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Correction: In volume 16, number 3, the name of author Abbey Berg was spelled incorrectly in the table of contents and on the front cover. *The Journal of Clinical Ethics* regrets the error.

At the Bedside

Shame, Slap Jack, and Familes That Should Lie

Edmund G. Howe

In this issue of *The Journal of Clinical Ethics,* Hilde Lindemann tells about a visit with her mother, who has Alzheimer's disease. Lindemann recalls, "I went into her bedroom and opened the drawer. As I slid my hand inside, I felt a hot rake of pain. I could smell the blood before I could see it. Blood was everywhere, flowing freely falling in great drops. I could see the razor blades that had been stuck to the top of the frame." Her mother says, "That's what happens to thieves. Get out of my house before I call the cops on you." This passage is from "On the Mend: Alzheimer's and Family Caregiving," that is as viscerally gripping as any piece *JCE* has published. It conveys accurately the horror patients with Alzheimer's and their loved ones may undergo.

This horror may involve violence. Much more often, it is silent: patients who have known and have been close to loved ones for decades no longer recognize them. Lindemann suggests that her initial response to this incident might have been "more kindly" if Lindemann had been able to see her as she had been at her best times, in the past. This would have been more beneficial for her mother. Quoting Wittgenstein, Lindemann states that persons are the "product of socialization and training," and so, she declares, are "essentially social."

The insight that loved ones might try to treat patients with Alzheimer's as kindly as possible can be highly beneficial to patients — improving their quality of life, if not its duration — and it is an insight that has been increasingly recognized and emphasized clinically in recent years.[1] Some of the new approaches that are advocated seem to be wholly counterintuitive, however, as they challenge what appears to be right, and raise ethical concerns that have hardly been addressed. In this essay I will discuss the three most important of these ethical questions.

The first is the extent to which loved ones should discuss with patients the difficult decisions that will arise for both of them in the future. Discussions could involve, for instance, what patients would want should the time come that they can no longer recognize

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those they love.[2]

The second question is the extent to which loved ones should try to "manipulate" patients; for example, asking patients about their preferences in ways that might tend to "predetermine" how they will respond. This approach may maximize patients' positive feelings and enable loved ones to proceed efficiently with the tasks they must carry out that involve patients, but, at the same time, it is implicitly deceitful.

The third question is whether loved ones, especially, should directly lie to patients in the third and final stage of their illness. This possibility is exemplified in Joanne Koenig Coste's recommendation on how loved ones should respond when patients accuse them of "crimes," as the mother in Lindemann's article did: "To the accusation 'You stole my special coat,' the best answer may be 'I forgot to tell you that I put it in storage for the summer,' even if the coat was sold twenty years ago."[3] Extrapolating from this, the daughter in Lindemann's article might have said, "Yes, you're right. I have taken some of your things. I'm sorry. I must have forgotten to tell you!" Both examples are outright lies, but they may leave patients more comfortable. As I shall discuss, this goal — to leave patients feeling comfortable — may be one of the most important for loved ones when they make choices involving patients with Alzheimer's. It is critically important for patients to know that loved ones won't abandon them. Coste states, "Paranoid behavior is usually directed at the closest family member, and that person should remain in the patient's world . . . no matter how bizarre the accusation."[4]

I will also present some general considerations that may help loved ones respond "better," and, finally, will discuss what patients and loved ones may be able to experience together, in spite of the patients' deficits.

Loved ones do not care for patients alone. Ethics consultants and other careproviders often work with loved ones and advise them how to best care for patients. It is thus essential that careproviders know both what loved ones can do to help patients and the ethical problems that may be involved. Thus, while this discussion focuses on what loved ones ideally should do, the issues raised are as critical for careproviders. As Lindemann contends, and as is true in most cases, careproviders may help patients most by helping their caregivers.

CORE PRELIMINARY CONSIDERATIONS

THE LIMITS TO WHICH LOVED ONES CAN BENEFIT PATIENTS

Even if loved ones respond to patients with Alzheimer's disease in ways that are optimal, it may not affect their course of illness. It is very important to wholly acknowledge this uncertainty; otherwise, loved ones may fear that they haven't done all they could. Such emotional adversity, in most contexts, has physical effects.[5] It is noteworthy that studies have reported that family conflict can take a short-term and a long-term toll.[6] By helping patients to feel more comfortable and thus provide them an "emotional safety net," loved ones may benefit the disease process indirectly.[7] All of the approaches I will recommend may enhance how patients feel, and, as a result, patients may feel more motivated to seek out treatments that will benefit the course of their illnesses. For instance, the medications currently available may slow down the progression of Alzheimer's disease; this, in turn, has been found to benefit patients' loved ones.[8]

LOVED ONES' WILLINGNESS TO "CHANGE COURSE"

Patients with Alzheimer's go through profound changes as their illness worsens. Thus, what may be best for them at the beginning of their illness may be bad for them later on. For instance, they may benefit most, early on, from being fully involved in planning the course of their futures, to the degree that they can. Later they may find this degree of involvement upsetting, and, more problematically, they

may deny that it is. They may, for example, become extremely frustrated when they lose the capacity to sufficiently understand what their loved ones are saying.[9]

Thus, loved ones must be aware at the outset that what patients most need at any one time may change. In all stages of illness, however, some responses to patients will remain consistently important. It is critical, for example, that loved ones always affirm what patients feel. In this issue of *JCE,* Tia Powell, in "Voice: Cognitive Impairment and Medical Decision Making," gives an example that suggests how this can be done:

> The daughter tucks an afghan blanket around her mother's legs. . . . the daughter says, "There, Mother. How is that?" The mother looks her daughter straight in the eye. . . . She says, "Lousy."

The daughter doesn't refute her mother, and, by not doing so, may imply that she understands. A loved one can go further and implicitly agree. Rather than remind her mother what about her life is still good — a reflex to which many of us might be prone — the daughter could say, "Yes. Surely it is lousy." Claudia J. Strauss, an authority on those with this illness and its treatment, says, "You can agree that life sometimes stinks."[10]

In many other responses, however, loved ones must be alert to changes they should make. Early on in patients' illness, for example, patients may find it essential for loved ones to tell the truth and the whole truth, because, otherwise, patients may feel distanced and infantilized. In time, though, patients may no longer understand as much. An example of this kind of change is when loved ones use pictures to communicate; a patient who has just begun to lose the capacity to understand verbal communication may find an offer to communicate in this way demeaning. In a more advanced stage of illness, however, the same patients may appreciate this strategy. Looking at pictures may even "elicit delight."[11] Loved ones must accept that, regardless of how much they try, there will be no "safe haven." To communicate most effectively with patients, for example, loved ones must increasingly, over time, slow down the pace of what they say. If they don't slow down enough, it may be frustrating to patients, but, if they talk too slowly, patients may find it condescending.

The obvious question this raises is how loved ones should know when to change what they are doing. The first answer is simply *to ask.* Loved ones can always ask, even when patients are no longer able to communicate verbally, it is still best to ask them what they prefer. For example, loved ones still can ask, "Is it okay with you if I touch you?"[12] Regardless of the answer, merely to ask such questions continues to give the patient a genuine choice, which remains extremely important. It also conveys that loved ones continue to love the patient because they continue to attempt to be caring. This may be more important than anything else to patients, as it implies that the connection they so much fear to lose, and, thus, crave, will continue. A particularly instructive (and sad) example is offered by Diane McGowin, when she was a patient still in the early stage of this illness. She tells of the recurring fear she felt that her husband might abandon her: "I repeatedly sought his vow to take care of me for the rest of my life. Upon receiving his assurance once again, I would inquire if he knew just how difficult keeping it may become in the future."[13] In other cases, loved ones can only try to infer what they might best do based on patients' behavior or responses. Here, the ground rule may well be: when in doubt, loved ones should try to leave patients feeling as comfortable as possible.

THE COURSE OF ILLNESS IS UNIQUE FOR EACH PATIENT

Daniel Kuhn states that the "experience of the disease is as unique as the individuals that have it."[14] This assertion may seem self-evident, but, with Alzheimer's patients, this is particularly, and counter-intuitively, the

case. The most important example of how patients may differ is that some may show new, advanced capacities, early on, before their illness progresses. The quality of art they create and their artistic productivity, may, for example, increase, although this may depend on the subtype of Alzheimer's. As Kuhn says, "The emergence of visual creativity in dementia [hints at] the extraordinary cognitive flexibility of individuals experiencing progressive loss of cortical neurons. . . . the art of individuals with AD [Alzheimer's disease] can show appealing use of color and form."[15]

The artist Willem de Kooning may be the best-known example. His art changed, and, for some, it got better. James C. Harris states that de Kooning's "final work was allusive rather than expository. Yet to many, [it] seemed beautifully simplified."[16] Such positive changes may occur, much more importantly, in patients' capacity for emotional richness. This change may be of greatest significance to loved ones, since it may change entirely what they may experience together — if loved ones are open to the possibility.

An example of a program in which patients have reportedly shown growth in both capacities (in art and in emotional richness) is a program called Memories in the Making. In this program, patients with Alzheimer's in the early and middle stages create paintings. Patients in this program often show more sustained attention, and some also express exceptional pleasure. One said, for instance, "In here I feel like a person again."[17] This may reflect that, in this setting, the patient didn't experience shame. (In the next section there will be more about the significance of this, and how loved ones can try to help patients not feel shame.) Another patient began the program "withdrawn," but, in time, "began to smile." After this change, the same patient observed that another participant was "having a difficult day." She said to the patient, " 'everyone in here has it rough, some days. . . . I understand.' "[18]

ETHICAL DILEMMAS AT EACH STAGE OF DISEASE

STAGE 1: SHOULD LOVED ONES INVOLVE PATIENTS MORE?

When patients first become ill, they still can understand and converse in regard to their needs, wants, and future preferences. Yet, more often than not, at even this earliest time, loved ones will leave patients out of discussions on these topics. Careproviders do this as well, sometimes, even talking to loved ones as if patients weren't there. Patients, fully aware of this, may feel enraged. As Strauss states, being talked about "makes them invisible — as if they are being erased."[19] Why does this happen? Are the reasons for this sound? These questions are considered below.

Insight Does Not Lead to Depression

There are many reasons that loved ones leave patients out of such discussions. They may do this, in large part, because they want to try to protect patients from knowing the worst that could befall them later. They are likely to believe, for example, that if patients know what most likely will occur, they will become severely depressed. It has recently been found, however, that when most patients acquire insight about their illness and their probable futures, they do not become depressed.[20] This finding has profound clinical implications for loved ones (and careproviders) who want to help these patients. They can feel more free, for example, to bring up with patients even very painful topics, such as what patients would want if they later lose awareness of who they themselves are, or who their loved ones are. The optimal approach may be to give patients a choice of being included in discussions and decisions as long as possible.

One reason to do this is that it respects patients' autonomy. A benefit for loved ones, obviously, is that they will know to a greater degree what patients think they will want, and then may feel less guilty if and when they carry out patients' stated desires. When loved ones feel less guilty, it may leave them more

capable of loving patients fully, later. Patients may benefit markedly as a result. Kuhn says, accordingly, "First of all, you should include the person with AD in decisions regarding his or her welfare whenever possible."[21] The strongest argument against this is that patients who indicate they want to remain fully part of discussions and who continue to make choices for themselves, as long as they can, may find the experience devastating. It may be that it is ethical to shield patients from what will eventually happen to them, as there is little that can be done for them, to spare them unnecessary worry. This is similar to the argument posed by those who adamantly oppose offering genetic test results to patients; even if the predictive value of genetic testing becomes much improved, patients should not have access to test results to spare them unnecessary worry.[22]

The finding that, in general, persons in the earliest stages of Alzheimer's don't become depressed when they acquire insight about their disease suggests that we should at least offer them the opportunity to discuss all present and future issues of possible concern for as long as they can do this. Patients can indicate when they would prefer not to. Alternatively, if patients want to be involved but become visibly distressed, loved ones can interrupt the discussion and ask patients what they are thinking and feeling, and whether they wish to continue. This may benefit patients as it shows a continuing commitment to them and to how they feel.

If, on the other hand, patients become very upset but deny it, this may be when loved ones begin to consider not offering them an opportunity to be involved to the same degree.

Loved Ones Can Help Patients Overcome Feelings of Shame

The earliest stage of Alzheimer's offers patients a unique opportunity to accomplish what they can't later, as their capacity to understand is still essentially intact. Since patients with early Alzheimer's generally don't become depressed when they discuss their probable futures, the question is: What else can loved ones do at this time to benefit patients?

One answer is that loved ones can try to help patients reduce their vulnerability to experiencing shame. The feelings of shame to which these patients are vulnerable are profound; the extent to which shame can strip patients of their capacity to spontaneously enjoy themselves is illustrated by a patient who was in a group of persons who were, as he said, "like him." Only in this group, he said, was he again able to "feel like a person." He added, " 'I am at peace when I'm with my group. I can be myself without pretending that I am a hundred percent.' "[23]

This loss of the capacity to feel wholly "okay" about themselves and to relate openly and spontaneously with their loved ones occurs, all too commonly, even in families and between couples who love each other dearly, and have for years or decades. An example is what the author Iris Murdoch apparently experienced with her husband, John Bayley. After Iris acquired Alzheimer's, John described their life together in a book, *Iris*.[24] The subtlety with which shame can manifest itself, even in patients who have known and loved each other as much as Iris and John did, is illustrated in the following passage John wrote: Iris, he says, "she used to weep quite openly, as if it were a form of demonstrable and demonstrated warmth and kindness. Now I find her doing it as if ashamedly, stopping as soon as she sees I have noticed."[25] He comments, "It makes me feel she wants to conceal it from me. Can she want to protect me from it?"[26] A goal that loved ones might pursue in the early stages of Alzheimer's is to help patients "get to the point" that they never feel shame at any time, for example, even when they can no longer identify loved ones, and can acknowledge this openly, without emotional pain. Feeling shame may cause patients to feel increasingly separated from loved ones, and such a loss of connection may be patients' greatest fear.

How can loved ones try to help them?

They can repeatedly "rehearse" interactions in which both the patient and loved ones pretend to forget things. When patients' loved ones also pretend, it may give them a greater sense of "being equal." In any case, it might also provide an opportunity to laugh together.[27] After enough "dry runs," patients may be able to laugh about forgetting, or at least feel accepted, if and when such forgetting occurs later.

Mary S. Mittleman, Cynthia Epstein, and Alicia Pierzchala recommend both rehearsal and role reversal for patients' caregivers as a way to help them better cope.[28] I suggest extending this to include patients. These "rehearsals" can continue until patients reach a point that they can simulate forgetting and experience no shame. A test case might be when a patient's loved ones can say, "Hello, dear," and the patient can say, without feeling shame, 'I'm sorry, but I don't know who you are."

Loved Ones Can Help Patients Reduce Anticipatory Grief

A still more difficult goal during this same period is for patients and loved ones to go through "anticipatory grief" together — to the degree possible. Anticipatory grief occurs before a loss and involves "the constant recognition" of the future loss and the process of gradual, continual, incremental detachment.[29] Unlike typical grief, which occurs after a loss and primarily involves acceptance, anticipatory grief is "a constant living with the uncompleted loss," and moving forward is more "complicated" when this is the case.[30] By confronting anticipatory grief together, purposefully, rather than just waiting, patients and loved ones can become "emotionally freer," and so be able to relate more meaningfully to each other later. This work is commonly done in hospices, for the same reason. As Beatrice Turkoski and Brenda R. Lance note, for patients and loved ones, "done constructively . . . anticipatory grieving can facilitate a healthier resolution of the entire grieving process."[31]

Patients and loved ones each grieve for something different: Patients grieve the eventual loss of even knowing who they are, in addition to dying; loved ones grieve the loss of the patients, first, as the persons they were, and, second, the loss once they die. Anticipatory grief, to the extent that it involves "letting go," occurs automatically, to some degree, if patients and loved ones discuss together patients' future options, as discussed above. Discussing the future in this way allows patients and loved ones to anticipate the grim realities that they may expect.

If they do this, they may also share painful feelings, and merely sharing this way may help patients and loved ones feel less alone. Careproviders can facilitate this process by adding guided imagery:[32] careproviders can encourage patients and loved ones to allow spontaneous visual images related to their discussions to emerge, to describe the images, and then discuss the feelings that they associate with them. Patients and loved ones can try to imagine the outcomes they would like to experience together in the future; they can also recall times they have enjoyed together.[33] The use of guided imagery with hospice patients and their families has often allowed both to "achieve a greater degree of intimacy."[34] This may be because it reduces "feelings of helplessness, hopelessness, depression, and apathy that often discolor the time a patient has left to share with family and friends."[35]

Visualization, like rehearsal and role reversal, is an approach that is already used to help caregivers of patients with Alzheimer's disease. It is particularly helpful in helping loved ones find new approaches to helping patients when they feel they are "stuck."[36] The approach suggested here involves not only loved ones, but also patients.

It might be asked whether patients with Alzheimer's are sufficiently capable of visualization, even at the earliest stage of their illness, for it to be successful. It might be assumed that this approach would be precluded because they can't sufficiently imagine themselves in past or future states. It may take these

patients more time; still, with extra time, patients may be able to visualize effectively. This was demonstrated by a patient who had dementia and needed a spinal tap, but was "phobic" about having the procedure done.[37] Hypnosis can enable some patients to overcome a "needle phobia" such as this. Patients must be able to become relaxed enough to achieve a hypnotic state and, in this state, they must be able to visualize enough to actually change their "instinctive responses" of experiencing fear and pain so that a spinal tap or other desired intervention becomes a procedure they can "endure." Slowly closing one's eyes is one method by which hypnosis can be initially induced. As patients slowly close their eyes, they are instructed to let themselves become exceptionally relaxed and go into a trance. This typically takes approximately five minutes. With this patient who had dementia, it took nearly 15 minutes to achieve.[38] The therapist also had to change how he gave the patient instructions; usually, these are only verbal, but, in this instance, the therapist found it effective to give the instructions non-verbally. He motioned with his head to show how the patient likewise should respond. It worked. He numbed the spot on this patient's back where he needed the spinal tap with lidocaine, and then told him that the injections he was giving were like "three mosquito bites." He also told a story about how the sweetest children are the ones that mosquitoes bite.[39] The patient was then able to tolerate the procedure.

STAGE 2: SHOULD LOVED ONES MANIPULATE PATIENTS?

As patients lose their capacity to understand and remember, they find making decisions more difficult. Consequently, loved ones may want to respond in ways that avoid forcing patients to make decisions — because this may evoke patients' frustration — but, at the same time, allow patients to feel fully involved. One approach is to use a so-called last-word connection. Here's how the technique works: "The care partner asks, 'Would you like to wear this green shirt today or the one that's blue?" Nine times out of ten, the patient says, 'Blue' — simply because it was the last word he remembered hearing."[40] Patients may respond to the use of this technique by feeling better, even though the involvement it invites is, to some degree, an illusion, as it allows them to maintain the sense that they have some control. Feeling they have some control and involvement may be exceptionally important to patients at later stages of their illness. Coste advises, "Guide the patient or take over as inconspicuously as possible to allow him to maintain a sense of control for as long as possible."[41]

This approach is manipulative, and, ethically, it is paternalistic; it is also deceptive. But it may have merit. Key questions in considering whether this deceit is justifiable (or at some point even morally obligatory) are: What are the alternatives? Is it possible, at this stage, that patients echo their loved ones' last words "nine out of ten times" because they believe, rightly or wrongly, that this response is what their loved ones most want to hear?

Patients may want to hold onto their connection with loved ones more than anything else, and so may do whatever they can to enhance this relationship. This could include agreeing with loved ones' "last words" even when they would prefer something else. Patients may respond to loved ones' last words in a way that actually is an attempt to manipulate their loved ones — they may do this to maximally maintain loved ones' positive feelings toward them. If this is the case, loved ones could ask "last-word connection" questions in a way that is not manipulative, but wholly genuine; they could also take special care to reassure patients that, regardless of which choice they make, it is "fine" with them.

The possibility that patients assign their relationships with loved ones top priority supports Lindemann's view that social factors are exceptionally important to patients with Alzheimer's.

STAGE 3: SHOULD LOVED ONES LIE?

During the middle and last stages of Alzheimer's, patients have greater loss of memory. Further, if confronted with this loss, patients, like Lindemann's mother, may deny it and instead feel enraged. It may be less emotionally painful to distort this particular reality than to accept it as it is, especially since this loss will probably continue. Lindemann's mother may have found it less painful to believe that her daughter stole from her, rather than accept that she was having trouble with her mind.

The question loved ones may face at these later stages is whether they should be honest and risk evoking patients' rage. Here, the overriding principle that authorities suggest is to avoid provoking distress. Strauss offers this guideline: "If you can't give a truthful answer that is believable or acceptable or not hurtful at the cognitive level, then tell an emotional truth."[42]

An example illustrating how loved ones can apply this concept is when patients repeat themselves because they forget what they have just said. It is important in this instance to keep in mind that patients truly believe that what they are saying, they are saying for the first time. Strauss suggests, "Every time they ask the question, it is a new question to them. You must act as if it is a new question to you."[43] Accordingly, loved ones should not say, "You just told me that." They should say, "That's interesting; I didn't know that," even though it is untrue.[44] Loved ones should respond to patients in as emotionally supportive a way as possible, regardless of the truth of the content, as this reduces patients' stress and leaves the relationship intact, or even enhances it.

An extreme example of memory loss occurs when patients can't recognize their loved ones. Then, as I have suggested above, it may be best for patients to be able to say openly, "I don't know you," without feeling shame.

This may not be possible. In such cases, Strauss recommends that loved ones should respond with "emotional rather than cognitive truths," that is, they might say something like, "No, we haven't met before, but it's really nice to meet you."[45]

CORE EMOTIONAL REALTIES

Authorities on Alzheimer's have recommended that loved ones try to meet patients' emotional as well as cognitive needs, but what are these emotional needs? I have suggested that loved ones can affect patients profoundly, as Lindemann contends, but what are *their* needs? Later stages of Alzheimer's may include hidden, significant potential for increased emotional richness for patients and loved ones. What, more precisely, could this potential be? The answers may help loved ones and the careproviders who advise them to better implement the specific approaches described above.

WHAT ARE PATIENTS' PRIMARY EMOTIONAL NEEDS?

All of these ethical questions involve the degree to which loved ones should abandon truth-telling to better meet patients' emotional needs. Strauss offers this general guideline: "Everything comes down to a simple question you can ask yourself: Will this make my loved one more comfortable or less comfortable?"[46]

It may be helpful to know more about what patients' most important needs are. It is difficult to know this with certainty, especially since, in the later stages of illness, patients may be unable to describe them verbally. Still, these needs, even then, may be reasonably imagined, if not inferred, from three sources: what patients say when they can still describe their feelings; what loved ones and others, such as careproviders, report; and what patients may reveal through other means, such as their art.

As a starting point, it must be recognized that patients with Alzheimer's can't seek the same goals as most other patients. They cannot, for example, seek to communicate intimately with loved ones during the final days of their lives. Likewise, careproviders can't respond as Cicely Saunders, who has done so much for hospice, advised; she suggests that careproviders say, "We will do all we can to

help you live until you die."[47]

These patients may lose the capacity to communicate, as well as the knowledge of who they and others are. At best, careproviders may be able to help them find meaning in other ways. They may explore with them, for example, whether they want to find ways to bear their losses gracefully, either for their own sake or for loved ones, such as the suggestions above regarding shame and anticipatory grief. As the disease progresses, patients' needs may change and be much like those experienced through childhood, but in reverse. Strauss adds that they also "need to make sense of why they are there."[48]

It is much harder to be a patient with Alzheimer's than to be a child. Unlike children, patients were formerly independent, and they may find it humiliating that others do not let them do what they were once able to do.[49] This suggests what has implicitly been stressed already: loved ones should give great priority to enhancing patients' comfort, and, in doing so, to maintain patients' self-esteem. This guideline can be useful to loved ones who are trying to decide what to do in other contexts. Patients may, for example, despite their impairments, give parental advice to adult children who care for them, or even reprimand them. Strauss says, when patients are "parental," "Don't say, 'I'm an adult, not a child.' Do say, 'You always look out for me. I love you for it.' "[50]

As patients get worse, their needs may then become more like those of younger and ever more younger children. What they may need most, for example, is frequent touching. What one can do to comfort these patients as this "regression" occurs is, however, limited only by loved ones' imaginations. Coste notes that "many good Alzheimer's programs now use aromatic therapy to help evoke pleasant memories."[51] Beyond this, and more specifically, Kuhn states that "people with AD require three things [other than physical needs] to be relatively happy: intimacy, community, and meaningful activity."[52]

The first, intimacy, particularly needs elaboration. Kuhn continues, "Without intimacy, fear and loneliness prevail. Just being in the physical presence of a trusted person at all times may offer reassurance to someone with AD who otherwise feels fearful while alone or with strangers."[53] It may be difficult for those of us who have not experienced intense fear, or who have not been exposed to someone who has, to imagine how important it is to be with someone who loves us when bad things happen. Patients who have panic attacks will know what a relief this can be. During these attacks, patients may fear they will die. They may develop an additional illness, such as agoraphobia, a fear of going outside in open spaces. Some patients can still function normally, but only in the company of those whom they trust. An example is a policeman I met who was decorated for bravery many times throughout a career of more than 20 years. He and his partner hadn't missed a day "riding" together during all that time. When his partner suddenly became ill, the policeman was unable to function; he could not go out in his squad car, even with another partner.

WHAT ARE LOVED ONES' PRIMARY EMOTIONAL NEEDS?

Any number of factors can cause a patients' loved ones to become "unglued." Among the most difficult emotions that they are likely to feel are helplessness and uncertainty, which often stem from, in large part, not knowing or being able to know what patients experience. As John Bayley, worried, "Does Iris speak, inside herself, of what is happening? How can I know? What is left is the terrible expectancy."[54] Helplessness and uncertainty are, some assert, among the most painful emotions we can experience.

Emotions such as these can affect loved ones profoundly and cause them to become different persons; it can also cause them to respond in ways they never had before. Iris's husband gives an example, of when he became angry: "I find myself looking in the mirror at the man who has been speaking. A horrid face,

plum colour."[55] He asks, "What can loved ones do about this?" and "I wonder briefly, if we'd had a child, would I have learnt not to be angry with it? In which case would I not be angry with Iris now?"[56] The answer for most loved ones is, probably that it is possible to learn not to respond to an infant with anger, and so it may be possible to learn to not become angry with patients, no matter how "regressed" they are due to Alzheimer's.

Kuhn suggests two approaches. First, loved ones can try to remember, at all times, that fear is often behind the anger that patients express. "If you can remember that," Kuhn says, "you'll be able to handle the anger washing over you with relative tranquility, and you'll be able to react with compassion."[57] Loved ones can repeat this to themselves, silently, like a mantra. If they do, each time they repeat it, it may reduce their anger. A second approach is to recall as vividly as possible a time that they, too, felt as the patient does. As Kuhn says, "much of it isn't foreign to you . . . the emotions people feel are familiar [within] your own experience."[58]

One example is the feeling of shame. The feeling of embarrassment, a less severe version of shame, is very common. When someone says or implies that we have just done something wrong, we may feel an impulse to come up with an elasticized or at least mildly stretched excuse. If our doctor says to us, for example, "Hmm. I see here that you were going to call for a follow-up appointment," if we didn't make that appointment, we might feel some shame.

A well-known writer who felt shame was August Strindberg. He wrote to his third wife, Harriet Bosse, "I feel shame without reason, remorse without having sinned, disgust with myself without knowing why."[59] He depicts shame in the words of Miss Julie, in the play by the same name. After Miss Julie "gave in" to the seductive efforts of a man who was "lower in station than she," she says, "I'm incapable of feeling, not able to be sorry, not able to go, not able to stay, not able to live — not able to die." Then she takes her life.[60] This description may come close to capturing what patients may feel when they can't remember. As a patient told me, when he is with his friends he is careful to not speak very often.

Loved ones who seek to remain close to patients with Alzheimer's shouldn't give up too easily on patients, but should proceed in the most emotionally soothing ways possible. As Kuhn notes, "It may take months, even years, before you become comfortable with using a new set of communication skills in your relationship."[61]

Yet there is another realm of possibilities to consider: some loved ones may find it nearly impossible to continue to feel strongly for patients; they may feel they need to distance themselves emotionally. They may be more acutely affected than others when patients' diseases worsen, and patients become more and more mere shells of the persons they once were. Loving patients may become too painful to bear. John S. Rolland says, "Clinicians should be sensitive to nodal points that may require discontinuous change for the family. For instance, one family tried at all costs to preserve the deteriorating father's role functions. . . . As disability increased, successful adaptation required acceptance of that which could not be changed."[62]

Accepting this need to "distance" may be also be difficult because of guilt, which may be compounded when loved ones can't keep the patient at home. As one person said, "It was a question of both obligation and gratitude, a way of paying back."[63] I experienced a need to distance myself after my father first had a persistent vegetative state. His heart stopped for several minutes before a rescue squad could get to him at his home. Before this, my father had been a person you would not want to play Scrabble with. He loved to make puns: in one rhyme he wrote, he described a tribesman looking for his wife at night in a tent in a desert in the Mid-East, who lifted up a tent flap and called, "Which Bed-u-in?" In a pre-persistent vegetative state, he would sit in his hospital bed, staring blankly.

I didn't want to visit my father daily. Or

weekly. I wanted to be with him as little as I could. Patients' loved ones may feel this way, too, and experience the patients' bodies, as I did my father's — as a cruel mockery of the person he had been. The tasks for loved ones, for their own emotional survival, may be to accept that the person they loved is no longer there, and to accept the change in their feelings that may go with it.

WHAT IS POSSIBLE IN PATIENTS' AND LOVED ONES' RELATIONSHIPS?

There is a third possibility that, for many loved ones, is quite far from gloomy. As Stephen G. Post says, "Because our culture so values rationality and productivity, observers easily characterize the life of persons with dementia in the bleakest terms. . . . The experience of the person with irreversible and progressive dementia is clearly tragic, but it need not be interpreted as half empty rather than half full."[64]

Patients may retain a considerable capacity of their ability to relate to others non-verbally. Thus, they and their loved ones may be able to continue an emotional relationship, even though it may be far different from what they experienced. Since patients may have lost all of their cognitive capacity, they may make no judgments about others based on "superficial" factors, such as what they *do.* Rather, patients may respond only to how their loved ones *are,* when they are with them. In earlier stages of illness, for example, patients may respond bluntly, like children. As Strauss says, "if you *really* want to know how your hairdo looks — just ask him!"[65] Later in their illness, patients may respond only to the moment at hand. As Coste says, "People with Alzheimer's live in the moment; to convey positive emotions, you need to live in the moment, too."[66]

Loved ones can learn to cherish the unique and unprecedented emotional richness of emotionally intimate experiences such as holding and comforting the patient, which may be very much like discovering (and later missing) similar opportunities with an infant or a very young child. For instance, I can recall the joy I felt as a young child playing Slap Jack for hours with my mother. In this game, one player flips over cards, and the first person to slap a hand down on a Jack "wins" that hand. The game is absolutely mindless, but the sense of peace and wholly unselfconscious bonding I had with my mother is the closest I have come to feeling bliss. I can't actually recall a greater joy. I suspect that patients can feel this kind of pleasure in intimacy at the end of their illness with their loved ones.

Loved ones may experience a new sense of meaning they wouldn't in any other way. As Strauss says, "they will only see *you.* They may be the only people who can do that. . . . When you are with them, you are stripped to your essence. . . . This is a great gift they can give *you.*"[67] I think in this regard of the singular, immense joy some parents experience, even with most severely impaired children, in response just to a smile. One parent and his wife provided continuous care, 24 hours a day, to their child. He said to me, "But it's all worth it every time I see him smile!"

Iris Murdoch's husband provides another example: "Tone is what matters," he says. "I stroke her back or pull her backwards. . . . I imitate the fond way her father used to say (she told me this long ago) 'Have you no sense at *all*?' . . . Iris's face always softens if I mention her father in this way. Instead of crying she starts to smile."[68]

CONCLUSION

Having Alzheimer's disease is, without question, among the greatest misfortunes any person can undergo. In the discussion above, I have explored three possible ways that loved ones can try to lessen patients' emotional pain. Patients' and loved ones' relationships, in sum, may become richer. Are there, however, real life examples of this? I refer once again to Iris and John.

John says, "Every day we are physically closer; and Iris's little 'mouse cry', as I think of it, signifying loneliness in the next room,

the wish to be back beside me, seems less and less forlorn. . . . She is not sailing into the dark: the voyage is over, and under the dark escort of Alzheimer's she has arrived somewhere. So have I."[69] Why would John say this? Because, in large part, of the incredible, rare love such patients sometimes can bestow. John reports, for example, "I make a savage comment today about the grimness of our outlook. Iris looks relieved and intelligent. She says: 'But I love you.' "[70]

NOTES

1. J.K. Coste, *Learning to Speak Alzheimer's* (New York: Houghton Mifflin, 2003); D. Kuhn, *Alzheimer's Early Stages* (Alameda, Calif.: Hunter House, 1998); and C.J. Strauss, *Talking to Alzheimer's* (Oakland, Calif.: New Harbinger, 2001). For a discussion of the original "case," see M. Strassnig and M. Ganguli, "About a Peculiar Disease of the Cerebral Cortex: Alzheimer's Original Case Revisited," *Psychiatry* 2005 2, no. 9 (September 2005): 30-3.

2. Some have said that, if they would experience this state, they would rather be dead, but since, at the time this occurs, they may not remember saying this, they should have assistance while they still can in dying.

3. Coste, see note 1 above, p. 112.

4. Ibid.

5. See, e.g., I. Hickie et al., "Reduced Hippocampal Volumes and Memory Loss in Patients with Early- and Late-Onset Depression," *British Journal of Psychiatry* 186 (2005): 197-202.

6. G.P. Sholvevar and P. Perkel, "Family Systems Intervention and Physical Illness," *General Hospital Psychiatry* 12 (1990): 363-72.

7. A. J. Cunningham, et al., "A Randomized Controlled Trial of the Effects of Group Psychological Therapy on Survival in Women with Metastatic Breast Cancer," *Psychooncology* 7, no. 6 (November-December 1998): 508-17; D.W. Kissane et al., "Cognitive Existential Group Psychotherapy for Women with Primary Breast Cancer: A Randomized Controlled Trial," *Psychooncology* 12, no. 4 (September 2003): 532-46.

