

At the Bedside

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How Should Careproviders Respond to Patients' Requests That May Be Refused?

Edmund G. Howe

ABSTRACT

Some requests made to careproviders by patients may be of great personal importance to patients. Careproviders may assign proportionally greater weight to these exceptional requests, and may choose to take exceptional measures to assist. A strong trust relationship may be formed with patients as a result.

In this issue of *The Journal of Clinical Ethics*, two articles address how careproviders should respond when patients request cosmetic surgery or to donate an organ: "Living Donation and Cosmetic Surgery: A Double Standard in Medical Ethics?" by Testa, Carlisle, Simmerling, and Angelos; and "Different Standards Are Not Double Standards: All Elective Surgery Patients Are Not Alike," by Ross, Glannon, Gottlieb, and Thistlethwaite.¹

In this article I will raise questions regarding how careproviders might best proceed when

a patient requests an intervention that might not be granted. Careproviders may want to consider the approaches I will recommend because of the exceptional importance that the requests may have for patients. I will describe responses regarding *what* careproviders decide, as well as *how* careproviders can respond optimally.

THE EXCEPTIONAL MORAL WEIGHT OF SOME PATIENTS' REQUESTS

Some requests, like those for cosmetic surgery or to donate an organ, may have great importance to the individuals who make them; the requests may, in some cases, be more important to the individuals making them than anything else in their life.

The epitome of such requests may be characterized by what some see as the far end of "the cosmetic surgery spectrum": individuals who want surgeons to amputate a non-diseased limb. The individuals seeking amputation may see this kind of surgery as deeply affecting their personal identity, and, when a surgeon refuses their request (as is inevitably the case in this country) they may continue to suffer profoundly; they may even, over time, contemplate suicide.² Individuals who seek to donate an or-

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gan to a stranger may feel this need exceptionally deeply, as well. They may feel that donating an organ will give unique meaning to their life that they couldn't have in any other way.

Because these requests may be of exceptional importance to those making them, careproviders may want to accord the requests greater moral weight than they otherwise might—although careproviders may differ on where they would “draw the line” in granting such requests.

REASONS TO ACCEPT PATIENTS' EXCEPTIONAL REQUESTS

Individuals who seek cosmetic surgery may believe—possibly rightly—that surgery is their best and even only chance to *be* how they want to be. After surgery, other people may respond differently to them, and they may believe (rightly) that surgery may change how they interact with others. Thus, with surgery, they may *be* more who they want to be, and also *live* more as they want to live. Neither is a small gain.

Others may see this desire as highly disheartening; they may believe that these individuals, rather than seeking cosmetic surgery, should strive to value themselves as they *are*, as opposed to how they *look*—that they should value themselves, regardless of how others respond. There is evidence that some patients feel better after cosmetic surgery, and that some relate better with others after surgery. In one recent study, 84 percent said they were satisfied or very satisfied with the results of their cosmetic surgery, and about the same percentage said they would make the same choice again. More importantly, 94 percent said they would recommend the surgery to others.³

A study that focused on changes in cosmetic surgery patients' emotions found that after surgery, the patients, by and large, became more “sociable” and acquired an increased ability to have “warm,” even “intimate” relationships with others.⁴ The authors speculate as to *why* these changes occurred, and propose that the patients may have previously felt “sadness and sorrow” caused by having a “lack of gratification” and “deprivation.” If so, the authors sur-

mise, surgery may have eliminated, to a significant extent, the sources of these negative feelings, and that, after surgery, the patients had less rigid “superegos.” (This is a psychoanalytic concept; *superego* refers to the part of our psychological make-up that is our moral conscience.) For example, the authors found that patients in the study became more flexible in pursuing their options and became less prone to having unwanted, morally based feelings such as obsessive guilt. The authors speculate that the last benefits may have occurred because surgery reduced the gap between how the patients *are* in reality (referred to in psychoanalytic theory as their *egos*) and how they feel they *should* be (their *ego ideal*). Put most simply, the patients accepted themselves better after surgery. Still more significantly, the authors found that, after surgery, patients had increased capacities to both be “creative” and “to love.”

If these findings are true, careproviders may want to accept patients' requests for cosmetic surgery more than they do now. It may be that, for these reasons, careproviders might consider altering their thresholds for accepting such requests: to increase respect for patients' autonomy and may make it more possible for patients to enjoy these benefits.

In their article in this issue of *JCE*, Ross and colleagues state that the *only* motivation that careproviders should accept for cosmetic surgery should be that patients want it to feel better about themselves. This leaves open the question of the threshold that careproviders should use to decide when patients' motivation is sufficient. But it may be difficult for careproviders to see the possible benefits of the surgery, and also the importance patients may place on it.

