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Taking Patients' Values Seriously

Edmund G. Howe

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Three articles in this issue of *The Journal of Clinical Ethics* discuss choices that patients sometimes make: purchasing a kidney illegally overseas, repeatedly seeking *in vitro* fertilization (IVF) despite increased risks, and altruistically donating an organ to a stranger. It's been argued that careproviders should feel morally obligated to remedy issues like these, rather than strive only to treat the patients we see to the best of our ability. This argument appears, for example, in discussions about whether careproviders should attempt to "game the system" for their patients. Many say careproviders should not game the system, but instead should try to change the system to help all patients.

There is no doubt that careproviders have a lot to offer — probably more than anyone else — in attempts to reform the healthcare system. When they do become involved in public policy, however, they may do so at a price. In my introduction to this issue of *JCE*, I will consider how, when careproviders choose to take on the larger issues, they may risk losing their capacity to take patients seriously.

PATIENTS WHO BUY KIDNEYS ILLEGALLY OVERSEAS

In "What Should We Do with Patients Who Buy a Kidney Overseas?" Marie-Chantal Fortin, Delphine Roigt, and Hubert Doucet describe several concerns careproviders have had in Canada when patients who have kidney failure purchase organs overseas. The authors report that this involves 30 to 50 Canadians each year and that this is, experts estimate, 3 to 5 percent of those who would benefit from kidney transplants.

In Canada, buying an organ is a criminal act. It violates a number of important ethical values, the three most important of which follow:

1. As noted above, it's against the law.
2. Should the patients later develop medical complications, they may use up limited resources that other patients may need more, which may violate the principle of justice.
3. Perhaps most importantly, purchasing an organ exploits the vulnerability of those worse-off, who sell their organs; presumably they wouldn't be willing to do this if they weren't badly off.

Fortin and her co-authors relate that, as a consequence of these ethical "wrongs," some careproviders may feel they no longer want to treat patients who buy organs, so long as the careproviders can help patients find another physician and patients are not in a medical emergency. Should careproviders withdraw from caring for patients based on a belief that buying an organ overseas is immoral?

On the one hand, careproviders are free to follow the dictates of their moral conscience. From this perspective, this becomes just another instance of a careprovider withdrawing from a patient's care — for

example, a careprovider who believes in the absolute sanctity of human life may opt to transfer the care of a patient who chooses to "go off" a respirator.

On the other hand, it could be argued that careproviders who wish to transfer the care of a patient who breaks the law to purchase a human organ cross a long-held professional boundary that many may see as sacrosanct: usually when a person commits a crime, it is the responsibility of the state, not the careprovider, to judge and possibly punish the person. A careprovider who withdraws medical care for this reason (we would hope) would not *intend* this to be a punishment, but, regardless, it is. Patients may experience the loss of their careprovider, and of the relationship, greatly. Patients may also feel much worse about themselves as a result. Fortin and colleagues point out that there are some instances in which "all" careproviders believe that they must never discriminate against a patient — for example, based on racial, sexual, or political views. The authors also note, rightly, that careproviders should treat patients who commit murder. Why, then, might an exception be made for a patient who purchases a human organ? Fortin and colleagues give additional reasons: for instance, a careprovider who treats such a patient may be seen as contributing to a continuation of this illegal practice.

Yet regardless of whether this can or cannot ultimately be justified, withdrawing care may cause the blurring of important realities regarding patients. When careproviders — or any citizens — address a question of public policy, at some point they must consider other patients who will be affected by the policy. Whenever persons are "lumped together" in this way, it is possible to oversimplify who each of the affected persons are, and thus to stereotype them. This can result in serious negative effects. First, it may cause the greater society to see members of the group in an inaccurately "reduced" way. Second, society tends to view its members as either like the majority, and thus part of the majority, or as unlike the majority, and thus as "marginal" or as "outsiders." Because careproviders have authority and a great deal of influence in regard to what "society" thinks, when careproviders respond to patients in a way that suggests that the patients are different, it may add greatly to that negative effect. Patients may become labeled, and the labels may become self-fulfilling prophecy: patients may become increasingly marginalized due to a process that is wholly outside their control. Patients who seek kidneys illegally, in particular, may be mislabeled by society as "criminals" in *all* respects, and careproviders who withdraw their care may increase the degree to which the greater society sees and treats these patients as social pariahs. Peter L. Berger and Thomas Luckmann are among those who have helped us understand how members of society may label and ostracize persons; as a result of this process, they say, "all men, once socialized" may become "traitors to themselves."¹

Careproviders, in this way, may become traitors to their patients, to themselves, and to their profession. Oversimplifying and stereotyping a group of patients — which may be necessary in considerations of the ethics of public policies — may distort a careprovider's clinical view of a patient. Then, even if the careprovider still can interact with the patient in the same way, the careprovider's moral judgments of the patient may change how the careprovider feels toward the patient — and the patient may sense this. In response, the patient may lose trust in the careprovider.