8. See, e.g., P.N. Tariot et al., "Memantine Treatment in Patients with Moderate to Severe Alzheimer Disease Already Receiving Donepezil," *Journal of the American Medical Association* 291, no. 3 (21 January 2004): 317-24; and C. Holmes, "The Efficacy of Donepezil in the Treatment of Neuropsychiatric Symptoms in Alzheimer Disease," *Neurology* 63 (2004): 214-9 for benefits of medications to patients and their loved ones, respectively.

9. Likewise, "open-ended questions may work in the early stages, [but] eventually questions will be a source of confusion." Strauss, see note 1 above, p 39.

10. Ibid., 63.

11. Coste, see note 1 above, p. 45.

12. "When to touch? When not to touch? It's simple. Ask." Strauss, see note 1 above, p. 56.

13. D.F. McGowin, *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's* (New York: Delacorte Press, 1993), 103, cited in Kuhn, see note 1 above, p. 83.

14. Kuhn, see note 1 above, p. 85.

15. B.L. Miller and C.E. Hou, "Portrait of Artists," *Archives of Neurology* 61 (June 2004): 842-44, 842-3.

16. J.C. Harris, "Excavation," *Archives of General Psychiatry* 62, no. 4 (April 2005): 359-60, *http:/archpsyc.ama-assn.org.lrc1.usuhs.edu/cgi/content/full/62/4/359,* 4.

17. C.A. Rentz, "Memories in the Making: Outcome-Based Evaluation of an Art Program for Individuals with Dementing Illnesses," *American Journal of Alzheimer's Disease and Other Dementias* 17, no. 3 (May/June 2002): 175-81, p. 178.

18. Ibid., 180.

19. Strauss, see note 1 above, p. 54.

20. C.G. Lyketsos et al., "Major and Minor Depression in Alzheimer's Disease: Prevalence and Impact," *Journal of Neuropsychiatry and Clinical Neurosciences* 9 (1997): 556-61, 557.

21. Kuhn, see note 1 above, p. 125.

22. See, i.e., M.A. Drickamer and M.S. Lachs, "Should Patients with Alzheimer's Disease Be Told Their Diagnosis?" *New England Journal of Medicine* 326, no. 14 (April 1992): 947-51.

23. Kuhn, see note 1 above, p. 95.

24. J. Bayley, *Iris* (London: Abacus, 1998).

25. Ibid., 275.

26. Ibid.

27. For comments on the potential importance of the use of humor with these patients, see M.S. Mittleman, C. Epstein, and A. Pierzchala, *Counseling the Alzheimer's Caregiver* (Atlanta, Ga.: AMA Press, 2003), 18-9.

28. Ibid., 66.

29. B. Turkoski and B. Lance, "The Use of Guided Imagery with Anticipatory Grief," *Home Healthcare Nurse* 14, no. 11 (1996): 878-88, p. 880.

30. Ibid.

31. Ibid., 878.

32. Turkoski and Lance, see note 29 above. Visualization is presented as a technique for caregivers in Mittleman, Epstein, and Pierzchala, see note 27 above, p. 67.

33. Ibid.

34. Turkoski and Lance, see note 29 above, p. 884.

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36. Mittelman, Epstein, Pierzchala, see note 27 above, p. 67.

37. E.P. Simon and M.M. Canonico, "Use of Hypnosis in Controlling Lumbar Puncture Distress in An Adult Needle-Phobic Dementia Patient," *International Journal of Clinical and Experimental Hypnosis* 49, no. 1 (January 2001): 56-67.

38. Ibid., 60.

39. Ibid., 62.

40. Coste, see note 1 above, p. 81.

41. Ibid., 114.

42. Strauss, see note 1 above, p. 14.

43. Ibid., 27.

44. Ibid., 101.

45. Coste, see note 1 above, p. 81.

46. Strauss, see note 1 above, p. 94.

47. I. Byock, "Patient Refusal of Nutrition and Hydration: Walking the Ever-Fine Line," *American Journal of Hospital Palliative Care* 12, no. 2 (March-April 1995) 9-13, p. 13.

48. Strauss, see note 1 above, p. 94.

49. Ibid.

50. Ibid., 101.

51. Coste, see note 1 above, p. 46.

52. Kuhn, see note 1 above, p. 93.

53. Ibid.

54. Bayley, see note 24 above, p. 266.

55. Ibid., 270.

56. Ibid., 271.

57. Kuhn, see note 1 above, p. 63.

58. Ibid., 14.

59. A. Strindberg, *Letters of Strindberg to Harriet Bosse,* ed. and trans. A. Paulson (New York: Thomas Nelson and Sons, 1959); 129, from a letter dated 4 October 1905.

60. A. Strindberg, *The Plays: Volume One,* trans. G. Motton (London: Oberon, 2000), 139.

61. Kuhn, see note 1 above, p. 150.

62. J.S. Rolland, "Anticipatory Loss: A Family Systems Developmental Framework," *Family Process* 29, no. 3 (September 1990): 229-44, p. 232.

63. L. Albinsson and P. Strang, "Existential Concerns of Families of Late-Stage Dementia Patients: Questions of Freedom, Choices, Isolation, Death, and Meaning," *Journal of Palliative Medicine* 6, no. 2 (2002): 225-35, p. 232.

64. S.G. Post, *The Moral Challenge of Alzheimer's Disease* (Baltimore, Md.: Johns Hopkins Press, 1995), 15, cited in Kuhn, see note 1 above, p. 85.

65. Strauss, see note 1 above, p. 115.

66. Coste, see note 1 aboce, p. 17.

67. Ibid., 16.

68. Bayley, see note 24 above, p. 287.

69. Ibid., 284

70. Ibid., 249.

Features

The District of Columbia Amends its Health-Care Decisions Act: Bioethics Committees in the Arena of Public Policy

Douglas B. Mishkin and Gail Povar

CASE 1: MR. B

Mr. B, a 30-something-year-old man, fell down a ladder and incurred severe head injuries that left him comatose and dependent on a respirator. His roommate of several years noted that Mr. B never was the sort of man to organize his papers, and that Mr. B had never executed a durable power of attorney for healthcare, despite frequently stating his intention to do so. Yet, the roommate had heard Mr. B say that he never would wish to be kept alive if he lacked cognition. Another friend affirmed this. Neither the roommate nor the friend had legal standing to authorize a do-not-resuscitate (DNR) order in the District of Columbia. Both were sufficiently uncomfortable with an initial court appearance to request guardianship that they were reluctant to continue the process.

The ethics committee met with them both, and considered them to be reasonable surrogates for the patient. Nevertheless, the hospital, under existing statutes, could not accept their DNR request without judicial authorization, which required further court appearances; both the friend and the roommate declined to participate.

CASE 2: MRS. G

Mrs. G had been widowed for 20 years. For 10 years, she lived with Mr. R, who had grown children and grandchildren. Because of concerns regarding the disposition of their individual estates, as well as their current Social Security income, Mrs. G and Mr. R never married, and

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they never executed advance directives. When Mrs. G suffered a devastating stroke, Mr. R stayed with her day and night in the hospital. He noted that he and Mrs. G often talked of death, as they were both in their mid-80s, and he pleaded with the physicians to adopt a "comfort care only" approach. However, Mr. R had no legal standing to participate in such decisions. Mrs. G was childless; her only living relative was an 88-year-old sister who had not seen Mrs. G for several years. Nevertheless, the sister came to the hospital and insisted on aggressive care, based on her personal religious views. (She admitted that her sister might very well not have agreed with her.) The medical staff felt, nevertheless, that they had to accept the sister as a decision maker, given the law in the District of Columbia.

The cases of Mr. B and Mrs. G illustrate situations that repeatedly challenged and frustrated clinicians and ethics committees in the District of Columbia until the spring of 2003. In June 2003, however, the District of Columbia amended its Health-Care Decisions Act in two significant ways. First, the list of statutorily recognized surrogate decision makers was expanded to include "domestic partners" and "close friends." Second, the amendment made the hierarchy of statutorily recognized surrogate decision makers flexible, to account for the possibility that a person lower in the hierarchy might serve the patients' interests better than someone of higher rank. The authors — with the support and participation of fellow members of the Ethics Committee of the George Washington (GW) University Hospital — conceived of and proposed the amendment to the chair of the Judiciary Committee of the D.C. City Council, who introduced the legislation and shepherded it to enactment.

In the following article, the authors not only report the substance of the new law, but also describe how the change occurred. We do so in the hope that readers from jurisdictions with similarly problematic statutes will draw guidance and inspiration from our experience in the District of Columbia. We also believe that our experience reflects the important role that clinical ethics committees can and should play in shaping public policy that affects issues within their realm.

D.C. LAW PRIOR TO JUNE 2003

The D.C. Law, as it existed prior to June 2003, posed two major problems for hospitals and ethics committees. The list of authorized decision makers did not adequately account for the range of common and important social relationships. Second, the hierarchy was inflexible, presuming an unfailing relationship between rank in the hierarchy and appropriate knowledge and emotional ties to make surrogate decisions. At minimum, these two characteristics of the statute assumed that any alternative arrangements should and could appropriately be managed by the judiciary. We will discuss each issue separately below.

AUTHORIZED DECISION MAKERS

Prior to the amendment, the D.C. Health-Care Decisions Act[1] recognized the following hierarchy of potential surrogates for an adult patient who lacks capacity to make healthcare decisions and who had not designated a surrogate in an advance directive:

- Spouse,
- Adult child,
- Parent,
- Sibling,
- Religious superior if the patient is a member of a religious order or a diocesan priest,
- Nearest living relative.

This arrangement, common to similar acts in other jurisdictions,[2] posed problems familiar to many urban ethics committees. First, the act was blind to domestic arrangements that have become increasingly prevalent in our society. Second, it failed to acknowledge the potentially critical role of friends as surrogate decision makers for those not involved in a partnership. As a result of these inadequacies, hospitals and their ethics committees

found themselves either having to go to court with unacceptable frequency, or having to quietly ignore the law. These unpalatable alternatives prompted the GW Hospital Ethics Committee to seek changes in the statutory hierarchy of potential surrogates.

ALTERNATIVE DOMESTIC RELATIONSHIPS

In the last half century, the prevalence of unconventional households has increased dramatically. Although gay and lesbian couples are an obvious example of relationships that are disenfranchised in jurisdictions where gay marriage is not recognized, the challenge extends further. Increasingly, elderly heterosexual couples, for a variety of reasons, elect to live together unmarried. Under the prior D.C. statute, neither a gay man's partner nor an elderly woman's male companion of many years would have been recognized as a legitimate decision maker.

In the case of a gay couple, the hospital was precluded from recognizing a gay patient's domestic partner as a surrogate decision maker in the absence of a properly executed durable power of attorney for healthcare. Furthermore, in order to abide by the statute, the hospital might well have to accept as a surrogate a family member who was troubled by the patient's homosexuality, might not have seen the patient for several years, or might never have discussed the management of serious illness with the patient.

Similarly, in the case of two cohabiting but unmarried adults (for example, an elderly couple for whom marriage would impose a "marriage tax," or perhaps lead to conflict among adult children), neither would be recognized as a potential surrogate for the other. On the other hand, a sibling or adult children who disapproved of the patient's relationship would have qualified under the statute. In either case, if the ethics committee chose to challenge the established hierarchy, the hospital felt compelled to obtain judicial authorization of such a choice — with the potential for additional distress for all involved.

FRIENDS WHO KNOW BETTER

In addition to its blindness to newer household arrangements, the statute failed to include "close friend" as a category of potential surrogate. A single adult patient without family and without active religious affiliation would be without a potential surrogate. Even a very close friend would not have been recognized under the statute. The high rate of divorce and the mobility of the population in the U.S., among other things, increase the probability that a single adult may have friends who know the patient better and care about the patient as much as (or more than) the family members recognized in the existing statutory hierarchy. Absent a formal durable power of attorney, the hospital would effectively be flouting the law whenever it turned to such individuals for guidance in the care of a patient. Worse yet, to have such a close friend acknowledged as a surrogate required the court to appoint the friend as a "guardian" — necessitating frequent court appearances and reevaluations that would, in fact, prove intimidating to many appropriate surrogates.

Clearly, the list of decision makers in the statute needed to be revised to reflect current societal norms.

THE INFLEXIBLE HIERARCHY OF AUTHORIZED DECISION MAKERS

Not only were critical individuals missing from the hierarchy, but the rigidity of the statutory hierarchy posed problems as well. Under the statute, a person higher in the hierarchy had automatic and virtually unchallengeable priority over a potential surrogate of lower rank in the hierarchy. The important concept of appropriate surrogacy based on knowledge of a person's values was supplanted by a formula without attention to the quality of a relationship between the patient and the decision maker. For example, an adult child who had only intermittent contact with a patient for several years might appear at the hospital and insist that treatment be withdrawn because "this is what my father would

have wanted." This patient's brother, who had lived nearby and had seen the patient regularly during his illness over the past several years, might appear asking that treatment be continued, because the patient wanted to continue aggressive treatment despite the obvious burdens of treatment. Before the law was changed, a healthcare provider would have been prohibited from (or at least would have had difficulty) abiding by the obviously better informed directive of the sibling, because the adult child would have had unchallengeable priority.

Over a number of years, we sought mechanisms whereby the hierarchy might be made more responsive to our needs without formal change in the law. We consulted outside legal authorities who emphatically rejected the non-mandatory interpretations we attempted to devise; we researched, but could not find, any legal authority for the proposition that the statute was not mandatory; and, finally, hospital counsel was repeatedly reluctant to interpret the law as anything other than mandatory. If the ethics committee could not achieve internal resolution of such situations, the hospital would have to obtain judicial authorization of decision-making status for the person lower in the hierarchy. The authors believe that the amendment described below significantly reduces the likelihood of having to obtain such authorization.

THE AMENDMENT TO THE D.C. LAW

The amendment remedied the identified problems as follows.

1. INCLUDING "DOMESTIC PARTNER"

The D.C. Health-Care Decisions Act now recognizes a "spouse or domestic partner" as a potential surrogate.[3] "Domestic partner" is defined as "an adult person living with, but not married to, another adult person in a committed, intimate relationship."[4] This is the definition used in the District of Columbia law recognizing the status of domestic partner.[5]

2. INCLUDING "CLOSE FRIEND"

The D.C. Health Care Decisions Act now recognizes a *close friend* of the patient as a potential surrogate, following a religious superior and preceding a nearest living relative in priority.[6] A "close friend" is defined as "any adult who has exhibited significant care and concern for the patient, and has maintained regular contact with the patient so as to be familiar with his or her activities, health, and religious and moral beliefs."[7]

Prior to the amendment, a healthcare provider wishing to obtain and abide by the guidance of a domestic partner or close friend would have been required to seek judicial appointment of that person before relying on that person as a surrogate decision maker for the patient. Resort to court in these situations is an inefficient use of hospital resources, does not improve the quality of the healthcare decision to be made for the patient, and unnecessarily burdens our courts. Now, resort to court in these situations is unnecessary in the District of Columbia.

3. MAKING THE HIERARCHY FLEXIBLE

Under the amendment, the order of priority laid out in the hierarchy simply creates a presumption that may be rebutted "if a person of lower priority is found to have better knowledge of the wishes of the patient, or, if the wishes of the patient are unknown and cannot be ascertained, is better able to demonstrate a good faith belief as to the interests of the patient."[8] For example, if an estranged spouse and a sibling with an ongoing close relationship to the incapacitated patient both appeared at the bed site, now a healthcare provider could treat the close sibling as the surrogate, because the presumption flowing from the estranged spouse's status would be rebutted either by the close sibling's better knowledge of the wishes of the patient or by that sibling's superior ability to demonstrate a good faith belief as to the patient's interests.

The amended law recognizes that a person lower in the hierarchy might be a better surrogate than a person who is higher. The

amendment addresses that reality by striking a balance: on the one hand, it is helpful to have a hierarchy of potential surrogates, so that a healthcare provider knows where to begin to look if more than one potential surrogate materializes and there is conflict among those persons; on the other hand, that hierarchy should be flexible, so that a healthcare provider may recognize as a surrogate a person lower in the hierarchy who gives evidence of being a better surrogate, because that person, in the words of the amendment, demonstrates "better knowledge of the wishes of the patient, or, if the wishes of the patient are unknown and cannot be ascertained, is better able to demonstrate a good faith belief as to the interests of the patient."[9]

THE LAW ELSEWHERE

With this amendment, the District of Columbia has joined the ranks of a minority of jurisdictions that include domestic partners and close friends as potential surrogates.

The Uniform Health-Care Decisions Act recognizes as a potential surrogate "an adult who has exhibited special care and concern for the patient, who is familiar with a patient's personal values, and who is reasonably available. . . ."[10] As of 1 July 2004, the District of Columbia and 40 states had adopted, in some form, the provisions of the Uniform Act that recognize potential surrogates in the absence of an advance designation of a surrogate; of those 41 jurisdictions, however, only 18 recognized "close friend" as a category of potential surrogates (see table 1).[11] Of these, only four separately recognized "domestic partner" or its equivalent: Arizona, D.C., Maine (adult in spouse-like relationship), and New Mexico (individual in long-term, spouse-like relationship). Although the "close friend" language in the amendment to the D.C. statute includes a domestic partner, the amendment identifies "domestic partner" separately, enabling "domestic partner" to be included with "spouse" at the top of the hierarchy. The "rebuttable presumption" to the statutory hierarchy is,

Table 1
States with Some Form of Uniform Health-Care Decisions Act

State	Recognizes close friend	Recognizes domestic partner or equiv.
Alabama		
Alaska	x	
Arizona	x	x
Arkansas		
California		
Colorado	x	
Connecticut		
Delaware	x	
District of Columbia	x	x
Florida	x	
Georgia		
Hawaii	x	
Idaho		
Illinois	x	
Indiana		
Iowa		
Kentucky		
Louisiana		
Maine	x	x
Maryland	x	
Michigan		
Mississippi	x	
Montana		
Nevada		
New Mexico	x	x
New York	x	
North Carolina		
North Dakota	x	
Ohio		
Oklahoma		
Oregon	x	
South Carolina		
South Dakota		
Tennessee	x	
Texas		
Utah		
Virginia		
Washington		
West Virginia	x	
Wisconsin	x	
Wyoming		

Source: *http://www.abanet.org/aging/HCPA-CHT04.pdf*

insofar as the authors can determine, unique. We are unaware of any jurisdiction that has adopted such an approach.

"HOW WE DID IT"

The making of public policy can seem daunting to those who have not participated in the process (and, indeed, to those who have). It need not be. Although our experience undoubtedly was more straightforward and less frustrating than one might have expected, it reinforces the importance of optimism and opportunism in effecting legislative change.

This change began in the spring of 2003 with a chance meeting with D.C. City Councilmember Kathleen Patterson. Councilmember Patterson is (and was) the Chair of the Councils Judiciary Committee, with jurisdiction over the Health-Care Decisions Act. Our ethics committee met with one of her staff, described the problems with the statute, conferred about solutions, and then prepared initial drafts of the amendment ultimately enacted. In the meantime, one of the authors (GP) sought and received support from other ethics committees and others in the community. Both authors also prepared extensive written comments outlining the legal and clinical problems remedied by the proposed amendment. In the end, the amendment passed without opposition and took effect 21 June 2003.

AFTER ENACTMENT: MORE TO DO

Although in legal terms the new law "took effect" on 21 June 2003, the new law could have no practical effect until healthcare providers were properly informed. Toward that end, we prepared a brief summary of the law (a "what practitioners need to know" memo) for our hospital's newsletter and adapted that article for dissemination by the D.C. Medical Society. The hospital issued a press release (as did Councilmember Patterson). And the authors ultimately sent notice of the amendment to the American Bar Association Commission on Legal Problems of the Elderly for inclusion in its valuable summary of Health Care Power of Attorney and Combined Advance Directive Legislation.

At the clinical level, the most obvious challenge created by the new legislation will be appropriately defining and including "close friend." The changes made to the D.C. law in fact impose on hospitals and clinicians the sober responsibility for wisely and carefully evaluating those who might meet the criteria for being a "close friend." As a practical matter, our ethics committee believes that we should assist clinicians by interviewing the candidate and that case-management specialists should attempt to corroborate the status of the person through interviews with other friends/family of the patient.

Similarly, the mere fact that the hierarchy is no longer rigid does not imply that it can or should be overridden out of concerns for convenience. Social workers and case managers will still have to make reasonable efforts to identify well-meaning and appropriate family members who might not immediately present themselves when a patient arrives at the hospital's door. Flexibility is also not intended to permit clinicians to pick and choose among potential surrogates for the one most likely to accept and implement the clinician's viewpoint. Flexibility also does not obviate the need to maintain appropriate relationships with the various family and friends who may be concerned about the patient's welfare. As in most cases, increased freedom (in the form of a more inclusive and more flexible legal environment) carries with it the burden to "get it right" at the bedside. This includes not only identifying the best surrogate for the patient, but also ensuring that the healthcare team, including the ethics committee, effectively manages any potential conflict arising from the selection of that surrogate. Thus, ethics committees can serve important roles in ensuring that the spirit as well as the letter of the new Health Care Decisions Act is respected.

THE FOUR MORALS OF THE STORY

Upon reflection, we believe that there are four morals to this story.

MORAL #1: THE EXISTING LAW IS DEFECTIVE IN MOST JURISDICTIONS

We have no doubt that the experiences on the GW Hospital Ethics Committee that prompted us to propose this amendment are not peculiar to the District of Columbia. Healthcare decisions laws in any jurisdiction should recognize domestic partners and close friends as surrogates for adult patients who have not signed advance directives. In the absence of such recognition, healthcare decision making unnecessarily excludes persons who can add to the quality of end-of-life decisions, and may even invite dreaded litigation over the decision-making process.

MORAL #2: POLITICIANS WILL TAKE THESE ISSUES SERIOUSLY

Skepticism about the political process must not obscure an encouraging truth: there are plenty of elected officials who are prepared to make important changes when they are presented with the right issue, the right supporting arguments, and detailed preparation. In addition, we are aware that our effort to change the law succeeded in no small part by the fact that: (1) everyone involved in the care of a patient is helped by expanding the pool of possible surrogates to include those currently disenfranchised who might be very well situated to speak for a patient who lacks capacity; (2) no one is significantly burdened; and (3) it costs virtually nothing to implement.

MORAL #3: ADVANCE DIRECTIVES CONTINUE TO BE IMPORTANT

Remedying the defects in the D.C. and similar statutes should not detract from the importance of encouraging adults (particularly the elderly and chronically and/or seriously ill) to execute advance directives, and, in particular, to appoint a durable power of attorney in any situation when the issue of who should be the surrogate might be in doubt. Many of the problems the amended D.C. statute seeks to resolve could be avoided altogether were more individuals to complete these documents.

MORAL #4: ETHICS COMMITTEES CAN HELP SHAPE PUBLIC POLICY

By dint of their multidisciplinary nature, clinical ethics committees occupy a special place in the institutions they serve. Into that special place come individual case consultations, hospital policy review, and educational responsibilities. That blend of activities leaves ethics committees well situated to extend their mission into the community that the institution itself serves. When the law or public policy fails to recognize important patient care values, an ethics committee can be a valuable agent for change.

ACKNOWLEDGMENT

The authors acknowledge the significant contributions of their fellow committee members in the development of the proposed amendment that was ultimately enacted.

NOTES

1. *D.C. Code Ann.* §§21-2201 et seq. (2004).
2. The Committee for the National Conference of Commissioners on Uniform State Laws, *Uniform Health-Care Decisions Act,* "Section 5. Decisions by Surrogate," *http://www.law.upenn.edu/bll/ulc/fnact99/1990s/uhcda93.htm.*
3. *D.C. Code* §§21-2210 (2).
4. *D.C. Code* §§ 21-2202 (2A).
5. *D.C. Code* §§ 32-701.
6. *D.C. Code* §§ 21-2210 (5B).
7. *D.C. Code* §§ 21-2202 (1A).
8. *D.C. Code* §§ 21-2210 (f).
9. *D.C. Code* §§ 21-2210 (f).
10. See note 2 above.
11. Idaho's informed consent statute provides that in the case of a never-married minor or mentally incompetent person, any individual representing him/herself to be responsible for the healthcare of the person may be recognized as a surrogate.

Special Section: Families and Bioethics

Families and Bioethics: Old Problems, New Themes

James Lindemann Nelson

Families, as has been observed before now, serve healthcare practitioners as conduits who can lead practitioners toward the choices, desires, and values of patients; help physicians and nurses through barriers of incapacitating illness or cultural differences to reach a sense of who a patient is; and what that means for how they, as professionals, ought to act. Families also increasingly see service in the role of semi-skilled providers of increasingly sophisticated forms of care, as financial pressures tend to push patients out of professional healthcare settings and back into such homes as they may have.

Families are also served by healthcare: whenever the ill, injured, or impaired are helped to become healthy and to function, everyone bound to them benefits. Families rely on healthcare resources to see them through many of the landmark events that define them: births and deaths, serious accidents and illnesses, addictions, eating disorders, and unwanted pregnancies. Perhaps most distinctively, healthcare serves families by overcoming the biological barriers to their formation or extension with ever-more-ingenious ways of overcoming infertility.

When families encounter healthcare, whether as servants or as those served, particularly tough ethical problems show up. When we deliberate morally, we seem most comfortable dealing with disputes that concern the distinct interests of distinguishable individuals, puzzles that lend themselves to calculative forms of rationality, situations that can be clarified by simple rules. That's just the sort of menu that's not on offer when families are in the center of the picture: interests and identities merge and oppose, sentiment and deliberation interpenetrate, and the arbitrariness of simple rules becomes almost embarrassingly plain. The ethical terrain at the intersection of families and healthcare pre-

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sents a challenge not only to our skills in wielding the tools we have, but to our imaginations as we work to make those tools better suited to the task.

The six articles that make up this special section of *The Journal of Clinical Ethics* take on both challenges. They offer distinctive ways of understanding what's at stake in specific kinds of interchanges between families, illness, and healthcare, and what responses are called for. But they also engage, more or less explicitly, with the enduring meta-problem of bioethics, and indeed, of ethics in general: how are we to think well about how we ought to live? In my own view, one of the great attractions of trying to "do ethics" within the rich texture of practices that constitute healthcare is that it becomes hard to rest content with arguments that have chiefly theoretical elegance to recommend them, and it is unsatisfying to draw, in a settled way, on images of lives and interactions that are pertinent only to some situations, or few, or none.

So when we consider families as avenues to patients' subjective preferences, we can ask not only, "How reliable?" or "How trustworthy?" families are (measured against the going alternatives), nor only, "How reliable or trustworthy do they need to be?" but also whether families have exhausted their value to healthcare once they have reproduced the formed preferences of their loved ones, acting as solely as transmitters, or, at most, interpreters. Might some family members also help *construct* preferences and choices out of what may be no more than a patient's inchoate, indeterminate scattering of values, interests, and desires? Might they take into account considerations whose connection to the patient is indirect, considerations that bear primarily on the needs of other family members or to the family, as such? When we consider how some families are being progressively transformed into professional healthcare providers manquè, we need to think about justice, not between strangers, but about between people who help constitute each others' evaluative outlooks. We must understand what notions of obligation and supererogation mean, in contexts of intimacy. And when we think about how to direct or whether to limit reproductive assistance, we need not merely specify and balance the standing moral terms, but to reflect on the impact of new technologies on standing conceptual systems, on imaginative and affective associations, and on material practices that make families the many things that they are. Can good intentions ensure that the new understandings of families' roles and responsibilities that are emerging from these techniques and practices are progressive? Can we purposively give these systems of meaning a shape that corresponds, at least tolerably, to our ideals, or are the norms they embody too deeply entrenched for us to sculpt as we please? Attending to intimacy, and to its powerful, sometimes violent, emotions, prompts a more realistic representation of what ethical thinking faces, nudging us to develop a more expressive vocabulary to describe problems and a more adequate store of tools to resolve them.

In articles touched off by stories of daughters tending mothers suffering from dementia, Tia Powell and Hilde Lindemann flag the implications for our understanding of "intimacy" and "empathy" that come into view, if we take seriously the thought that human lives are often shared, and hence are *sharable things.* An appropriate appreciation of that idea, theoretically supported by a view of selfhood that stresses its analogies with narrative form, has consequences for how we make sense of the authority that people have to make decisions for their incapacitated intimates, as Powell argues. At the same time, it should alert us to intimacy's dangers, of how, in particular, the identities of persons need to be protected against the kind of iatrogenic injuries that can come from care provided by intimates, as Lindemann urges. Carelessness with how we think about those we are closest to can be damaging, as can the influence of theories of minds and selves that, in effect, deny some of our special vulnerabilities to each other.

The articles by Catherine Belling and Laura Purdy address expanding families in

ways that involve eliminating any involvement of biological fathers and mothers, respectively. Belling focuses on fathers who are removed from nurturing roles through anonymous donor insemination. Purdy addresses a more radical means of canceling the connection between the social and the biological — the prospective use of female fetuses as a source of ova. Both authors deal with another fraught connection: that between cultural and bioethical constructions of sentiment and rationality. Policy and standard ethical analysis tend to dissociate these features of human lives; the lived experience of reproduction and family life tends in another direction. Belling argues against a bifurcation of sense from sensibility as we think through what children can demand from their progenitors; Purdy's article inspires a critical assessment of the very fountainhead of assisted reproduction, the "pronatalist" yearning that the children one cares for must be, if at all possible, of one's own body.

John Hardwig and the team of George Hardart and Robert Truog consider the role of families in making clinical decisions. Hardwig's examination of challenges to family decision making that are based on futility portrays these disputes as due, not to irrational families, but to medicine's culture — its propaganda, its rhetoric, its resident moral understandings — all of which inveigle some families into just the resilient hopefulness that providers sometimes abruptly abandon. Hardwig sees this impact of medical culture as another kind of iatrogenic injury, a cost that healthcare extracts from families. Hardart and Truog discuss the results of their study of clinical conceptions of the role of families' interests in treatment decisions. They investigated whether and to what extent the standard view that the welfare of patients trumps the interests of others actually guides clinical self-understanding and action. Their findings suggest that practice in healthcare is much less regimented by the primacy-of-the-patient view than might be thought, given the consensus of normative authority that stands behind it. Instead, on reflection, very few of the physicians in their sample are willing to endorse a purely instrumental view of the role of families in healthcare. They also found that different moral understandings and strategies emerged from different kinds of practice and from different amounts of experience.

As all of these authors are more than capable of stating their own cases clearly and economically, I will say no more here about the specific arguments and conclusions they advance. Despite the fact that their readers are also more than capable of making their own assessments, I will conclude by calling attention to the persistence of certain themes in these articles that strike me as especially important to ongoing thinking about patients, families, and the ethics of healthcare. One such theme concerns what I'll call — not without some misgivings — the relationship between sentiment and rationality. Something in the neighborhood of how this distinction is often understood can be detected easily in the contributions of Powell, Purdy, and Belling, and is not far below the surface in some of the other essays. The passion with which people seek out lives within families — an institution whose instrumental goods, while no doubt very important to individuals and societies both, could be more efficiently and perhaps more justly secured in other ways — can be seen as an instance of the "heart's reasons": clearly powerful, clearly motivating, hard to articulate. Bioethics, both in and outside of family contexts, encounters such reasons a good deal, sometimes in the guise of "yuck" factors, sometimes more gravely presented. Both "reason" and "sentiment" have their champions in the field; it seems to me that it is well past the time to move beyond partisanship here and to try to better understand the deep and interrelated importance of these core dimensions of human life.

Another important, and related, theme might be called the "moral psychology" of bioethics. What do our favored conceptions of moral deliberation and decision making say about our psychological propensities and

powers, about what kind of selves we fundamentally are? A related question needs to be pressed as well: How might our best conceptions of what we are and what we can do influence our ideas about the character of moral problems and the best ways of solving them? The Lindemann, Powell, and Belling articles in particular all view images of human selves, their powers, and their relationships that have strong family resemblances, and that also stand as alternatives to assumptions that are prevalent in a good deal of the ethical theorizing available to, and sometimes prompted by, bioethicists; they ought to incite further, explicit work on how various conceptions of human selves operate in bioethics.

A third theme I find in several of these essays resonates with both considerations of sentiment and selfhood; it might be called the "situatedness" of practical rationality. Hardwig's article might be read — superficially, I think — as claiming that families who insist on treatments that professional tell them will not work are in fact being, in some objective sense, irrational, but they have an excellent excuse for it: they have been mightily encouraged to believe that healthcare is capable of near miracles by people they have good reason to regard as experts. If the experts start contradicting themselves, you can hardly blame the laity for getting confused and digging in.

But Hardwig also points out how forms of life that seem pointless to professional health providers may seem deeply significant to families whose own lives are caught up in caring for their relatives; there need be nothing irrational about that at all. It is in part through awareness of what people make of their situations that we can understand the sense in what they do. Hardart and Truog's study helps to alert us to differences in notions of what counts as a "good reason" for action within a "healthcare culture" that might strike those outside it — patients, families, even some bioethicists — as monolithic. Their work provides a basis for thinking that even those moral maxims that seem to form the most venerable and respected part of healthcare's evaluative outlook may penetrate practice incompletely, and serve as reasons for action to different extents in different situations and with different providers. Further studies, focusing on how differently situated patients and families understand themselves, their relationships, their decision making, and their disputes with healthcare providers, need to be part of a continuing effort to encourage us to keep better track of all those whom healthcare serves, and all those who serve healthcare.

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I'm grateful to Hilde Lindemann for her reading of an earlier draft of this introduction.

Voice: Cognitive Impairment and Medical Decision Making

Tia Powell

On a leafy, sun-dappled front porch in a suburb of Washington, D.C., are two women. The younger woman is not young; she is tiny, silver-haired, and 65. Her mother is there, too, and she is even tinier, far more frail, and 97 years old. The mother is severely demented, and has not spoken a word for several years. She lives here, in the modest split-level home she has owned for many years, with a home attendant. Her daughter visits daily. The daughter has taken advantage of this warm, early spring day to settle her mother comfortably in the sun, outside on her porch, where she has not been for many months. The daughter tucks an afghan blanket carefully around her mother's legs. The mother knit this blanket herself in cheerful colors and happier times, many years ago. Seeing her mother so nicely settled, and proud of her efforts at taking such good care of her, the daughter says, "There, Mother. How is that?" The mother looks her daughter straight in the eyes. Her face is struggling. She makes a sound; she is trying to speak. At last the mother produces a single word, said with clarity and fierce intensity. She says, "Lousy."