An example is a patient I was seeing who was in her late sixties who wanted facial cosmetic surgery. She had been married, more-or-less “happily,” for decades. I had been seeing her primarily to help her cope with the stress of a sick adult child. She looked okay to *me*, and, imposing my own, unenlightened view, I found it impossible to imagine why she would want surgery. I chose to not be involved to any extent in making the decision, because I feared, based on my bias, that others would turn her down,

and that if I were part of the decision-making group, she would distrust me later. (I should add here that I would not have joined the decision-making team in any case, for fear that my patient would distrust my treating her and being in this group that could “rule” against her. I shall discuss this in more detail later.)

But the decision-making group didn’t rule against the surgery, and she had it. To my surprise, she seemed genuinely much happier after the surgery. This kind of positive response is, in fact, common; but, as my response illustrates, the importance that this surgery can have may be greater than imagined.

This seems especially to be the case when patients want another kind of cosmetic surgery: cosmetic genital surgery, not for “function,” but for “looks.” There is evidence that patients who have this kind of surgery may respond most beneficially.⁵ That the outcomes are beneficial may be surprising to many, because they don’t know (and can’t imagine) how and why this surgery may be so important, especially to women.⁶ This example may best exemplify how, when we recognize that we don’t understand, we should, in every instance, ask ourselves whether there might be an important factor for patients that we are *entirely* denying or missing. (Individuals who want to donate an organ to a stranger will be discussed later, but I should note here that this is a good example of another kind of request that is of great importance to patients that careproviders may miss.)

REASONS TO OPPOSE REQUESTS

What, then, *are* good reasons for opposing a patient’s request for cosmetic surgery? Ross and colleagues give three: (1) When patients are “surgiholics,” that is, are addicted to having surgeries (2) When patients feel external pressure to have surgery. (3) When patients have “body dysmorphic disorder” (deep concern about a perceived physical defect).

1. “Surgiholics”

The first contraindication that Ross and colleagues suggest—that a patient is addicted to surgery—is greatly problematic: clinically, and,

thus, also, ethically, it is difficult to tell when persons are addicted. Even when a patient has had numerous surgeries and is (or may be) addicted, a surgery may still be beneficial. It may also, for that reason (or some other, less “justifiable” reason), be what the patient most genuinely wants. Ethically, then, it may remain open to question when (if ever) a patient should *not* be able to have surgery, even if he or she is (or might be) addicted. It could be, as suggested by the two studies cited above, that the possible gains from surgery—in spite of a patient’s real or possible addiction—may ethically offset the risks, even when the request isn’t freely made. What should careproviders do when they suspect “addiction”? What should the threshold be for surgery? Should its importance to the patient matter? If addiction seems plausible, and especially if it seems likely, is there a need to have surrogate decision makers agree that a surgery is in the patient’s best interest before it can be done? If so, what should the threshold be for imposing a requirement for substitute decision making?⁷

2. External Pressure

The second contraindication on the list, that a patient feels pressured, also generally warrants—and should warrant—great concern. For example, when an individual, especially a patient, wants to participate in therapeutic research, there is a great deal of concern that, in addition to being pressured from “without,” that the patient may be pressured from “within,” that is, she or he may want to get better, or get well, and being in a research study may be the only way to accomplish this.⁸

A comparison with therapeutic research may be illuminating, as it brings out a counterintuitive consideration regarding “undue influence,” which may apply to patients who want cosmetic surgery (particularly cosmetic genital surgery) in part to please others (or even to those who want donate a kidney!). That is, one involving a critical question in research is how much individuals should be paid to participate in research. They should be compensated for the risk, harms, and losses (such as time) that they accept. It has been generally assumed in

recent years that compensation should not be too great; it should not be so much, for instance, that it “lures” participants into not disclosing health risks, as has happened in the not-so-distant past.

Alan Wertheimer, a leading philosopher on ethical considerations in research, has (with others), however, recently challenged an all-or-none prohibition against offering too much money, at least on theoretical grounds.⁹ He asserts that a research participant’s consent is ethically compromised by “undue influence” only if the offer of payment distorts the person’s evaluation of the risks and benefits of participation. Conversely, a participant’s consent is *not* compromised by undue influence if an offer of payment merely moves the participant to make a decision that she or he otherwise, without monetary compensation, wouldn’t make.

