, "The Vulnerable and the Susceptible," *Bioethics* 17 (2003): 460-71.

## *Perspectives*

# Universal Health Care and the Cost of Being Human

*Roger Strair*

### ABSTRACT

In this article I argue that the biological processes that make us human have error rates that distribute illness on a no-fault basis. I propose this as an ethical foundation for universal health-care.

The United States Affordable Care Act was, in part, designed to increase the number of residents who have health insurance. Subsidies were provided for many who do not have workplace insurance benefits, and insurers must accept clients independent of their health status. In many states, Medicaid was expanded, and Medicare reforms that were designed to change careproviders' reimbursement were also instituted. It was estimated that nearly ten million previously uninsured people in the U.S. would have coverage. Nevertheless, high co-payments and deductibles limit access to healthcare, even amongst those with higher end healthcare insurance. Despite this advance towards more accessible universal healthcare, there were still many patients who were either uninsured or underinsured. What is the ethi-

cal obligation to those without adequate insurance? The answer may lie in our biology, encoded in our DNA.

We are a dynamic species, the product of hundreds of thousands of years of evolutionary response to threats. We have a remarkable capacity to deal with danger. However, to be human and dynamic, we must each copy so much DNA and respond so rapidly to threats that random, no-fault errors occur. There is only so much one can do error-free, and we must exceed those limits to survive. These errors are the price of our complexity and adaptability. Occasionally they result in disease.

Consider just our blood. It is composed of many different types of cells: red blood cells that carry oxygen, white blood cells of several types that coordinate a refined defense against infection, and platelets that prevent bleeding. Each of these cell types engages also in other complex interactive physiologic processes. Blood cells are produced in the bone marrow. We must make 500 billion ( $5 \times 10^{11}$ ) new blood cells each day to survive. The DNA in each cell contains  $3 \times 10^9$  bits of information (nucleotides). A lot of DNA to be copied in a short period of time! We need so many cells so fast that we must compromise quality for quantity. It is chemically impossible to accomplish this task at 100 percent efficiency. Errors in copying DNA occur at a rate of  $10^{-8}$  to  $10^{-10}$  at each nucleotide in each cell during DNA replication.<sup>1</sup> These mistakes occur in all of us,

---

**Roger Strair, MD, PhD**, is a Professor of Medicine and the Division Chief of Hematologic Malignancies, Blood, and Marrow Transplantation at Rutgers Cancer Institute of New Jersey, Rutgers, the State University of New Jersey, in New Brunswick, New Jersey. [strairrk@cinj.rutgers.edu](mailto:strairrk@cinj.rutgers.edu)

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

as they are the embedded foundation and consequence of evolution. Given the number of blood cells that must be made every day, there are tens of millions of bone marrow genetic mutations per second occurring in each of us. In the U.S. (population 322 million),  $3.2 \times 10^{15}$  mutations are estimated to occur in bone marrow per second.

Making so many cells requires an immense biochemical burden that, by the restrictions of chemical reactivity, cannot be perfect. Mistakes abound: to be perfect would require us to be too slow to survive. To perfect the system and free it of mistakes would deprive us of flexibility and leave us as losers in the evolutionary battle. Lewis Thomas wrote: "The capacity to blunder slightly is the real marvel of DNA. Without this special attribute, we would still be anaerobic bacteria and there would be no music." Without these errors, we would not be human and we could not survive.

We almost always bear these DNA (genetic) errors without problem because they occur at a low rate per cell division (~three changes in three billion bits of information) and we have adapted a philosophy of survival. Any single cell gone bad can do harm, but no single cell is essential, so we have mechanisms to get rid of nearly any cell that has even a hint of a problem. However, on rare occasions, the "monkey at the typewriter"-type random changes in the bone marrow cell can result in significant changes that result in the development of a blood cell cancer (leukemia, lymphoma, Hodgkin lymphoma, multiple myeloma, and related diseases), an equally distributed no-fault side-effect of being human.<sup>2</sup>

What's true in the bone marrow for blood-related cancers is true in all tissues. Without the error rates that result in someone getting cancer, we could not replicate enough DNA to carry out the physiologic processes of humanity, and we would all die. Evolution has treated us as a species and spared almost all of us by sharing the risk. The process of disease is a mandatory by product of biological success. It is insurance for our species.