This word was my grandmother's last. It came in the last year of the long life of Mercedes Phelan Hayden, a life that was full of many events and satisfactions. The word was spoken to my mother, and it is unlikely it would have been spoken at all but for the presence of my mother, there with her mother on that day. It cost something for my grandmother to summon the strength to say her word; it surely cost something for my mother to hear it. An isolated word, after years of silence, takes on depth. Language can be like a broth, simmering for years, reducing and condensing into sharper and deeper flavor with every day that passes, until finally there is just the one word that stands for all that has happened and that has needed saying. The word could have meant that my grandmother didn't like sitting in the sun on her porch that one day, but my mother took it to have wider implications. My mother took the word as a summary of the experience of being demented, 97, and

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no longer ever comfortable, not even on the best days.

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The sweep of developments in bioethics and the law of the last decades has lead to an increase in autonomy in medical decision making, but only for the privileged few. Patients who retain decision-making capacity, or those who clearly recorded their wishes when they had capacity, have gained a greater role in shaping their medical care than was previously available. For those who always lacked capacity, or who lack it now and failed to comment on their wishes when they might have, the developments of recent decades are less benign. The vast majority of patients who now lack capacity have not provided properly executed advance directives indicating their wishes for medical care. The focus on individual autonomy in law and bioethics has failed to improve medical decision making on behalf of this majority of incapacitated patients.

Bioethics must look to new ways to acknowledge and respect the experience of those who lack decision-making capacity. For decision making to be truly ethical for those without capacity, we must find a middle ground between the full-scale autonomy of those with capacity and the abnegation of current participation by those who lack capacity. For the severely cognitively impaired, significant medical decisions must still be made by concerned others. However, those others should be guided by their knowledge of the impaired person's experience, either pleasurable or painful, by the expressions of this person's will and by other factors that I will refer to as the "voice" of the incapacitated person. Voice may refer to literal speech or its remnants, as in the case of my grandmother, or it may refer to nonverbal acts of attempted communication. Voice may also, for those most severely impaired, come down to our efforts to understand the experience of the cognitively impaired person whose ability to communicate may be vestigial. In these cases, the voice of the cognitively impaired is heard only through the empathic efforts of one who seeks to appreciate the experience of the injured person. An emphasis on voice, which in turn relies upon empathic communication, will support a robust role for surrogate decision making by family members, as opposed to legally appointed strangers and the courts.

AUTONOMY RISING

As stated famously by Justice Benjamin Cardozo, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."[1] However, the right to medical self-determination was not established by Cardozo's landmark opinion; it took many years, further legal decisions, and considerable public debate to secure a measure of reliability for the right of those with sound minds to determine their medical care.

The efforts of Dax Cowart were significant in the struggle to permit patients with decision-making capacity to exercise their rights to make controversial medical decisions, and in particular to refuse medical treatment. Cowart was a robustly healthy young man who was severely burned in an explosion in the 1970s. Cowart survived the explosion and fire, but the treatment for his burns was excruciating, as captured in the widely known documentary, *Dax's Case*.[2] Interviews with Cowart, his family, his physicians, and others confirm his superlative cognitive capacity, yet his voice and well-articulated refusal of treatment were ignored. Cowart survived to build a life he found meaningful; blind and with some other physical disabilities, he attended law school, married, and successfully pursued other professional and personal goals. However, he has argued forcefully that only he suffered the pain of his rehabilitative surgeries and other treatments, and that only he, given his cognitive capacity, should have had the right to determine whether the possible benefit of a fulfilling future life outweighed the immediate pain of his symptoms and their treatments. Such an abrogation of a capable patient's decision-making rights would be far

less likely in the U.S. today, in part because of Cowart's crusading efforts. Moreover, the far greater attention today to pain control might have permitted Cowart to attain the benefits of rehabilitation without such an extraordinary burden of suffering.

THE VOICELESS PATIENT

Gains in the freedom of cognitively intact patients to reject unwanted treatment are important and positive. Unfortunately, decision making for the cognitively impaired has not evolved to the same extent. In particular, the voice of cognitively impaired patients has been harder to incorporate into medical decision making and the law. Nowhere has the absence of voice for the cognitively impaired been more obvious than in New York State.

New York courts addressed surrogate decision making in 1981 on behalf of John Storar, a 52-year-old severely retarded man with terminal bladder cancer.[3] Storar's medical situation, although familiar to many, bears review. Storar was born in the 1920s and was institutionalized, as was common for children with his level of severe retardation. His cognitive abilities in adulthood were described as comparable to those of an 18-month-old. In practical terms this meant that Storar could walk, could communicate in a rudimentary fashion, and was not capable of higher order thinking. Throughout his years of institutionalization, his mother visited him virtually daily; her standing as a loving parent was unquestioned throughout the ensuing legal case.

In July 1979, John Storar was diagnosed with bladder cancer. His mother, wishing for him to receive appropriate curative treatment, obtained legal status as his guardian for the express purpose of agreeing to radiation therapy and transfer to a hospital that performed the necessary treatment. After these radiation treatments, Storar's cancer went into remission for eight months, but recurred in March of 1980, when he also developed hematuria. His physicians made various attempts to curb his recurrent bleeding through cauterization, also agreed to by Storar's mother, but these attempts proved unsuccessful. Storar continued to lose blood, and his anemia was treated by transfusion. Alas, transfusion is not as straightforward for a terminally ill, severely retarded man as it might be for another. Storar's transfusions required that he remain still without disturbing an intravenous infusion for hours at a time. He was incapable of understanding the reason for this treatment, and was unable to comply voluntarily with the restrictions on his movements. To receive transfusions, Storar was physically restrained and given sedatives. Storar was anxious during the treatment as well as afterward, since transfusion was often followed by the appearance of large blood clots in his urine. Storar's cancer was widely metastasized, causing him considerable pain. In addition to the pain of his illness, he was also forced to endure the pain and fear of his treatment "because of the force that compelled him to submit"; the result was that he became withdrawn, keeping to his room far more than previously.[4] Unlucky Storar; his medical treatment undermined his limited ability to communicate with others while he was dying and most in need of comfort.

Mrs. Storar grew distressed by the effect of the transfusions on her son and sought to stop them, stating that they served "only to prolong his discomfort."[5] The hospital refused and went to court to get permission to transfuse Storar over the objections of his legal guardian, his mother. At a hearing in September, his physicians noted that Storar had entered the terminal phase of his illness, that is, that his cancer had widely metastasized, and that he was likely to live another two and six months, even with transfusions. The case wound its way through the New York judicial system, and the final decision was handed down in March 1981. Storar was dead by then, having received transfusions to the last. The decision supported the right of the physicians to transfuse Storar over the objections of his mother.

Much has been written about Storar and the decision by Judge Sol Wachtler, then New York's highest judge. The case has been alter-

natively viewed as a defeat for those who support the right to die and as a victory for those who support the right to full treatment for the disabled.[6] What the Storar case does most effectively, however, is to illustrate the lack of John Storar's voice in the decision made for him, and the suffering that ensues from ignoring that voice.

Wachtler did attempt to assess the best interest of Storar, but he did so in a way that ignored Storar's individual experience. Wachtler noted that Storar's mental capacity was that of an "infant," and that therefore his rights would be evaluated like those of other infants. Wachtler compared Storar's case to that of transfusion cases involving infants of Jehovah's Witness parents, and found that, in these cases, the benefits of transfusion clearly outweighed the burden. If Storar were an otherwise healthy infant requiring a transfusion, Wachtler's reasoning might be compelling. However, Storar's circumstances differed from those in the cited cases in crucial details. Storar was not like an 18-month-old with a treatable illness; he was in fact a 52-year-old man dying of cancer. Although most other patients do not experience transfusions as painful, Storar required physical restraint and sedation. For Storar, transfusion imposed a burden of fear that made these treatments comparable to a treatment that would be far more invasive for most patients. Moreover, Storar was terminally ill, and all parties agreed that these treatments would at most only briefly prolong his life.

Wachtler's decision reflects a failure of empathy; he does not attend to the voice of Storar. To say that Wachtler lacks empathy for Storar does not suggest that Wachtler is cruel or even indifferent to Storar. On the contrary, Wachtler tries to do what he believes is in Storar's best interest. However, the information he uses to determine that best interest does not depend on empathic knowledge of Storar's condition, but entirely excludes it. Wachtler therefore does not succeed in making a decision that corresponds to Storar's actual circumstances. For Wachtler, Storar becomes a sort of human widget, an ageless, featureless, nonspecific entity. If Storar were like a healthy baby with a curable disease, or like a capable adult who comprehended the purpose of transfusion, the decision might have corresponded to Storar's situation. As it was, the decision did not fit the circumstances of the specific individual who was John Storar.

In *Storar*, the court nominated itself to the role of decision maker, although Judge Jones, in his dissent, stated a decided preference for the family. In his dissent, Judge Jones noted that Storar's "mother over his lifetime had come to know his wants and needs and was acutely sensitive to his best interests; that she had provided more love, personal care, and affection for John than any other person or institution, and was closer to feeling what John was feeling than anyone else."[7] The dissenting judge thus privileges the role of Mrs. Storar in interpreting her son's communications and experience. Judge Jones goes so far as to say that he doubts that courts have, in general, a useful role to play in surrogate decision making. Rather, Judge Jones notes that there is "no empirical evidence that either society or its individual members have suffered significantly in consequence of the absence of active judicial oversight."[8] Nor would Judge Jones recognize the standing of the medical facility to seek judicial authority to continue transfusions over the objection of Mrs. Storar, finding the interests of the medical providers "tangential" in comparison to those of the patient and family. Had Jones's decision stood instead of that of the majority, it would have radically altered the process of surrogate decision making in New York and perhaps nationally. Such a decision would have invited greater attention to the role of families and of empathy in decision making for incapacitated patients.

EMPATHY IN MEDICAL DECISION MAKING

Jodi Halpern, in *From Detached Concern to Empathy,* calls for the greater use of empathy in a somewhat different context, that is, she focuses on the use of empathy by physi-

cians.[9] Halpern offers a "skeptical questioning of the norm of detached concern" for physicians, and instead suggests that retaining the capacity to be moved by patients is a crucial part of being an effective healer.[10] Our focus here is not to examine the use of empathy by doctors, but rather to draw a parallel to decision making on behalf of impaired patients by judges, who also favor detachment over emotionally connected reasoning. Halpern provides a defense of empathy, which she describes as an emotional and experiential comprehension of the situation of another, as opposed to a form of knowing that comes through purely theoretical and intellectual reasoning.[11]

To accept that empathy has an appropriate role in decision making for others, one must first agree that emotion, upon which empathy depends, can contribute to the process of reasoning. Halpern reviews the work of the many philosophers and other scholars who denigrate the use of emotion in decision making. She cites Descartes's argument that, since emotions can be spontaneous and automatic, they must therefore be irrational and not subject to revision by the processes of reason.[12] Kant also devalued the role of emotions, arguing that only by detaching reason from emotions and social influences can one generate the sort of thought that constitutes the exercise of autonomy.[13]

Halpern, however, refutes this bias against the use of emotion in reasoned decision making. She draws upon the work of contemporary philosophers like Bernard Williams to illustrate the limits of Kant's emphasis on reason in the absence of emotion.[14] As an example of autonomy, Kant described the case of a suicidal man deciding whether or not to end his life. For Kant, the man will choose to live if he exercises his reason and finds that he cannot support the notion of a universal maxim that permits one to commit suicide when there is no longer a reason to live. Halpern, a psychiatrist and a philosopher, is well aware that this is not the sort of thinking that generally helps desperate people refrain from suicide. However, even if a person did reject suicide based on purely detached reason, this act would not, for Halpern, constitute an expression of autonomy. For Halpern, "the capacity to make use of detached reason to commit to impersonal goals" is not enough to produce autonomous decisions.[15] Fully autonomous reasoning requires that an individual generate goals with personal meaning. In the example of the suicidal man, deducing a universal maxim neither fully expresses his autonomy nor provides sufficient motivation to tolerate the continuation of a painful life.

It is interesting that accounts exist of the mental processes that suicidal persons actually use to find a reason to continue living. One such account occurs in *Undercurrents: A Life Beneath the Surface,* psychologist Martha Manning's narrative of her descent into and recovery from suicidal depression.[16] Manning confesses to her psychiatrist that she contemplates suicide and he asks, "What stops you?" Referring to her only child, she replies, "Keara, I can't leave Keara. . . . She is the only thing that stands between me and dying."[17] Manning's irreplaceable obligations as a mother demand that she tolerate her present pain to raise a beloved daughter; she finds her reason for being within her family, in the emotional bond to her daughter. That Manning's choice is suffused with emotion makes it no less a reasoned moral choice, and a painful one. This sort of choice requires a person to make a life and death decision by reflecting not only upon critical values, but also by weighing the full emotional consequences to the self and to valued others. This choice, more than an abstract, purely rational choice, more closely reflects the sort of autonomous choice that is relevant to medical decision making.

Manning is a capable decision maker, despite her depression, and she withstands the pain of depression long enough to find an effective treatment (electroconvulsive therapy in her case) and regain a life she enjoys living. But how are we to imagine a form of surrogate decision making that would similarly permit the use of emotionally laden information on behalf of the incapable patient? Judge

Jones, in his dissent in *Storar,* seems to be arguing for just such a system when he questions both the role of the courts as decision makers and the standing of healthcare providers to question the decision of a parent on behalf of the adult child for whom she has cared for decades. Jones relies upon the interpretation of one who has an intimate relationship with the incapacitated patient. He privileges information derived from that relationship above the knowledge accrued by professional training for either judges or physicians.

SURROGATE DECISION MAKING: WHO VERSUS WHAT

The battle over surrogate decision making has raged for more than 25 years. No sooner is victory declared than a fresh skirmish breaks out, and the illusion of consensus is once again destroyed. The recent *Schiavo*[18] case is but one more example in a chain stretching back to *Quinlan,*[19] and including *Storar, Cruzan,*[20] and a host of other legal cases. The distinction between *who* makes surrogate decisions versus *what* decisions are made has been a key theme in this saga. Commentators with strong opinions about *what* is decided are willing to subjugate the decision-making authority of various groups; those who favor process over outcome insist on determining the right answer to *who* should decide and must accept a wider range of decisions about *what* is decided.

The argument over who should make surrogate decisions can be resolved in favor of families, courts, specific types of surrogates, or some combination of these three. In *Storar,* the court nominated itself to the role of decision maker, although one judge dissented, stating a decided preference for the family. The bioethics literature has addressed this topic exhaustively; many commentators uphold the family as the proper decision maker. For instance, the President's Commission report on end-of-life care argues that the family should be the presumptive surrogate for the incapacitated patient.[21] The President's Commission recommends that the family be thus privileged for various reasons, including:

- The family is most interested in the patient's well-being;
- The family is "most knowledgeable" about what the patient would choose;
- The family's important and long-standing social role as caretaker for its members should be recognized;
- Families require privacy to flourish, and the state "should be reluctant to intrude" upon such personal matters.[22]

Although many authors agreed with the preference for family decision makers expressed by the President's Commission, not all did. Ezekiel Emanuel, for instance, strongly criticizes the fitness of families as surrogate decision makers.[23] He argues that it is not always easy to determine who forms part of a patient's family, as families are currently defined. He cites compelling evidence that family members are not well-informed about each other's preferences,[24] and notes that they may also disagree with one another about the incapacitated patient's wishes. Moreover, family members may know the patient's preferences and choose to ignore them.

Emanuel is surely correct that families exhibit many flaws as surrogate decision makers. His proposed solution, however, hardly represents an attractive alternative. Emanuel suggests that the delegation of surrogate decision-making authority to families reflects society's inability to wrestle with the difficult choice of *what* should be decided on behalf of incapacitated patients. He prefers a system in which communities articulate their values and accompanying medical choices. "Citizen-members" of various health plans would examine their beliefs and options, allowing them to reach a consensus about the appropriate treatment for a given situation.[25] For instance, within a given health plan, all or no patients in a persistent vegetative state (PVS) might receive artificial nutrition and hydration, depending on this community's vision of the good life.

Events during the decade since Emanuel proposed his model of decision making by

"citizen-members" of health plans do not support the notion that communities would successfully reach consensus about end-of-life treatment decisions. Americans hold widely varied and passionately defended notions of when treatment must and must not continue for incapacitated patients. Those who did not concur with the policies of an Emanuel-style health plan would be forced to find care elsewhere. For urban dwellers, this might be possible, although inconvenient. For Americans in rural areas, where healthcare facilities are fewer, Emanuel's system might create the medical equivalent of the partitioning of India, with like-minded citizens moving en masse from one section of the country to another. Emanuel finds fault with the family as surrogate decision maker, but, in its stead, offers a system that is unworkable on two accounts. First, as a practical matter, communities are unlikely to attain the necessary degree of consensus on contested end-of-life treatments. Second, if the system did exist, it would create unacceptable levels of dislocation and anguish in the healthcare system.

Rebecca Dresser, in "Relitigating Life and Death," also rejects the family as surrogate decision maker.[26] Dresser stresses the importance of the incapacitated patient's current interests, and argues that neither the family's views of the patient's interests, nor even the patient's own statements expressed when competent, should take precedence over those interests. Dresser assigns to the courts the weighty task of determining just what the patient's current interests might be. Dresser acknowledges that her proposal would vitiate the effect of a living will or other advance directive, and she accepts that outcome. She would have the courts mandate treatment that they determine is in the patient's interests, and forbid treatment that is not, regardless of the family's opinion or the patient's own advance directive. Dresser elevates the importance of the current experience of the incapacitated patient, but she offers no reasonable means to understand the particularities of that experience. Once again, the incapacitated patient is a voiceless everyman, a human widget who is interchangeable with any other patient with the same diagnosis. This style of decision making turns its back on the role of empathy in caring for incapacitated patients.

Like Emanuel, Dresser believes it is possible to find a "right" answer for a treatment decision for a specific person without consulting his or her family. However, Emanuel would find that answer through an open political process akin to Jeffersonian democracy, while Dresser would let judges choose the "objectively" correct answer — without any semblance of consensus building. In both cases, the decision-making authority of the family is transferred to strangers who have no connection to the incapacitated patient, and who have no track record that might suggest they would make better decisions.

FAMILY DECISION MAKING

Both Emanuel and Dresser correctly note that families have an imperfect track record on making wise decisions, or even ones that reflect the wishes and interests of the patient. In contrast, Hilde Lindemann and James Lindemann Nelson acknowledge those flaws, yet still insist on the importance of family as interpreter for the incapacitated patient.[27] In their book, *The Patient in the Family,* Lindemann and Lindemann Nelson describe, among other things, the roles and values that families maintain. Familiar tasks taken on by families include those of protecting, nurturing, and socializing not only children, but all members of the family. In addition to these functions, Lindemann and Lindemann Nelson examine the role of the family in forming an individual's identity. The history of the family intertwines with that of the individual. This mutually developed narrative contributes "both to our sense of who we are and to our sense of why it matters who we are."[28]

Families do not rely solely upon abstract principles when they make decisions on behalf of an incapacitated member. In contrast to other ethical systems that value impartiality, a family's ethical obligations require a focus on a particular individual. Family deci-

sion making may entail a search for equal justice between members, such as when apportioning goods and privileges among siblings, but that justice will require knowing the specific circumstances of the family members, and the valuation that the particular members assign to the goods and privileges under consideration. It is not equal justice to put both the three-year-old and the 17-year-old to bed at 8 p.m., nor to allow each to drive the family car one night per weekend. But family members do not only have factual information about each other. They are uniquely qualified to supply the emotional knowledge about patients upon which empathy depends, and which is so crucial for making a surrogate medical decision.

Lindemann and Lindemann Nelson note a number of guiding principles that capture the ethics of families. Among these "stars to steer by" is the notion that "family members aren't replaceable by . . . better qualified people."[29] This principle has important implications for the role of families in surrogate decision making. To take an example, suppose that in the course of your life you mourn the loss of a loved one. Your friend, whose first language is not English, sends you a letter of condolence that is genuinely comforting, despite a number of lapses in spelling and grammar. What matters to you, and what makes this gesture meaningful, is not that this is the best possible letter. For that, you might wish to review condolence letters by great authors of the past, such as Abraham Lincoln. What gives this letter meaning is that a specific person who cares about you took some trouble, perhaps a great deal of trouble since English is not easy for her and the letter is specifically for you, in your present difficulty. It is the act of caring that matters. This example involves a friend rather than a family member, but it is by similar acts of caring that families maintain bonds. Lindemann and Lindemann Nelson argue compellingly that it is for this reason that families have a meaningful role as surrogate decision makers in medicine. It is not that families necessarily know best what to do; the value of a decision made by family is that it is made by a specific person or persons who matter to the patient and to whom the patient matters. To the family, the patient is a person, not a widget, in a way that can never be true for the impartial decision maker, who is to this person a judge, physician, or other neutral yet anonymous professional. The form of knowledge that makes this person unique cannot be derived in the abstract, but grows from lived relationships between people.

Numerous authors have attempted to describe ethical systems that are based on caring. Joan Tronto, in *Moral Boundaries,* describes four phases of caring.[30] In the first phase, "caring about," a need is noted and recognized as such; this phase includes noting the plight of another, for instance a homeless person. Next, in "taking care," the one who has observed the need accepts responsibility for it. This phase might include voting in a way that will support improved services, or donating money to a charity that addresses the identified problem. Tronto's third phase is called "care giving," and involves directly meeting a need for care. This phase generally requires physical work and person-to-person contact for the caregiver; one example would be the adult daughter who takes a leave of absence from work to care for a dying parent. The fourth phase is that of "care receiving," since the recipient shares in the process in important ways. The capacity to give thanks and to offer reciprocal caregiving shape the meaning of receiving care for both giver and receiver. Tronto, focusing on the political context of caring, notes that these four phases interact with gender, race, and class. The first two phases, which can be accomplished with money and influence, generally are duties of those with power in contemporary society. Those with less power are far more frequently involved with the second two phases, caregiving and receiving.

By Tronto's system, the assignment of decision-making authority to the courts corresponds to keeping that authority in the hands

of those who already have a disproportionate share of societal power, and who never deliver the actual care to those in need. In contrast, relying on the family as first choice for making surrogate medical decisions acknowledges the family's role in providing care in a direct way and over time. This power will rely less on societal status and more on the knowledge that particularizes the needs of this incapacitated patient. Relying on the family as default surrogate decision makers keeps these decisions closer to the people who will provide and supervise the actual care, and who are thus in a better situation to observe the ethical dimensions and outcome of their choices.

VOICE

The ability to appreciate the voice of the incapacitated patient decreases with emotional distance and increases with intimacy. Family members may not bring optimal levels of empathy to every encounter with cognitively impaired relatives, but they are better situated for empathic communication than judges, who often never see the person whose life is determined by their decisions. A patient's physician may have an ongoing relationship and a clearer sense of the patient's circumstances, but is less likely in general than a family member to have a sustained emotional relationship with the severely impaired patient.

Empathic connection can amplify the impaired person's ability to communicate, as may have happened when my grandmother last spoke to my mother. The incapacitated patient may be moved to reach out to someone who is listening; the attentive listener is more likely to perceive an effort to communicate. When impaired patients can communicate, empathy enhances the signal and permits decision makers to incorporate this information.

Knowledge that is gained through empathic communication increases our ability to understand the patient's wishes and preferences. The focus here is exclusively on patients who lack decision-making capacity; the preferences of these patients cannot solely determine medical decisions made on their behalf. Current practices often exclude entirely the experiences and communications of the impaired patient, and that seems as wrong as letting an impaired patient make a choice without the requisite capacity. Attention to the voice of the incapacitated person permits others to make decisions that reflect the needs and circumstances of this specific, loved individual. When communication is no longer possible, a family member's intimate, sustained relationship allows decisions to be made in the best interest of that person. This version of best interest does not rely upon a generic definition that is applicable to anyone who might appear to be similarly situated "on paper," but relies on the interests of *this* person, seen in intimate detail.

Attention to the voice of cognitively impaired patients offers us two ways of improving decisions on their behalf. We can use empathic knowledge to draw out the patient's ability to communicate preferences, and factor that information into decision making. We can also use empathic knowledge to determine the best interests of this unique and valued person, and make medical decisions that are shaped by such intimate knowledge.

CONCLUSION

Sadly, anyone may cite instances of families in which members appear to know or care little for each other's deeply held personal values. Even in caring families, casual acquaintances may sometimes know what family members do not. A spouse may be the last to know of a partner's infidelity or alcohol addiction; parents may not know their son is gay although his siblings and friends do. Worse still, family members may intentionally place their own interests ahead of those of the incapacitated patient.[31] Other families may correctly reflect a patient's wishes, but insist upon treatment that physicians and fa-

cilities find is inappropriate; these families may need limits on the treatment they can request. Family members may disagree with one another about a surrogate decision. These families should be offered mediation so that they may reach agreement, but some may force the courts to serve as the final arbiter. Finally, some patients lack family altogether, and assigned professionals will inevitably make decisions on their behalf.

Nonetheless, families should serve, whenever possible, as the surrogate decision maker for patients who did not or could not express their medical preferences. Knowledge that is earned by living with and caring for another person, that is suffused with time and shared emotional experience, is the form of knowledge that is demanded for making medical decisions on behalf of another. The family provides history, identity, and cultural and ethnic specificity in a way that impartial decision makers cannot. The family can see the patient over time and in different roles. A single word, spoken to someone who can hear it in the fullness of its meaning, can speak volumes. Imperfect as they are, families still serve as the best source of information that distinguishes this person from all others. Medical decisions cannot be made on a generic basis, but they affect a specific person, and should reflect the circumstances of that person. To borrow from Winston Churchill, families are the worst solution for making surrogate medical decisions, except all other systems that have been tried.[32]

DISCLAIMER

The views expressed are solely those of the author and do not reflect the opinion of the New York State Task Force on Life & the Law nor of the government of the State of New York.

NOTES

1. *Schloendorff v. Society of New York Hospital* (1914) 105 N.E. 92, 92-94.

2. *Dax's Case: Who Should Decide?* VHS (New York: Unicorn Media for Concern for Dying, 1985); see also, E.A. Rosenberg and D.A. Karides, "An Interview with Dax Cowart," *Journal of the American Medical Association* 272, no. 9 (1994): 744-5.

3. *In the Matter of John Storar* (1981) 420 N.E. 2d 64; 52 N.Y. 2d 363.

4. Ibid., 280.

5. Ibid., 260.

6. G. Annas, "Help from the Dead: The Cases of Brother Fox and John Storar," *Hastings Center Report* (June 1981): 19-20; A. Asch, "Disability, Bioethics, and Human Rights," in *Handbook of Disability Studies,* ed. G. A. Albrecht, K. D. Seelman, and M. Bury (Thousand Oaks, Calif.: Sage, 2001).

7. See note 3 above, p. 281.

8. Ibid., 278.

9. J. Halpern, *From Detached Concern to Empathy: Humanizing Medical Practice* (New York: Oxford University Press, 2001).

10. Ibid., xvi.

11. Ibid., 72, 75.

12. Ibid., 45.

13. Ibid., 108.

14. Ibid., 110.

15. Ibid., 111.

16. M. Manning, *Undercurrents: A Life Beneath the Surface* (New York: HarperCollins, 1995).

17. Ibid., 105.

18. *In re Guardianship of Schiavo*, 800 So. 2d 640 (Fla. 2d Dist. Ct. App. 2001).

19. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

20. *Cruzan v. Director, Missouri Department of Health,* 497 U.S. 261 (1990).

21. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington, D.C.: U.S. Government Printing Office, 1983), 127-9.

22. Ibid., 128.

23. E.J. Emanuel, *The Ends of Human Life: Medical Ethics in a Liberal Polity* (Cambridge, Mass.: Harvard University Press, 1991).

24. Ibid., 56-7.

25. Ibid., 178-80.

26. R. Dresser, "Relitigating Life and Death," *Ohio State Law Journal* 51 (1990): 425-37.

27. H.L. Nelson and J.L. Nelson, *The Patient in the Family: An Ethics of Medicine and Families* (New York: Routledge, 1995). Hilde (Lindemann coauthored this book as H.L. Nelson.)

28. Ibid., 42.

29. Ibid., 74.

30. J. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York: Routledge, 1993).

31. J. Hardwig, "The Problem of Proxies with Interests of Their Own: Toward a Better Theory of Proxy Decisions," *The Journal of Clinical Ethics* 4, no. 4 (Winter 1993): 20-7.

32. W. Churchill, "Speech in the House of Commons," 11 November 1947. Churchill stated, "democracy is the worst form of government except all those other forms that have been tried from time to time."

On the Mend: Alzheimer's and Family Caregiving

Hilde Lindemann

As she let me into the kitchen I've known all my life, her eyes were too bright — as if at any moment they might spill over with excitement or anger or some third uneasy thing. I set the groceries down on the counter and took off my coat, watching her warily as she put the food away. She doesn't let me help with this because she wants to show me that she can still do it by herself, I suppose, so I sat down at the table and told her that Ellen sent her love.

"Ellen?" She trotted quickly from cupboard to counter to refrigerator, not with the old competence but forcefully, as if propelled.

"Your granddaughter, Mama. She would have come with me tonight but she's studying for a history test. It's the first free evening she's had all — "

"I know who you're talking about and I don't want her coming around here anymore," she interrupted. "She's a thief, that one. She steals from me. First she stole my —" she stopped, groping for the word "— my silver engine starter." She looked puzzled, but ploughed on, "And then she stole my car, but she won't get any of my money, that's for sure. That's hidden someplace where she'll never find it."

I took a deep breath. "Oh Mama, Ellen didn't steal your car. We sold it for you last month, after the doctor told you it wasn't safe for you to drive anymore. Don't you remember?"

She shut the refrigerator door and turned to face me, moving crabwise to the nearest chair as if she needed to keep the table between us. "What did you do with the money?" she demanded.

"It's in the bank." I tried to keep the patience out of my voice. "You got in my car and we drove to the bank, and you deposited it in your checking account. Really you did."

She sat down, her back stiff and her mouth a thin tight line. It was a look I had seen sometimes in childhood, when she fought with my father about money. Their fights terrified my brother and me, possibly because they hap-

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pened so seldom. We would sit at this table, the gravy congealing on our plates, while he raged at her for her miserliness and she drew herself up into a figure of imperious resistance. At those moments we children got a glimpse of something hard inside her that was usually buried deep under many layers of softness. A splinter of cruelty that her disintegrating self could no longer conceal.

"Mama," I said desperately, "have you had your supper yet?" I'd tried diversionary tactics before and they sometimes worked. They worked now. She'd been waiting for the groceries, she said, and yes, an omelet would be nice. I sautéed onions and mushrooms, made tea, buttered toast, threw a handful of Swiss cheese on top of the half-set eggs, added the sautée, and folded the omelet. As I cooked, I jollied her. "What does the Perfect Housewife do when supper's late?"

She grinned. "Fry an onion!"

"So your hungry family knows that help is on the way," I finished. "Best piece of advice you ever gave me."

"That, and 'Never marry on the rebound'," she agreed. The kitchen returned to normal. I brought her food to the table and poured tea for myself in the special blue mug I'd been drinking from since I was nine. As she ate, we talked of her own mother and dad, and her childhood in German-speaking Milwaukee. She liked that topic because she could remember it, and remembering made her feel safe. We lingered over her meal, me playing the straight man and she preening, and both of us content.

Finally I rose from the table and began to clear away the dishes. "It's getting late," I said. 'I'll look in on you tomorrow — maybe around six?"

"Six is fine."

"Okay then, sleep tight." I put on my coat and kissed her, and then I remembered her meds. "I almost forgot your pills. Stay put — I'll get them."

I went into her bedroom, switched on the lamp on her nightstand, and opened the drawer. As I slid my hand inside, I felt a hot rake of pain. I could smell the blood before I could see it, and I pulled the drawer wide before I carefully extracted my hand. Blood was everywhere, flowing freely from the four long gashes on the top of my hand, oozing and sticking around my palm, falling in great drops onto the wooden bottom of the drawer. Bending down, I could see the old-fashioned razor blades that had been stuck with some kind of caulk to the top of the frame. I straightened up, looking for something to stanch the bleeding, and saw my mother standing in the doorway.

"That's what happens to thieves," she spat. She had drawn herself up to full majesty, and she was shaking with fury. "Thief! Robber! Get out of my house before I call the cops on you!"

• • •

There are currently 4 million people in the United States who suffer from Alzheimer's or some other progressive dementia; the Alzheimer's Association estimates that this number will increase to 14 million by 2050 unless a cure is found. At present, of course, there is no cure. Those who are afflicted will surely and inexorably lose their memories, their speech, and then all their capabilities. In the end, the disease will kill them unless a more merciful death intervenes.

There is no restitution narrative to be told for Alzheimer's — no story of health, then illness, then illness overcome. But because any serious disease attacks the person and not just the body, and because progressively dementing diseases are particularly efficient in this respect, we may speak here of a certain kind of *moral* mending and of the narratives that are needed to bring it about.

In this article I invite you to consider with me just exactly what this moral mending amounts to. Using my opening story as a case in point, I'm going to try to accomplish three things. First, I'll motivate the thought that the daughter in the story has a duty to hold her mother in personhood — and I'll explain what I mean by that phrase. Second, I'll argue that

one thing preventing the daughter from holding her mother in personhood as well as she should is a story that collaborates with the Alzheimer's disease in damaging her mother's identity. Third, I'll sketch out a counterstory that could repair the mother's identity and so mend the injury to her personhood.