This analysis suggests that two steps, rather than one, are necessary before concluding that outside pressure is undue: (1) one must first decide whether there is such pressure, then (2) one must decide whether the outside pressure has (or has not) so adversely affected the individual that it distorts, and, thus, impairs his or her capacity to make a choice. Wertheimer states that monetary incentives, even when they are an outside pressure, may not be ethically wrong (at least for this reason) if they present a “win-win” for the individual involved.¹⁰

We can apply this same reasoning and two-step analysis to patients who feel outside pressure to request cosmetic surgery or cosmetic genital surgery. Surgery could be a win-win for them. If they want surgery for themselves, and also feel outside pressure, they could see surgery as beneficial in its net effect, because it will please them, it will also please someone else, and, in turn, this will please them. Wanting surgery under these conditions may not make a decision to have surgery a “distorted” evaluation.

3. Perceived Physical Defect

A third possible contraindication is when patients seek cosmetic surgery to address a deep concern about their physical appearance. A example at the far end of this spectrum may be patients who want to have a non-diseased limb

amputated, a desire called *apotemnophilia*. These individuals want a surgeon to amputate an arm or leg that they don’t want because, to them, it feels like an unwanted appendage, a tail, or a foreign body. Carl Elliott, an MD who writes about the philosophy of psychiatry, studied this group; he found that “there are enough people within it interested in becoming amputees to support a minor industry.”¹¹ Some in this group, he writes, not only want amputation, but believe that having it will enable them to be more true to their identity, or, as I would try to phrase this, they believe that the surgery will enable them to *be* how they feel they already *are*. Perhaps surprisingly, after surgery this is often how many say they *do* feel. Elliott reports that he struggled for several years while working with members of this group to try to understand how the individuals used what he calls a “language of self and identity” to explain *why* they want an amputation to surgically enhance themselves.¹² The notion that these individuals identified themselves as finally whole *after* surgery might function as “empirical bedrock” for the suggestion that some requests made by patients may be exceedingly important to them.

Elliott reports that one man who had already had an amputation said he had wanted his leg amputated since he was eight years old, and this, and other, similar examples contributed to Elliott’s concluding that there are “true apotemnophiles.” Elliott cites a study of 50 such people, three-quarters of whom reported they had felt urges to have a limb amputated before they were 15 years old.¹³ He reports several examples in which the individuals were even younger. Are these people delusional? Or is this more a case of just how they *are*?

Even assuming that careproviders would not—and should not—agree to give these patients an amputation, how does this bear on where, for less extreme requests, careproviders should draw the line?

For instance: our society increasingly accepts people who want surgery to change their gender. Individuals who seek this surgery may see it as enabling them to “become” their basic “identity.” Another ethicist, Timothy Murphy, provides key insights.¹⁴ He points out that the

American Psychiatric Association (APA) presently still classifies these individuals as having an illness, but that “it is not surprising that some transgender men and women prefer to bypass psychiatric treatment for their ‘disorder.’”¹⁵ Some, Murphy says, will seek psychiatric assessment, “but only because some clinicians require as much before they offer surgery and hormone treatment, not because they believe themselves psychiatrically disordered.”¹⁶ He adds that “perhaps the APA will someday look back on GID [gender identity disorder] as a mistake, in the way it looks back on pathological interpretations of homosexuality as a mistake.”¹⁷

Perhaps people who want to change their gender and have surgery may, like those with apotemnophilia, believe surgery will enable them to be who, and how, they already feel they really are. Our greater society recognizes the exceptional importance of this surgery to patients who seek it, and surgeons do this surgery, even though some patients later change their minds, despite the precautions taken to try to prevent this from happening.

In regard to individuals’ “true identity,” the time of the onset of their preference regarding gender comes early; according to one report, approximately 44 percent of those with gender dysphoria or crossgender identification first experienced these feelings during their preschool years.¹⁸ Most importantly, if they receive no counseling during this time, they may have more behavioral and emotional problems later—as one might expect.¹⁹ Still more importantly, and often tragically, if they don’t see a careprovider at an early enough age, they may undergo physical changes that are incompatible with the gender they want to be that can’t be reversed later. This is because medical treatments given at later stages of adolescent development are much less successful in suppressing the physical changes resulting from puberty. For example, genotypic men who identify themselves as female may experience the virilization of their hair follicles, a lowering of the pitch of their voice, and a prominent Adam’s apple that are irreversible. Genotypic females who identify as male may have earlier closure of their epiphyseal plate, thus preventing them from

gaining greater height.²⁰ Genotypic females often “present” to careproviders later; this may be because society accepts adolescent girls who show behaviors that are more common in boys—“androgyny”—to a greater extent. To prevent this, pediatricians should ask the parents and children they see about gender-related issues.²¹ Clues regarding genotypic boys may be, for example, a preference for female clothing and underwear, always sitting to void, exclusively playing with female toys when given a choice, and desiring long hair. Clues in genotypic females may be their choice of underwear, breast binding, refusal to wear female swimsuits, and psychological problems at the first onset of menstruation.²²