The same is true of many diseases. Even some behavioral diseases evolve in the context of social stresses that are adaptive and evolutionary.<sup>3</sup> Our success and evolution as a society may be dependent also upon processes that benefit most, but cause problems for others. For example, psychopathic traits may necessarily evolve to facilitate the leadership and the high-risk occupational experts necessary for group survival, but psychopathy may also foster antisocial and criminal behavior.<sup>4</sup> Hence, adaptive changes may result in neuropsychological

changes or behaviors that may be labeled or perceived as illness. As DNA must blunder, so must we.

So there are many lessons from illness. Perhaps nearly all disease occurs as a consequence of the biological and sociologic processes that make us human. Pollution, smoking, addiction, unhealthy diets, and other factors that adversely affect our health may arise in part as the consequence of cultural, social, and biologic evolutionary forces outside the control of the individual. We are linked by the interrelatedness of our endogenous and exogenous life-sustaining processes, and the risks inherent in these processes are shared amongst all humans. They are essential for all, but result in illness for some.

These biological facts may inform our perspectives on the justice of healthcare. At a mandatory  $3.2 \times 10^{15}$  species-sustaining mutations occurring in just the bone marrow per second in the U.S., some people will get sick. Some people will be randomly forced to assume the inevitable burden of illness/disease. When viewed from a Rawlsian impartial distribution of goods, we are invited to an "original position" behind a "veil of ignorance" that denies us knowledge of our own biases, status, and character.<sup>5</sup> In this state of fairness, many would feel that we must care for those biologic martyrs who drew the bad "hand" of illness. It is the natural response to the shared egalitarian risk of being human. In this setting, we must develop a healthcare system that better fits our needs and condition as a species.

#### ACKNOWLEDGMENTS

Work was motivated by colleagues, patients, and by the founders and participants of "Century for the Cure" Charitable Bicycle Ride. The author appreciates editing assistance from the journal.

#### NOTES

1. A. Kondrashov, "Genetics: The Rate of Human Mutation," *Nature* 488, no. 7412 (2012): 467-8; A. Kong et al., "Rate of de novo Mutations and the Importance of Father's Age to Disease Risk," *Nature* 488, no. 7412 (2012): 471-5.

2. P.A. Blombery, M. Wall, and J.F. Seymour, "The Molecular Pathogenesis of B-cell non-Hodgkin Lymphoma," *European Journal of Haematology* 95, no. 4 (2015): 280-93.

3. S. Cohen, D. Janicki-Deverts, and G.E. Miller, "Psychological Stress and Disease," *Journal of the American Medical Association* 298, no. 14 (2007): 1685-7; J.C. Phelan, B.G. Link, and P. Tehranifar, "Social Conditions as Fundamental Causes of Health Inequalities: Theory, Evidence,

and Policy Implications," *Journal of Health and Social Behavior* 51, suppl. (2010): S28-40.

4. S.O. Lilienfeld, R.D. Latzman, A.L. Watts, S.F. Smith, and K. Dutton, "Correlates of Psychopathic Personality Traits in Everyday Life: Results from a Large Community Survey," *Frontiers in Psychology* 5 (2014): 740.

5. J.C. Moskop, "Rawlsian Justice and a Human Right to Health Care," *Journal of Medicine and Philosophy* 8, no. 4 (1983): 329-38.