HOLDING SOMEONE IN PERSONHOOD

Implicit in the notion of personhood is the complicated set of reactions and attitudes that both express and sustain what is fundamentally a particular kind of moral relationship. To elucidate this relationship, I begin with Wittgenstein's observation in the *Philosophical Investigations* that "the human body is the best picture of the human soul."[1] All of the section containing this remark deals with how we recognize and respond to people's so-called psychological or mental states — what we tend to think of as people's inner lives. It's by paying attention to their bodily postures, gestures, and expressions that we can tell whether they are excited, puzzled, or interested; whether they are praying, fearing, or intending. And it's our ability to read these states off human bodies that allows us to see human beings as personalities rather than as furniture, plants, or pets. The capacity to generate selected items in the changing procession of sensations, emotions, beliefs, attitudes, wishes, misgivings, and other mental states that cross a human consciousness has been taken by some philosophers to be either necessary or sufficient for personhood, but if we take seriously that these states are socially mediated and that persons too are essentially social, then, rather than tying personhood solely to capabilities and competencies residing within the individual, we have to see it as partly also an interpersonal achievement.

The construction and maintenance of a personal identity is an integral part of this achievement. I have argued elsewhere that identities, in the sense of how we see ourselves and who other people understand us to be, are narratively constituted. They consist of tissues of stories and fragments of stories, generated from both first- and third-person perspectives, that cluster around what we take to be our own or others' most important acts, experiences, characteristics, roles, relationships, and commitments. In short, they are narrative understandings formed out of the interaction between one's self-concept and others' sense of who one is.[2]

Many of the narrative understandings forming a part of a personal identity draw on stock plots and character types that are familiar to us all: Cinderella, the whore with a heart of gold, and the Good Samaritan, for example, are characters whose stories we know so well that we readily use them to make sense of actual people. Socially shared narratives contribute to the identities of groups as well as individuals, and members of the group draw a part of their identity from how the group identity is narratively constructed.

Other parts of the narrative tissue that constitute a personal identity consist of the localized, particular stories that pick an individual out as distinct from others in the groups to which she belongs: these are the stories that distinguish this mother from the other members of her family, or from the class of people with Alzheimer's disease. They are the stories of the mother's childhood in a German-speaking immigrant family, of her college days during the Second World War, of her marriage to a man who was 15 years her senior, of her living children and the daughter who died in infancy, of her years as a high school teacher, her widowhood, her retirement. And among them is the story of the evening I just recounted, when the mother hurt her daughter's hand.

Personal identities function as counters in our social transactions, in that they convey understandings of what those who bear them are expected to do. If an answer to Who are you? is "the bartender," for example, I expect you to know how to mix a martini; if the answer is "a practicing Muslim," I don't. Moreover, identities also stand surrogate for how those who bear them may be treated. If you're my three-year-old son, I can remind you to use the toilet, but if you're my dean, I'd better

not. Personal identities make intelligible to us, then, not only how other people are supposed to act, but how *we* are supposed to act with respect to them. And because stories depict time passing, the narratives that constitute identities can reflect the respects in which we change, as well as how we remain the same.

Pushing Wittgenstein's "picture" remark one step further, I propose that (1) our socially mediated psychological states, (2) their bodily expressions, (3) others' recognition of these expressions, and (4) the treatment based on that recognition all play a part in the formation and maintenance of the relationship called personhood. Indeed, I argue that personhood just *is* the expression on a human body of the socially mediated feelings, thoughts, desires, and intentions that constitute a human personality, as recognized by at least some others, who then respond in certain ways to what they see. *Recognition* includes establishing a personal identity by engaging in the narrative activity that constitutes our sense of who the person is. *Response* includes the attitudes and actions we take toward the person — what we do to or for the person and what we expect from the person — on the basis of that identity-constituting, narrative activity. The bodily depiction of the succession of mental states and the uptake of that depiction by others in the form of recognition and response make up the social practice of personhood, the practice on which all other social practices rest.

The ability to participate in this practice can be blocked when any of its four components fail to function normally. There are, speaking very generally, two sorts of causes for these components' failure to function. The first is natural contingency. Mental retardation, progressive dementia, and mental illness, for example, can diminish or fragment the thoughts, feelings, and attitudes that find bodily expression. Paraplegia, muscular dystrophy, and amyotrophic lateral sclerosis immobilize the body, so that even if the individual can form sound beliefs, intentions, and so on, their expression is relatively difficult.

The second cause of the components' failure to function is human agency. The features of a human personality can be shattered by traumatic brain injury, whether accidentally inflicted or deliberately engineered. Bodies can be immobilized in ways that precludes the expression of attitudes or ideas, by maiming the bodies or keeping them in solitary confinement.

With respect to bodies and what Wittgenstein calls souls, then, human agency and natural contingency are equally capable of wreaking the kind of havoc that keeps a human being from participating in the ordinary practice of personhood. But where human agency has the advantage over nature is that it can also sabotage recognition and respect, the other two components of the practice. By refusing to recognize that certain human beings are actually expressing the thoughts, temperament, and so on that constitute a personality, powerful persons can consign them to the status of nonpersons, thereby blocking their participation in the practice of personhood. And finally, by ignoring or covering up expressions that are properly recognized, persons can refuse to respond to others, and once again their participation in the practice of personhood is blocked.

The practice of personhood, which is unreflective, reciprocal, and as common as breathing, can be distinguished from the practice of *holding* someone in personhood, which is often equally unreflective, but one-sided, and far less common. It is done by recognizing and responding to someone who cannot, for one of the aforementioned kinds of reasons, engage in practices of personhood herself. When a person with Alzheimer's is cared for at home, for example, family members may maintain her personal identity for her. As she loses her ability to contribute first-person stories to the tissue of narratives that constitute her identity, her caregivers and other intimates can persist in the third-person narrative activity that has already constituted their sense of who she is. They can continue to combine the plot templates and personae of widely

known and socially shared narratives with their own, more local stories of who she is, and then treat her according to the narrative understanding they have created for her. In this way they hold her in personhood, even though she can contribute very little to the practice herself.

Now let's return to the story of the mother and daughter with which I began. Does the daughter have a duty to hold her demented mother in personhood? Holding someone in personhood keeps the individual within the special place reserved for persons inside the moral community. To fall outside that place in the community is to lose one's claim to a particular kind of moral consideration, and that is a serious harm. Personhood is, I repeat, at bottom a moral relationship. As such, it commands the particular moral consideration that Kant called respect and the high moral valuation that he called dignity.

This mother *is* a person. But she is having serious trouble maintaining her personhood, and is losing her ability to recognize and appropriately respond to those who care for her. Given how eggshell-thin the protection can be that stands between any one of us and the exile from humanity that is the essence of Alzheimer's, I believe we must all take responsibility for holding in personhood those who fall prey to this disease. And because the mother-daughter relationship is one that ordinarily gives rise to special responsibilities, the mother's moral vulnerability exerts a particularly strong pull on her daughter.

NARRATIVE COMPLICITY

A crucial part of what's involved in holding someone in personhood is the narrative activity of maintaining the person's identity, as the stories that constitute our sense of who the person is are the ones that guide our treatment of her. If, for example, I draw on the stock character of the gay man as child molester that has circulated widely through our culture since the late 1930s,[3] and I learn that my child's kindergarten teacher is gay, my response to him may well be a mixture of fear and loathing, and I am likely to treat him with contempt, if not worse. It matters very much *which* stories contribute to a person's identity, and we are morally responsible for the ones we endorse. The story of the gay child molester damages this teacher's identity. It's not only a dignitary offense and a slur on his reputation — it could cost him his job and maybe even his life.

I want to suggest that the daughter in my opening story has endorsed a narrative that damages her mother's identity. Like the child molester narrative, the story in question is widely shared and socially circulated. Unlike the child molester narrative, though, the story the daughter has incorporated into her mother's identity has a surface plausibility that makes it appear innocent and harmless. It's the story of the "real self."

Recall that when the mother accuses the granddaughter of having stolen her car and demands to know what happened to the money, the daughter's tale goes like this:

> We would sit at this table, the gravy congealing on our plates, while he raged at her for her miserliness and she drew herself up into a figure of imperious resistance. At those moments we children got a glimpse of something hard inside her that was usually buried deep under many layers of softness. A splinter of cruelty that her disintegrating self could no longer conceal.

The daughter's presupposition of her mother's real self lies in the notion of a splinter of cruelty where the mother's heart should be — a splinter buried deep under many layers of maternal warmth, love, and kindness. All those layers of softness, the daughter seems to think, are just a civilized outer wrapping. Now that Alzheimer's has rotted the wrapping so that long strips of it have begun to fall away, the daughter can see who her mother really is.

But does the term "real self" refer to anything actual? If, as I have argued, personal identities are narrative understanding of

selves as they change over time, then a claim to know someone's real self presupposes something about what the identity represents or how it represents it. I can think of three possibilities here. First, the claim might be less about the self than about the identity: a "real self" might be the one that a defective set of stories failed to capture. That the stories constituting an identity could misrepresent the person is certainly a possibility, but that doesn't seem to be what people mean when they say that they have finally discovered who someone really was — they seem to mean that they've discerned some core or inner self they hadn't seen before.

This suggests a second possibility, namely, that the reference is to a self that is credibly depicted by the narratives that constituted the person's identity *at a certain time,* which was then covered up by later accretions and is now uncovered again as a result of progressive dementia. But then we need to explain why that earlier point in time carries more narrative weight than any other, and how we can know that dementia has uncovered it. Is the thought here that Alzheimer's has loosened the inhibitions that formerly kept the authentic self in check? And are we privileging the self that is now uncovered because it's what is left at the end of the actions and choices the person has been responsible for in the course of her life? While it's true that some judgments about someone's life can only be made after one knows how various choices, deeds, or guesses ultimately turned out, there's no good reason to suppose that the knowledge of how things turned out must coincide precisely with the final years of the person's active biography. The consequences of some choices will be apparent much earlier; the ramifications of others may continue long after the person is dead. It is worth bearing in mind that the decline into dementia offers no more of a God's-eye view from which to judge a life than any other location; it too is a particular context with its own limited sight-lines.

That leaves a third possibility, which is that the reference is to an aspect of the self depicted by a particular *story line* that runs throughout a person's life, rather than attaching to a specific point in time. Does the daughter suppose that the narrative that binds together all of the episodes of avarice in her mother's life is the one that shows her as she really is? In that case, we need to explain why *that* story depicts something more real than the other stories that constitute the identity. Was she often avaricious? Apparently not, or her children wouldn't remark on how seldom these episodes took place. Was she deeply cruel on the few occasions when avarice entered the picture at all? We have no reason to think so. In the absence of something that explains why we should give extra narrative weight to either an earlier point in the mother's life or a particular story line that runs throughout it, it's hard to see how one part of her self could be more real than all the others.

In a recent essay in the *Hastings Center Report,*[4] the philosopher and neurosurgeon Grant Gillett rejects the familiar conception of the self and mind, whereby the higher brain keeps a tight rein on the hidden snakepit of wayward impulses that constitutes our real selves. This picture, promulgated in various guises by Freud, Darwin, and Jaspers, has been called into question not only by Wittgenstein, but a number of others who have proposed instead that conscious thought is the product of socialization and training within a given form of life. "It is only as we engage in the everyday forms of life, those communal patterns of behavior where we learn to think and talk about things, that the contents of the mind take on a determinate shape," says Gillett.[5] We live out our lives in this interaction between mind and world, participating in the discursive activity that forms us as persons and then shaping our experiences through the choices we make and the interpretations available to us in the social locations we inhabit. Gillett likens the shaping of a human self to the weaving of a tapestry. And he insists that it would be as mistaken to say that the real self is the one degraded by Alzheimer's as to say that the real tapestry is the "mish-mash of disordered threads and fragments of intact weaving"[6] left after the moths have gotten at it.

I believe Gillett is quite right about this, and that the narrative of the "real self" is pernicious. If the daughter in my story were actively to endorse it (rather than tacitly presupposing it, which is all she's done with it at this point), she would, I submit, do serious damage to her mother's identity. And she would be damaging it at a time when it's already heavily under siege. One of the most devastating effects of Alzheimer's is to disorder the mental processes that are most intimately bound up with the self, at the same time as it robs people of the words that give the self much of its physical expression. Increasingly, the disease will disable the mother's capacity to contribute first-person stories to the narrative tissue that is her identity; increasingly, the task of identity maintenance will fall on those who care for her. If the daughter now characterizes her mother as essentially flint-hearted, she collaborates with the disease in the damage it inflicts.

And this in turn makes it harder for the daughter to hold her mother in personhood. Recall that I analyzed the practice of personhood into four components: our socially mediated psychological states, their physical depictions, others' recognition of these depictions, and the treatment based on that recognition. Alzheimer's has begun to fracture the mother's psychological states and has driven her to physical expressions — the razors in the drawer — that are appallingly off-kilter. Two of the four components of personhood are therefore already malfunctioning. Should the daughter fail to *recognize* who her mother is because she employs a faulty identity-constituting story, the third component misfires as well. And if she *responds* to her mother on the basis of that faulty story, she has nothing left with which to hold her mother in personhood.

THE COUNTERSTORY

The daughter needs a counterstory — an identity-constituting story that resists the ravages of her mother's disease and reidentifies her mother as a morally valuable person. The story should be true, as mending an identity requires *accuracy: t*he story must be a faithful likeness. But faithful to what? To the woman standing in the doorway in triumph as her daughter bleeds copiously into the drawer? No, for that isn't a story — it's just a snapshot of a particularly awful moment in this woman's life. A *story* depicts that life over time, selecting characteristic episodes, interpreting the life through what it selects, and connecting itself to a vast web of other stories that also contribute to its overall meaning. A *good* story does all these things *well.* The daughter's counterstory needs to be such a story, more dynamic than Gillett's tapestry but just as sweeping. And if it includes episodes of anger or betrayal, it had better also include the hand-drawn paper dolls the mother used to make for the daughter, the boxes of treats sent to her dorm room, the exquisite malapropisms the daughter finds so delightful. For the mother is surely all of that, and it's all of that to which the daughter must now respond. First, her hand needs a little medical attention. Then, her mother needs a little narrative attention. The relationship between mother and daughter has hit rock bottom, but with any luck, it will soon be on the mend.

NOTES

1. L. Wittgenstein, *Philosophical Investigations,* 3rd ed., trans. E. Anscombe (Oxford, U.K.: Blackwell, 2001), 152.

2. The author, writing as H.L. Nelson, *Identities Damaged, Narrative Repair* (Ithaca, N.Y.: Cornell University Press, 2001).

3. G. Chauncey, Jr., "From Sexual Inversion to Homosexuality: The Changing Medical Conceptualization of Female 'Deviance'," in *Passion and Power: Sexuality in History,* ed. K. Peiss and C. Simmons with R.A. Padgug (Philadelphia: Temple University Press, 1989).

4. G. Gillett, "You Always Were a Bastard," *Hastings Center Report* 32, no. 6 (2002): 23-8.

5. Ibid., 25.

6. Ibid., 27.

Imaginary Fathers: A Sentimental Perspective on the Question of Identifying Sperm Donors

Catherine Belling

> [Donor insemination] children may desire to know their biological parents. . . . But is this desire a rational one?
>
> — Michael D. Bayles, *Reproductive Ethics,* 1984

> Artificial impregnation . . . may at first shock the delicate sensibilities of the sentimental who consider that the source of the seed indicates the true father.
>
> — A.D. Hard, *Artificial Impregnation,* 1909

The traditional secrecy surrounding donor insemination is giving way to increased openness. Gamete recipients are increasingly encouraged to tell their children about the conditions of their conception.[1] Less clear, however, is what follows when the child wants to know more about the donor, who in the United States usually remains anonymous. How do children conceive of biological parents they can never meet? Is rationality the best criterion for evaluating the desire of offspring to track down their donors, or we do need to look at the question in a different way? The struggle over disclosure of donors' identity may be seen as a struggle between reason and imagination, or between information and narrative.

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The protagonist of Charles Dickens's fictional autobiography *Great Expectations* introduces himself to the reader by attempting a paternal genealogy. "I give Pirrip as my father's family name," Pip says, "on the authority of his tombstone."[2] This stone is a source of more than a name, however. He continues: "As I never saw my father or my mother . . . my first fancies regarding what they were like, were unreasonably derived from their tombstones. The shape of the letters on my father's gave me an odd idea that he was a square, stout, dark man, with curly black hair." In the absence of a living, corporeal, and visible father, Pip makes do with what concrete evidence is available: the words on the tombstone, and not their content, not the objective information they convey, but the impression of a kind of person evoked by the form and style of the letters. For Pip, "father" is the personification of the attributes of an inanimate object.

New legislation in the United Kingdom means that sperm donor anonymity is no longer an option. Children of men who donated after April 2005 will be given their genetic fathers' identifying information, including last known address, when they turn 18.[3] Sweden, Austria, Switzerland, and the Netherlands have similar laws.[4] In the United States there are no laws governing donors' anonymity, but individual facilities enable donors to allow themselves to be identified, and recipients to choose donors their children will be able to learn about and possibly meet later on. The Sperm Bank of California, for example, gives donors the option to be part of an Identity Release Program that provides identifying information to offspring who are 18 or older.[5] I suggest both that the identity-release model should be standard for sperm donation, even if this reduces the number of donors, and that perhaps information should be provided to children younger than 18. The legal ramifications of this second suggestion are probably prohibitive, but the age restriction raises significant questions about the offspring's need for, and right to, access to the biological father while still a child. The problem of nomenclature that arises when discussing donor insemination (DI) is revealing. Just as we are all, no matter how old we get, always our parents' children, so the offspring of donors are particularly marked by their special condition as the children of people who are not, in many senses of the word, parents. To this extent, perhaps "childishness" should be acknowledged as a problematic part of the identity of donor offspring. Perhaps the struggle so many children of donors experience as they search for their biological fathers is about reconciling the demands of the adult world for reasonableness with children's need to imagine who made them.

In *David Copperfield,* Dickens includes an additional dimension in the protagonist's fantasy about his father: "I was a posthumous child. My father's eyes had closed upon the light of this world six months when mine opened on it. There is something strange to me, even now, in the reflection that he never saw me; and something stranger yet in the shadowy remembrance that I have of my first childish associations with his white gravestone in the churchyard, and of the indefinable compassion I used to feel for it lying out alone there in the dark night. . . ."[6]

David feels an emotional connection to the object that stands for his absent father. He pities the gravestone. The adult David considers this compassion "strange" and his attachment "childish." To personify this inanimate object is irrational and sentimental, he implies, as it shows the unformed ideas and uncontrolled feelings of the immature. Similarly, the adult Pip in *Great Expectations* retrospectively describes the picture of his father that was derived from the tombstone as "unreasonable." Both of Dickens's adult protagonists see their father fantasies as childish and irrational, but both Pip and David grow up, in their respective novels, formed and flawed by the absence of a knowable biological father.

For the child of traditional, anonymous DI, the biological father is, of course, not necessarily dead. He may be — but not even this much can be known. This father has been almost completely erased. Traces, however, remain. He is signified in his child's imagination not by a gravestone, but by the material technology that surrounds conception, the signs of science: a labeled straw of frozen sperm, a laboratory.

One woman conceived by DI remembers wanting to know what a test tube looked like, since she was told as a child that she was conceived the way "cows [are] 'injected' with test tubes of sperm," leading her to imagine "a picture of grunting farm animals, test tubes, sperm, and me."[7] The instruments associated with the procedure come to stand metonymically for the father separated from his genetic material. An obstetrician can ask, "Is there a single person among us who would not be shocked to learn that his father was a sperm bank?"[8] Another states rather gratefully, "I wouldn't care to owe my origins to a liquid nitrogen tank."[9]

This dehumanization of the sperm donor is usually, for the adult participants in the

process, voluntary and deliberate. A 1951 account in the *Journal of the American Medical Association* of the psychological and social issues surrounding donor insemination focuses only on the "patient" — that is, the woman to be impregnated — and her husband. Neither donor nor offspring is mentioned. The authors warn that care must be taken in selecting patients because the procedure "involves the invasion of a woman's body for purposes of reproduction by a man not her husband, [and as such] it does overstep the bounds of the conventional social mores."[10] The authors reassure themselves, however, that well-chosen patients are unlikely to be offended by such irregularity: "Feminine psychology is not intrinsically antipathetic to donor insemination . . . indeed, some [patients] derive a peculiar satisfaction from the coldly scientific nature of the operation."[11] It seems likely that the physician carrying out the "operation" is also reassured by its scientific coldness. Medicalizing DI allowed it to be framed as a treatment for infertility rather than as the conception of a child. This effort to elide the donor is made explicit in the following admonition, given by a DI practitioner, in 1981. He expects recipients of donor sperm to play a careful mind game with themselves: "The myth of 'blood and flesh' has to be uprooted and a state of consciousness has to be achieved in which the donor, from the psychologic point of view, does not exist. Donor semen should then be regarded as 'material' from anonymous testes, the donor actually being a 'nonperson.' "[12] The biological father, then, was no more than a "myth," a fantasy easily expunged from the minds of any healthy, newly expectant couple. Once DI is acknowledged, however, the blood and flesh person, both real and missing, is hard to eradicate.

The donor is frequently reduced to the act by which he is defined, an act at once clinical and embarrassing. One adult DI offspring describes the way her own children imagine their genetic grandfather: "They talk about my donor father with irreverence . . . as to them he is just some old bloke whose only known attribute is an ability to masturbate to order. . . . He is perceived as a figure of fun and ridicule rather than as a real person. . . ."[13] The sexual aspect of sperm donation becomes the only knowable aspect of the donor, and anonymity increases the sense of it as a shameful sexuality.

A blank screen on which fantasies can be projected, the biological father is also often idealized. Donor offspring talk in interviews about adolescent fantasies of a "real dad" who is a famous celebrity or a Nobel scientist. A picture book written to explain DI to children carefully affirms that the social father is the only "dad" a child has. "Will I ever meet the donor?" asks the first-person narrator, a little boy conceived by DI.[14] "Dad says probably not. It usually doesn't work that way. It would be hard to find him because we don't really know whose sperm it was. . . . I got his genes and that's an important part of who I am, but he's not my dad." The language itself reveals the difficulty of articulating this nonperson. The donor is "him," but a "him" who doesn't exist, because the only aspect of him relevant to the boy is genetic material, "sperm" and "genes" that are human but personless. The donor pronoun "he" has no precisely identifiable antecedent. At the same time, however, an illustration in the book visually represents this permanently unknowable man. The boy is shown playing ball with his mother and social father, and the donor is drawn in the air above them, a fantasy portrait. He physically resembles the child and the mother — all three are blonde, unlike the dark-haired "dad." The donor hovers above the social family like a kind of guardian angel, or the desirable apex of a mystical parental trinity. The book cannot maintain the delicate balance between acknowledging DI conception to a child and eliding the biological father as a person. The author and illustrator cannot be wholly honest in their depiction of the anonymous sperm donor, who is necessarily and permanently invisible.

Uprooting the myth of the flesh and blood donor and replacing it with an abstraction is meant to relieve the anxiety of the physician

and of the recipient of the donation. But what about the human being who is the result of the procedure? Unfortunately, this dehumanization has significant implications for the child. One man conceived by DI describes the effect of this abstracting on his own sense of self: "As a person conceived through donor insemination . . . I have an additional question besides 'who' I am. How do I describe *what* I am? There are no satisfactory labels to describe people like me . . . we became 'donor offspring,' and finally products of therapeutic gamete donation.' The media have facetiously labeled us 'test-tube babies,' 'kidsicles,' or 'spermees.' All these labels have served to dehumanize us, to make our human condition even more abstract."[15] [Emphasis added.] Eliding the donor also emphasizes the technological creation of the child: "Doctors are like fertility gods who view us purely as abstract commodities to assist [those] who are unable to have children. They rarely look beyond the microscopic view of gametes, zygotes, blastocysts, embryos, or the ultrasonic images of fetuses, to see the human face of the people they create."[16] The effacement of the donor leads to offspring who feel faceless. As another says: "I felt like I was the product of some science experiment — a freak."[17]

M.D. Bayles, in his 1984 book, *Reproductive Ethics,* seems puzzled by those who question the value of donor anonymity. He appeals to reason — or rather he assumes that rationality is the only criterion that counts in evaluating the desire to know the genetic father: "children may desire to know their biological parents. . . . But is this desire a rational one? Finding out who one's genetic father is means learning his personal identity. Why would that be important? The mere knowledge does not entitle one to inheritance, other financial support, or love. What one's genetic father is or was — criminal, actor, politician, industrial worker — does not, except for certain genetic traits, determine or indicate what type of person one is or is going to become."[18] By reducing the value of knowing one's biological father to its instrumental uses, Bayles avoids more complex existential motivations. He dismisses most interest in finding parents as "culturally conditioned (and exaggerated by the media)," but he does accept one good reason for learning more about biological paternity: "the possibility of inheriting a genetic disease. Such a concern is certainly rational, but fulfilling it does not require learning the donor's identity." He concludes that "Overall it appears that retaining records of the personal identity of donors . . . is not worth the effort."[19]

Providing abstract, non-identifying information about the donor, while certainly better than nothing, does not address this sense of freakishness. Just as David Copperfield and Pip imagine their dead fathers less according to the names and dates on their gravestones than according to the concrete reality of the stones themselves, and as the children's book's author cannot resist including a picture of the donor's fantasy face, so donor offspring can't help but imagine their biological fathers as something more than collections of facts.

The limitations of this view reflect a dichotomy that seems to underlie the bioethical debates about whether or not it is right to include the future disclosure of identity as a requirement of gamete donation. I want to suggest that an offspring's "irrational" need to encounter the donor as a flesh and blood person is a significant need, and should probably be a legal right. Dismissing this need because it seems irrational — or sentimental or childish — reveals a limited view of the role of genetic parenthood in the identity of offspring. Identity is not only about information; it is also, fundamentally, about *narrative.*

It is not uncommon for sons and daughters of anonymous sperm donors to describe themselves in bibliographic terms, as feeling like a book without an author, or as one missing the first chapter. Much work has been done on the narrative nature of human identity; a significant aspect of this is the place of parentage and heritage in the individual's life story. Identity is historical, extending over time beyond birth and death, part of a collective narrative rooted in heredity biology.

This fact reverberates through the great literary Rorschach of reproductive technology,

Mary Shelley's *Frankenstein,* to which I returned after reading the words of one writer on a donor offspring internet group: "I am a 19 [year old] female who is searching for her father. . . . My entire life I felt like there was a piece of me missing. . . . I was 'put together' in Vancouver. . . . I believe the month was January or February. The man who donated was a medical student. . . ."[20]

"I was put together." She views her conception as the mechanical compilation of fragments. The "missing piece" in her identity should be a central character in her autobiography, one who partook in an irreversible founding act of creation. This sense of loss exceeds the "genealogical bewilderment" often associated with adoption.[21] The donor is needed not only to provide information about ancestry, but to act as evidence of humanity. In her guide to donor insemination, Elizabeth Noble provides a list of things donor offspring wonder about. It includes: "I wonder what it feels like to have been naturally created?"[22] This is an extraordinary concern. The 19-year-old does not imagine herself born, or conceived, just assembled by medical science.

The medicalized secrecy model produces a sense of shameful abnormality that is not at all inherent in the process of DI conception itself. This imposition of shame on the meaning of an essentially beneficent process is what causes the creature in *Frankenstein* to become monstrous. Dr. Victor Frankenstein begins his project filled with scientific idealism. By harnessing the secret of life, he will outwit disease and death. He carefully selects the best parts when putting together his creature, but then it comes to life and it looks at him. Suddenly he is filled with horror and remorse, and he disowns the creature, saying, "I was unable to endure the aspect of the being I had created."[23] He flees, hoping perhaps that by escaping the creature's need for him he will escape accountability for the creation itself. Frankenstein's offspring is made monstrous not by his unconventional conception, but by the fact that his creator sees the end of his project — and of his responsibility — as the production of offspring. This is not unlike solving the problem of childlessness simply by putting together a pregnancy.

The anonymity of donors fosters the pretence that DI is a medical procedure that is performed on a single patient, the woman who becomes the mother, and that the doctor alone "cures" her childlessness. Historically, the secrecy surrounding DI was linked to the extreme informality by which donors were selected: in 1979, it was found that "62 percent of DI practitioners used medical students" as donors.[24] Both convenience and a eugenic sense that, as one doctor put it, "physicians and true scientists make ideal donors," produced the dual role of medical professionals as both facilitators of the conception process, and as genetic fathers.[25]

One of the medical students present at the first recorded medical donor insemination, carried out by William Pancoast on an anesthetized woman (in Philadelphia in 1884), published an article in 1909 on the eugenic value of "artificial impregnation." In it he uses an astonishing analogy to try and demonstrate that biological paternity may easily be separated from parenting: "The man who thrusts his nose into a beautiful blossom to surfeit his sense of smell on the sweet perfume, is merely breathing the lustful odor from the sexual organ of the plant; and if his nose displaces some of the pollen, he may be the father of the next flower. If the honey bee does the work, it might be called the father."[26]

What this shows, as well as the author's evident preference for the coldly scientific over that which might produce "lustful odors," is a misattribution of biological paternity. If the flower's father is the nose or the bee, then, by this analogy, in donor insemination, the offspring's father is the one who transfers the "pollen" to the mother: not the donor, in other words, but the doctor. This Promethean view of physician-inseminator-creator is rationally and biologically flawed — unless we change radically our definition of the word "father" — but it reveals perhaps a not-wholly-conscious reason for medicine's tenacious denial of long-term connections between donor and offspring. The responsi-

bility for so many new lives had to be carefully delimited.

This same medical student himself admits, in a reply to the letters his article provoked, that "I would not wish to own a child that was bred with a hard-rubber syringe. And I do not care to think that my child bears toward the millennium no traces of his father's personality."[27]

One possible advantage of removing the option of donors' anonymity is that different people may choose to donate gametes. In Sweden, where donors' anonymity has not been the norm since 1985, the demographics of donors have changed. Fewer medical students donate sperm, and more older, married men have taken their place.[28] Even though the sperm supply would probably be reduced, at least temporarily, this change might in the long term be better for those who are conceived with the sperm of men who may recognize the extended implications of their gift.

As well as fewer donors, those who support continued anonymity fear that offspring will make unreasonable claims on their donors. In *Frankenstein,* the creature tracks down Victor Frankenstein and confronts him, saying: "You, my creator, detest and spurn me, thy creature, to whom thou art bound by ties only dissoluble by the annihilation of one of us. . . . How dare you sport thus with life? Do your duty towards me, and I will do mine towards you and the rest of mankind."[29] Frankenstein, as scientist-practitioner, and as father-creator, has a duty to fulfill. Daniel Callahan, in his discussion of bioethics and fatherhood, distilled the claim on which, in his view, unavoidable paternal obligation rests: "Because of you I exist in this world."[30]

The creature makes the same claim on Frankenstein's attention. He does not want money or even affection from his creator. He wants two things. One is unique to his uniquely man-made origin: a second act of artificial reproduction, making another who is like himself, in order, he says, to "become linked to the chain of existence and events from which I am now excluded."[31] He needs a community in which to embed his story. Second, and also to end his isolation, he wants his own life narrative to be acknowledged by his parent. At first, Frankenstein refuses to listen to the creature's story. What he says seems to me, in this context, the most telling line in the whole novel: "I will not hear you," says Dr. Frankenstein to his offspring. "There can be no community between you and me."[32]

Community can mean many things. In Shelley's novel, it may be as limited as a mutual gaze of recognition and assent. For many DI offspring, it may be no more — or less — than this, too. The creature makes Frankenstein listen to him, and, on hearing his autobiography, Frankenstein begins to recognize the person he has brought to being. He admits, "For the first time . . . I felt what the duties of a creator towards his creature were."[33]

I do not meant to suggest that DI is monstrous unless donors effectively become social fathers to all offspring. I am arguing, however, that the child's sense of incompleteness and abnormality is directly linked to a narrative rift between progenitor and protagonist. Knowing one's genetic parentage is as much biographical as it is biological. Or, to be more precise, and admittedly more essentialist: for most people, especially those denied knowledge of a progenitor, biological identity and biographical identity cannot be separated.

On an internet website, one can buy child-size tee-shirts and bibs bearing the words, "My Daddy's name is Donor."[34] Parents who put these on their children are probably making a brave attempt to diminish the stigma of DI. Their ventriloquism exposes, however, the same curious generational shortsightedness that characterized the historical origins of artificial insemination by donor, when seen as a cure for adults' infertility rather than as an experimental new form of reproduction that would produce a generation of children with unprecedentedly asexual origins. Much like the Dickensian tombstones, these post-modern clothes are inscribed inanimate objects that represent unknowable people. Unlike the tombstones, they represent not the child's imaginings, but the parents', and while the

clothing acknowledges as well as trivializes the place of the "Daddy's name" in the child's identity, the joke marks its unconsenting wearer with loss, rather than with defiance. While concealing DI assumes that a child can be conceived in a narrative vacuum and then slotted into a pre-existing master narrative about the "normal" nuclear family, exposing DI without providing access to the identity of the donor removes the master narrative without giving the child enough material to construct a new narrative.

Maggie Kirkman, in her study of the stories parents tell their DI offspring, states, "Parents are the narrators from whose stories their children begin to construct their own narrative identities."[35] She points out that the social parents of DI offspring are "in the vanguard of the challenge to normative narratives of conception," for they are required to tell brand-new family stories. In the context of these new stories, Kirkman asserts the value of offsprings' thinking of the donor as a person, even if they cannot know his identity. I want to suggest that the only real way to have a sense of the donor as a person — a particular person, rather than a fantasy — is by knowing his identity.

The medical student who was involved in the first acknowledged act of human artificial insemination by a donor ascribes an additional value to DI. He explains the eugenic value of allowing human reason to assist nature in avoiding the hereditary disadvantages of human love. "From a nature point of view the idea of artificial impregnation offers valuable advantages. The mating of human beings must, from the nature of things, be a matter of *sentiment* alone. Persons of the worst possible promise of good and healthy offspring are being lawfully united in marriage every day. . . . Artificial impregnation by carefully selected seed, alone will solve the problem [although] it may at first shock the delicate sensibilities of the sentimental."[36]

Perhaps the very pragmatic project of achieving conception with donor gametes — like the broader and equally pragmatic project of medicine itself — has for too long underrated the "sentimental," the emotional, the irrational. It may well, by some criteria, be unreasonable to want to know one's biological father, but, if so, this should serve less as a reason for concealing donors' identity than as a guide to rethinking the extent to which we rely on rationality alone in making policy that will govern the identity of new generations of children, who surely deserve to know the person who remains — no matter how happy and sufficient the child's social family — a particular person of immense imaginative significance. This flesh-and-blood person cannot be "uprooted," and will never be reducible simply to information.