It may be that pediatricians may not do this to the extent that they could; if so, one of the reasons could be that they don’t sufficiently recognize the importance that these issues and early surgery has for patients. For example, a child psychiatrist who was a specialist in this area was treating such a child. The child was fortunate to have found the psychiatrist, but when another careprovider learned from a colleague that the psychiatrist was seeing the child to try to help the child sort out feelings about gender, the other careprovider sought to have the child psychiatrist’s license revoked.

Careproviders may want to consider how they should decide on requests of exceptional importance to patients, and on whether such requests should be accorded special moral weight because of their importance. Careproviders may want to assess their own biases. If so, to begin, they may want consider whether there is negative bias on this topic present in our society. When it seems warranted, careproviders can devalue and attack such societal values. For example, they may say to a patient, “It makes *sense* for you to want surgery even though you are 70 years old,” or “It makes *sense* for you to want cosmetic genital surgery,” or “It makes *sense* for you to want surgery to change your gender.” When just one careprovider says this, it may move and sustain a patient so that he or she can later survive numberless stresses, through thick and thin, whether or not, rationally, this should be the case.

SURGERY CAN ADD MEANING

In their article in this issue of *JCE*, Testa and colleagues note, “any suggestion of psychological distress or disorder may make a potential organ donor unacceptable.”²³ They cite a study reporting that the rate of “non-acceptance” of people wanting to donate an organ is between 20 and 36 percent. Individuals may want to donate for many reasons, but the reason that many find most important—in addition to wanting to help others (and the reason I will focus on)—is a belief that donating an organ will, uniquely, give meaning to their life. People have sought and found ways to give their life meaning for millennia. For example, Homer records that Greek warriors sought meaning by having others remember their valor in battle. Today, some people seek to leave loved ones with a memory of how they died with dignity, and they may want, more than anything else, for loved ones to remember them in this way. As in the discussions regarding patients’ reasons for seeking cosmetic surgery or other surgery, careproviders may choose to give such requests exceptional moral weight (or, more radically, give patients more autonomy).

A rationale for this is that the desire to feel our life has meaning is among the very deepest, personal concerns we may have. The need for meaning, in general, may be far more important than many realize. A paradigmatic example is the need for new or renewed meaning individuals feel after they have been mugged or raped. The need may be particularly extreme if the mugging or rape occurred when the individuals believed they were safe. Prior to a mugging or rape, they may have viewed their world as safe, and they may have thought that, if they were circumspect, they would be free from danger. After a mugging or rape, their beliefs may be shattered. They may have to find a new, different, and revised view of their world to carry on and survive, in a reasonable way. Some may try fruitlessly to restore the worldview they’d had; they may, for example, re-frequent the place where they had been mugged or raped.

It might be inferred from this that the individuals return because they want to get mugged

or raped again—or, even worse, that they had wanted it to happen all along. Returning to the same place has, most likely, a wholly different function: they may return, unconsciously, to try to convince themselves that what they experienced was an “exception,” not the rule, so they can restore to themselves a safe worldview. Thus, they return not *because* it is dangerous, but *in spite of* its being dangerous. Feeling that life has meaning may be the most important meaning individuals can seek. Some individuals may, for example, seek meaning as a participant in research, even if they believe the research may not help them personally.²⁴

This may also be the case when individuals ask to donate an organ, and this may particularly be the case when they want to donate to a stranger. Some find the desire to donate an organ to a stranger questionable; not feeling a need to do this personally, they may not only underestimate the importance of donation to people who want to donate, but they may judge people who want to donate to strangers—and careproviders may be among this group. An article published in 1971 reported that “most physicians” viewed people who wanted to donate a kidney to a stranger as being, among other qualities, “suspect” and “repugnant,”²⁵ and some careproviders may retain this view even now.

An example illustrating the search for meaning—as well as distrust—is that of Zell Kravinsky, whose story was well publicized not long ago. Kravinsky gave, as a reason for wanting to donate his kidney to a stranger, “However I screw up morally in the future, this is something nobody can take away.”²⁶ Some of his family members were furious. After he donated an organ, his wife was “beyond human rage.” His mother was “so filled with anger” that “she couldn’t speak.”²⁷ The surgery was performed at the Center for Renal Dialysis at Albert Einstein. Kravinsky’s doctors were hesitant and ambivalent: “we put him off,” one said; “you want to make sure this is the real deal.”²⁸ One of the many valid concerns behind the careproviders’ hesitation was the possibility that persons who request to donate are, unconsciously, responding to guilt.²⁹ For example, Kravinsky felt “devastated” by the death of the elder of

his two sisters from lung cancer. He was 30 years old when she died; at that time, he felt guilty, first, for not having shown her enough affection during her life, and, second, for not having persuaded her to quit smoking.