The fact is that patients who buy organs *are* criminals. Still, we may be able to see *some* distinctions that separate these patients from persons who commit serious crimes. Patients who buy organs commit this crime to prolong their life. This may be seen as a selfish act, but it may also have been done to benefit the patients' loved ones, such as young children. Further, Fortin and colleagues tell us, some patients who purchase organs see this as a "win-win" situation: they believe, as some claim, that people who sell an organ do it to serve their own interests. Of course, while they well may believe it, this is also a rationalization.

Still, there may be distinctions that separate such rationalizations from those of others who commit more serious crimes. Fortin and colleagues tell us, for example, that some transplant surgeons report that if they were in the same situation, they might consider purchasing an organ.

My point is not that this crime should be viewed as different, nor that any exceptional factors should "count" as moral, much less legal, excuses. My intent is to illustrate how considerations of this kind can become blurred for careproviders. There are several reasons why careproviders should not transfer the care of these patients. First, they would abandon their medical role, which requires careproviders to uncondition-

ally accept patients and *always* be there for them, regardless of what they may have done. Second, as noted above, transferring patients to another careprovider may have serious adverse social effects; even if it doesn't contribute to the labeling and marginalization of patients, it may cause the patients to feel worse. All patients, including patients who break the law, need careproviders' unconditional care and support. The patients may, in this regard, rightly see careproviders as their only "court," and perhaps even refuge of last resort. Careproviders who withdraw care are not able to offer patients this potentially pivotal and life-changing role.

If, however, careproviders lose respect for patients when they buy a kidney, careproviders may not be able to serve in this role. Careproviders who feel profound disrespect for these patients might most benefit them by withdrawing from their care. These careproviders would not do this to serve their own moral conscience, however; they would do this to provide patients maximal benefit. To protect patients from harm, they might tell patients, "I'm not sure I can help you now, due to my feelings in response to what you have done. Still, what helps you the most remains the most important thing to me. I just don't have control over these feelings, and I'm sorry." Saying something like this could make a difference in how patients respond.

If careproviders don't want to withdraw from these patients, what *can* they do? Stated more generally, what can careproviders do when patients make big mistakes, even including committing a crime? Much. Here are two examples.

First, careproviders can explicitly acknowledge that making big and small mistakes is something that we all do, careproviders and patients — and when it comes to erring, patients should never feel isolated and alone. For example, one of my patients told me that he had "permanently blown" his relationship with his teenage son. No small loss. I responded, "One of the most painful things in life for me — probably for all of us — is when we do something we later regret, and we can't undo it. I imagine it is something like this now for you." On hearing this, the patient changed his mind, and decided that he would not yet give up on trying to be close to his son.

To "validate" patients means to tell them that *something* in what they have done, in *some* way, makes *some* sense. We might say to a patient who bought an organ, for example, "Of course you want to live longer if you can. Wanting this makes sense." We might add, "I can even imagine how I could rationalize away sound arguments against it, without knowing I was doing that." Adding the last sentence is to give a patient the "benefit of the doubt" — greatly. The patient might respond, "Yes, this is what happened," truly or falsely, or "No, this isn't what happened," truly.

It doesn't matter. Most likely patients already know, at some level, that they have erred, and rationalized it. In any case, for careproviders to say that patients rationalize their actions is implicitly a moral judgment, and saying this won't change patients' subsequent response. In fact, it may make it more likely that patients won't change their response. If careproviders give patients the benefit of the doubt, patients are likely to remember that their careprovider "accepted" them at this time and continued to believe that they *still* had another, "higher" side. I recall as a child having done something that made *everybody* angry. One neighborhood child said, though, "I'm sure he didn't mean it." Obviously, I remember that to this day!