NOTES

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The first epigraph in this article is from M.D. Bayles, *Reproductive Ethics* (Englewood Cliffs, N.J.: Prentice-Hall, 1984), 20. The second is from A.D. Hard, "Artificial Impregnation," *Medical World* 27 (April 1909): 163.

1. See, for instance, R. Rowland, "The Social and Psychological Consequences of Secrecy in Artificial Insemination by Donor (AID) Programmes," *Social Science and Medicine* 21, no. 4 (1985): 391-6; C. Lorbach, ed., *Let the Offspring Speak: Discussions on Donor Conception* (New South Wales, Australia: Donor Conception Support Group of Australia, 1997); A. Rumball and V. Adair, "Telling the Story: Parents' Scripts for Donor Offspring," *Human Reproduction* 14, no. 5 (1999): 1392-9; A.J. Turner and A. Coyle, "What Does it Mean to be a Donor Offspring?" *Human Reproduction* 15, no. 9 (2000): 2041-51; A. McWhinnie, "Gamete Donation and Anonymity," *Human Reproduction* 16, no. 5 (2001): 807-17.

2. C. Dickens, *Great Expectations,* ed. E. Rosenberg (New York: Norton, 1999), 9.

3. See UK Department of Health policy,

http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/AssistedConception.

4. L. Frith, "Gamete Donation and Anonymity: The Ethical and Legal Debate," *Human Reproduction* 16 (2001): 818-24.

5. J.E. Scheib, M. Riordan, and S. Rubin, "Adolescents with Open-Identity Sperm Donors: Reports from 12-17 Year Olds," *Human Reproduction* 20, no. 1 (2005): 239-52; The Sperm Bank of California, *http://www.thespermbankofca.org/idrelease.html.*

6. C. Dickens, *David Copperfield,* ed. G.H. Ford (Boston: Houghton Mifflin, 1958), 10.

7. R. Snowden and G.D. Mitchell, *The Artificial Family: A Consideration of Artificial Insemination by Donor* (London: George Allen and Unwin, 1981), 88.

8. E. Noble, *Having your Baby by Donor Insemination: A Complete Resource Guide* (Boston: Houghton Mifflin, 1987), 329.

9. Ibid.

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11. Ibid., 1064.

12. M. Glezerman and R. White, "270 Cases of Artificial Donor Insemination: Management and Results," *Fertility and Sterility* 3, no. 2 (1981): 180-7.

13. C. Lorbach, *Experiences of Donor Conception: Parents, Offspring, and Donors through the Years* (London: Jessica Kingsley Publishers, 2003), 172.

14. J.T. Schnitter, *Let Me Explain: A Story about Donor Insemination* (Indianapolis, Ind.: Perspectives Press, 1995), 25.

15. B. Cordray, "Reproductive Technologies: Emotional Adoption," 2000, *http://www.americanadoptioncongress.org/articles-archives/reproductive-tech.htm*, accessed 20 June 2005.

16. See note 13 above, p. 167.

17. A.J. Turner and A. Coyle, "What Does It Mean to be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counseling and Therapy," *Human Reproduction* 15 (2000): 2043.

18. M.D. Bayles, *Reproductive Ethics* (Englewood Cliffs, N.J.: Prentice Hall, 1984), 20.

19. Ibid., 21.

20. "I am searching for my father," online posting, 3 April 2000, Yahoo! Health E-Groups: Sperm Donors, *http://groups. yahoo.com/group/SpermDonors/message/50?source=1,* accessed 13 June 2005.

21. H. Sants, "Genealogical Bewilderment in Children with Substitute Parents," *British Journal of Medical Psychology* 37 (1964): 133-41.

22. See note 8 above, p. 306.

23. M. Shelley, *Frankenstein* (Harmondsworth, London: Penguin Books, 1985), 105.

24. M. Curie-Cohen, L. Luttrell, and S. Shapiro, "Current Practice of Artificial Insemination by Donor in the USA," *New England Journal of Medicine* 300, no. 11 (1979): 585-90, 587.

25. See George Annas's discussion of the eugenic implications of physician-selected donors in his early alert that the interests of the offspring should take precedence over concern for the donor. G.J. Annas, "Fathers Anonymous: Beyond the Best Interests of the Sperm Donor," *Family Law Quarterly* 14, no. 1 (1981): 1-13, 6.

26. A.D. Hard, "Artificial Impregnation," *Medical World* 27 (April 1909): 163.

27. A.D. Hard, "Artificial Impregnation" letter to the editor, *Medical World* 27 (July 1909): 306.

28. L. Beecham, "B[ritish] M[edical] A[ssociation] Annual Representative Meeting: Sperm Donors Should Be Guaranteed Anonymity," *British Medical Journal* 329 (2004): 72.

29. See note 23 above, p. 145.

30. D. Callahan, "Bioethics and Fatherhood," *Utah Law Review* 3 (1992): 735-46, 739.

31. See note 25 above, pp. 192-3.

32. Ibid., 146.

33. Ibid., 147.

34. E. Marquardt, "Kids Need a Real Past," *Chicago Tribune* online edition, 15 May 2005, *http://www.chicagotribune.com/news/opinion/chi-0505140249may15,0,7939985.story?coll=chi-newsopinion perspective-hed,* accessed 19 May 2005.

35. M. Kirkman, "Parents' Contributions to the Narrative Identity of Offspring of Donor-Assisted Conception," *Social Science and Medicine* 57, no. 11 (2003): 2229-42.

36. See note 26 above.

Like a Motherless Child: Fetal Eggs and Families

Laura Purdy

Although using fetal eggs or ovaries from aborted fetuses could help some women become pregnant, research directed toward this goal has raised a storm of controversy.[1] Yet within the overall context of promoting desired reproduction, making fetal materials available could have significant benefits. In particular, it could much reduce the burden on adult women of providing eggs for assisted reproduction. So this potential technology should be investigated for its own sake, and also because such inquiry might help us think through other possible future technologies.

Some will reject the use of fetal reproductive materials because of concerns about fetus' moral status, because of the alleged dehumanizing "manufacture" of children,[2] dismay at the instrumental use of female fetuses, or using genetic material that has not been subjected to evolutionary pressures.[3]

Additional objections may arise from concerns about family relationships. Specifically, using fetal eggs or ovaries[4] risks psychological harm to children by creating motherless children, makes fetuses parents without their consent, and distorts family relationships. This article will concentrate on these family issues.

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BACKGROUND ISSUES

Why is there a need for donor eggs at all? Some infertile women, especially older ones, are unlikely to conceive without them. Also, some women desire donor materials to protect their children from serious genetic diseases they carry. In addition, their use could help single men, older women, and same-sex couples have children.

Although some "spare" eggs are now available, they are in short supply. Fetal materials could be made available for general "adoption."[5] And, they could either be donated, or offered for sale. However, issues raised by paid donation (commercialization of body parts[6] and the possibility of pregnancies undertaken to sell fetal reproductive materials) will be set aside for another day.

MOTHERLESS CHILDREN?

A key objection to the use of fetal eggs is possible psychological and emotional risk to resulting children. One typical worry is that "these children could be treated as lepers or pariahs," and, quite reasonably, it is argued

that careful debate should precede any adoption of this technology.[7] In response, Susan Golombek suggests that "it is not inconceivable that children who have been born from the eggs of a dead donor could cope with that information. Adopted children have to assimilate that they were born to someone who then gave them away."[8]

Although Golombek's comment is an appropriate stopper to those who imagine only gloom and doom arising from reproductive innovations, the logical possibility that children will cope is clearly insufficient grounds for going forward. Recent research indicates that children born of assisted reproduction are doing well psychologically, and that what wreaks emotional havoc is a lack of trust generated by inappropriate secrecy about how a child was created, not the technical details of conception.[9]

While this may be true in general, there are — of course — no children yet born of this particular technology to study. So, we need to create a picture of how it might work from bits and pieces of other situations.

First, there have always been children whose biological or social mothers were not the same woman, as many women have died giving birth, or while their children were very young. Some of those children were mothered by stepmothers or female relatives. Others went to orphanages, and it may be that their experience might have had something in common with that of children born of fetal eggs. After all, for much of human history, few images and little or no genetically based health information would be available to their children. Still, those who remained close to home probably heard stories about their biological mothers, and could ask questions about them, unlike those in orphanages.

Another possibly relevant kind of case is postmortem pregnancy (PMP), where children are gestated for some period and then birthed by women who have died while pregnant. Although these children will likely see photographs, receive some health information, and therefore get some idea of their biological mothers, the "yuck" factor here is at least as significant as for children from fetal eggs. Many, especially feminists, are appalled by PMP, in part because of the coldly instrumental use of women's bodies, especially when they have not consented to their body's use to birth a child they had hoped and expected to mother. The media tend, nonetheless, to portray these cases favorably, modeling the attitude of "giving the kid a chance." It may be that the same would be true of the use of fetal eggs, despite consistently negative public opinion now. So this case may enlighten, despite the fact that the genetic mothers of children from fetal eggs never were "persons," and there is nothing to know about them.

Opponents of fetal egg use believe this lack would be devastating to a child's sense of identity, even though the situation doesn't seem all that different from egg donation in general. But what role does knowledge of your genetic forebears play in identity, really? Even a cursory look at this large issue casts doubt on the common view that children born of fetal eggs would necessarily be deprived of some important value.

We know that many adopted children urgently desire to know their biological parents. John Harris observes that knowledge about one's genetic roots could be of interest for two quite different reasons: "One is curiosity about who the individuals are or were whose genes I share what their stories were, how I came to be conceived, and so on. The second is concern about genetic traits that I may have inherited."[10] He rightly concludes that knowledge about medical matters is important, but the costs of recognizing a right to know one's genetic forebears could be "alarming," in part because significant numbers of children turn out not to be genetically related to their fathers. There may be good medical reasons in some cases for revealing this fact, but routine disclosure would "threaten the peace and harmony of very many families to no obvious purpose."[11] I concur, given the prevalence of domestic violence against women. In any case, this may become far less important as our ability to do genetic tests on individuals themselves lessens the need for genetic histories.

Does Harris's use of "curiosity" inappropriately ignore "identity"? And is the sometimes desperate search for biological connections mere curiosity, or is something more at stake? The most extreme versions of evolutionary psychology hold that our natures — personality, attitudes, interests — are largely genetically determined. Genetics obviously influence our development in important ways, but this claim is still questionable. Even if it were true, what follows? Suppose I learn that my mother (and her mother) had, like me, a violent temper? This approach seems to constitute an infinite explanatory regress — explaining nothing much about me, as an independent individual. In any case, there are competing explanations: I could have acquired my temper by observing my mother's, and concluding that such behavior is okay, just as did my adopted sister. . . .

Moreover, siblings are often, of course, quite different, and families routinely liken them to older family members. But, going back in time, the number of ancestors multiplies rapidly, and the more ancestors there are, the easier it is to find people like oneself. In addition, it doesn't take many generations before we start encountering individuals with no more alleles in common with us than with any randomly selected human being.[12]

Plus, the world is immensely different than it was even a century ago. So, again, unless we are extreme biological determinists, it's not obvious what we know about ourselves by knowing more about our great-great-grandparents, great-grandparents or even grandparents, interesting as that information might be. The same is true of individuals who are adopted soon after birth into vastly different circumstances. Given all of these considerations, it is more plausible to seek our identities by exploring and tidying up our own attitudes, principles, and values, not simply seeking repetitions from past generations.

Why do we want to know more about our ancestors? And why is there ever-more emphasis on ethnicity and genetics? No doubt social science research on this issue would be informative. In the United States, it seems reasonable to suppose that it is at least, in part, a response to heavy-handed attempts to impose melting pot metaphors that ignore immigrants' ethnicity, language, or race. But one cannot discount ethnocentrism and racism either, and, more recently, the political and commercial possibilities that are inherent in highlighting biological links rather than environmental influences, that emphasize differences rather than commonalities.

How then might these issues play out in families in which children are born of fetal eggs? Answering this question requires us to contemplate the nature of parenthood, and the meaning of words like "mother" and "father." Beguiled by cultural ideals, we tend to forget that their meanings have always been less stable than we now sometimes imagine,[13] yet recent reproductive developments have truly shattered anything like conventional understandings of these terms. First, sperm donation split genetic and social fatherhood. Then, contract pregnancy ("surrogacy") forced us to distinguish between genetic mothers (supplying eggs), gestating mothers (carrying children), and social mothers (rearing them). Now we face still finer distinctions between women who supply eggs, women (or, potentially, men) who supply nuclear DNA, and women who supply mitochondrial DNA, and no doubt still further distinctions will be required in the future. Gay and lesbian families and single parents also force us to think about the prerequisites for social parenthood — whether, for example, a gay couple has one "mothering person"[14] or two, two fathers, or something in between.

These developments must themselves be placed in the context of the thoroughly contested — and politicized — concepts of parenthood and family. The "modern" family of sociological theory and historical convention has not reflected the reality of contemporary families for quite awhile.[15] The "modern" family has been overwhelmed by single-parent and blended families, childless couples (heterosexual and homosexual), extended working-class families,[16] and community (rather than genetically based) support groups among

African-Americans.[17] Yet old assumptions and ideals — which never made sense in the past and certainly don't now, such as the supreme value of genetically related children — continue to dominate reproductive discourse.

As the socially constructed character of parenthood has become more apparent with the proliferation of new family forms, other possible candidates for grounding it have emerged. G. Fuscaldo, for example, suggests four possible criteria for parenthood: biology, convention, cause, and children's welfare.[18] He finds serious problems with each, and concludes, "perhaps it is time to relinquish the view that genetic, gestational, and social parenthood are competing positions. We could align the social facts with an acceptance of the new scientific facts — that a child can have many different parents."[19] Thomas Murray and G. Kaebnick go one step further and argue that mutuality (between parent and child) is central to parenthood, and thus childrearing is what matters most.[20]

Although these matters obviously require further thought, we urgently require guidance now, as new technologies and practices rapidly deconstruct the family. Fuscaldo, and Murray and Kaebnick point the way toward a plausible resolution of contemporary struggles over the nature of parenthood. Perhaps we should be conceiving of parenthood as shifting configurations of features and relationships that are now being considered in the literature, such as the intention to create a child, a genetic or other biological connection, a rearing role, the welfare of the child, and so on. These elements will, like Wittgensteinian family resemblances, reappear in various patterns, such that no particular feature is necessary or sufficient.[21] So sources of eggs, like fetuses, needn't be recognized as "mothers" at all, and rearing mothers can be "real" mothers, even without any genetic contribution

Useful as this framework might be for definitional purposes, moral argumentation still recognizes that some mother-making properties have greater moral weight than others. Thus Andrea Bonnicksen contends, "to speak of fetal 'motherhood' is to make shallow and undermine the meaning of 'mother'."[22] Perhaps she means to assert that there is some essence of motherhood, but her claim might instead imply that there is a moral ranking of mother-making properties, in which a decision must be made about *who* a particular child's mother is. These considerations help circumvent objections to fetal egg use because they make fetuses parents without their consent, and the use of fetal eggs within families is bound to confuse family relationships.[23]

If providing eggs doesn't necessarily make one a mother, then fetuses are not parents, and so consent is moot. Nor, if full parenthood requires no genetic connection, would the use of fetal eggs confuse family relationships: why wouldn't rearing women be mothers, their own mothers grandmothers, and so on? Even if one insisted on a role for genetics in family relationships, the moral primacy of rearing could be conceded, such that mothers of rearing women could still quite reasonably be "grandma," despite their somewhat more remote genetic relationship.

Sadly, discourse about the family is now so politicized that considerations such as these are getting lost in the shuffle, and promoting the use of fetal eggs might, after all, undermine the principle that individuals should not be made parents without their consent. Recognition of a right to control one's reproductive life is already spotty, and further erosion would constitute a critical loss of autonomy and welfare.

CONCLUSION

Objections to using fetal eggs that are based on concerns about the family thus rest on fictions about families, and are therefore far less compelling than they might at first appear. Still, harm to children cannot be ruled out. Some believe that this potential needn't be an obstacle unless any resulting children would be so miserable they wished they'd never been born.[24] Others would resist the creation of any child who could be expected to suffer any harm. Neither position is all that

appealing. The first espouses a moral minimalism that condones much unnecessary suffering; the second would prohibit far too many births. Clearly, we need to carve out some middle ground.[25]

To avoid the charge that bioethics simply puts out fires instead of preventing them, it is essential to question the most basic assumptions about reproduction. For without the intense pronatalism that lends such urgency to the quest for motherhood (or fatherhood) at almost any cost — and, in family donation, the geneticism that recruits women willing to become pregnant — one can hardly imagine anyone suggesting the use of fetal eggs.[26] The inability to have children now causes enormous suffering. But many, especially those who recognize pronatalism and geneticism as socially constructed desires, are inclined to dismiss that suffering, given that large numbers of children are in need of good homes and that North American children use a disproportionate share of world resources. Adoption — already second-best in many eyes — is more ethically problematic than one might think. Thus it is unfair to finger the infertile when the fertile could just as well adopt, too.[27]

Moreover, focusing on the infertile once again shifts attention from the underlying pronatalism and geneticism that drive risky new approaches to have children (and that create so many other harmful consequences). Bioethics must make a focus on the nature and consequences of pronatalism and geneticism a priority. Otherwise, society will continue to chase ever more invasive and potentially problematic technologies designed to fulfill their imperatives.

Equally worrisome is the increasing commercialization of healthcare. Even if society rejects the commodification of fetal eggs, these eggs could still form the basis for lucrative clinical services that focus more on the bottom line than on patients' welfare.

Both of these factors — fulfilling the desires of those driven by pronatalism and geneticism to accept almost any proposed remedy, and the profit motive — already diminish the quality of reproductive care in the U.S.[28] By themselves, they do not constitute a decisive case against using fetal eggs (for they would justify the prohibition of other reproductive technologies as well), but they could tip the balance against the technology, were other objections shown to be sound.

ACKNOWLEDGMENT

Many thanks to biology professor Candace Collmer for her careful reading and thoughtful comments on this article.

NOTES

1. Techniques for using fetal materials are still under development. However, it is important to evaluate developing technologies before they become available.

2. L. Kass, "Making Babies: The New Biology and the 'Old' Morality," in *The Future is Now: America Confronts the New Genetics,* ed. W. Kristol and E. Cohen (Lanham, Md.: Rowman and Littlefield, 2002), 54-60, 55.

3. J. Berkowitz, "Mummy Was a Fetus: Motherhood and Fetal Ovarian Transplantation," *Journal of Medical Ethics* 21, no. 5 (1995): 298-304, 298-9. Berkowitz believes there is no reason for this concern, and suggests that it might be beneficial to use eggs that have not been subjected to the environmental assaults that eggs maturing in grown women experience (see 298-99).

4. From here on out I will simply use "fetal eggs" to cover all uses of fetal materials.

5. For some concerns about "altruistic" reproductive services offered within families, see U. Narayan, "The 'Gift' of a Child: Commercial Surrogacy, Gift Surrogacy, and Motherhood," in *Expecting Trouble: Surrogacy, Fetal Abuse & New Reproductive Technologies,* ed. P. Boling (Boulder, Colo.: Westview Press, 1995), 177-201.

6. For a recent discussion of paid donation, see, for example, C. Cohen, "Selling Bits and Pieces of Humans to Make Babies: The Gift of the Magi Revisited," *Journal of Medicine and Philosophy* 24, no. 3 (1999): 288-306.

7. L. Dillner, "Use of Fetal Eggs for Infertility Treatment is Banned," *British Medical Journal* 309, no. 6950 (30 July 1994): 289.

8. Ibid., 289.

9. See note 3 above, pp. 300-1; see also, S. Golombek, "Parenting and Secrecy Issues Related to Children of Assisted Reproduction," *Journal of Assisted Reproduction and Genetics* 14, no. 7 (1997): 375-7.

10. J. Harris, "Assisted Reproductive Technological Blunders (ARTBs)," *Journal of Medical Ethics* 29, no. 4 (August 2003): 205-6.

11. Ibid., 206.

12. Assuming Harris is correct (that mothers share 99.95% of their alleles with their daughters, and that 99.90% of alleles are shared between any two randomly chosen humans), after fewer than five generations, on average, one would share the same amount of genetic material with her ancestor as with a perfect stranger. Jennifer Robbins, Assistant Professor of Biology, St. Mary's College of California, 31 July 2004, personal communication with the author.

13. See H.L. Nelson and J.L. Nelson, *Encyclopedia of Bioethics,* 2nd ed., p. 4.

14. See V. Held, "Non-Contractual Society," *Science, Morality, and Feminist Theory,* ed. M. Hanen and K. Nielsen, *Canadian Journal of Philosophy,* suppl. vol. 13 (1987): 111-37.

15. J. Stacey, "Backward toward the Postmodern Family: Reflections on Gender, Kinship, and Class in Silicon Valley," in *Rethinking the Family: Some Feminist Questions,* ed. B. Thorne and M. Yalom (Boston: North Eastern University Press, 1992), 91-118, 92.

16. Ibid.

17. Ibid.; R. Rapp, "Family and Class in Contemporary America: Notes toward an Understanding of Ideology," in *Rethinking the Family,* ibid., 49-70; D. Roberts, "The Genetic Tie," *University of Chicago Law Review* 62, no. 1 (Winter 1995): 209-71.

18. G. Fuscaldo, "What Makes a Parent? It's Not Black or White," *Journal of Medical Ethics* 29, no. 2 (April 2003): 66-7, 66.

19. Ibid., p. 66.

20. T.H. Murray and G. E. Kaebnick, "Genetic Ties and Genetic Mixups," *Journal of Medical Ethics* 29, no. 2 (April 2003): 68-9, 68.

21.Wittgenstein recognized that in many cases seeking a word's essential core meaning will not help us understand the way it is used. Instead, he proposed an analogy with "family resemblances" such that is may be appropriately applied to a set of cases sharing no such single characteristic. A. Biletzki and A. Matar, "Ludwig Wittgenstein," *The Stanford Encyclopedia of Philosophy (Summer 2005 Edition)*, edited by E.N. Zalta, *http://plato.stanford.edu/archives/sum2005/entries/wittgenstein/*

22. A.L. Bonnicksen, "Fetal Motherhood: Toward a Compulsion to Generate Lives?" *Cambridge Quarterly of Healthcare Ethics* 6 (1997): 19-30.

23. Ibid., p. 24.

24. See Parfit, who regrets reaching this conclusion, and Robertson, who thinks it is reasonable. D. Parfit, *Reasons and Persons* (Oxford: Oxford University Press, 1985) and J. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton, N.J.: Princeton University Press, 1994): 75-6. For discussion of Robertson's inconsistencies on this issue, see L.M. Purdy, "Children of Choice: Whose Children? At What Cost?" *Washington and Lee Law Review* 52, no. 1 (1995): 197-224.

25. There is now a substantial literature on this topic; see e.g., D. Davis, "Genetic Dilemmas and the Child's Right to an Open Future," *Hastings Center Report* 27, no. 2 (1997): 7-15; L.M. Purdy, "Loving Future People," *Reproducing Persons: Issues in Feminist Bioethics* (Ithaca, N.Y.: Cornell University Press, 1996), 50-74; C.B. Cohen, " 'Give Me Children or I Shall Die!' New Reproductive Technologies and Harm to Children," *Hastings Center Report* 26, no. 2 (1996): 19-27; and B. Steinbock and R. McClamrock, "When is Birth Unfair to the Child?" *Hastings Center Report* 24, no. 6 (November-December 1994): 15-21.

26. For a recent treatment of this topic, see S.J. Douglas and M.W. Michaels, *The Mommy Myth: The Idealization of Motherhood and How It Has Undermined Women* (New York: Free Press, 2004); see also D.T. Meyers, "The Rush to Motherhood: Pronatalist Discourse and Women's Autonomy," *Signs* 26, no. 3: 735-73. For further discussion of need, see note 2 above.

27. See "Another Look at Contract Pregnancy," in *Reproducing Persons: Issues in Feminist Bioethics* (Ithaca, N.Y.: Cornell University Press, 1996).

28. Of course, the latter factor affects all healthcare in the U.S.

Families and Futility: Forestalling Demands for Futile Treatment

John Hardwig

A few years ago, an article by Helft, Siegler, and Lantos in the *New England Journal of Medicine* chronicled the rise and fall of the futility movement.[1] The concept of futility was largely unrecognized 20 years ago; 10 years ago, futility was hotly debated; now it attracts little attention. However, the *problem* of futility has not gone away. "Futile treatment in hospitals is still very much an issue, yet doctors today are no more empowered to declare futility unilaterally than they were 15 years ago."[2] Delivering futile treatment remains as demoralizing as it ever was. And the problem of futile treatment takes on a special urgency in a climate of unrelenting cost-containment pressures — What care could be less cost worthy? What care could we more legitimately refuse to give?

Moreover, the problem of futility will only get worse. Medical progress will enable us to sustain some form of life for ever longer periods. New, even more expensive treatments will come into use, exacerbating cost-containment problems. Patients and families will become better informed about the "miracle treatments" available or promised soon. We must not give up on some kind of attempt to deal with the problem of demands for futile treatments.

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POLICY VERSUS DISCUSSION

Helft, Siegler, and Lantos explain the two main approaches to the problem of futile treatment. The *unilateral declarations* approach aims to empower physicians to not offer or to refuse to deliver futile treatments. This approach obviously runs the risk of arbitrary refusals of care — refusals that are motivated, perhaps subconsciously, by the values or attitudes of the individual physician. The second and more popular approach has been *hospital futility policies.* These policies state that a hospital — or group of hospitals — will not deliver futile treatments, and outline procedures for declaring treatment to be futile. Futility policies are often difficult to put into place. One administrator killed the fledgling effort to create a futility policy for his hospital by proclaiming, "This hospital is not about to become the 'futility hospital' in this area!"

But even when they are in place, futility policies may still fail to protect physicians and hospitals from demands for futile treatment. I recently asked a hospital ethics committee for an example of one of their policies that is not working, and was greeted with a chorus of, "the futility policy!" And this in a metropolitan area in which all hospitals had worked together for a year to formulate and adopt a common policy on futile treatment.

Both of these familiar approaches are deeply flawed. They contain similar defects, and carry the seeds of their own failure within them. Both infuriate patients and families who do not share the physician's conviction that the treatment is, indeed, not worth continuing. Both approaches are unilateral and strike families as blatant assertions of the power of the hospital to have its way. Both are predictably sources of rage and a sense of betrayal, so both are sources of bad publicity and potential lawsuits. The hostility predictably generated by these approaches is surely one reason for the failure of hospital futility policies and the decline of the entire futility movement.

Both approaches to the problem have assumed that demands for futile treatment are both intractable and irrational. The care *is* futile, after all, and discussion and negotiation have already been tried, without success. This assumption about demands for futile treatment tends to harden both sides into their respective positions. On one side, it fuels anger and hostility as it becomes evident to patients and families that they are being perceived and treated as obstinately irrational. Nobody sees themselves that way; nobody likes to be treated that way. On the other side, having labeled requests for futile treatment *irrational* and *intractable,* physicians are freed from any responsibility to probe for the sources and roots of demands for futile treatment. There is then no point in trying to treat anything more than the symptom — the demand itself. The power to issue unilateral declarations of futility — either by physicians or by a hospital committee — seems to be the only solution. If demands for futile treatment can be rendered inefficacious, the *hospital's* problem is solved. That's all one could hope for in response to an irrational and intractable demand.

However, the assumption that demands for futile treatment are both intractable and irrational should be questioned and tested. Also, instead of just asking how a physician or hospital can respond to demands for futile treatment, we should ask how we might work to reduce the incidence of such demands. This would give rise to a third approach to the futility problem, an approach that would be dialogic, piecemeal, and case-by-case. A case-by-case approach obviously lacks the sweeping generality of a policy. As such, it does not hold out the promise of dealing with all requests for futile treatment. Some of the most frustrating and intractable cases will remain. However, this is the only approach that attempts to deal with both the hospital's problem and the patient's or family's problem, and thus holds the promise of resolving the problem of demands for futile treatment in a way that does not generate anger and ill will. Besides, the idea that a hospital policy would sweep away all the problems of futile treatment has proven illusory anyway. A *reduction* in futile treatment is perhaps the only realistic hope for *any approach* to the problem of futility.[3]

Helft, Siegler, and Lantos also conclude that "talking with patients and families should remain the focus of our efforts."[4] But without greater clarity about the nature and goals of this discussion, it remains unclear how their recommendation would differ from the discussions already taking place between patients or families, and physicians or hospital staff. I will argue that a *talking with patients and families* approach cannot succeed without moving beyond three simplifying assumptions that undergird much hospital care in the United States today, because these assumptions help to fuel demands for futile treatment. The approach I will advocate is compatible with hospital futility policies. Where they exist, futility policies can provide support and

backup when dialogue fails. But they should not be our focus and we should usually, I believe, acknowledge our own failure when a futility policy is invoked.

I will focus on requests or demands by *families* for futile treatment. These are the most common and also the most troubling cases. They are the most common because patients are normally no longer competent by the time treatments have been determined to be futile. Cases of an alert, oriented patient who desperately wants her life prolonged — even if it is only existence in an intensive care unit — are much less common but also less troubling. Such patients create understanding and command sympathy. None of us wants to die. Demands by *families* for futile treatment are much more common, and are much more troubling because they raise ethical questions about whether the requested treatment even represents the wishes of the patient. The agendas of the proxy deciders seem so clearly in play in most of these cases.

COMING CLEAN: CONFLICTING VALUES AND IATROGENIC SOURCES

We might begin by at least "coming clean." Many of the treatments we deem futile do prolong life. In fact, that is precisely what distinguishes futile treatment from ineffective or impossible treatment. But the life they prolong is unconscious or semiconscious life, life in the twilight of senility, or life confined to an ICU. There *may* be a consensus among physicians that prolonging life under these conditions is not an appropriate goal for medicine. But this is a value judgment that many people do not share. When the clash over demands for "futile" treatment represents this kind of value conflict, we should forthrightly admit as much. In such cases, we will be able to make progress with families only by acknowledging the basic conflict of values. Attempts to paper over the conflict with a declaration of futility will rightly bear the opprobrium of disingenuousness. Moreover, in cases in which there is a conflict of values, the demand for futile treatment is not simply irrational. It is not irrational to believe that human life in any form must be respected and preserved. Perhaps this belief is somehow deeply antithetical to the proper practice of medicine, but it is not clear why this should be so. Given a conflict of basic values, mediation efforts seem to be called for, not a unilateral assertion of the power to withhold or withdraw treatment.

We should also acknowledge the extent to which the problem of futile treatment is an *iatrogenic* problem, at least in the slightly expanded sense that includes problems caused by healthcare institutions. We should, for example, acknowledge that families have been given false hopes, both by the healthcare industry at large and often by their physicians as well. On the national level, we muster financial support for medical research by promising miracles. The media and various fundraising campaigns spread these reports to a very interested public. "We're closing in on a killer!" a billboard on the way into my hometown proclaims. *The killer is leukemia and the cure is at hand!* Physicians may understand that we are a long way from understanding, let alone being able to cure, many of today's "killer diseases." Physicians also know that even if a cure were discovered tomorrow, it would not be widely available soon enough to help most patients who are dying today. But hopes are generated in the public. The billboard has been announcing for about a year now that they're closing in on this killer. So surely they must have it cornered by now. If we can somehow keep our daughter alive a little longer, they will have eliminated this killer and she will be cured!

There is little an individual physician or hospital can do to roll back unrealistic expectations. But the American Medical Association or the American Hospital Association could make substantial contributions to the reduction of demands for futile treatment by promoting a more realistic social assessment of the power — and also the drawbacks — of modern medicine. But it is in the interest of

neither to do so. Nor are there any public education campaigns that proclaim, "Caring families don't let their loved ones die in an ICU!" Demands for futile treatment could be seen as the price we pay for having generated and profited from unrealistic expectations of modern medicine and medical science.

Unrealistic expectations and false hopes are also generated within the hospital, as has often been pointed out. Some of this is the result of the specialized reports from the various specialists involved in a particular case. After all, if Dad's lungs are better, it seems only logical to conclude that *he* must be better, too. Treatments are often tried that have only a small chance of producing the hoped-for result. Near-futile treatment is routinely delivered with words of encouragement. Treatments are also tried that don't have a clear time frame, a time when the treatment ends, and we will learn whether it has worked. Bad news is often not presented clearly enough, often enough, and in simple enough terms so that it gets through to families.

There are also important issues of time that surround all of this. Too often, families are expected to turn completely around, in a day or two, from a hopeful and cautiously optimistic stance to agreeing to withdraw all life-prolonging treatments. Frustration over a family's inability to change direction then develops, and this frustration can easily harden into a confrontation over futile treatments.

Finally, we should also acknowledge that we — our health care systems — have contributed to situations in which caring for a chronically ill loved one is the sole source of meaning in the caregiver's life. We happily externalize the costs — both financial and personal — of chronic care, arguing that home care is best for the patient, which effectively reduces the family to a "patient-support system." We thereby create lives for family caregivers that include no time or energy for anything but struggling to deliver the care we require. Careers are destroyed, friends fall away, hobbies and other leisure interests are extinguished. None of this bothers most physicians and bioethicists, for we are single-mindedly pursuing what is best *for the patient.* Then we react with shock and horror when family caregivers cling to their loved one because she or he is the only remaining source of meaning in their lives. We forget that medicine created and bioethics sanctioned these lives that no longer contain anything but caring for their loved one.

ASSUMPTIONS OF MEDICINE AND BIOETHICS

We can address many of these iatrogenic sources of demands for futile treatments within the normal paradigm of hospital medicine. But exposing and treating the deeper roots will require that we move beyond three traditional, simplifying assumptions of medicine and bioethics. These three assumptions are interrelated, but they can be teased apart conceptually. Like all simplifying assumptions, they persist because they work — most of the time they simplify situations, and focus healthcare professionals on the most salient features of the cases before them. But as with all simplifications, they ignore features of cases that sometimes become pivotal. Then our simplifying assumptions turn against us, and misdirect attention and create rather than resolve problems. Demands for futile treatment are partly generated, I contend, by three simplifying assumptions of modern medicine and modern bioethics.