An ethical view that supports such requests is that of the philosopher Peter Singer, who has said that if we can prevent something bad for others (such as their dying), without our sacrificing significantly, then we ought to do it.³⁰ A test case for the extent (if any) to which careproviders might ethically accept such requests, in spite of possible feelings of guilt or other factors, may be that of people in prison, on death row, who want to donate an organ to a stranger. For example, a prisoner named Christian Longo said he would drop his legal appeals if he was able to donate. He was (and still is) on death row because he killed his wife and three children.³¹ The question that Wertheimer encouraged us to ask in regard to participation in research could also be asked here: Should it matter to careproviders and patients whether an offer to donate could be a “win-win”?

There may be many other exceptionally important requests that patients may make of careproviders that are as important as these, and perhaps even more important. A core question here is, if it is right for careproviders to accept patients' exceptionally important requests, how far should such exceptional acceptance extend? Ross and colleagues emphasize the possibility that patients and careproviders can make shared decisions in these contexts. In the next section I will extend their discussion and explore how careproviders may best respond when they serve as decision makers as well as patients' primary sources of emotional support.

POSSIBLE ROLE CONFLICT

Careproviders with patients who make exceptional requests may serve in either or both of two roles. They may see a patient initially, when the patient makes an exceptional request, and then, ideally, continue to “follow” the patient, regardless of the outcome. Or, careproviders may be among those who decide the outcome. As discussed below, it may be prefer-

able for careproviders to not fill both roles, because, if they do, patients may feel less trust for them. This is primarily why I chose not to be any part of deciding whether my patient in her sixties who wanted cosmetic surgery should have the surgery. On the other hand, there may be contexts in which serving in both roles could be advantageous; for example, careproviders may know a patient better than any other potential decision maker, and, if in favor of accepting the patient's request, they may be able to make the strongest case for the patient.

Serving in Both Roles

It may be that careproviders will see a patient who has an exceptional request initially, and thereafter follow the patient *and* be tasked with helping to make decisions about the patient's request. Serving in both roles may be advantageous, as the careproviders may know the patient best. Knowing the patient better, the careproviders may also be better able to discuss and decide these issues with him or her. Still, mixing the two roles may bring about profound problems; for example, a patient may not know from the start that a careprovider will take on a decision-making role later. Thus, the patient may give a careprovider information that the patient believes will be used for “treatment” purposes, and only later find out that the information was used “against,” the patient as it was among the factors leading decision makers to turn down the request. The patient may feel betrayed, as if deceived into giving potentially self-incriminating information. In addition, careproviders may feel internally conflicted. In this regard, there may be few worse feelings than having to go against another's prior trust.

A common example illustrating this is the decision parents may feel they have to make if their child is being bullied at school. Their child may want them to take no action, yet they may believe that they must, even though this will go against their child's heartfelt request.

There are several reasons why careproviders may take on both roles and not be aware of how their patient may see this—and them. Careproviders may simply not have considered it; or they may have considered it, consciously or

unconsciously, and denied it. They may have rationalized away the potential conflict, telling themselves that this is the best that the medical system can offer, and since they already know the patient best, they can make these difficult decisions better than anyone else.

This last rationale may be true; it may be much more probable, however, that if a patient initially provides information that could “go against” the patient later, he or she will regret having provided the information, and resent that the careprovider served in both roles without saying so beforehand. Careproviders who serve in both roles have three options: (1) share with all of their patients that they have this mixed agency, (2) tell only patients who have an exceptional request about these dual roles, (3) try to avoid dual roles altogether.

When careproviders serve in both roles, it may be that they should tell patients this in advance. They might also add their reasons. They could state, for example (if is the case), that they believe that they and their patients might best approach decisions by working together, at least initially. Examples in which this might be the case are when a patient requests cosmetic genital surgery to improve function because it was suggested by a partner, or when a patient wants to donate an organ to a stranger. When careproviders do this, though, they should always tell the patient that, when all is said and done, if they believe the patient’s request *should* be opposed, they will oppose it as a decision maker.