## Vaccine Exemptions and the Church-State Problem

*Dena S. Davis*

### ABSTRACT

All of the 50 states of the United States have laws governing childhood vaccinations; 48 allow for religious exemptions, while 19 also offer exemptions based on some sort of personal philosophy. Recent disease outbreaks have caused these states to reconsider philosophical exemptions. However, we cannot, consistent with the U.S. Constitution, give preference to religion by creating religious exemptions only. The Constitution requires states to put religious and nonreligious claims on equal footing. Given the ubiquity of nonreligious objections to vaccination, I conclude that the best response is to remove all exemptions, as two states have already done. But removing exemptions should not end our concern for children. Removing exemptions only bars children from public schools; it still leaves them unvaccinated, a danger to others, and reliant on whatever nonpublic schooling is available. If public school attendance is not enough of an incentive for vaccine reluctant parents, perhaps we should look into stronger measures.

The 2014 measles outbreak in the U.S. brought public attention to the ease with which vaccine exemptions are available. According to the U.S. Centers for Disease Control and Prevention, the U.S. experienced a “record number” of measles cases that year, the majority in people who had not been vac-

inated against the disease. This was the largest number since measles had been declared “eliminated” in the U.S., in 2000.<sup>1</sup> The 2015 outbreak, originating in California’s Disneyland theme park, was blamed on “substandard vaccination compliance” that shone “a glaring spotlight on our nation’s growing antivaccination movement and the prevalence of vaccination-hesitant parents.”<sup>2</sup>

Given that vaccination is required for entrance to public school in all states, how do so many children remain unvaccinated? Part of the answer lies in a system of exemptions: 48 states allow for religious exemptions, while 19 states also offer exemptions based on some sort of personal philosophy.<sup>3</sup>

In this essay I make two claims. First, I argue that we cannot, consistent with the U.S. Constitution, give preference to religion by creating religious exemptions only. Using the historical parallel of religious exemptions to the military draft, I argue that it is constitutionally required to put religious and nonreligious claims on equal footing, if they fulfill certain requirements. Given the ubiquity of nonreligious objections to vaccination, I conclude that the best response is to remove all exemptions, as two states have already done. Second, I argue that removing exemptions should not end our concern for children. Removing exemptions only bars children from public schools; it still leaves them unvaccinated and reliant on whatever nonpublic schooling is available. If public school attendance is not enough of an incentive for vaccine reluctant parents, perhaps we should look into stronger measures.

---

**Dena S. Davis, JD, PhD**, is Endowed Presidential Chair in Health (Humanities/Social Sciences); Professor of Bioethics; and Professor of Religion Studies at Lehigh University in Bethlehem, Pennsylvania. [d311@lehigh.edu](mailto:d311@lehigh.edu)

©2017 by *The Journal of Clinical Ethics*. All rights reserved.

### **The Problem with Religious Exemptions**

The Religion Clauses of the First Amendment to the U.S. Constitution consist of two parts: "Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof." Beginning with the "incorporation" of these clauses in the middle of the 20th century, from the U.S. Congress alone to all federal, state, and local government entities, the clauses have been the topic of much scholarly analysis. Many scholars agree that, when pushed to their limits, the clauses are inherently in conflict.<sup>4</sup> If "establishment" means government preference and support for religion, then the accommodation of religion to allow for free exercise can be seen as an establishment. For example, a public university that gives students extra "cuts" for religious holidays, without also acknowledging the need to miss class to care for sick children and other serious commitments, is arguably "establishing" religion.

From one perspective, religious exemptions would seem to be about free exercise, that is, not forcing persons to do something that is against their religion. But any time the state offers an exemption, it runs into Establishment Clause issues as well. If the state is supposed to be neutral on issues of religion, why should it offer exemptions based on religious grounds and not on equally serious philosophical or personal grounds? Should the state be labeling religious reasons as "better"? And if religious reasons really are better, then what counts as religion? Should you have to bring a note from your imam, pastor, or rabbi? Brian Leiter suggests that privileging religious exemption is attractive because religions usually have "texts, doctrines, and commands . . . practices, rituals, and ceremonies,"<sup>5</sup> that make it easier for the state to sort out legitimate claims from self-serving ones. But what if your religious practice doesn't include joining an official church? Or what if your denomination supports vaccination but you believe otherwise—are your religious reasons still legally valid? Pretty soon the state is acting like some sort of religious certification board. Not only is that untenable, but it is in itself a violation of the Establishment Clause; the state should not be acting as an arbiter of religious orthodoxy. As the Supreme Court wrote in 1981, "religious beliefs need not be acceptable, logical, consistent, or comprehensible to others in order to merit First Amendment protection."<sup>6</sup>