PATIENTS WHO SEEK *IN VITRO* FERTILIZATION

In "As Sure As Eggs? Responses to an Ethical Question Posed by Abramov, Elchalal, and Schenker," Deborah Sarah Ferber reports on careproviders' response — or rather lack of response — to that article on IVF. Ten years ago, Abramov, Elchalal, and Schenker described several "downsides" or worst side-effects from IVF, which included women having a 20-fold increase in the incidence of so-called ovarian hyperstimulation syndrome (OHSS). (The syndrome can involve loss of the ability to urinate, blood clots resulting in strokes, and liver and kidney failure.) Ferber reports that the article by Abramov, Elchalal, and Schenker received little comment in the medical literature, even though it depicted what Ferber calls a "state of emergency." Based in part on these side-effects, Ferber describes how patients may seek IVF even at extreme personal risk and expense, and comments that patients who seek and continue to seek IVF, given these risks, may have a problem that is emotional rather than solely physical.

Ferber acknowledges that she is not a careprovider, but a cultural historian. Her raising these concerns is important, because careproviders who have this information may be wiser and better address these possibilities with their patients. Conversely, should careproviders act on this, it may present certain risks. For example, careproviders might come to assume that their patients probably seek IVF because they are depressed, and so could become less sensitive to their patients' other possible motivations, such as wanting to become pregnant because they find it uniquely meaningful. Research indicates that some women do seek IVF for this reason, even though it may make them feel *more* depressed.² They may feel, for example, extremely guilty because they are aware that they could choose to adopt.³ As this is the case, when careproviders participate in shaping public policy, it is important, *clinically*, that they not assume that patients' desire for IVF — or desire for any treatment, for that matter — is psychiatric illness, regardless of the degree to which this seems logical. Should they do this, patients may (rightfully) resent them, and then listen to little, if anything, they say.

What may be most difficult for careproviders to imagine is that women pursue IVF because becoming pregnant is singularly meaningful to them, and they will pursue it, even given the risks that Ferber describes. This may seem irrational, but, in other contexts, persons have made similar choices throughout time. A classical example is that of warriors who are willing to die so they are well remembered, as described by Homer in the *Iliad*. Many patients report a similar quest for meaning in their later years. I recall, for instance, a patient who forgot to change his clocks one spring to Daylight Savings Time. That fall, he became highly anxious; the summer had passed, he said, as if he hadn't existed. What bothered him most was that he could not do anything that he considered meaningful. This critically important aspect of many persons' reality, rational or not, was identified by Shakespeare, whose work is considered timeless and universal, with good reason. He writes,

Like as the waves make towards the pebbled shore,
So do our minutes hasten to their end.

. . .

Nativity, once in the main of light,
Crawls to maturity . . .⁴

Another example that illustrates the need for careproviders to stay aware of patients' unique need for meaning is a medical practice that is less common and far more controversial than IVF, so-called cosmetic plastic surgery procedures on women's vaginas.⁵ Some women seek this surgery to tighten their vagina after it becomes stretched from childbirth. Women may do this for their husbands, to improve their relationships with them, but some say they do it for themselves. As one might expect, when women say they do this to please their husbands, some become enraged. Perhaps it brings to mind the unconscionable status of women in the past, as exemplified by Henry the VIII's beheading his wives when they did not deliver a surviving male heir.

This discomfort or ambivalence furthers the purpose of this article, which is to suggest that even if careproviders strongly oppose a practice as a matter of a medical policy, their strong feelings may inadvertently rob them of the capacity to provide optimal clinical care. For example, a physician suggests women may seek vaginoplasty due to an underlying psychiatric illness called "body dysmorphic disorder."⁶

Careproviders may miss the fact that, for some patients, pleasing their husbands may be more important than anything else. If careproviders feel repulsion at this, even if they don't express it, their patients may still perceive it. This may cause patients to consider their careprovider worthy of contempt. Some careproviders may see these responses as wholly irrational. If so, they may want to consider the arguments of the late philosopher G.E.M. Anscombe. She saw *intention* as all-important, and viewed what persons connote to often be as important as, or more important than, the content of what they say.⁷ If we can't see how pleasing a partner could be most important to patients, and, moreover, we can't respect it as a choice, it may eliminate our capacity to help those patients.

This possibility is illustrated by considering a different group of patients who undergo vaginoplasty: patients who have a vagina created for them, perhaps in part to please a partner, when they change their gender from male to female.⁸ In these cases, careproviders take due pride in being able to perform surgery for patients in a way that most helps them. Why might this differ from similar surgery for women? One common error in thinking is to allow ourselves to think of others only in terms of what they *should* do. In this instance, for example, careproviders may believe that a husband should love his wife just as she is! Of course, people often don't "work" as we think they should. Thus, vaginoplasty may be exactly what some women want it to be: it may improve their life, whether or not others think it *should*.