Serving as a Decision Maker

If careproviders serve only in a decision-making role, ethical questions will arise as to how they should best assess patients who have exceptional requests. There are two main concerns. The first is the extent to which careproviders should express their usual warmth and support to patients. This is important, because if careproviders respond with their usual warmth, patients may overly trust careproviders—as patients would in a usual clinical context—and possibly give out information that “works against” them. For example, they may share unrealistic expectations regarding facial cosmetic surgery, or that they are pressured by

another to have cosmetic genital surgery; or that they experience pressure to donate an organ, as Kravitz and Longo may exemplify, due to prior, profound sources of guilt. Any of these may cause a decision maker to turn down a request.

The second concern applies only when careproviders decide they should show less than their usual warmth, because, serving as a decision maker, they may go against what the patient wants. These careproviders may want to determine the extent to which they would explain to a patient why they are acting less warmly than they otherwise would. This is emotionally and ethically complex. Taking this special initiative will enhance a patient’s autonomy, and so, emotionally, it may increase a patient’s trust. But this increased trust may offset and undo whatever careproviders say, and may lead a patient to share additional information, even though the patient believes or suspects this may go against his or her interests.

It is ethically complex to determine whether careproviders, as decision makers, can help patients more by getting as much information as they can, or whether they should clearly identify themselves as serving in a potentially adversarial role. The alternatives are open to strong debate, and careproviders who take on this role would do best, it would seem, to at least consider both of them.

Giving Patients Maximal Support

Careproviders who want to maximally support a patient who has an exceptional request may want to separate and exclude themselves from taking on *any* decision-making role, even though this may result in benefitting some patients to a lesser extent.

To maximally support patients, careproviders should try to ensure they don’t have any unconscious bias against a patient’s request. Why might they have a bias? One reason is many in the general population view such requests negatively, and careproviders, even without being aware of it, may share some of society’s negative response. For example, some see any kind of cosmetic surgery as reflecting superficial values, based only on appearance. This negative bias may be especially strong regarding cosmetic

genital surgery. Likewise, others may exceptionally distrust the motivation of individuals who want to donate an organ to a stranger.

It may be instructive here to consider another much more common bias, but little known, called “disenfranchised grief.”³² This is grief that often is not openly acknowledged or publicly mourned, or that does not usually elicit social support. It may occur in a surprisingly large number of contexts, for example, a lack of social support after the death of an ex-spouse or, for that matter, the death of any close partner in a dyadic relationship outside of marriage. A lack of social support may also occur when the “survivors” are foster parents, colleagues, or in-laws. It may occur even in the loss of a pet. Parents commonly experience disenfranchised grief when a fetus dies.³³ This especially is the case when the fetus dies early on. It is uncommon to have a funeral for a fetus, for example, even though it can greatly help bereft parents to acquire closure and work through their grief.

Still sadder examples occur when “society,” for some reason or other, affixes blame, and this blame is often extended to family members. Probably the most obvious example is when a person is executed in prison, or even just dies while in prison.³⁴ Typically, little support is often to family members. This same blame may occur for individuals who have engaged in unprotected sex or used intravenous drugs and acquire AIDS, and may occur even when people die from lung cancer after a life of smoking. This public response may occur most tragically when people commit suicide or die due to alcoholism.³⁵ This lack of support is fueled by irrational bias. Since careproviders cannot *not* exist within their own culture, they are vulnerable to having these same biases, even when they are unconscious. A first step in seeking to eliminate these possible biases may be to see if the biases exist within our greater society. If they do, we can probably assume that, to some extent, they may also exist within us.

A second step is to inform patients about these biases (after the biases have been “researched” and identified within the greater society), and then to explicitly verbally attack the

identified biases. A useful example is how careproviders could respond when a patient requests cosmetic genital surgery. Careproviders could say, “I don’t know if you know this, but some people criticize patients who have this surgery. I want you to know, in case you ever might run into one, how strongly I think they are totally dead wrong.” Even if only one careprovider takes the initiative to say or do this, it may wholly (and “disproportionately”) offset the validity of others who have other views—even when the others are careproviders.

A third step is still more controversial: careproviders may anticipate the kinds of questions that decision makers will likely ask, and they can tell patients what these questions might be. For example, careproviders can tell patients who want cosmetic genital surgery that they are likely to be asked about pressure from their partner. Or individuals who want to donate an organ to a stranger can be told that they may be asked about their own feelings of guilt. Careproviders can tell a patient that one of the main reasons they are informing the patient in this way (if this is true), is to let him or her know that those making decisions about granting the patient’s request actually are on the patient’s “side”—that they are truly seeking to do the best they can for the patient, in a different way. Careproviders can explain that the decision makers, based on their own knowledge of research and their own experiences with other patients making similar requests, have some generally sound notions about the circumstances in which patients will benefit, and also of the circumstances in which patients are more likely not to benefit. Careproviders can add that there are always exceptions, and that this patient may be one.