1. Medical treatment decisions should serve the interests of the individual patient. By implication, the interests of others — the patient's family, other patients, insurers, the hospital, and physicians themselves — are simply to be ignored whenever they conflict with the interests of the patient. Except, perhaps, in situations that involve rationing medical resources. This patient-centered ethics of medicine is ancient, going back at least as far as the Hippocratic Oath. It continues to the present day, and has received the imprimatur of contemporary bioethicists. Unswerv-

ing fidelity to the interests of patients serves as a healthy reminder that patients are vulnerable, that medicine is a caring profession and not just another business, and that the interests of vulnerable — and often disvalued — patients are not to be routinely sacrificed to some greater, common good.

But as I have argued in this journal and elsewhere, a patient-centered ethics of treatment decisions is mistaken, because the interests of patients sometimes conflict with legitimate interests of others.[5] The interests of other members of the patient's family (at least) cannot ethically be ignored. Indeed, sometimes the interests of a patient's family should take precedence over the interests of a patient. Sometimes a family has more at stake in treatment decisions than a patient.

Two consequences of this simplifying assumption are germane to demands for futile treatment. (1) As mentioned above, if only the interests of the patient are considered, this implicitly reduces the rest of the family to a "patient-support system." As mentioned above, this contributes to situations in which the family ends up with nothing to give meaning to their lives except providing care for their loved one. We need to ask more seriously and more routinely, What is too much to ask of patients' families? We need more often to give them permission to refuse to deliver care. (2) This patient-centered ethics of medicine tempts — even urges — us to ignore the impending family crisis created by an accident, a catastrophic illness, or impending demise of a loved one. Medicine is about caring for the sick, period. The family needs to work out their own solution to the demise of a loved one. That is not a medical problem, for the patient is by then deceased and the case is closed.[6] But sometimes we pay a very large price for ignoring the family crises that serious illnesses cause, as they give rise to demands for futile treatment.

2. Death is a medical problem, a medical crisis. This is normally a reasonable assumption. We love life and cling to it; we want to live. Medicine is sometimes what enables us to do so. Many Americans also believe that we have an obligation to live, even if we don't want to. But if we see medicine as an enterprise devoted to saving lives, *every* impending death is turned into a medical crisis. This is a deeply damaging oversimplification. And it fuels demands for futile treatment that will, after all, ward off death. In our medicalization of death, we have radically misidentified the kind of a crisis that death is.

The death of a patient is normally a crisis for doctors and other health professionals, as it represents the failure of an intense effort to preserve life. For *doctors,* death may, indeed, normally be a medical crisis. Impending death is often also a crisis for the dying patient. But for the patient, it is not a *medical* crisis, although it may be foretold and marked by medical indicators. Death is not bad primarily because of its physical symptoms — because it is painful, or because it is accompanied by nausea or dyspnea. The dying person may have suffered much greater physical discomfort before. The pain or nausea could be easily, even cheerfully borne if it would be followed by recovery and a return to healthy life. If death is a crisis for the patient, it is a crisis because it is *the end of the patient,* or at least the end of the patient's existence as we know it. Secondarily, chronic illness or death may also be a crisis for the patient due to awareness of the possibilities for the future that are going to be lost. But all this is an existential, or, as I prefer to call it, a *spiritual crisis,* not a medical crisis.[7] A *spiritual crisis* is, by my definition, a challenge to someone's fundamental values, commitments, and the basic beliefs that have shaped the person's life.

The crisis of death can be resolved only by deep acceptance of our finitude and by activities that are appropriate to a life that will not last forever. The solution to the problem of unfulfilled potential and unfinished business is not an attempt to employ medical means to live longer and longer. It is a call to live differently *now.* Without this kind of deep reorientation, we will not complete unfinished business nor realize unfulfilled potential even

if we survive the present health crisis. And even if we live much longer, we will never do and experience everything we would like. We need to make our peace with that. Medicine is distorted and held captive by our deep cultural inability to accept our finitude.

However this may be, it is all arguably somewhat beside the point. For in the cases we are concerned with here — those that lead to proxy requests for futile treatments — we need to recognize that death is not a crisis *for the patient* at all. Sometimes, of course, death is not even a bad thing for the patient, because it brings to a merciful end a long period of suffering. In many other cases, death is not a crisis for the patient because, through loss or lack of mental capacities, she does not have a sense of self as an enduring entity. Death poses no problems for one who has no conception of death or no recognition of self. (This is why animals presumably do not bemoan the fact that they will die.) Death can be a crisis for the patient only if the patient is able to appreciate that it is the patient who is alive, that the patient's life is the life that is threatened. Infants, small children, and the senile have no such sense of self. Without awareness of self, it is not even clear that a shorter run of relatively pleasant moments is worse than a longer run of them. *Shorter* and *longer* are impositions of other, quite different points of view than many incompetent patients are capable of.

The kinds of deaths that lead to proxy demands for futile treatment are, then, *spiritual* crises. But they are normally spiritual crises for the patient's *family,* not for the patient. In the cases in which proxy requests for futile treatment arise, death is usually no longer a crisis of any kind for the patient. With this observation, we move to a third simplifying assumption.

3. The job of doctors and hospitals is to deliver medical care to patients, not to address the spiritual needs of their families. In some ways, this assumption is a combination of the first two. Doctors and hospitals are focused on patients, on providing for their medical needs by prolonging life and restoring health. When health can be fully restored, this is almost always a useful assumption. It focuses and directs activities appropriately. But as patients develop chronic or fatal illnesses and begin to fail, medicine is brought face-to-face with the fact that the needs of these persons cannot be so neatly divided into the medical and the nonmedical, and also that the lives of patients are deeply interwoven with the lives of their loved ones. This inseparability of the lives of those who are close is increased and underlined by the facts of vulnerability and dependence.

Many deaths — and almost all deaths that precipitate proxy requests for futile treatment — are deaths *in the family.* A death in the family is most often, as we have seen, a *spiritual* crisis and normally a crisis *for the family,* not for the patient. We will be unable to adequately address situations that threaten to harden into demands for futile treatment until we acknowledge as much. By contrast, the standard approach to requests for futile treatment is to insist that it is the proper role of hospitals and doctors to deliver medical care to patients, that the need to sort out what are sometimes dismissively called the "psychodramas of patients' families" is not a justifiable use of medical resources. End of story.

Some of this is undoubtedly true — if death is not a crisis for the patient, and, indeed, is not a medical crisis at all, a medical response to a nonmedical problem seems inappropriate — perhaps even a perversion of medicine — costly and probably ineffective.[8] Here, as elsewhere in medicine, a patient-centered ethic fails us. We recognize that increasing debility and impending death are crises for the patient. Some physicians try to address the emotional and spiritual crises these problems pose for the patient. But we do not fully acknowledge in practice that this crisis is often at least as profound for the family as for the patient. Even if we recognize the family crisis that serious illness represents, we usually do little to address it. The family is not our patient.

We will not get to the root of demands for futile treatment nor will we be able to develop approaches that are likely to reduce the incidence of such demands if we end the story with the flat assertion that medical care should not be used to help families sort out their spiritual crises. Any preventive approach to the problem of futile treatment will have to attend to these issues. For it is precisely the "psychodramas" of families that give rise to proxy demands for futile treatment. An attempt to avoid dealing with them is doomed, as it will result in treating only the symptoms. What is needed is spiritual care for the family, not medical care for the patient. And except for cases of truly unforeseeable events (a car accident or massive stoke), it usually should have already been the focus of care for months, even years before the patient's terminal admission.

THE NEEDS OF THE FAMILY

Time is required to come to terms with an impending death in the family. The loss of a loved one is itself a kind of death; the meaning and purpose that have sustained lives oriented around family are lost. The surviving family members must be reborn as new and very different selves before they can go on. Time is also required before the death for the human task of winding up unfinished business that families so often bring to end-of-life treatment decisions. "Thank you," "I love you," and "Good bye" need to be said, preferably while the patient is alert enough to appreciate them. Difficult tasks, such as burying old grievances, acknowledging guilt, and asking for and giving forgiveness, must be undertaken, again preferably while the patient is still aware enough to participate.

Even more difficult is coming to terms with the death of an infant or young child. Babies and young children are the very embodiment of promise and hope. We plan to take joy in their growth and development, not to watch them wither and die, or lie unconscious in a hospital bed. Many adults are also more emotionally involved with their children than with their parents. Parents have invested so much of themselves in their children, and we normally feel much more responsible for how their lives turn out. Finally, the death of a child — even an adult child — is "unnatural." Children are supposed to bury their parents, not the other way around. We are, then, on some level, emotionally prepared for the deaths of our parents; we are supposed to witness the deaths of our parents. Even the death of our partner, forsaken though it makes us feel, is more bearable than the death of our child.

Also, we all need hope. Perhaps we humans cannot live at all without hope, and certainly no one can thrive without it. But families need to be helped to relinquish one hope in favor of another. Families may hope against all odds that Mom's disease will miraculously reverse itself and she will return to lucidity, thanking everyone for the aggressive, life-prolonging treatment that pulled her through. This is a fragile hope, however. Regardless of how well fortified it may be against doubt, it will be shattered by subsequent events if treatment is indeed futile. Nor is it at all clear that the *family's* interests are well-served by treatments that allow it to cling to a hope for months, even years. The family members live in a kind of suspended animation, waiting for a recovery that will never come.

So families need to be helped to come to new hopes: to the hope that Mom will be granted a peaceful and pain-free death, that she knew she was loved, and that the unraveled fabric of the family can be reknit without the pivotal role Mom always played. Or, to the hope that the other members of the family will be able to come through the loss of their daughter or sister relatively unscarred, that the family will be able to pull together instead of pulling apart in the face of this tragedy, that their faith in the goodness of life will not collapse under the weight of this loss, and that they will be able to give to each other the love and care they formerly devoted to her.

Failure to accomplish the human tasks surrounding death contributes to families' needs, which in turn fuel demands for futile

treatment. Families must be encouraged not to postpone these difficult tasks and must be helped to avoid doing so. Once we acknowledge that family issues (such as guilt, loss of meaning, and an inability to envision how one will go on) often motivate requests for futile treatment, it becomes obvious that helping families to resolve such issues is one way to forestall requests for futile treatment.

Families also need help to distinguish — and to separate emotionally — withdrawal of life-prolonging treatments from abandonment, for abandonment of one's own parent or child is one of the worst things a person can do. In many medical settings, the opposite message is more commonly given. If the treatment team has not yet abandoned hope, families are often not really given permission to withhold treatment. This is evident in the *pro forma* consents to treatment that physicians extract from families. "Your daughter's blood gases are dropping, so she needs. . . ." Here the clear message is that if family members do not consent to treat this medical problem, they are not giving their own daughter the care she needs. We should not be surprised if family members, after weeks of being urged to equate caring for their loved one with consenting to high-tech, life-prolonging medical treatments, have difficulty separating withdrawing treatment from abandonment. Often, the distinction and possible conflict between care and more treatment should have been under discussion for a long time before the final hospitalization.

Yet quite often, the distinction and possible conflict between care and more treatment should have been under discussion for a long time before the final hospitalization. One young doctor said to other doctors on the team, "When I'm dying, if anyone does to me what we're doing to this guy, I'm gonna come back and get 'em." But this message is not usually conveyed to the nonmedical world. Families need our help to understand that transferring a loved one to an ICU, or persisting in high-tech rescue attempts, can be a form of abandonment. Even taking a dying loved one to the hospital sometimes can be abandonment. The ICU is certainly not the best place to die. Even hospitals are often not good places to die. We need to say that clearly and often to families, publicly and privately.

This is appropriate care for distraught families. The appropriate response to a guilty son's request that we "do everything for Dad" is not to prolong Dad's life in an unconscious state or an ICU. That much the futility movement has right. But it is also not appropriate to vilify the son for demanding inappropriate treatment. (Let he among us without unfinished business with his parents cast the first stone.) The appropriate response is to address the son's guilt, his concerns that he will now never be able to make things right, and his very human emotions connected with the death of his father. Even more appropriate would have been a phone call to the missing son months earlier, when the death of his father was foreseeable — if the son has anything he needs to say to his father, he had better say it soon, for in just a little while his father will no longer be able to hear what the son needs to say.

If we wish to forestall requests for futile treatment, hospitals should support grieving families. We could, for example, provide someone to talk with families, preferably someone with enough medical knowledge to help clear up misconceptions families might have about what they have been told. Family members could be encouraged to talk about what the patient has meant to them, about the complexities of their relationships with the patient, about the patient's role in the family, about the families' fears of having to go on without the patient, and so on. It might well take hours, but, given a sympathetic ear, one would expect the "irrational" hopes and fears to come out, the hidden agendas to begin to surface. When they come out, we can help families begin to deal with them. Even giving voice to these fears and agendas will sometimes be enough to help families get beyond them.

Such care is *preventive* care. It should normally be started weeks or months before requests for marginally useful treatment

harden into demands for futile treatment. This is not always possible, as when an unforeseeable incident suddenly renders a member of the family permanently unconscious. But more often, such supportive family care can be begun even before the family is able to acknowledge that Mom or Junior is dying. Indeed, there are family issues that can only be completely resolved if they are approached months before the patient dies. Forgiveness cannot be given by an unconscious mother; the terminal admission is far too late for a father to really be there for his dying son.

It may be objected that none of these measures address the heart of the problem — the sheer irrationality of some of these requests. Families persist in hopes for miracles and stubbornly refuse to face reality. But we will not know how *intractably* irrational such hopes are or how *irresolvably* hidden such agendas are until we at least attempt to address them.

And if it still seems that addressing the family crises surrounding the death of a loved one is no part of the work of medicine, then we should simply acknowledge that the problem of futile treatment is part of the price we pay for the medicalization of death and dying, for promoting an overly optimistic picture of the powers of medicine, and for focusing too exclusively on the medical needs of the patient.

But what about the costs of such care of families? In an era of cost-containment, ancillary services of all sorts are being cut or eliminated. Yet the very term *ancillary* evinces the deep commitment to the simplifying assumptions that exacerbate the problem of futile treatment. What, after all, is central to the care of the dying and what is ancillary to that? Moreover, the sort of family support I advocate might well turn out to be a cost-saving measure. ICU care is very expensive. If a hospital could avoid even a few weeks of uncompensated or under-compensated ICU care each year, it might actually save money through the provision of such family care. There is, of course, no way to bill for such care. Families are not even patients.

Granted, this approach will not resolve every request for futile treatment. But this is an approach that might well *reduce* the incidence of demands for futile treatment. Perhaps most importantly, spiritual care for families is the only approach to the problem of futility that offers even a chance of a healing process for the family, not merely a mechanism to treat the hospital's problem of futile treatments. As such, it is an approach that deserves full discussion and some serious "clinical trials."

NOTES

1. P.R. Helft, M. Siegler, and J. Santos, "The Rise and Fall of the Futility Movement," *New England Journal of Medicine* 343, no. 4 (2000): 293-6.

2. Ibid., 293.

3. There is also a fourth approach to the problem of futility that should at least be mentioned in passing. We could be more open about the fact that one of the main reasons healthcare professionals find futile treatment so demoralizing is that it is a simply horrible use of scarce medical resources, including themselves. Though we may legitimately claim that the futility problem is different from the problem of rationing healthcare resources, few physicians and nurses get too upset about requests for simple, relatively inexpensive treatments that don't work — antibiotics for viruses, large doses of vitamins to prevent cancer, alternative medicines used in conjunction with standard therapies, etc. If we honestly admitted that we ration healthcare all of the time, we could fold the futility problem into the problem of scarce, pooled healthcare resources. Then we could refuse to deliver futile treatment simply because there are much better uses of the available resources. "We do not prolong life we believe to be permanently unconscious because we believe it is much better to devote those medical resources to preserving the life of conscious patients." Although I believe this approach also has merit, I will focus in this article on approaching the problem of futility through talking with patients and families.

4. See note 2 above, p. 296.

5. J. Hardwig, "The Problem of Proxies with

Interests of Their Own," *The Journal of Clinical Ethics* 4, no. 1 (Spring 1993): 20-7; J. Hardwig, "What About the Family?" *Hastings Center Report* 20, no. 2 (March-April 1990): 5-10; J. Hardwig, "SUPPORT and the Invisible Family," *Hastings Center Report* 25, no. 6 (November-December 1995): S23-5.

6. Hospice care is a noteworthy exception. Hospice continues to care for the "survivors" after the patient has died.

7. J. Hardwig, "Spiritual Issues at the End of Life: A Call for Discussion," *Hastings Center Report* 30, no. 2 (March-April 2000): 28-30.

8. Note that we happily pursue medical solutions to all kinds of nonmedical family problems without feeling any sense that medicine is thereby perverted. Think of cosmetic surgery, for example. If a husband's dislike of the crow's feet around the eyes of his 40-year-old wife is not an inappropriate reason to use medical resources, why is the spiritual crisis of a dying patient's husband not an equally appropriate use of them? We are faced with the difficult question of which nonmedical needs pervert medicine. The answer to this question cannot be that patients themselves pay for cosmetic surgery, for that would draw a connection between two problems that we have insisted are distinct — the problem of futility and the problem of scarce, pooled resources.

9. Needless to say, this is not an argument for converting ICUs into hospice units. But it may be a plea for returning ICUs to their proper mission of helping those who can be restored to a full-enough functioning to be discharged from the ICU.

Practicing Physicians and the Role of Family Surrogate Decision Making

George E. Hardart and Robert D. Truog

Despite the active and lively discussion being held in the published pages of philosophers and medical ethicists regarding the role of family members in medical decision making, little is known about how physicians who work with patients and their families on a daily basis to make medical decisions approach this challenging issue.[1] We recently conducted and published a survey of physicians that explored their attitudes and preferences regarding this issue.[2] This survey was limited to making decisions for incompetent patients. In the paragraphs that follow we will summarize the results of this survey, discuss interesting findings with moral significance, and explore how the knowledge gained concerning the attitudes and preferences of this group of physicians adds to the ethical debate over the role of the family in medical decision making.

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THE CONCEPTUAL FRAMEWORK

Our conceptual framework of surrogate decision making for incompetent patients imagines the degree of the incorporation of interests of the patient's family along a spectrum: at one end, family's interests are rejected, and, at the other end, family's interests are the primary determinants of the decisions that are made. Four distinct models can be identified along this spectrum.

In the *Intrusive Family Interests Model,* family's interests are seen as being in conflict with and as an intrusion into the expression of a patient's individual rights, and should not be considered. In the *Derivative Family Interests Model,* the family's interests should be given consideration in medical decisions if the patient had explicitly stated that the family's interests are important to him or her. Under the *Intrinsic Family Interests Model,* the family's interests are considered in medical decisions whether or not their interests were identified as important by the patient. Finally, in the *Pure Family Interests Model,* patients' interests are not given preferential status in medical decisions; rather, decisions are made to maximize the family's welfare.

Figure 1 is a graphic depiction of this conceptual framework, which shows the inverse valuation of the individual's interests and the family's interests along a spectrum. As the focus of decision making moves from the patient to the family, the focus moves from a more protective role for physicians (toward the patient) to a less protective role. That is, the Intrusive Family Interests Model is the most patient-centered model, with the most protective role for the physician; and the Pure Family Interests Model represents the most family-centered model, with the least protective role for the physician. Those who favor protective models of medical decision making give proportionately more importance to the prevention of abuse by families and family members who would give undue attention to their own interests in medical decisions. Those who favor more family-centered models give proportionately more importance to the burdens that can be imposed on families by medical decisions.

THE SUBJECTS AND THE SURVEY

For our sample population, we chose critical care physicians because they are commonly involved in surrogate decision making, as well as in "high stakes" decision making that has substantial potential to affect patients' family members. A total of 327 physicians responded anonymously to our mail survey, representing 55 percent of those who were sent mailings. Of the 327 subjects, 25 percent were internists specializing in critical care for adults; 34 percent were pediatricians specializing in critical care for children, ranging from newborns to young adults; and 38 percent were pediatricians specializing in critical care for newborns only. The primary purpose of the survey was to determine which of the four decision-making models the respondents preferred, based on their responses to a series of declarative statements. Responses were ordered on a Likert scale from "strongly agree" to "strongly disagree." Although the survey included a number of clinical vignettes (see table 1) that had been designed to place respondents in a deliberative mindset, and perhaps remind them of scenarios in their own practice in which the interests of family members were potentially relevant, no statement specifically referred to any case. The actual survey items, or statements, that the subjects responded to are found in table 2 and table 3.

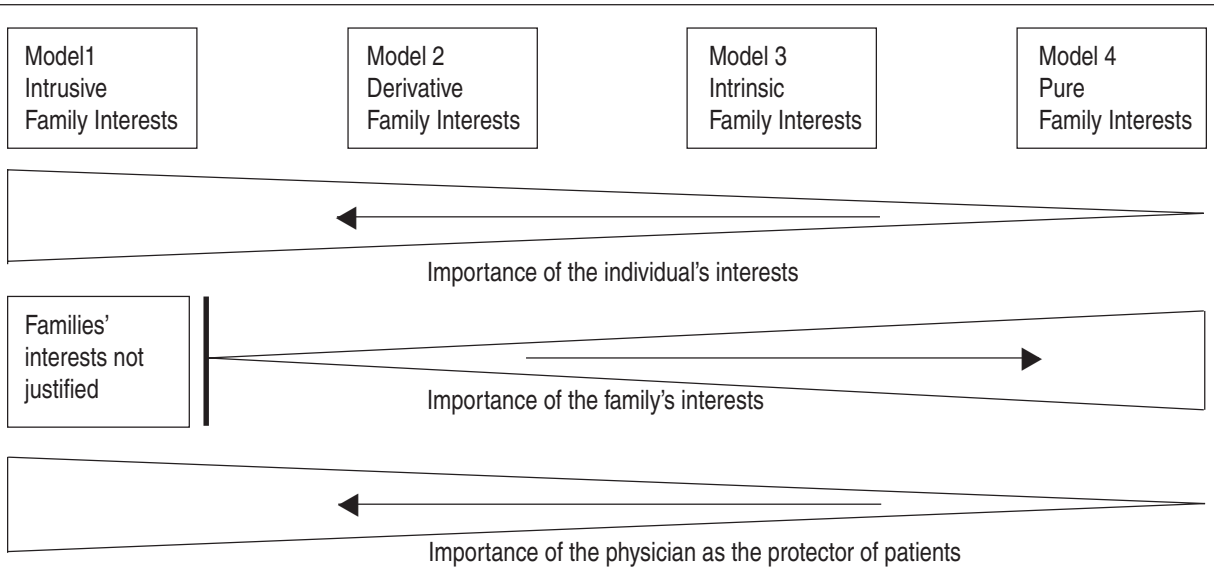

Figure 1. Conceptual model of surrogate decision making by patients' family members.

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One of the secondary purposes of the study was to test our hypothesis that the age of the patients that physicians treat would affect their approach to the interests of family members. To test this hypothesis, we surveyed three physician subspecialties that are responsible for the treatment of three distinct patient age groups.

On the basis of a logical interpretation of the conceptual framework, we developed a set of categorization patterns to relate the responses to the survey items in table 2 to a preference for one of the decision-making models. Subjects whose responses matched one of the four patterns were categorized as preferring that decision-making model. If a subject's responses did not match one of the categorization patterns, they were not assigned to a pattern. For example, if a subject's responses agreed with the concepts specific to the Intrusive Family Interests Model *and* the concepts specific to the Derivative Family Interests Model, we determined this (prospectively) to be inconsistent with a preference for any of the four models, and we did not categorize the subject's responses. This rigorous algorithm for determining preferences allowed us to successfully categorize 85.6 percent of the subjects. The remaining 14.4 percent were not included in our subsequent analyses.

Table 1
Clinical Scenarios Used in the Survey

Scenario
The husband of a legally incompetent 68-year-old woman with multi-infarct dementia refuses dialysis for her, stating that he has an obligation to think about the needs of his daughter and her family (who has been supporting the patient financially) as well as his wife.
When a family refuses a lifesaving tracheostomy for their nine-year-old son who has a progressive muscular dystrophy, the physician reacts by saying that this would be against hospital policy and asks how they will defend themselves in court.
The parents of an infant with a severe familial cardiomyopathy refuse a heart transplant for her two years after another of their children had been heart transplanted, believing that the strain of caring for two chronically ill children would place their marriage at risk and unfairly impact their other healthy children.
It is discovered that an elderly man, who had been requesting less-aggressive treatment for his 78-year-old wife with Alzheimer's disease who was being treated for pneumonia in the ICU, had recently become engaged to the couple's housekeeper of many years.
A wealthy family refuses surgical intervention for their newborn with newly diagnosed Down's syndrome and duodenal atresia, and requests that the child be treated with comfort measures only, since they prefer not to raise a disabled child.
A man threatens to sue the hospital if they withdraw ventilation from his 20-year-old son who has Duchennes's Muscular Dystrophy and respiratory failure because he cannot bear the thought of losing his son, despite his son's persistent and authoritative requests to have support withdrawn.

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THE RESULTS OF THE SURVEY

Regarding the primary purpose of the study, we found that 61 percent of all respondents preferred the Intrinsic Family Interests Model, 17 percent preferred the Derivative Model, 15 percent preferred the Pure Family Interests Model and only 6 percent preferred the Intrusive Family Interests Model. Our suspicions regarding the effect of physicians' subspecialty on which model they preferred were borne out; internists were most likely to prefer the Intrusive Model and neonatologists were most likely to prefer the Pure Model. However, despite the finding that internists were least likely to strongly incorporate family's interests into medical decision making among the three groups, fully 59 percent of the internists we surveyed preferred either the Intrinsic Model or the Pure Family Interests Model, and only 12 percent preferred the Intrusive Family Interests Model. Further, the

items on the survey that explored the exclusivity of the physician-patient relationship indicate that only 12 percent of all of the respondents agreed that physicians have no obligation to anyone in the patient's family, other than the patient.

Of the 327 respondents, 84 percent reported that they at least occasionally were confronted by situations similar to the survey scenarios in their practice; 69 percent believed that proxies from patients' families commonly make decisions that are based, at least par-

Table 2
Models and the Corresponding Survey Items

Model	Corresponding survey item
1. Intrusive Family Interests	• Surrogates who are family members should not allow the impact of various treatment options on the family to affect their decisions concerning a sick family member under any circumstances. • Surrogates who are family members should consider the well-being of the family as a whole when making decisions for incompetent patients. • The impact of medical decisions on the family must not be given any consideration when family surrogates are making decisions.
2. Derivative Family Interests	• Family interests should be given weight in a decision if the patient had once been competent and stated that she or he never wanted to be a burden on the family. • Family interests should be given weight in a decision if the patient had once been competent and stated that important family interests were more important to him or her than the patient's own life. • Family interests should count in decisions for incompetent patients because most people have an important interest in the well being of their families.
3. Intrinsic Family Interests	• Family interests should matter in a decision, even if it isn't known whether the family's interests are important to the patient. • Family interests are morally legitimate factors in the decision for the family members who act as surrogates, even if family interests are not an important interest of the patient's. • Given the high value placed on good health and longevity, the patient's interests will take precedence over the family's interests in the vast majority of decisions. However, when the benefits to the patient are likely to be small and the burdens imposed on the family are large, then the family's interests should become a critical factor in a medical decision.
4. Pure Family Interests	• Medical illness should give a person preferential status over other members of the family when medical decisions are being made. • All members of the family, including the incompetent patient, should be considered equals with a stake in a medical decision, and the choice that maximizes the welfare of the family as a whole should be chosen. • Medical choices should always be made to maximize the welfare of the family as a whole, even if the welfare of the patient must suffer.

Note: For each concept, the sum of the responses to each item (scored 1 to 5) was calculated. Agreement, disagreement or neutrality was evaluated using the aggregate score for each concept. The scores for negatively phrased items were reversed. Reprinted with permission from G.E. Hardart and R.D. Truog, "Attitudes and Preferences of Intensivists Regarding the Role of Family Interests and Decisionmaking for Incompetent Patients," *Critical Care Medicine* 31, no. 7 (2003): 1895-1900.

tially, on how the decision will affect the family. These findings suggest that the cases and the questions they raise are far from merely theoretical "thought experiments."

Gender, race, and religion were not found to correlate with the decision-making strategies preferred by respondents. The age of respondents, the percentage of their practice time spent in the intensive care unit, their experience with situations that are similar to the scenarios, and their years of ICU experience all directly correlated with a preference for a family-centered model, but only experience with situations similar to the scenarios remained statistically significant after we subjected them to multivariate testing, which suggests that experience was the underlying concept driving respondents' preference for a particular model among these factors. The only other factors found to correlate with preference for a model after multivariate testing were: how religious the respondents considered themselves (the more religious respondents preferred models that were more patient-centered), and physicians' subspecialties.

We explored respondents' attitudes toward healthcare rationing and found that 48 percent believed that physicians should consider the costs to society of interventions taken on behalf of patients (the dollar costs); physicians who supported healthcare rationing were more likely to prefer family-centered decision-making models.

Questions designed to investigate the level of trust that physicians have in the motives of family members who act as surrogates indicate that 44 percent felt some degree of skepticism regarding the motives of family members; the degree of trust (or lack thereof) did

Table 3
Related Attitudes and Peferences and the Corresponding Survey Items Designed to Test Agreement with Each Concept

Concept	Corresponding survey item
The role of the physician as protector of patients	• An important duty of the physician is to defend the patient from others with competing interests.
The exclusivity of the physician-patient relationship	• Physicians have no ethical obligation to anyone in the family other than the patient.
	• The physician has an obligation to consider the effect of his/her interventions on the family of the patient as well as the patient.
Physicians' perceptions of families' motives	• I trust that family surrogates have good motives when making critical decisions for their incompetent family members.
	• Physicians should maintain a healthy skepticism concerning the motives of the family surrogate.
Physicians' attitudes regarding healthcare rationing	• It is the physician's duty to save and/or preserve the lives of her patients regardless of the consequences for society (e.g. the dollar costs of treatment).
	• The physician has an obligation to consider the costs to society of interventions taken on behalf of patients.

Note: For each concept, the sum of the responses to each item (scored 1 to 5) was calculated. Agreement, disagreement, or neutrality was evaluated using the aggregate score for each concept. The scores for negatively phrased items were reversed. Reprinted with permission from G.E. Hardart and R.D. Truog, "Attitudes and Preferences of Intensivists Regarding the Role of Family Interests and Decisionmaking for Incompetent Patients," *Critical Care Medicine* 31, no. 7 (2003): 1895-1900.

not correlate with the respondents' preference regarding models.

IMPLICATIONS OF THE PRIMARY RESULTS

These findings suggest that physicians in practice — specifically critical care physicians who are routinely involved in making decisions with tremendous consequences regarding patients' survival, quality of life, and family — hold preferences and attitudes regarding making medical decisions that are not predicted by the traditional, individualistic standard for making these decisions that has been developed, taught, and institutionalized by the medical profession in the last half century. Our findings support what certain authors, most notably John Hardwig and James Lindemann Nelson, have argued for the last 15 years — that the current standard of purely individualistic decision making that is considered to be orthodox by the medical profession does not serve as an effective model for real patients as they are encountered in the real world, as people accompanied by persons with whom they have strong personal relationships.[3] It is striking that the sizable majority of physicians in our study who preferred family-centered decision-making strategies effectively espoused an approach to decision making not even offered as an option (let alone taught as the standard) in commonly read medical ethics texts or the curricula of American medical schools. How do these physicians justify their preferences? Where do they acquire them? While we did not directly address these important questions in this limited survey, certain clues to the thought processes of the survey respondents will be discussed in subsequent sections. Ultimately we are left to speculate about the meaning of these findings; in an editorial that accompanied an earlier article reporting our results, Lindemann Nelson argued that our survey "gives reason to believe that concern about the moral standing of families in healthcare decision-making is not restricted to a small number of dissident bioethicists or family advocates, but operates strongly in the way in which at least some physicians understand their own responsibilities in the light of moral tensions involved in contemporary health care."[4]

Pediatricians and Internists

Why is it that the pediatricians in our study preferred family-centered decision-making strategies more than doctors in our study who treated adults? It is often said in pediatrics (and family practice, for that matter) that "the family is the patient," but this rather vague maxim may simply reflect the observation that the family serves as informants, caregivers, and surrogate decision makers in the vast majority of pediatric cases.[5] To the extent that it difficult to separate a patient from her or his family as a practical matter, it follows that the family is the patient. The findings of our survey, however, suggest something deeper. Applying the conceptual framework tested in our survey, we find that physicians tended to be less protective of patients' interests and more willing to consider the interests of family members when they treated children and neonates. While the notion that physicians would not protect the interests of infants and children as vigorously as they would an adult may, at first glance, seem offensive, deeper reflection suggests that it may have an ethical basis.

First, as never-competent individuals, young children have not developed the capacity to acquire values, preferences, or personal conceptions of the good life, and so they have no personal values (distinct from the values of their families) to serve. A neonate is in no position to exercise self-determination, and so there is no autonomy to be respected. Consequently, the potential for insoluble conflicts between the patient's interests and the family's interests is greatly diminished and takes on an almost abstract quality that has little relevance in day-to-day medical decision making.

Second, a neonate's future is so dependent on its family's future that, at that point in time,

the patient's interests and the family's interests may seem to be completely fused. Studies have consistently reported that the health of patients is directly related to the "health" of the family, across a range of medical conditions.[6] Therefore, to act in the family's interests is to act in the patient's interests, and to act against the family's interests is to act against the patient's interests.

Third, our society entrusts parents with the power to determine what is in the best interests of their child. Traditionally, a high threshold must be met before physicians and the state can challenge and overrule determinations by a child's parents.

Fourth, the authority of parents extends beyond their discretion in determining a child's best interests. In fact, parents are not required by society to always act in their child's best interests. Countless societally accepted examples of parents acting in ways that are not in their child's best interests exist: deciding not to send Max to baseball camp so that Annie can take piano lessons; choosing to send a child to an inferior school to save money for other purposes; removing children from school to attend a parent's college reunion as a family; to name a few. In essence, society has traditionally allowed parents and families to compromise the interests of children to serve familial goals and purposes.[7] In healthy families, a natural balance develops between the interests of individual family members and the family itself, and society (including the pediatric profession) gives parents wide latitude in raising their children.