Church-state scholar Winnifred Fallers Sullivan, drawing upon her extensive experience as an expert witness, has concluded that at this point in time, the beginning of the 21st century, it is almost im-

possible for the law to "get it right," because the religious life of most people "resists legal definition in a fundamental way."<sup>7</sup> She is speaking here primarily of religion in the U.S., with all its pluralism and individuality, what some people call "cafeteria religion," in which individual persons choose what elements of a religion they wish to adopt, perhaps even choosing from more than one religion. "Ordinary religion," says Sullivan, "that is, the disestablished religion of ordinary people, fits uneasily into the spaces allowed for religion in the public square and in the courtroom."

To understand the constitutional issues, consider the military draft and the exemption for conscientious objectors. Congress was not constitutionally required to include an exemption in the draft law, but once it did, it was required to do so in a fair and constitutional manner. At first, the exemption was open only to members of established peace churches, such as Mennonites and Quakers. That made it easy for draft boards, but was obviously unfair. To use legal jargon, it was both under- and overinclusive. One could be a Mennonite or Quaker and not be a pacifist (as Quaker history during the Civil War shows, for example) or be a devout pacifist but not belong to an historic peace church. Eventually, the exemption was broadened to include pretty much anyone who could make a case for being a pacifist (defined as opposed to fighting in any and all wars) and who also believed in a Supreme Being.

In 1958, Dan Seeger, a young man on a spiritual journey from Roman Catholicism to Quakerism, claimed to be a sincere pacifist, but not too sure about a Supreme Being. He took his case all the way to the Supreme Court, which, quoting theologian Paul Tillich, adopted a more expansive view of religion as the "ground of being," without requiring belief in a Supreme Being.<sup>8</sup> In 1970 the other shoe dropped, when Elliott Welsh successfully argued that the law could not privilege religious beliefs over purely secular, philosophical ones.<sup>9</sup> On the other hand, a young man who opposed only some wars, in line with the Roman Catholic belief in "just war theory," did not win his case, despite his religious orthodoxy. The Supreme Court upheld the right of Congress to offer the exemption only to pacifists who opposed all wars.<sup>10</sup>

It is worth considering the probable outcome if a young man who identified as Roman Catholic nonetheless rejected just war theory in favor of pacifism. Would the Court have rejected his claim because he wasn't being a consistent or orthodox Roman Catholic? Almost certainly not. In 1981, faced with a Jehovah's Witness whose beliefs differed from

the majority of his co-religionists, the Court “declined to inquire whether the petitioner or his fellow worker more correctly perceived the commands of their common faith. Courts are not arbiters of scriptural interpretation.”<sup>11</sup>

Returning to vaccination, we now see that trying to separate religious from philosophical or “personal” reasons won’t work, either as a neat way to draw a line, or by using “religious” as a proxy for “serious.” And we have not even discussed the problem of people who pretend to be religious objectors to invoke an exemption to which they are not entitled. Parents who remain convinced of the (disproven) connection between vaccines and autism, for example, may recast their objection as religious in order to win an exemption. That is already happening in Vermont, which repealed its philosophical exemption in 2015. “I will become religious, if need be, to get a religious exemption,” said one parent. “I will believe whatever I have to believe to not have my kids vaccinated.”<sup>12</sup>