A fourth and final step is for careproviders to invite a patient to explore, *together*, the underlying, unique importance and meaning the patient’s request has for her or him.

Using the first of these three steps may enhance patients’ trust, and may enable them to see decision makers as allies, not adversaries. If careproviders instead initially respond to patients’ exceptional requests by asking, “What is most important to you in making this request?”

or “What might this mean to you to have—or not—your request accepted?” patients might come to view all of the careproviders they encounter as potential adversaries. After all, one or more of the careproviders will decide whether or not to accept their request, and, rationally or not, this request may be exceptionally important to them, as discussed above. If the first careprovider they meet asks them these questions, early on, patients may think they “smell a rat,” and not that the careprovider is asking to share decision making—as Ross and colleagues urge—but is asking to gain information that could later be used to refuse the request.

When careproviders take the initiative to attack those who might criticize a patient’s request and share all they know about the kinds of questions that decision makers are likely to ask, it may dispel and negate the patient’s fears. Telling a patient about the kinds of questions that decision makers may ask could prevent decision makers from obtaining the kind of information they might use to turn down the patient’s request, making it more likely they will accept the request. With this unexpected support, a patient may feel more protected and unafraid, and, as a result, he or she may make better decisions.

All of the suggested interventions involve establishing a closer personal relationship with patients, and, to the extent that they help in the ways I described and/or enhance patients’ autonomy, they may help to reduce patients’ suffering. For example, a recent study explores what patients most want if they feel afraid as they die; it is the first study to explore the topic using neuroimaging.³⁶ Researchers found that what may support patients the most is for their careprovider to engage with them, much as I have suggested here. Patients want, more than anything, to be with loved ones at this time.

CONCLUSION

I have suggested here that some patients’ requests may have great importance for them, and thus, may be qualitatively different from other kinds of requests. Careproviders may want to give such exceptional requests greater moral

weight, whether this would mean that they would accept the requests when they wouldn’t otherwise, or would just let this greater importance serve as a “tie-breaker” when making decisions.

If a careprovider is a patient’s primary source of support, she or he may take several exceptional measures to help the patient as much as possible. A by-product is the relationship that may be formed with the patient, which is sacrosanct. This point is illustrated and supported strongly by a sad and most negative finding regarding individuals with apotemnophilia that Elliott reports: “many are desperate and vulnerable to exploitation. . . . more than a few of them have never even spoken face to face with another human being about their desires.”³⁷

NOTES

1. G. Testa, E. Carlisle, M. Simmerling, and P. Angelos, “Living Donation and Cosmetic Surgery: A Double Standard in Medical Ethics?” in this issue of *JCE*; L.F. Ross, W. Glannon, L.J. Gottlieb, and J.R. Thistlethwaite, Jr., “Different Standards Are Not Double Standards: All Elective Surgery Patients Are Not Alike,” in this issue of *JCE*.

2. C. Elliott, “A New Way to be Mad,” *Atlantic Monthly* (December 2000): 73-84.

3. N.A. Papadopoulos, L. Kovacs, and S. Krammer, “Quality of Life Following Aesthetic Plastic Surgery: A Prospective Study,” *Journal of Plastic, Reconstructive & Aesthetic Surgery* 60, no. 8 (2007): 915-21. In this study, of 46 people between the ages of 16 to 65 who had surgery, 66 percent involved facial cosmetic surgery.

4. G. Rubesa, T. Tic-Bacic, H. Svesko-Visentin, and G. Bacic, “The Influence of Aesthetic Surgery on the Profile of Emotion,” *Collegium Anthropologicum* 35, supp. 2 (September 2011): 51-5, 51-2.

5. “Indeed, the professionalism of the physicians performing these procedures and the ethics and propriety of the procedures themselves have been called into question.” M.P. Goodman, “Female Cosmetic Genital Surgery,” *Obstetrics and Gynecology* 113, no. 1 (January 2009):154-9, 155. See also, M.P. Goodman, “Female Genital Cosmetic and Plastic Surgery: A Review” *Journal of Sexual Medicine* 8, no. 6 (June 2011): 1813-25.

6. M.P. Goodman et al., “A Large Multicenter Outcome Study of Female Genital Plastic Surgery,” *Journal of Sexual Medicine* 7, no. 4 (part 1) (April

2010): 1565-77; A. Ostrzenski, "Cosmetic Gynecology in the View of Evidence-Based Medicine and ACOG Recommendations: a Review," *Archives of Gynecology and Obstetrics* 284, no. 3 (September 2011): 617-30.