Healthcare Rationing

The debate over the proper role of the interests of the family in making medical decisions bears similarities to the debate over the proper role of bedside rationing in making medical decisions. In both cases, the patient-centered ethic of decision making is challenged by the observation that the patient is not the only person affected by these decisions. It has been argued that all parties who will be seriously affected by a medical decision must be considered when such decisions are made, to meet the requirements of distributive justice.[8] It was our hypothesis that, if this was so, we would find a correlation between our respondents' attitudes supporting the rationing of healthcare services and their preferences regarding family-centered decision making. Indeed, not only did we did find a statistically significant relationship between support for bedside rationing and family-centered decision making, but the relationship was the most statistically robust correlation in our results. Fully 89 percent of those respondents who supported the rationing of healthcare services preferred either the Intrinsic Model or the Pure Family Interests Model. We infer from this finding that an appeal to distributive justice is at least part of the respondents' justification for preferring family-centered decision making.

There are, however, some important differences between rationing healthcare services and family-centered decision making that must be developed. "Healthcare rationing" is used to describe a variety of practices, but its unifying theme is a consideration of the monetary cost of medical tests and treatments to society. Close scrutiny of our survey items concerning healthcare rationing reveals that we tested the attitudes of our respondents toward one specific type of healthcare rationing: rationing at the bedside. The essence of rationing at the bedside is that medical professionals use their discretion and professional knowledge to save money (serving the interests of society) while they provide adequate, if not the best, care to their patients. Some see physicians who act in this way as "good citizens" who merely recognize the inevitable necessity of considering cost in decisions regarding healthcare services.[9] To others, these physicians are "double-agents" who are less likely serving society's interests than lining their own pockets, or filling the coffers of a hospital or insurance company.[10] Even granting these physicians the best motivation, critics see the potential risks of rationing at the bedside: by diluting the fiduciary duty of

physicians to patients, rationing may erode trust in the medical profession, which remains a critical component of the healing relationship between doctors and patients. One final concern is the fear that physicians might make discretionary determinations without the explicit knowledge of, or involvement of, the patient — which magnifies the possibility that such behavior may limit fair access to care for members of certain groups.

In contrast, in family-centered decision making, patients' interests are balanced against the full range of a family's interests, not just their financial interests. Additionally, the possible impact on the family of a medical decision, while the decision may involve many assumptions and a great deal of uncertainty, is less abstract than a general appeal to the interests of society expressed in dollars. Finally, the decision-making process in these cases will virtually always involve participants other than physicians (that is, members of the patient's family), who will typically be exquisitely sensitive to and aware of potential consequences for the patient and his or her family. The involvement of family members in making decisions will likely serve as a check limiting the opportunity for physicians to unilaterally make decisions that favor the family's interests. Nevertheless, it is possible that physicians might bias medical decisions for the patient to favor the interests of the family without explicitly disclosing such bias. For example, neonatologists who claim that they are purely promoting the best interests of the neonate may actually be giving parents a range of options that includes sacrificing the interests of the neonate for the interests of the family as a whole.

Protection and Trust

Even the most ardent promoters of family-centered approaches to decision making admit that not all families are healthy and harmonious, and that the potential for some proxies to act with malice toward their family member is very real.[11] It is not surprising, therefore, that 78 percent of the respondents agreed that physicians should protect their patients from others who have competing interests.

Of course, one of the most consistent arguments used to defend a patient-centered ethic in surrogate decision making is that it is foolhardy to assume that all family members will have proper motives.[12] Further, it has been argued that the very nature of families — as close communities with shared values, goals, interests, and identities — makes family members *less* qualified to serve as surrogates, as their close, intertwined relationship with the patient would make it difficult for physicians to detect choices that are driven by factors other than the patient's interests.[13] If this highly skeptical attitude were prevalent, we would expect that physicians in our study who strongly preferred the Intrusive Family Interests Model would not trust the motives of surrogates who were family members. After all, such a mindset suggests that a high degree of suspicion of such a surrogate's motives would be a prerequisite to aggressively protect patients' interests, and that even the tightest scrutiny might fail to detect deviation from exclusive consideration of patients' individual interests. Consequently, we were surprised to find that the degree of skepticism our respondents had regarding the motives of surrogates who were family members did not correlate with their preferences regarding the models for decision making. In fact, only 16 percent of respondents reported that they did not trust family surrogates,[14] while 16 percent were neutral and 55 percent trusted families' motives. These findings lead us to construe an encouraging mindset of physicians in practice — that they generally trust that the families they work with have good intentions as they make difficult decisions, but feel it is their fiduciary duty to protect their patients' interests nonetheless.

Experience and the Family-Centered Ethic of Decision Making

Our data (after it was adjusted for confounding) support the notion that more expe-

rienced physicians tend to prefer family-centered decision-making strategies. Why might this be so? One attractive and plausible explanation is that inexperienced physicians are merely expressing the priorities that were clearly established in their medical education. How else would we expect young physicians to handle these admittedly "messy" situations, other than to refer to the principles they have learned in their training? Without other influences, it is entirely predictable that they would rely on the orthodoxy of the principle of respect for autonomy, as established in the halls of medical school, residency lectures, and standard textbooks.

How experience leads to a more family-centered approach calls for even more speculation. Yet we argue that it is precisely experience — phenomenal experience in direct medical care of patients as well as in one's personal life experience independent of professional practice — that leads clinicians to question approaches that are strictly patient-centered, as they struggle to apply these approaches to the morally complex and important scenarios they encounter in real life, as opposed to hypothetical situations from textbooks. The rivalry between an ethic that values decisions made by family members and the prevailing ethic for medical decision making is manifested in such a progression of experience. A realization that patients are not rugged individuals who demand to have their interests "maximized" seems to come with experience. And, with experience, physicians learn to acknowledge the inadequacies of the traditional paradigm of medical decision making and to rediscover the virtue of a more complex, but more realistic, paradigm that includes the patient's family.

This Study and the Ethical Debate Over the Role of Families' Interests in Medical Decision Making

These data suggest that, among American physicians, there is probably not a monolithic acceptance of a patient-centered ethic of decision making that has served virtually as a mantra for medical educators and bioethicists in the last few decades. While it is appropriate to be circumspect in drawing sweeping conclusions from a limited study such as this one, we found that family-centered decision-making strategies may actually be more the rule than the exception, at least in the critical care setting.

Assuming these fairly conservative conclusions to be correct, there is a great deal of work to do and a great number of questions to be answered, including:

- How are such attitudes applied in the clinical setting by physicians?
- It has been suggested that families conceal their consideration of their interests because the medical system actively discourages and stigmatizes anything but the most patient-centered approach. Is this true? Do physicians who support family-centered approaches similarly feel stigmatized and conceal their beliefs?
- What does it mean to take families seriously? Does it mean favoring a family's interests over the patient's interests? Does it mean allowing a family's "usual" decision-making processes to continue, with less interference by the medical community? Does it mean that the medical community should take more responsibility for how the consequences of a medical decision may affect a family's interests?
- What are the attitudes and preferences of the lay public regarding this issue?
- Do today's medical educators adequately prepare young physicians for the types of decision-making situations they can be expected to confront?
- Should the medical system be refashioned to support, perhaps even encourage, family-centered decision making?
- Would the rights and interests of vulnerable patients be put at risk by adopting a system that promotes family-centered decision making?

That so many of the physicians in this cohort confront these issues on a frequent basis argues for explicit and serious consideration of this issue by the medical community.

That experiences seem to lead physicians to manage difficult situations in a more comprehensive manner is intriguing, and suggests that prevailing decision-making models may be deficient; however, it is unlikely that experience, trial and error, and intuition represent the optimal approach to improve how decisions are made.

Empirical research can begin to answer some of these challenging questions. Equally important, however, to improving our such processes is open, informed, and structured debate — in medical schools, professional organizations, hospitals, and doctors' offices. Medical ethicists can play a vital role in this process by providing a moral framework that clinicians and families can use to explore how to develop new decision-making paradigms that are designed to serve the needs of patients and their families more fully.

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Clinical Research Ethics

The State of Research Ethics: A Tribute to John C. Fletcher

Franklin G. Miller and Jonathan D. Moreno

The ethics of research involving human subjects was one of the first topics on the agenda of bioethics when it emerged approximately 40 years ago. It remains central to the work of bioethicists today in scholarship, teaching, and institutional service. We dedicate this essay on the state of research ethics to the memory of John C. Fletcher, who died 27 May 2004. From the beginning to the end of his remarkable career, he grappled with ethical issues relating to human experimentation.[1]

As a young theologian interested in ethics, Fletcher undertook fieldwork at the Clinical Center of the National Institutes of Health (NIH) in the mid-1960s, at a time when American theologians, philosophers, and legal scholars began to focus systematic, ethical reflection on medicine and biomedical research. Fletcher wrote what may be the first PhD dissertation in bioethics, devoted to the ethics of clinical research, with particular attention to informed consent. The very first issue (1973) of *Hastings Center Studies,* an early publication of the Hastings Center, contained an article by Fletcher entitled "Realities of Patient Consent to Medical Research."[2] Facing the realities of research involving human subjects from a moral perspective occupied much of Fletcher's professional attention over the next 30 years. From 1977 to 1987 he served as the first chief of bioethics at the NIH Clinical Center, bringing the "soft" but powerful discipline of ethical thinking to bear on hard-core biomedical investigation. Fletcher's last sustained systematic contribution consisted of a commissioned paper for the National Bioethics Advisory Commission (NBAC) on the ethics of embryonic stem cell research, published in 2000.[3]

Over time, religious vocabulary dropped out of Fletcher's ethical reflections, and he ultimately resigned from the ministry. However, he carried the pastoral style of teaching and

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leadership into his secular vocation of bioethics. Teaching and preaching interpenetrated in Fletcher's work. Accordingly, we have developed this essay on the state of research ethics today as a secular sermon, oriented around five maxims that encompassed Fletcher's scholarship and teaching on the ethics of clinical research. (1) Because moral goals conflict, balancing competing considerations is unavoidable. (2) Bioethicists need to do their homework to understand methodological issues relevant to research design. (3) The history of research ethics is an invaluable source of moral reflection. (4) Institutional resources for promoting the ethics and regulation of clinical research must be developed, and their integrity must be maintained; and (5) Respect for the self-determination of research subjects remains a basic moral requirement. These maxims, and the issues to which they pertain, remain salient in contemporary research ethics and vital to progress in this domain of bioethics. Neglecting the moral force of these maxims, we shall argue, accounts for some of the prominent weaknesses in current scholarship and practical service in the field of research ethics.

COMPETING MORAL CONSIDERATIONS

Research ethics is often understood as the protection of human subjects of biomedical research. Though obviously central, this is only part of the story. The ethical imperative to protect human subjects operates as a moral constraint on the ethically grounded goal of promoting socially valuable science in the service of public health and improving medical care. Whereas the primary benefits of clinical research accrue to future patients and society, the risks and burdens of research interventions are borne by research subjects. This is not to suggest that there are no benefits to research subjects deriving from their participation in research. In some cases, enrolling in a clinical trial offers the best medical option available to some patients. Yet virtually every research study involving human subjects poses some risks to subjects that are not compensated by the medical benefits to them. Many studies carry risks to some or all subjects without any prospect of direct medical benefit. Accordingly, the central challenge of research ethics is how to promote valuable and valid scientific investigation without exploiting research participants.

The very nature of research involving human subjects, from a moral perspective, calls for a readiness to compromise experimental design to protect human subjects. Anyone with moral sensitivity recognizes that methods of valuable experimentation that pose lethal consequences to laboratory animals such as rats and mice would be "unthinkable" in the case of human subjects. Nevertheless, the dark history of human experimentation in Nazi Germany involved just such unthinkable abuses of human subjects, who were treated essentially as laboratory animals—research that was rationalized by the fact that the human subjects were condemned to die in any case, and that they came from a despised ethnic group believed by the investigators to be subhuman.[4] Lesser but morally outrageous abuses of human subjects occurred in the United States, despite *The Nuremberg Code*.[5]

Santayana famously declared that those who cannot remember the past are condemned to repeat it.[6] But we also are at risk of learning the wrong lessons from history. It would be a mistake to infer from this historical legacy of abuse in experimentation involving human subjects that the only ethical desideratum is to protect the subjects. If we take seriously the moral considerations favoring the pursuit of biomedical research, then we must recognize that, inevitably, tensions and conflicts arise between promoting socially valuable science and protecting human subjects. How do we balance, and make the tradeoffs necessary to do justice to, these competing moral considerations?

Situations that call for moral balancing often provoke moral discomfort. In cases of moral complexity, it is natural to search for

moral formulas that give us the right guidance without facing the burdens of moral uncertainty and fallible judgment. Thus bioethicists not infrequently appeal to absolute, categorical pronouncements aimed at settling moral conflicts. A notable example is the principle of clinical equipoise, widely believed to be an unassailable axiom governing the ethics of clinical trials. This principle requires, as a condition for ethical clinical trials, the existence of a state of uncertainty in the expert medical community concerning the therapeutic merits of the treatments under investigation, and other clinically available treatments, if any.[7]

Clinical equipoise is often invoked to rule out randomized, placebo-controlled trials whenever a proven, effective treatment exists for the disorder under investigation. Behind this principle lies the seemingly unobjectionable idea that patients who seek treatment in the context of a clinical trial should not have their medical care compromised by being randomized to interventions known to be inferior to the standard of care. Apart from conflating the ethics of clinical research with the ethics of medical care, clinical equipoise pre-empts ethical reflection aimed at balancing considerations of scientific validity in the design of clinical trials with adequate protection of subjects from undue risks of harm.[8] To be sure, in many cases the implications of clinical equipoise would be endorsed by all morally serious commentators. Virtually no one advocates randomizing patient-volunteers to placebo controls, when withholding clinically available treatment would pose substantial risks of death or irreversible, serious morbidity. But there exists a wide range of cases in which placebo-controlled trials are methodologically indicated, and the risks to subjects from withholding proven effective treatment are relatively minor or not excessive, so long as adequate safeguards are in place.[9] Is it clear that the use of placebo controls is always unethical in such situations? If not, how do we decide what level of risks to subjects is morally acceptable and what criteria must be met for these trials to be ethically justifiable, all things considered?

Clinical equipoise is by no means the only example of this strategy of evading moral conflict by issuing categorical pronouncements. A related case is the debate over invasive placebo controls in randomized trials of surgical interventions. Faced with the complex case of a sham-controlled trial evaluating fetal neural tissue transplantation to treat refractory Parkinson's disease, several bioethical commentators went far beyond the facts of the case at hand to claim that sham surgery is always unethical.[10] They argued that it violates the therapeutic obligation of physician-investigators to promote the medical best interests of patients enrolled in surgical trials and/or that it necessarily violates the ethical requirement to minimize risks. Ethical analysis of sham-controlled surgery trials that pose considerably less risks to subjects than the case of fetal tissue transplantation research demonstrates that the categorical prohibition is erroneous.[11]

The point of invoking these examples is not to contribute to the debate over placebo-controlled trials; rather, it is to suggest that some prominent positions in research ethics short-circuit the challenging task of balancing competing moral considerations. Moreover, we speculate that such positions become entrenched, despite being dubious in theory and practice, because they promote the comforting illusion of moral certainty, which obviates the anxiety provoked by moral conflict and the hard work of seeking morally satisfactory, but uncertain, compromises aimed at doing justice to competing moral considerations. John Fletcher, who late in his career came to embrace American philosophical pragmatism as a guide to bioethics, always eschewed "the quest for certainty." The first chapter of John Dewey's masterpiece, *The Quest for Certainty,* is entitled "Escape from Peril."[12] The search for and appeal to categorical, absolute principles manifests an escape from the peril of uncertainty inherent in the task of facing and balancing conflicting val-

ues and norms. In formulating ethical positions, Fletcher didn't always get it right, but he never flinched from the challenge of making fallible but reasoned judgments, knowing that reasonable people might differ.

Once we take to heart the recognition that research ethics inescapably involves balancing the competing moral considerations of promoting valuable science and protecting subjects, it becomes apparent that there are two ways that we can go wrong in the effort to find morally satisfactory resolutions. First, we can err by failing to provide adequate protection for human subjects. The severe abuses of the past have largely been avoided, owing especially to the innovation of prior independent review and approval of research protocols, which we discuss below. Nonetheless, complex issues of trial design continue to raise difficult challenges for the protection of subjects, as exemplified by the recent debate over a prominent critical-care trial comparing two methods of mechanical ventilation.[13] Second, we can err by unduly constraining valuable research. Overprotection of human subjects may prevent or severely hamper the conduct of important studies with significant potential for improving medical care, when such studies might be designed in a way that provides adequate protection of subjects. Vigilance, creative thinking, and honest debate are needed to find acceptable balances of the competing moral considerations at stake in the design and conduct of clinical research.

UNDERSTANDING SCIENTIFIC DESIGN

The most interesting and difficult issues of research ethics derive from the intersection of methodological considerations relating to the design of research and ethical concerns for protecting subjects. It is tempting to see this territory as "science versus ethics," and to adopt the moral posture that ethics trumps. However, this perspective is based on a false dichotomy. The first two requirements of research ethics are that research protocols must have adequate potential social value and that these studies must be designed with sufficient methodological rigor to produce valid results.[14] Otherwise, the risks to which research participants are exposed cannot be justified. It follows that methodological considerations are integral to research ethics.

When bioethicists operate with a mindset that problems in research ethics are a matter of science versus ethics, they may presume that they possess the moral resources necessary and sufficient to resolve these problems without the need to study carefully the methodological considerations that are relevant to sound study design. This presumption is erroneous. The ability to diagnose pertinent ethical issues and balance competing moral considerations depends on appreciating the scientific reasons that underly the choices of research design that investigators make and defend. When participating in institutional review boards (IRBs), bioethicists are just as responsible for making judgments about the social value of research and the adequacy of research design as members with scientific training, although they certainly may need to seek advice from experts.

Moreover, the obviously ethical requirement of minimizing risks is impossible to apply without bringing methodological considerations to bear. Minimizing risks is not an imperative to eliminate risks, which would prevent nearly all clinical research; nor does it require that research risks are no more than "minimal." Rather, it calls for choosing those research designs that are methodologically adequate for producing valid, generalizable knowledge and that pose the least risks to subjects. For example, in the case of surgical trials aimed at evaluating treatment efficacy in terms of an inherently subjective outcome such as relief of pain, it is arguable that methodologically sound research design requires a sham surgery control.[15] These trials, then, satisfy the requirement of minimizing risks, despite the fact that they pose more than minimal risks to subjects who have been randomized to the sham control without the prospect of compensating medical benefit.

The upshot of these reflections is that bioethicists who are interested in research involving human subjects need to develop a basic understanding of the methodological principles of research design and do their homework in studying research protocols and the relevant scientific literature. Otherwise, they are ill-equipped to engage responsibly in debates over complex issues of research ethics. If the categorical pronouncements criticized above held sway, then bioethicists would be free of this professional obligation. There is no need, for example, to understand the methodological reasons for using placebo controls, despite proven effective treatment, if clinical equipoise is a valid absolute requirement of all clinical trials. It suffices to know that proven effective treatment exists. Such moral simplicity, however, *is* simplistic. There is no professional substitute for bioethicists doing their homework. Long experience in the ethics and regulation of research involving human subjects, and the exemplary performance in this respect of John Fletcher (who always did his homework), indicate that this responsibility is not merely an onerous task, but a source of intellectual stimulation, as well as a vital component of moral reflection.

THE RELEVANCE OF HISTORY

Bioethicists are not required to be historians, but they are obliged to be informed about the origins, development, and historical context of the central concepts of the field. This professional requirement follows from the fact that bioethics is, in part, a humanistic study, and that human values are shaped and tested in the crucible of concrete experience. Nor can we escape our collective past; it lives in our language and subsists in the way we conceptualize the moral life and the ethical problems that confront us.

A bioethics that lacks historical self-consciousness is liable to lapse into smug self-confidence about the soundness of its moral compass, and a naïvete about its intersection with social, political, and economic currents. Take, for example, the standard "origin story" of bioethics, that it emerged practically *de novo* in the late 1960s among a few farsighted physicians, philosophers, and theologians in response to drastically novel issues created by breakthroughs in the life sciences. These few perceptive thinkers, the story goes, suddenly recognized the unacceptable influence of physicians' paternalism; the social implications of genetics, artificial organs, and organ transplantation; and the threats to human dignity represented in thoughtless applications of technology.

This account not only ignores the complex history of medical ethics, it removes the founders of modern bioethics from their personal and professional experience, and suggests a purity of purpose that drains the field of its relevance. For example, the original icon of research ethics, Henry Beecher, had written about problems in human experiments since the late 1950s, a period during which he and many other distinguished scientists were supported by federal agencies that were interested in the national security implications of their work. Beecher himself conducted LSD research under military auspices and regularly updated the Central Intelligence Agency on his talks with his European colleagues.[16]

Beecher died in 1976, just as the first series of scandals about secret government-sponsored experiments were being investigated, so we will never have direct knowledge of his views on the matter. But we do know that Beecher was a profoundly religious man who read the Bible daily. In a 1994 interview, Beecher's former research assistant and Louis Lasagna, also an early commentator on bioethics, reflected "not with pride" on that period.[17] Beecher's subsequent interest in ethics and his preoccupation with the need for virtuous investigators must surely have flowed partly from similar considerations.

Beecher's devotion to the ideal of the virtuous scientist as the best protection for the human subject of research, the position for which he was criticized by Fletcher, also led

him to oppose the application of *The Nuremberg Code* by Harvard researchers. Beecher took this position in 1962, when U.S. Army contracts began to incorporate *The Nuremberg Code* by reference. He joined a committee of Harvard faculty that protested this measure until the Pentagon backed down and agreed to let the scientists devise their own ethics code.[18] Our point is not to depreciate the courage required for Beecher to separate himself from many of his colleagues and identify unethical practices in his justly celebrated 1966 essay, but to exemplify the complexities and ambiguities of the origins of modern bioethics in the experience of one of its founders, and the relatedness of bioethics to society well beyond the boundaries of medical science itself.[19]

Similarly, to learn that *The Nuremberg Code* was adopted by the U.S. Department of Defense long before its tenets were recognized as applicable to civilian research, or that at least some research hospitals had IRBs 40 years before they were mandated by federal regulation, or that scandals and debates about the morality of experiments involving human subjects started as early as the 1890s, challenges our prejudices and vastly enriches our appreciation of the depth of the problems confronted today and how much we owe to previous generations. Perhaps even more jarring for Americans is the way that our German colleagues view the history of bioethics, as rooted in the first journal devoted to ethics in medicine (called simply *Ethics*), which started in the early 1930s as a forum for serious debate about values in medicine, and deteriorated into an organ for Nazi eugenics. Our judgment is likely to be far more measured and supple as our sophistication about the forces at work in bioethical issues is informed by a quantity of experience far greater than any one generation can acquire.

John Fletcher enjoyed his role as a continuous student of the history of bioethics because he understood that the past resides in the present. Although the victims of the Tuskegee Syphilis Study received federal compensation in 1978, Fletcher appreciated that money does not in itself provide moral closure. Thus, in 1995 at a public meeting in Charlottesville, Virginia, he proposed a long overdue presidential apology, an idea that made its way to the White House and was realized in a Rose Garden ceremony in 1997, just before the deaths of the study's remaining survivors. Fletcher's concern with this issue joined his early and long-standing commitment to the Civil Rights Movement with his understanding of bioethics as a social and political movement.

THE INSTITUTIONAL DIMENSION OF RESEARCH ETHICS

The leading innovation in the history of research ethics is prospective independent review of protocols for clinical research. The familiarity of this institutional innovation obscures its vital importance. *The Nuremberg Code* makes no mention of independent review. Nor was it mentioned as a safeguard in the path-breaking 1966 essay by Beecher that exposed abuses of research subjects in studies conducted by leading investigators, mostly in prestigious academic medical centers and often funded by the U.S. government.[20] In a valuable historical essay on informed consent to research, Fletcher criticized Beecher for emphasizing the integrity of the conscientious investigator as the primary safeguard for protecting human subjects.[21] He rightly argued that oversight by an impartial, independent committee whose members had no vested interest in the particular research project under review was essential both to assure that the rights and well-being of research subjects would be adequately protected, and to provide an institutional mechanism of public accountability for a social practice that exposes some to risks for the benefit of society.

The interests of investigators who seek to promote their professional careers in conducting biomedical research inherently diverge from the interests of patient-subjects who participate in clinical trials to receive potential

medical benefits or to contribute altruistically to the improvement of medical care. This divergence opens the door to exploitation, especially insofar as patient-subjects confuse research with medical therapy or feel under pressure from their treating physician to enroll in research. The primary purpose of the IRB is to protect human subjects from exploitation and harm while at the same time permitting valuable research to go forward.

Independent review is, in part, a mechanism of peer review, familiar to the scientific world. But it is more than that, because the federal regulations that mandate review and approval by IRBs require that these committees include at least one member who is not a scientist and at least one member who has no other affiliation with the research institution.[22] In addition to being charged with protecting subjects, these committees must include members who do not bring a professional commitment to biomedical research to the table. Many IRBs also include bioethicists as members.

The IRB can be seen as an example of democratic governance, even though there is no democratic procedure involved in appointing or removing its members. Just as national defense is too important to be left up to the generals, so the design and conduct of medical research should not be left to the discretion of investigators. Ethics is everyone's business. The fact that IRBs make their decision by vote, with a majority determining the outcome, signifies that the voice of each member ultimately counts equally.

The role of bioethicists on IRBs has not received the attention it deserves. The medical world is governed by a culture of expertise. In this world, the bioethicist may be seen as an ethics expert. Long ago, Ruth Macklin distinguished between expertise *about* ethics, which bioethicists possess, and expertise *in* ethics, which is a philosophically dubious concept.[23] Even if expertise in ethics exists, there is no guarantee that it will be possessed by those who have most assiduously cultivated expertise about ethics. Although moral wisdom exists, it is probably a category mistake to understand it as expertise. In any case, bioethicists can make no claim to moral wisdom simply by virtue of long pursuit of ethical scholarship or competence in ethical analysis. Nonetheless, bioethicists may be perceived as experts in ethics, and it behooves them not to cultivate the false impression that this is the case.

Despite a proper humility about the source of their expertise, bioethicists still may find themselves in a position of power or authority. Their voices may carry considerable weight, not based on the transparent rightness of their views or the merits of their arguments, but because they come from a person with the professional credentials of being a bioethicist. Bioethicists should take care, accordingly, that their expressed views have been reflectively validated and that they are backed by cogent arguments. They owe this responsibility, both on the basis of professional integrity, and as a morally appropriate accompaniment to the power they exercise, even when this power derives from a misperceived ascription of expertise.

IRBs work best when their mission is understood to include an educational dimension, in addition to passing judgment on research protocols and assuring compliance with regulatory guidelines. Here bioethicists have an important role to play in sparking moral reflection, elucidating confusions that impede accurate moral judgment (most notably the pervasive tendency to regard clinical trials from a therapeutic perspective that distorts moral reflection and judgment), and making sure that all morally relevant considerations have been articulated and duly weighed. The role calls for a willingness to be a Socratic gadfly. When bioethicists do their homework in coming to appreciate methodological considerations relevant to research design, their educational role is more likely to be respected.

THE ENDURING IMPORTANCE OF INFORMED CONSENT

In the history of research ethics, the moral importance of informed consent has both been exaggerated and underappreciated. The first

principle of *The Nuremberg Code* declares, "The voluntary consent of the human subject is absolutely essential."[24] Strictly understood, this cannot be a sound principle for research that involves human subjects, for it would rule out research involving children and incompetent adults, making it impossible to make progress in combating dreaded diseases that afflict these populations. Even in the case of research involving competent adults, it is a mistake to see informed consent as *the* cornerstone of research ethics. Issues of informed consent should not even come into play in evaluating research protocols, unless these studies have been assessed as having adequate potential value, deploying valid methods, selecting subjects fairly, minimizing risks, and offering a favorable risk-benefit ratio.[25]

Putting informed consent in its place, however, also involves giving this moral consideration its due. Recently, some disturbing trends have emerged in the research ethics literature that point to unjustified erosion of commitment to informed consent. Three articles are notable in this respect. Truog and colleagues argued a few years ago that informed consent for participation in research is not ethically necessary in a class of randomized trials that compare two medically indicated treatments for a given disorder that pose comparable risk-benefit profiles, such that the reasonable patient would have no reason to prefer one over the other.[26] In this situation, an informal informed-consent process that is adequate to medical treatment should ethically suffice. Specifically, if this position is sound, there would be no reason to inform patient-subjects of randomized treatment selection. Recently, Sreenivasan has argued that it is a mistake to require that research subjects enrolled in randomized controlled trials (RCTs) possess some minimal degree of understanding about the basic elements of participation in research.[27] As long as trials have been judged by a competent IRB to meet the basic ethical requirements, including a favorable risk-benefit ratio, the duty of obtaining informed consent requires adequate disclosure of relevant information, but not comprehension on the part of subjects. Empirical evidence regarding the understanding of trial participants indicates that many, if not most, fail to understand basic elements disclosed in the informed-consent process, such as randomization, and they confuse the experimentally structured allocation and provision of treatment in RCTs with the patient-centered context of medical care. If comprehension of these features of participation in research were strictly required, many valuable RCTs would be judged ethically invalid. Accordingly, ethical honesty calls for a minimalistic requirement of informed consent. Finally, Evans has recently contended, in an even more-radical article, that we should dispense entirely with voluntary participation in many RCTs.[28] Since all patients benefit from the progress of medical research, they should be subject to a legally enforceable duty to participate in available and clinically appropriate RCTs when they seek care in a public healthcare system. He uses taxation as an analogy to bolster the position that voluntary consent is not a valid requirement.

Each of these positions warrants detailed critique. We limit our discussion here to examining the ethical premises that underlie these provocative but dubious challenges to informed consent. The doctrine of clinical equipoise, criticized above, plays a central role in grounding these positions. It is important to point out that there is no inherent logical connection between clinical equipoise and ethical positions that obviate the need for informed consent. Certainly, it was not part of the agenda of Benjamin Freedman, who developed the concept of clinical equipoise, to promote the sorts of positions advocated by Truog and colleagues, Sreenivasan, and Evans. Nonetheless, the doctrine of clinical equipoise attempts to bring the RCT under the Hippocratic ethical umbrella that covers therapeutic medicine, such that the therapeutic obligations of physicians to their patients can be preserved in the context of participation in trials. Insofar as it is presumed that when clinical equipoise obtains, participation in a trial is ethically congruent with medical care, the

stage is set for arguing that no more is needed for informed consent to participate in an ethically justified RCT than to receive medical care. Such a position is explicitly adopted by Truog and colleagues, who emphasize that trials for which informed consent for participation in research is not required must satisfy clinical equipoise. Clinical equipoise is also an explicit background ethical condition for mandatory participation in trials in Evans's argument, and it is implicit in the argument of Sreenivasan.

Contrary to the thrust of the equipoise doctrine, clinical trials must be understood from an ethical perspective as fundamentally different from medical care.[29] Clinical trials are aimed at and designed to produce generalizable knowledge about the safety and efficacy of treatments; in contrast, medical care aims at promoting the best medical interests of particular patients. Consequently, the ethical imperative of respect for persons calls for assuring that research subjects have a minimally adequate understanding of how participation in trials differs from medical therapy. Sreenivasan is right that it is unrealistic and unreasonable to demand full comprehension of all of the ethically relevant aspects of participation in research. It doesn't follow that we should dispense with requiring any level of understanding on the part of research subjects. What constitutes an adequate minimum of understanding and how it is to be assured are tasks for future work in research ethics. However, if we permit the erosion of informed consent as a result of theoretically misguided views about the ethics of clinical trials, or out of despair over evidence that patient-volunteers "just don't get it," then we will have failed to do our part to uphold and maintain the historical legacy of bioethics.

CODA

John Fletcher played a leading role in getting research ethics off the ground. His teaching, including the five maxims around which we have oriented this essay, offers a rich source of enduring moral wisdom regarding the ethics of clinical research. In bioethics almost nothing remains settled. Views that once seemed unassailable are challenged, calling for reconstruction of moral perspectives. Always hard at work in promoting ethics services, doing ethics consultations, teaching, and scholarship, John C. Fletcher used to quip that "bioethics never sleeps." More importantly, his exemplary career teaches us that, in bioethics, there is never a time for "dogmatic slumber."

DISCLAIMER

The opinions expressed are those of the authors and do not necessarily reflect the position or policy of the National Institutes of Health, the Public Health Service, or the Department of Health and Human Services.

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Informed Consent: An End or a Means? A Response to Miller and Moreno

Robert D. Truog

Franklin Miller and Jonathan Moreno's tribute to John Fletcher is a most appropriate memorial to his prestigious career. In addition to his personal contributions to bioethics, I will remember him as a wonderful mentor. At the beginning of my own interest in bioethics, I sent him an unsolicited manuscript, seeking his help and advice. Although we had never met, he spent many hours with me over the phone, developing and revising the paper. Our coauthored manuscript ultimately appeared in the *New England Journal of Medicine,* my first publication in the field. He continued to be a close friend, colleague, and mentor of mine until his death.

Miller and Moreno correctly emphasize that John Fletcher was not a man to be bound by dogmatic orthodoxy, but, as they put it, one who always eschewed "the quest for certainty." They reflect on the importance of this perspective in relation to their own views on placebo-controlled trials, arguing that those who take the position that placebo-controlled trials are always unethical may be seeking the "comforting illusion of moral certainty, which obviates the anxiety provoked by moral conflict and the hard work of seeking morally satisfactory, but uncertain, compromises aimed at doing justice to competing moral considerations."

I was surprised, then, to see that they have taken such a dogmatic position with regard to the priority of informed consent in research. In particular, they referred to "disturbing trends" illustrated by the ideas my colleagues and I proposed several years ago, that outlined conditions under which randomized, controlled trials could be ethically conducted without the informed consent of the subjects.[1]

The essence of our idea can best be expressed in terms of a hypothetical case, closely related to an actual case I recently encountered. Consider a hospital that stocks two different brands of soap for pre-operative scrub of the patient's surgical site. For reasons of simplicity and economy, the operating room leadership wants to standardize the procedures and use only one soap. Rather than arbitrarily choose one brand over the other, or make a choice based solely upon price, they decide to determine which soap best prevents post-operative wound infection.