Although the Supreme Court decided in 1905, in *Jacobson v. Massachusetts*, that states have the power to require vaccination as a condition of school enrollment,<sup>13</sup> litigation at the state level continues. In 1979, the Mississippi Supreme Court followed *Jacobson* and other cases in holding that the state’s interest in public health was sufficient to override the religious rights of parents seeking religious exemptions. However, the Mississippi court found the state’s exemption law unconstitutional because it violated the equal protection rights of parents who wanted the exemption but did not qualify on religious grounds.<sup>14</sup> Mississippi responded by dropping the exemption altogether.<sup>15</sup> In 2001, a U.S. District Court in Arkansas found that state’s law unconstitutional because it exempted only members of a “recognized church or religious denomination,” thus violating both the free exercise and the Establishment Clauses.<sup>16</sup> Arkansas responded by rewriting the law in a much more permissive fashion, including exemptions based on philosophical belief.<sup>17</sup> “Religious exemptions that require only a “sincerely” held religious belief are more likely to prevail against a constitutional challenge, although they may still be found to discriminate against those with “sincerely” held nonreligious beliefs about vaccination.<sup>18</sup>

#### WHERE DO WE GO FROM HERE?

If we acknowledge that no constitutionally defensible line can be drawn between religious and philosophical beliefs, we can either give exemptions to practically every parent who asks, or make vacci-

nation mandatory with virtually no (nonmedical) exemptions. Given the anti-scientific suspicion of vaccines, propagated by Hollywood celebrities and even by some political candidates—including those who are physicians themselves<sup>19</sup>—and given that most people who are parents today have never seen a case of diphtheria or polio, the number of parental refusals under a permissive system would probably be quite high.

There are a number of suggestions as to how to push more parents toward vaccination, without completely closing the current loopholes. One way in which we could tweak the present system is to make the process of getting an exemption a bit more onerous, although not so much as to be a “burden” upon free exercise. At the very least, parents could be expected to undergo a counseling session with a health-care provider, or to watch a video or in some other way to show that they have seriously considered the health consequences to their children and to others in the community. In New York State, for example, parents wishing the religious exemption must write an annual letter explaining in their own words “the religious principles that guide [your] objection to immunization.”<sup>20</sup> In Vermont, parents are required to read a three-page educational leaflet on the safety and benefit of immunization.<sup>21</sup>

A legal scholar has hypothesized that tort law “has the potential to be the best method of preventing religious and philosophical exemption abuse and compensating victims of vaccine-preventable disease outbreaks. . . .”<sup>22</sup> However, our goal should be deterrence to avoid injury, not compensation after the fact, and it is unlikely that parents would be deterred from leaving their child unvaccinated by the farfetched scenario of a class-action suit by those who believe they have been harmed because of vaccine-refusers’ subversion of herd immunity.

A controversial suggestion put forth by a group of pediatricians, including a past chair of the American Academy of Pediatrics (AAP) Committee on Bioethics, argues for singling out the measles vaccine because that disease is uniquely contagious and dangerous, and because of the relative ease of vaccine administration (a two-shot series with no booster shots required).<sup>23</sup> They suggest eliminating all non-medical exemptions for the measles vaccine, while retaining exemptions for the others. The authors’ goal is “to see as many children immunized as possible,” and they believe that this “least restrictive compromise” is the best way to proceed, given that states are unlikely to repeal all exemptions. This plan is roundly criticized by another group of pediatricians, who dispute this view of the facts, and who

appear to be in favor of repealing all laws that grant religious *and* nonreligious exemptions.<sup>24</sup>

These and other proposals are unlikely to make a serious dent in vaccination refusals. Routine vaccination (in the absence of an epidemic) presents an interesting ethical conundrum. From the perspective of parents, whose primary concern usually is and arguably ought to be, their child's well-being, the best possible outcome would be if everyone *except* their child were vaccinated. Due to herd immunity, a small fraction of people can remain safely unvaccinated if most of the "herd" is protected.<sup>25</sup> However, for very infectious diseases such as measles, that fraction is quite small, and there are always people who, due to age or medical conditions, cannot safely be vaccinated. Thus, the number of "free riders" who can act in this self-serving fashion, without bringing the system down, is relatively small. That suggests that a permissive attitude is not congruent with children's safety and public health.