7. It might be possible that gains from the surgery could help some patients be able to overcome their addiction, as it may enable them to feel better, and, due to this, feel that they are at a place that they need no more surgery.

8. Both of these concerns may be strongest when patients agree to participate in a phase I study. A recent study found that it is not as uncommon as previously believed that individuals participate in research partly due to altruism: "almost a third spontaneously mentioned an altruistic benefit . . . though this contrasts with previous studies." R.D. Pentz et al., "Research Biopsies in Phase I Studies: Views and Perspectives of Participants and Investigators," *IRB* 34, no. 7 (March/April 2012): 1-7, 6.

9. A. Wertheimer, "Is Payment a Benefit?" paper presented at a PRIM&R conference, Advancing Ethical Research, held 1 December 2011 at National Harbor, Md. See E.A. Largent, C. Grady, G.F.G. Miller, and A. Wertheimer, "Money, Coercion, and Undue Inducement: Attitudes about Payments to Research Participants," *IRB* 34, no. 1 (January/February 2012): 1-8.

10. Even if it is a "win-win," Wertheimer does not believe that this alone makes such research "right." There may other important concerns; for example, society may see some a practice as so degrading to human dignity that it is wrong.

11. C. Elliott, see note 2 above, p. 73.

12. *Ibid.*, 74.

13. *Ibid.*, 76.

14. T.F. Murphy, "The Ethics of Helping Transgender Men and Women Have Children," *Perspectives in Biology and Medicine* 53, no. 1 (Winter 2010): 46-60.

15. *Ibid.*, 49.

16. *Ibid.*

17. *Ibid.*, 58.

18. N.P. Spack et al., "Children and Adolescents with Gender Identity Disorder Referred to a Pediatric Medical Center," *Pediatrics* 129, no. 3 (March 2012): 418-25, 423. See, also, L. Edwards-Leeper and N.P. Spack, "Psychological Evaluation and Medical Treatment of Transgender Youth in an Interdisciplinary 'Gender Management Service' (GeMS) in a Major Pediatric Center," *Journal of Homosexuality* 59 (2012): 321-36.

19. Spack et al., *ibid.*, 422.

20. *Ibid.*, 423.

21. *Ibid.*, 424.

22. *Ibid.*, 424.

23. Testa, Carlisle, Simmerling, and Angelos, see note 1 above.

24. See note 8 above.

25. These results were published in *Seminars in Psychiatry* in 1971 and are cited in I. Parker, "The Gift," *New Yorker* (2 August 2004), 54-63.

26. *Ibid.*, 62.

27. *Ibid.*, 61.

28. *Ibid.*

29. This may be extremely difficult for care-providers who have never experienced unconscious mental defenses that resulted in their doing something they otherwise wouldn't do. I experienced this when I had an "anniversary reaction": I behaved in a very unusual way and had no idea why. Then it occurred to me that it was exactly a year since a person I'd loved dearly had died.

30. Singer is quoted in Parker, see note 25 above, p. 59.

31. A.S. Persky, "Life from Death Row," *American Bar Association Journal* (April 2012): 16-8.

32. K.J. Doka, "An Historical and Cultural Perspective," *Handbook of Bereavement Research and Practice/Advances in Theory and Intervention* (Washington, D.C.: American Psychological Association, 2008), 223-40.

33. A. Lang et al., "Perinatal Loss and Parental Grief: The Challenge of Ambiguity and Disenfranchised Grief," *Omega* 63, no. 2 (2011): 183-96.

34. S.J. Jones and E. Beck, "Disenfranchised Grief and Nonfinite Loss as Experienced by the Families of Death Row Inmates," *Omega* 54, no. 4 (2006-2007): 281-99.

35. Doka, see note 32 above.

36. Recent work has investigated how people's brains "work" when they experience feelings of terror, such as fear in the face of death. (Such fear may be triggered unconsciously in a lab setting by input that provokes fear outside the conscious awareness of the research subjects.) In the study, researchers watched which parts of research subjects' brain "lit up" using magnetic resonance imaging (MRI), relative to a control group, when the fear of death was triggered. The part of the brain that lit up was the same part of the brain that lights up when individuals find solace with another in a meaningful relationship. M. Quirin et al., "Existential Neuroscience: a Functional Magnetic Resonance Imaging Investigation of Neural Responses to Reminders of One's Mortality," *Social Cognitive and Affective Neuroscience* 7 (2012): 193-8.

37. Elliott, see note 2 above, p. 84.