Prior to the proposed study, each patient is scrubbed with whichever soap the operat-

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ing room nurse happens to pick from the shelf, and both brands are in common use. In the proposal, the hospital plans to stock half of the operating rooms with one brand and the other half with the alternative brand. The hospital already tracks post-operative wound infection, so it will be a simple matter to correlate each instance of infection with the brand of soap used through the operating room logbook. Based on a statistical power calculation, the hospital estimates that they can answer the question within three to four months, at which point they will switch to exclusive use of the superior brand.

When the proposal is presented to the hospital's institutional review board (IRB), however, objections are raised. The IRB correctly determines that the study design is actually a randomized controlled trial, such that the patients are randomized on the basis of their assigned operating room. The IRB therefore insists that all patients give their informed consent before data on them can be used in the study.

As in many hospitals, the operating room is already running under significant personnel constraints. While it could spare the resources to correlate wound infections with brand of soap through the logbook, the leadership decides that they cannot afford to free up a nurse to meet with all patients pre-operatively and seek their informed consent. Seeing no other alternatives, the leadership simply decides to stock only the less-expensive soap, and the study proposal is abandoned.

The case reveals several paradoxes. At the time the study was proposed, patients were scrubbed with either of the two soaps, at the discretion of the operating room nurse. They were not informed that two soaps were in use, that one of the soaps might be more effective at preventing post-operative wound infection, and they were not given a choice about which soap they would receive. Had the proposal been carried out, none of these features of the situation before the study would have been changed by introduction of the study.

Furthermore, if the study had been performed, the operating room personnel would have faced an interesting dilemma of what to do for patients who refused to give their informed consent for the study. One option would be to treat patients who refused consent with the soap stocked in their assigned room, and to honor their refusal only by not using the data on whether or not they had a post-operative wound infection. But if the question is only one of whether to use this data from the medical record, then it is not clear that their informed consent is necessary at all, since informed consent is commonly waived for research involving only data abstraction from the medical record.

Another option for patients who refuse to consent for the study would be to assure that the choice of their soap was not determined by the research protocol. This could be accomplished by randomizing them between the two available soaps, so that there would be no correlation between the soap they received and the room to which they were assigned. The problem with this alternative, of course, is that we generally believe that patients should not be randomized between treatments without their informed consent.

Neither of these approaches can avoid either internal contradictions or absurd implications. Franklin Miller has argued for the clear separation of research from therapy,[2] but cases like this one present difficulties precisely because the implications of the research are virtually identical to those of the therapy.

The IRB would be correct to regard this proposal as a randomized controlled trial, but, by insisting upon a traditional approach to informed consent, it would merely be assuring that a valuable opportunity to improve the care of patients would be lost and that an important medical decision would be made solely on the basis of cost considerations rather than optimal outcomes. While it is true that informed consent is a very important component of the conduct of most randomized controlled trials, in this particular case there would be no reason to believe that the pro-

cess of informed consent would be doing anything to protect or preserve the autonomy or the right to self-determination of the patients in question.

The problem with the priority traditionally given to informed consent is that it mistakes a means for an end. Informed consent is not a goal in itself; rather, it is often an important means for achieving a larger and overriding goal, which is respect for persons. Just as obtaining a signature on the bottom of a form has been mistaken as ensuring the process of informed consent, so has insisting upon the process of informed consent sometimes been mistaken as ensuring respect for persons. In most cases, IRBs should insist that informed consent forms be signed, but it is a mistake to see this as the goal, and, in certain circumstances, informed consent may be perfectly adequate without a signed form. Similarly, the informed consent of the subject should generally be required for the conduct of randomized controlled trials, but it is not the goal in itself, and sometimes respect for the patient's right to autonomy and self-determination can be assured without the necessity of obtaining informed consent. (This idea is not novel — regulations now permit certain types of research on emergency interventions without the informed consent of the subject).

One response to the case study described above is to claim that I have made a category mistake, and that this is not, in fact, a case about research, but rather about quality improvement. Quality improvement initiatives are often conducted without the informed consent of the subject.

This possible solution to the dilemma has a number of problems. The commonly accepted distinction between quality improvement initiatives and research is that quality improvement seeks to acquire local and particular knowledge, whereas research seeks broad and generalizable knowledge. Some have attempted to further elaborate the differences between quality improvement and research,[3] but this fundamental distinction remains. In an operational sense, IRBs commonly state that if one plans on publishing the results of a study, then the activity is research, whereas if there are no plans to publish the results, then the activity may be quality improvement.

Defined as such, the study described above could probably have been approved as a quality improvement initiative, since it was seeking a solution to a local and particular question. But suppose that the hospital had found a difference between the two soaps in the incidence of post-operative infection rates. Should it be prohibited from sharing this finding with the medical community? To the contrary, if the results of the work would be useful to other hospitals, then there must be a countervailing ethical reason why this knowledge should not be published and shared.

But even more to the point, how can it be that the intentions of the researchers determine whether it is ethically necessary to obtain the informed consent of the subjects? The informed consent of the subjects should be required whenever this is necessary to assure that they are being treated with respect. This has nothing to do with whether the researchers are seeking knowledge that is local or generalizable, or whether the researchers are planning on publishing their results. The question of whether informed consent is necessary should be based solely upon patient-centered factors, not upon the intentions of the researchers.

In the manuscript to which Miller and Moreno refer, these ideas are developed more generally, and my coauthors and I proposed five criteria that must be met before an IRB could consider permitting a randomized controlled trial without requiring the informed consent of the subjects. They are:

1. The treatments in either arm of the trial should not require specific informed consent if they were offered separately outside the trial. This is often the case when a trial is comparing two therapies that are already in use, or when an existing therapy or medication is being used for a new indication.

2. Neither arm of the trial should involve more than minimal additional risk in comparison with any of the alternatives. Assuming that the risks associated with each of the options are comparable, then the patient could presumably be treated outside of the trial with any one of the interventions under study.
3. Genuine clinical equipoise must exist between all of the treatment arms of the trial. Although Miller and Moreno dismiss the ethical relevance of clinical equipoise, their view remains controversial.
4. Most importantly, no "reasonable person" should have a preference for one arm of the trial over any other. In other words, whatever differences exist between the treatments being compared, none of them should be relevant to the interests of a reasonable person. This would include not only the direct effects of the intervention being studied, but also the indirect effects associated with the research, such as whether the study would require any extra clinic visits or other inconveniences.
5. Finally, patients should be informed that the institution or clinical setting in which they are being treated uses these standards as guidelines for determining the need for informed consent. This would provide patients with an opportunity to seek additional information about the policy or to transfer their care to another setting if they so choose.

The application of these criteria, with examples of studies that would be permissible as well as prohibited, are described more fully in that manuscript.

One hypothesis, which could be tested empirically, is that studies that meet the criteria we described are often categorized by IRBs as quality improvement initiatives, and are conducted without the informed consent of the subjects. If the hypothesis turned out to be true, it would be evidence in favor of the claim that research is currently being done without informed consent, but that it is labeled as quality improvement rather than research. Or, to state it differently, when IRBs determine that research may ethically be conducted without the informed consent of the subjects, they label the activity as quality improvement. If so, then I suggest we should directly consider the question of when research may be ethically permissible without the informed consent of the subject, rather than trying to preserve the traditional orthodoxy by simply giving these studies a name other than research.

I do not know what John Fletcher would have thought of these ideas, but they certainly would be consistent with his continual willingness to challenge the accepted paradigms, and to achieve what Miller and Moreno call the "hard work of seeking morally satisfactory, but uncertain, compromises aimed at doing justice to competing moral considerations."

NOTES

1. R.D. Truog et al., "Is Informed Consent Always Necessary for Randomized, Controlled Trials?" *New England Journal of Medicine* 340 (1999): 804-7.

2. F.G. Miller and D.L. Rosenstein, "The Therapeutic Orientation to Clinical Trials," *New England Journal of Medicine* 348 (2003): 1383-6.

3. D. Casarett, J.H. Karlawish, and J. Sugarman, "Determining When Quality Improvement Initiatives should be Considered Research: Proposed Criteria and Potential Implications," *Journal of the American Medical Association* 283 (2000): 2275-80.

Informed Consent and the Therapeutic Misconception: Clarifying the Challenge

Gopal Sreenivasan

In their insightful review of the state of research ethics, Franklin Miller and Jonathan Moreno include a discussion of some "disturbing trends" in the literature on informed consent. They regard these trends as threatening an "unjustified erosion" in our commitment to informed consent as a requirement of ethical medical research. As the author of one of the articles discussed in this connection,[1] I am grateful for the opportunity to clarify some of the issues at stake in the debate. While I shall not try to do much more than that here, I agree with Miller and Moreno that these issues merit more sustained examination.

Let me begin by summarizing some important points of substantive agreement. Doctrinally, as it were, I agree with Miller and Moreno that the two core duties of informed consent are morally binding on the conduct of clinical trials: participation in clinical research should be strictly voluntary (consent) and investigators are required to disclose adequate information about the research to prospective subjects (disclosure). Philosophically, it seems that we also agree about two of the central inferences in my critique of the standard interpretation of informed consent. First, from the (apparent) fact that many subjects in clinical trials suffer from a "therapeutic misconception"[2] — in particular, they "systematically misinterpret the risk/benefit ratio of participating in research"[3] — it follows that they fail to exhibit adequate comprehension of the standard disclosure. Second, *if* adequate comprehension of the disclosure is a *necessary* condition of valid consent, then many prospective subjects should be excluded from participation in clinical trials. Enforcing this exclusion would bring enrollment in many valuable and otherwise ethical clinical trials near to a halt.

Where we disagree, of course, is in what to do with these inferences. Specifically, we disagree about whether adequate comprehension *is* a necessary condition of valid consent. I do not think it is, whereas Miller and Moreno (along with most everyone else) do. Yet, before we explore further points of difference, it will be instructive to dispel a misunder-

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standing of the structure of my argument — and hence, of its force — that may arise from Miller and Moreno's presentation.

At one point, Miller and Moreno warn against the erosion of informed consent "out of despair over evidence that patient-volunteers 'just don't get it.' " From this formulation, it is certainly possible to gain the impression that the challenge posed by the therapeutic misconception lies simply in a demonstration that adequate comprehension of the standard disclosure is very difficult to achieve. Adequate comprehension *is* very difficult to achieve (or so it seems), but it hardly follows without further ado — and here I agree with Miller and Moreno — that adequate comprehension is not required. Still less does it follow that investigators should therefore not bother trying to help prospective subjects to achieve it. However, that is not at all my argument.

My argument has a rather different structure. On the one hand, given the difficulty in achieving adequate comprehension of the standard disclosure in a suitable number of prospective subjects, a predictable consequence of enforcing a requirement of adequate comprehension will be to imperil clinical research of considerable moral value and importance. Hence, our *justification* for this requirement had better be pretty impressive, so as to warrant a moral cost of that magnitude. (I assume that the option of espousing, but not actually enforcing, such a requirement is morally untenable because utterly hypocritical). The real challenge posed by the therapeutic misconception, then, is to supply an affirmative answer to the question: Is there an adequate justification for the standard interpretation of informed consent, on which comprehension of the disclosure is a necessary condition of valid consent?

On the other hand, when we actually turn (under pressure from the therapeutic misconception) to examine alternative justifications critically, what we find is that none of them is adequate to warrant a requirement of comprehension. In my *Lancet* article, I mainly examined variations on the argument that comprehension is required to *protect* prospective subjects. I shall not rehearse my criticisms of that argument here, except to reiterate that they are restricted (as, therefore, is my position) to clinical trials in which the ratio of risk to *direct* benefit for individual participants is favorable. In any case, I accept that a more thorough examination of alternative justifications is in order (something I hope to pursue on another occasion). For the present, the important point is that the case against a comprehension requirement rests on the *absence of a sufficient justification* for it, rather than on the difficulties in satisfying it. The practical difficulties exposed by the therapeutic misconception merely serve to help define the scales in which the sufficiency of candidate justifications is weighed — weighed, and found wanting.

Finally, Miller and Moreno suggest that what "constitutes an adequate minimum of understanding and how it is to be assured are tasks for future work in research ethics." It seems to me that this puts the emphasis in the wrong place, especially on the first point. Investigating definitions of an "adequate minimum" of understanding presupposes that some adequate minimum is indeed required. In this context, that is to put the cart before the horse. The fundamental question is *whether* there is sufficient justification to require adequate comprehension of the disclosure in the first place. It is not clear what Miller and Moreno take that justification to be. Their emphasis (in rejecting equipoise) on the distinction between clinical research and medical care suggests an appeal to protection, but elsewhere in their article they (quite reasonably) deny that subject protection is the whole of research ethics. They also appeal to the "imperative of respect for persons." However, this imperative is symmetrical as between informed consent and informed refusal, whereas presumably no one thinks that failure to comprehend the disclosure invalidates a *refusal* to participate in clinical research. I am by no means suggesting that the nature of the justi-

fication for a comprehension requirement is something Miller and Moreno ought to have addressed, let alone settled, in their article. But I do think that addressing this question is a vital task for future work in research ethics, one that ought to be tackled before pondering what makes for an adequate minimum of comprehension.

Although I deny that adequate comprehension of the standard disclosure is a necessary condition of valid consent, I nevertheless agree that it is a goal worth pursuing.[4] Moreover, I also agree that investigators bear some responsibility for achieving it. I therefore agree with Miller and Moreno that it remains an important task to determine how adequate comprehension can be achieved in practice. The difference is that, in my view, this enquiry should be explicitly structured in terms of a *division of responsibility* between investigators and (prospective) subjects. What we need to define, more specifically, is a set of "reasonable steps" that investigators must take to ensure adequate comprehension on the part of subjects. It would be useful to open a debate on what steps are reasonable to require. However, implicit in the idea of only requiring investigators to take reasonable steps is that of a limit, beyond which responsibility falls on the prospective subject, and failure to achieve adequate comprehension does not invalidate consent. Unlike Miller and Moreno, I think we also have to acknowledge that there is some such limit on the investigator's responsibility to achieve adequate comprehension of the standard disclosure.

NOTES

1. G. Sreenivasan, "Does Informed Consent to Research Require Comprehension?" *Lancet* 362 (2003): 2016-8.

2. P.S. Appelbaum et al., "False Hopes and Best Data: Consent to Research and the Therapeutic Misconception," *Hastings Center Report* 17, no. 2 (1987): 20-4; S. Joffe et al., "Quality of Informed Consent in Cancer Clinical Trials: A Cross-sectional Survey," *Lancet* 358 (2001): 1772-7.

3. See Appelbaum et al., note 3 above; compare S. Horng and C. Grady, "Misunderstanding in Clinical Research: Distinguishing Therapeutic Misconception, Therapeutic Misestimation, and Therapeutic Optimism," *IRB* 25 (2003): 11-6.

4. See note 1 above.

Response to F.G. Miller and J.D. Moreno, "The State of Research Ethics: A Tribute to John C. Fletcher"

H.M. Evans

Miller and Moreno's thoughtful and interesting "secular sermon" praises the work of John Fletcher, partly for its virtues and partly by contrast with the perceived vices of more questionable work on the part of others who, in the matter of consent to clinical research, reach conclusions at odds with his own. Unfortunately, I appear to have a small walk-on part in this villainous role discussed near the end of their engaging article. This is a little frustrating, since, in the article of mine that is discussed,[1] I agree with much of what they say in their wider argument and in their thoughtful reflection on some early influences upon modern bioethics. I also cordially endorse their willingness to consider arguments in favor of uncomfortable resolutions to difficult moral challenges in clinical research (although I am unconvinced by their account of acceptably minimized risk in the case of "sham surgery").

Most pertinently, I strongly share their suspicion that superficially attractive categorical pronouncements are, in the wrong mouths, too easily used as a means for evading moral conflict. So I fervently wish that they might not have me in their sights in such a stricture, but sadly I fear that they may, insofar as their main exemplar of a categorical pronouncement is the notion of clinical equipoise, upon which I conditionally ground my arguments. My defense here is signalled, I hope, by the "modest proposal" reference at the start of my article: *What if* we take clinical equipoise seriously?

Let me elaborate on this a little. Miller and Moreno condemn, reasonably enough, arguments founded uncritically upon a theoretically deficient understanding of clinical research. Readers of my article must judge this aspect for themselves, of course, but my argument is a conditional one that proceeds from taking the idea of clinical equipoise seriously. I do not assert that clinical equipoise applies

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in any particular case — as a non-scientist and non-clinician I would be in no position to make such an assertion; rather, I explore what follows from its being true, if and when it ever is true. This conditionality is stated and emphatically restated; my challenge is to those who would assert clinical equipoise and yet deny my conclusion.

I will come back to the question of the consequences of equipoise, but first let me deal with what presumably disquiets Miller and Moreno, namely the headline conclusion that I reach, but which I think they rather misportray. It is misleading to suggest, I contend, that we should "dispense entirely with voluntary participation in many RCTs." Under my "modest proposal," participation in all kinds of clinical research would remain voluntary — but the opportunity to opt-out of *some* very tightly specific kinds of research would come at an unusually high price, that is, the price of being denied free treatment under a publicly funded system, and being asked to obtain treatment elsewhere, not at the public's expense.

This more restricted sense of "voluntary participation" obviously requires some defense, and my article is devoted to that; but one aspect of it is raised distinctly now, and my response here is, I concede, not explicit in my original article.

First, it is not part of the meaning of "voluntary" that the chosen good (be it a process, event, or behavior) be free of cost. I think that I am acting voluntarily when I buy something I want, even though it comes at a monetary cost and monetary costs by definition entail opportunity costs at the price in question.

Second, this surely remains true even if I am buying something that I need, even vitally need, such as food. I definitely have to buy food from time to time; yet on any particular occasion I believe that I do so voluntarily even when I hand over cash for necessary basic foodstuffs, let alone "luxury" foods.

Thus we cannot conclude that my participation in something (be it handing over money or entering into a trial protocol) is nonvoluntary simply because it constitutes the price of getting something that I want, or even need, such as the food on my table or publicly funded healthcare that is otherwise free at the point of use.

Note, also, that my nonparticipation in research effectively comes at a price now, even though officially it does not. The costs are contingent: for example, at a direct and individual level I am sometimes liable to receive somewhat less close medical attention and scrutiny than I would as a research subject; at a general level the overall research effort is delayed to the extent of the recruitment of a replacement participant. (If in practice fewer volunteers are recruited then the price is the statistical security of the data of an additional subject.) This might look like a cost to society in the abstract, but I may well find myself contributing to the price in terms of marginal limitations on the confidence with which my own future treatment is prescribed to me.

Now let us return to the disputed matter of clinical equipoise. The role of equipoise in my argument is to bring out the force of the "modest proposal," that is, to disclose and, in this case reluctantly, to embrace the logical consequences of a declared position. When clinical research is justified on the basis of a claim of clinical equipoise, we are, I think, entitled to take the claim seriously for its implications as well as its rhetorical force.[2] If I *really am* as likely to receive the best available balance of benefit over harm from treatment P as I am from treatment Q, then I *really don't* have any obviously legitimate grounds for preferring one to the other. This is, it seems to me, a logical consequence of taking equipoise seriously — something the clinical research community generally do, and (presumably) wish us as patients to do.[3]

Once we admit there being no grounds for preferring one treatment to another, then much else follows: as I tried to show in stepwise fashion, a randomizing algorithm is as legitimate a means of allocating presumptively equivalent treatments as is the personal whim or hunch of a doctor, providing the presump-

tion is serious. (If it isn't serious in any given case, we shouldn't be using it as the basis of that research protocol anyway.)

Given all of this, my "even more radical" position is, I think, simply an unfamiliar consequence of the doctrine of clinical equipoise as part of the official basis of much clinical research.

Miller's and Moreno's general opposition to this is grounded on their view that "clinical trials must be understood from an ethical perspective as fundamentally different from medical care." The distinct aims of clinical research and clinical treatment are indeed as they set them out (respectively, generalizable knowledge *versus* individual benefit), and, indeed, I set them out myself in exactly such terms — twice, for good measure — in my own article.

But I dispute that their conclusion follows from such differences in aims. First, different aims are not necessarily *ethically* different as such; helping Smith and helping Jones may constitute obviously different aims, yet they can still be ethically comparable, unless we add in compelling moral differences from somewhere else (such as differences in desert, for instance). Second, it is true that helping Smith as an individual and helping humanity as a whole may be ethically different — but we most obviously notice this when we cannot do both at the same time. The point about taking equipoise seriously is that we *presume* it is indeed possible to do both at the same time. In helping humanity as a whole (via the generation of new knowledge or the reduction of future uncertainty) we also at the same time help Smith, because if equipoise is true then we have no reason to think that he is receiving anything other than the best treatment via random allocation. The study results may subsequently disclose otherwise — but so may the course of his ordinary clinical treatment which is, after all, an experiment upon a population of $n = 1$. To repeat, if we don't believe equipoise is true in a particular case, we have no business appealing to it in justification of randomizing someone's treatment, and then my own argument no longer applies (as Miller and Moreno accept: they note, correctly, that it is "an explicit background ethical condition for mandatory participation in trials in Evans's argument"). Other difficult questions would arise in such cases, which my article does not aim to cover.

Finally, Miller and Moreno suggest that respecting patients as persons "calls for assuring that research subjects have a minimally adequate understanding of how participation in trials differs from medical therapy." At one level one could hardly disagree with this. The question is what goes into such an understanding, and I'm not sure that analyzing it should, or need, be deferred to "future work in research ethics." I have set out what I think are compelling reasons — *if* we believe that equipoise applies in a particular case — for showing how participation in clinical trials *aligns with* medical therapy in morally important respects, for all that their aims are distinguishable, precisely because those aims can coincide when (and if) clinical equipoise really applies.

Miller and Moreno find this a radical view, but they do not show that it is wrong. They may claim (if it is indeed my article that they have in mind at this point) that there lurks a "theoretically misguided" view of the ethics of clinical trials, contributing to "the erosion of informed consent," but these strictures are, if the authors will forgive me, unsupported by specific demonstration. I would be glad to find common ground with them over the content of a proper understanding of the relation between clinical research and ordinary clinical treatment. It may be that the research community at some stage, quietly or otherwise, lays aside the notion of clinical equipoise as too-often indemonstrable, or as not being held with sufficient conviction by individual researchers, or, in response to the authors' anxieties, as too ready a means for evading moral conflict — but we should not expect this any time soon. Meanwhile, taking seriously clinical equipoise's specific consequence, that at the point of randomization one may truthfully

expect to receive the best treatment whatever one receives, requires that a "minimally adequate understanding" of the relation between medical therapy and participation in trials covers not only how they differ, but also how they are the same.

NOTES

1. H.M. Evans, "Should Patients be Allowed to Veto their Participation in Clinical Research?" *Journal of Medical Ethics* 30 (2004): 198-203, pp. 199-200.

2. B. Freeman, "Equipoise and the Ethics of Clinical Research," *New England Journal of Medicine* 317 (1987): 141-5.

3. C. Weijer, S.H. Shapiro, and K.C. Glass, "Clinical Equipoise and Not the Uncertainty Principle is the Moral Underpinning of the Randomised Controlled Trial," *British Medical Journal* 321 (2000): 756-8; D. Machin, S. Day, and S. Green, *Textbook of Clinical Trials* (Chichester, U.K.: John Wiley, 2004). E.g., "It is this [genuine] uncertainty which provides the necessary equipoise . . . to justify random allocation to treatment after due consent is given." (p. 14)

Informed Consent and the Ethics of Clinical Research: Reply to Commentaries

Franklin G. Miller and Jonathan D. Moreno

We appreciate the thoughtful commentaries by Sreenivasan, Evans, and Truog, both for their positive remarks about our article, "The State of Research Ethics: A Tribute to John C. Fletcher," and their constructive criticisms, which appear in this issue of *The Journal of Clinical Ethics.* They raise several important issues that deserve much more systematic treatment than is possible in a brief reply. All three rightly criticize us for being dogmatic about informed consent to research in a way that runs contrary to the spirit of our tribute to John Fletcher; accordingly, we are grateful for being awakened from our own "dogmatic slumber."

Sreenivasan argues that the comprehension of research participants is not a necessary condition of valid informed consent to clinical trials and suggests that our assertion to the contrary is question-begging. On reflection, we think that he is correct about both of these points. Nevertheless, it is very important to recognize the limitations of his account of informed consent to clinical trials, as spelled out more thoroughly in his *Lancet* article.[1] There, the claim that comprehension — specifically, the absence of a therapeutic misconception about research participation — is not necessary for valid consent to randomized controlled trials (RCTs) was premised on the condition that such RCTs have a *personally* favorable risk-benefit ratio for the research participants. An example would be a trial comparing two or more medically indicated treatments for a given disorder, as in the important, recently reported research comparing newer antipsychotic medications to an older antipsychotic medication in patients with schizophrenia — an example that is also relevant to Truog's commentary.[2]

We agree that with respect to a trial of this sort, Sreenivasan makes a persuasive case that defective comprehension — for example, in the form of a belief by a participant that she

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will be receiving antipsychotic medication based on a personalized medical judgment of what is best for her — would not invalidate her consent to participate. But it is essential to recognize that RCTs are heterogeneous in their ethically relevant features. Whether, for example, a therapeutic misconception is compatible with informed consent for RCTs that have a personally favorable risk-benefit ratio for all participants but include a placebo control is open to question. Moreover, consider placebo-controlled trials that withhold proven effective treatment. One of us (FGM) has argued elsewhere that such trials can be justified.[3] Although this is a controversial stance, assume for the sake of argument that it is correct. We would dispute that a strong therapeutic misconception about such a trial — for example, an RCT comparing a novel antidepressant agent to a placebo control — would be compatible with valid informed consent. When participants are placed at a predictable prospect of disadvantage in a given RCT, as compared with standard medical care, then some minimal level of comprehension of key features of trial design (such as randomization and the use of placebo controls) is necessary for valid informed consent. Defense of this claim would require detailed discussion. The point of making it here, however, is simply to show that because comprehension is not a necessary condition of valid consent for *all* RCTs, it doesn't follow that comprehension is never required for valid consent. We suggest that an adequate account of valid consent to clinical research requires the type of careful and systematic contextual analysis exemplified by Alan Wertheimer in his *Consent to Sexual Relations*.[4]

Evans's commentary raises some deep issues, especially how to think about voluntariness as it relates to enrolling in clinical research. He correctly notes that his argument would not elide voluntary participation to equipoise-satisfying RCTs, but would make nonparticipation come at "an unusually high price." This seems to us to be a price too high to pay; however, a critique of Evans's position, and other recent comparable arguments,[5] would merit a paper of its own. We confine our reply to only a couple points.

Evans describes the way we distinguish between clinical research and medical care solely as one of different aims of the two activities. And he is right to suggest that different aims, by themselves, don't entail different ethical standards. However, as our discussion indicated, the distinction is also a matter of characteristic methods — RCTs contain procedures such as randomization, placebo controls, and masking of treatment, which are foreign to medical care — and, most importantly, the justification of risks; RCTs, unlike medical care, typically contain procedures that pose some risk or burden to participants that are not justified by the compensating prospect of medical benefit to them. This trio of differences calls for different ethical principles governing clinical research as compared with medical care.[6]

Evans is mistaken in his belief that whenever clinical equipoise obtains, there is no ethically significant difference between research participation and receiving standard medical care, that enrollment in RCTs "*aligns with* medical therapy." Here it is sufficient to point out a counter-example. Consider the following case of an RCT of antibiotic treatment for chronic Lyme disease.[7] Prior to the trial, patients with chronic Lyme disease often were being treated with prolonged parenteral antibiotic therapy without any rigorous evidence to support its efficacy. Given the lack of evidence-based treatment for this condition, a placebo-controlled trial of antibiotic treatment would be consistent with clinical equipoise. The trial involved randomizing patients either to intravenous antibiotic therapy for 30 days, followed by 60 days of oral antibiotic treatment, or to intravenous dextrose followed by pill placebo. All the participants received a lumbar puncture to satisfy eligibility criteria for the trial and to characterize the study population. Placement of intravenous placebo is not without risk or burden. (Patients were monitored by home visits from study nurses every

two days during the intravenous treatment phase.) Similarly, lumbar puncture is an invasive procedure that carries a risk of prolonged headache. Although clinical equipoise was satisfied and maintained during the trial, the participants all received lumbar punctures that were not justified on medical grounds, and those in the placebo arm got a sham invasive intervention without medical justification. Accordingly, equipoise-satisfying trials can present participants with significant risks and burdens that they would not undergo in receiving standard medical care. The same point can be made about trials comparing two cancer chemotherapy regimens when the research requires a biopsy, which is not medically indicated, to measure study outcomes. We have described the Lyme disease trial at some length to reinforce the thesis in our article that careful attention to methodological and contextual features of clinical research is vital to ethical analysis in this domain.

Truog accuses us of being dogmatic about the *priority* of informed consent. We made clear at the outset of our all-too-brief discussion of informed consent that this norm is only one of several ethical requirements; that it is not the "cornerstone" of research ethics, and not necessarily the most important ethical requirement. We would add that informed consent is neither necessary nor sufficient for ethical clinical research.[8] There is a range of legitimate situations in which informed consent to clinical trials can be waived, including emergency research. When specifying this range, however (as in bioethics in general), the devil is in the details.

We have no qualms with waiving informed consent for the example that Truog develops in his commentary. How could it really matter to patients which of two standard soaps is used to scrub their surgical wound when it is not known whether one might be more effective than another? It gets more tricky in the case of RCTs evaluating two or more medically indicated treatments. Consider, here, the recent RCT, mentioned above, comparing newer antipsychotic drugs to an older-line drug.[9] Would this satisfy the conditions that Truog specifies, such that informed consent to research participation, arguably, is not required? The key condition in question would be item number 4 in Truog's article — that no reasonable person would have a preference for one arm over the other. It is not clear whether this would apply to the antipsychotic RCT. None of the drugs under investigation previously had been shown to be superior in efficacy to any of the others. All the drugs have disturbing side-effects and are difficult to tolerate; however, the side-effects are different. Perhaps, then, reasonable persons informed about the known side-effect profiles of these drugs might prefer one arm of the trial over another. But let's assume for the sake of argument that this trial meets all of the requisite conditions. Nevertheless, why should we waive informed consent? Might reasonable persons want to know that they are participating in an experiment rather than merely receiving standard medical care, and that the drug they are getting is being selected, not because it is thought that it might be best for them? (We suggest that the reasonable person is more likely to care about being enrolled in an RCT comparing two pharmacologic treatments than one comparing two types of soap.) If conducting a valuable RCT with informed consent would not be feasible, as Truog indicates in his two-soap case, then this might be a valid reason to weigh in the balance in judging whether this sort of treatment trial should go forward without informed consent. But, certainly, obtaining informed consent for head-to-head trials of medically indicated treatments is not impossible or generally unfeasible, although it does add some burden of time and expense. We believe that the informed consent waiver advocated by Truog and his colleagues, which we do regard as a salutary challenge to thinking about the value of informed consent in clinical research, would only justifiably apply to a narrow range of cases. There remains to be considered, moreover, a slippery-slope risk that making an exception for these legitimate cases will lead to

an erosion of standards of informed consent for a wider range of trials.

Finally, we would like to endorse the sentiments about John Fletcher expressed by Truog at the beginning of his commentary. We imagine that Fletcher would have enjoyed this colloquy about informed consent and the ethics of clinical research and would have urged all of us to get to work to do a better job in thinking through these issues.

DISCLAIMER

The opinions expressed are those of the second author (FGM) and do not necessarily reflect the position or policy of the National Institutes of Health, the Public Health Service, or the Department of Health and Human Services.

NOTES

1. G. Sreenivasan, "Does Informed Consent to Research Require Comprehension?" *Lancet* 362 (2003): 2016-8.

2. J.A. Lieberman et al., "Effectiveness of Antipsychotic Drugs in Patients with Chronic Schizophrenia," *New England Journal of Medicine* 353 (2005): 1209-23.

3. F.G. Miller, "Placebo-controlled Trials in Psychiatric Research: An Ethical Perspective," *Biological Psychiatry* 47 (2000): 707-16; E.J. Emanuel and F.G. Miller, "The Ethics of Placebo-controlled Trials — a Middle Ground," *New England Journal of Medicine* 345 (2001): 915-9; F.G. Miller and H. Brody, "What Makes Placebo-controlled Trials Unethical?" *American Journal of Bioethics* 2, no. 2 (2002): 3-9.

4. A. Wertheimer, *Consent to Sexual Relations* (New York: Cambridge University Press, 2003).

5. D. Orentlicher, "Making Research a Requirement of Treatment: Why We Should Sometimes Let Doctors Pressure Patients to Participate in Research," *Hastings Center Report* 35, no. 5 (2005): 20-8.

6. F.G. Miller and D.L. Rosenstein, "The Therapeutic Orientation to Clinical Trials," *New England Journal of Medicine* 348 (2003): 1383-6; F.G. Miller and H. Brody, "A Critique of Clinical Equipoise: Therapeutic Misconception in the Ethics of Clinical Trials," *Hastings Center Report* 33, no. 3 (2003): 19-28.

7. M.S. Klempner et al., "Two Controlled Trials of Antibiotic Treatment in Patients with Persistent Symptoms and a History of Lyme Disease," *New England Journal of Medicine* 345 (2001): 85-92.

8. E.J. Emanuel, D. Wendler, and C. Grady, "What Makes Clinical Research Ethical?" *Journal of the American Medical Association* 283 (2000): 2701-11.

9. See note 2 above.

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NOTES

1. J.L. Smith, R.M. Miller, Jr., and W.C. Callahan, "Tracking the Virus in Africa: The Etiology of AIDS," Journal of AIDS Epidemiology 124, no. 6 (June 2003): 1147-59.

2. L. Greene and W.K. Nelson, "The Ethics of Care," in Principles of Nursing Science, vol. 2, ed. W.K. Nelson (Plano, Tex.: Nursing Administration Press, 2002): 122-4; T.M. McCall et al., "Cost-Effectiveness v. Total Patient Care: Who Wins?" Health Care Administration Quarterly 6, no. 2 (Summer 2002): 150-6.

3. See note 1 above, pp. 1147-8.

4. Ibid., 1149.

5. Greene and Nelson, "The Ethics of Care," see note 2 above.