A different tack would be to refuse virtually all nonmedical exemptions. From a legal viewpoint this is an attractive position because it removes the difficulties of adjudicating religious versus philosophical versus personal reasons. "If we are not to unfairly privilege religious claims of conscience by allowing their adherents to opt out of neutral legal requirements while nonreligious conscientious claimants must bear the burden of defeat . . . then perhaps it is time to say, the law is the law, and there will be no exemptions for claims of conscience, religious or otherwise?"<sup>26</sup> This position is also attractive from a medical point of view, at least at first glance. The AAP "advocate[s] for school entry immunization policies that ensure full immunization in the school setting."<sup>27</sup> An AAP "Advocacy Flash" from February 2015 asks state chapters to contact governors and legislatures to urge them to "rescind or restrict" personal belief exemptions:<sup>28</sup> "religious exemptions are not required by the First Amendment. . . . Rather, they are the product of legislative activity in the 1960s and 1970s, and thus can be repealed. Indeed, one could argue that nonmedical exemptions are themselves unethical and represent shortsighted policy, as they allow families a free ride on the immunization decisions of others while placing others at risk."<sup>29</sup>

#### THE PROBLEM WITH TIGHTENING EXEMPTIONS

Removing virtually all nonmedical exemptions is quite problematic, for a number of reasons. By

focusing on tightening exemptions but ignoring the implications of the penalty for nonvaccination—exclusion from school—we satisfy a superficial yearning for consistency without thinking through the consequences for children. First, children encounter other children and vulnerable people all of the time in playgrounds, swimming pools, grocery stores, *et cetera*, so barring them from public schools and day care does not protect the public. Some states extend the vaccination requirement to private schools, but others do not.<sup>30</sup> Thus more unvaccinated children would be clustered in some private schools, further endangering each other. Further, vaccination requirements tied to school enrollment ignore the large numbers of home-schooled children in the U.S.. According to a 2013 report of the National Center for Education Statistics, between one and one-half and two million children are home-schooled, representing between 3 and 4 per cent of the school-aged population.<sup>31</sup> "More children are educated at home than are educated in the public schools of Wyoming, Vermont, Delaware, North Dakota, Alaska, Rhode Island, Montana, and Hawaii combined. In fact, the total number of children educated in home schools outnumbers the aggregate of children educated in the public schools of 41 states."<sup>32</sup>

Second, while I acknowledge parents' rights to home school their child, I would not support any policy that made home schooling more attractive. It is true that vaccine refusers are likely to be affluent and well educated,<sup>33</sup> but one can't help wondering how well these parents will teach science education and basic logic.

So that leads to a somewhat draconian position, one that I confess makes me uncomfortable: to make vaccination legally required, with no (nonmedical) exemptions. Failure to vaccinate a child would subject the parent to the same penalties as failing to enroll a child in school. I understand how terrible and overreaching that must seem to parents who honestly believe that vaccines are introducing poisons into the vulnerable body of their young children. It may be that, in one or two generations, this will come to seem so routine that it will go virtually unremarked, like fluoride in the public water supply. Meanwhile, we need to think about the whole child. To allow children to remain unvaccinated as long as they don't enroll in public school is a disfavor to them and to other children as well.

#### NOTES

1. <http://www.cdc.gov/measles/cases-outbreaks.html>.
2. M.S. Majumder, E.L. Cohn, and S.R. Mekura, "Re-

search Letter: Substandard Vaccination Compliance and The 2015 Measles Outbreak," *JAMA Pediatrics* 169, no. 5 (May 2015): 494.

3. <http://www.ncsl.org/research/health/school-immunization-exemption-state-laws.aspx>.

4. M. McConnell, *Religion and the Constitution* (New York: Aspen Casebook Series, Wolters Kluwer, 2002), 105.

5. B. Leiter, *Why Tolerate Religion?* (Princeton, N.J.: Princeton University Press, 2013), 95.

6. *Thomas v. Review Board of the Indiana Employment Security Division*, 450 U.S. 707 (1981).

7. W.F. Sullivan, *The Impossibility of Religious Freedom* (Princeton, N.J.: Princeton University Press, 2005), 138.

8. *United States v. Seeger*, 380 U.S. 163 (1965).

9. *Welsh v. United States*, 398 U.S. 333 (1970).

10. *Gillette v. United States*, 401 U.S. 437 (1971).

11. *Thomas v. Review Board of the Indiana Employment Security Division*, see note 6 above.

12. P. Achen, "Parents Seek Way around VT Vaccination Law," *Burlington Free Press*, 8 June 2015.

13. *Jacobson v. Massachusetts*, 197 US 11 (1905).

14. *Brown v. Stone*, 378 So. 2d 218 (1979).

15. D.S. Diekema, "Personal Belief Exemptions from School Vaccination Requirements," *Annual Review of Public Health* 35 (2014): 275-92.

16. *McCarthy v. Boozman*, 212 F Supp. 2d 945 (WD Ark. 2002).

17. D.S. Diekema, "Personal belief exemptions," see note 15 above.

18. *Ibid.*

19. M.E. Miller, "The GOP's dangerous 'debate' on vaccines and autism," *Washington Post*, 17 September 2015.

20. J. Sykes, "NYC Department of Education. Memo to Parents of NYC Public School Children: Request for Exemption from Immunization Requirements," (n.d.), <http://schools.nyc.gov/NR/rdonlyres/E369FA10-ABC0-43AB-BDE6-062F4ACF7D0D/0/Parentletterreexemption reqs.pdf>.

21. Vermont Department of Health, School Year 2016-17, "Religious Immunization Exemption: Child Care and Schools," <http://healthvermont.gov/hc/imm/schoolentry.aspx>.

22. A. Ciolli, "Mandatory School Vaccinations: The Role of Tort Law," *Yale Journal of Biology and Medicine* 81, no. 3 (2008): 129-37.

23. D.J. Opel et al., "Childhood Vaccine Exemption Policy: The Case for a Less Restrictive Alternative," *Pediatrics* 137, no. 4 (2016): e20154230.

24. C.L. Byington, E.W. Clayton, and K.M. Edwards, "Childhood Vaccine Exemptions: A Broader Perspective is Required," *Pediatrics* 137, no. 4 (2016): e20160189.

25. <https://www.vaccines.gov/basics/protection/>.

26. B. Leiter, *Why Tolerate Religion?* see note 5 above, p. 101.

27. American Academy of Pediatrics, "State Advocacy Focus: Childhood Immunizations," December 2015, <https://www.aap.org/en-us/advocacy-and-policy/state-advocacy/Documents/Immunizations.pdf>.

28. American Academy of Pediatrics, "Advocacy Flash: State Immunization Exemptions, State Chapters Can Help," February 2015, [https://www.aap.org/en-us/advocacy-and-policy/state-advocacy/Documents/Advocacy FLASH\\_2\\_6\\_15.pdf](https://www.aap.org/en-us/advocacy-and-policy/state-advocacy/Documents/Advocacy FLASH_2_6_15.pdf).

29. Byington, Clayton, and Edwards, "Childhood Vaccine Exemptions," see note 24 above.

30. U.S. Centers for Disease Control and Prevention, "SchoolVaxView, Requirements and Exemptions," <http://www.cdc.gov/vaccines/imz-managers/coverage/schoolvaxview/index.html>.

31. [https://nccs.ed.gov/programs/digest/d13/tables/dt13\\_206.10asp](https://nccs.ed.gov/programs/digest/d13/tables/dt13_206.10asp).

32. B. Colwell and B. Schwartz, "Implications for Public Schools: Legal Aspects of Home Schools," *Education Law Reporter* 173 (2003): 381.

33. Y.T. Yang, P.L. Delamater, T.F. Leslie, and M.M. Mello, "Sociodemographic Predictors of Vaccination Exemptions on the Basis of Personal Belief in California," *American Journal of Public Health* 106, no. 1 (January 2016): 172-7.