How does this apply to careproviders who treat patients who repeatedly seek IVF? When careproviders do not judge or stereotype their patients, they can improve clinical outcomes. For example, careproviders can help IVF patients prepare for the possibility that IVF will fail. First, careproviders can help their patients expect the worst. Second, they can help patients learn how best to handle failure, should it occur. Careproviders can repeatedly say to patients that if they will feel disappointed if they do not become pregnant, it may be because they have allowed themselves to have overly positive expectations. Careproviders can advise patients that, before IVF succeeds (or fails), whenever they feel hope, they can say silently but firmly to themselves, "Whoa. I am expecting something that may never occur."

Secondly, careproviders can tell patients that no matter how much they prepare themselves, if IVF fails, they will feel sad; a voice within them may say over and over, "How sad! How could this happen to you?" Careproviders can tell patients that, rather than be in pain and try to "fight" hearing this voice, they can limit their pain by doing the opposite. For example, patients can learn to "quantify" various aspects of this voice each time they hear it; they could note how loud or how shrill it seems on a scale of 1 to 5, for example. "Quantifying" in this way can reduce pain remarkably. This technique can be effective even when the pain is wholly physical, as from cancer, much like a woman's counting during contractions may distract her from pain during labor.

The "success" of this approach is stated nowhere more clearly than by the writer and social critic Simone Weil, who said the following about how she became able to "distance" herself from pain she had due to headaches: "I was able to rise above this wretched flesh, to leave it to suffer by itself, heaped up in a corner. . . ."⁹ Careproviders can tell patients that they may practice this strategy any time during the IVF procedure that a voice inside them introduces "its" doubts. Careproviders can suggest that patients can get better and better at this, the more they practice. If they don't support their patients in seeking IVF, careproviders may not be able to convey these skills effectively. This is true for patients who have a vaginoplasty; this procedure, like IVF, can fail and have highly adverse side-effects.

PATIENTS WHO DONATE ORGANS TO STRANGERS

Finally, David Steinberg, in "How Much Risk Can Medicine Allow a Willing Altruist?" asks whether there should be a socially based process to help decide when persons should be able to donate organs — and, if they are allowed to donate, who should receive the organs. It is obvious that those potential donors act primarily to benefit others. They do not expect to gain anything — unlike someone who purchases an organ and so lives longer, or someone who has IVF and so is able to bear a child that is biologically her own.

Steinberg notes the perspective of Aaron Spital, who believes that when donors are "relatives and intimates," they should be allowed to accept greater risks than they should when they donate to strangers, because *they are likely to derive more benefit in the first instance*. The point I wish to make is that this view might be problematic for careproviders to adopt. First, it overlooks the meaning that potential donors may find in donating to strangers. Second, it assumes that those who donate to strangers will receive a benefit; but, as discussed above in regard to IVF, those who donate to strangers may give even when doing so makes them feel worse.

Usually, people who help others — especially their loved ones — feel good about it. When careproviders assume that a person would like to donate simply because a loved one will benefit, it may alienate the

potential donor, and even enrage him or her (and, I would say, with good reason). Why? Because, briefly, this assumption regards the donor as less of a person than she or he is. This kind of assumption may oversimplify and "reduce" the motivation of a potential donor. It also ignores a donor's strengths, and presumes that, as a person, a donor is more limited than she or he may actually be. As Steinberg notes, in fact, individuals may want to donate, especially to a stranger, with the reason that all human beings belong to an "extended family." Why might careproviders not share this belief? One possibility is that careproviders may presume that others "work" emotionally as they do, and thus couldn't choose freely to be so altruistic.

Should careproviders encourage the view that donors must be self-interested at best, or emotionally impaired at worst, society may come to adopt that view. In fact, the desire to donate an organ to a stranger may be the "highest" moral response a person can have. One of life's most important and real philosophical questions is, in this regard, how someone such as myself can live — having many things — knowing that others who are badly off greatly suffer — while it is possible that I could change this. In regard to this question, I think of the answer of the Australian philosopher Peter Singer. He states that he believes that all of us who can give to relieve other's significant suffering *should* give, unless this would cause to us or our loved ones a comparable burden.¹⁰ Singer "walks the walk." He doesn't eat animals that he believes have the capacity for sentience and can suffer, and he continually strives to update his knowledge, based on new scientific findings, of which kinds of animals these are. Singer also gives a substantial portion of his income to help others who are much "worse-off," and he acknowledges that, in comparison to what he believes that he and others should do, he fails.

Some believe that we, as humans, unlike other animals, have acquired a unique capacity to give to other persons who aren't closely related to ourselves.¹¹ The "highest" moral use of this unique human capacity may be giving an organ to a stranger, not because we believe we will benefit, but because we believe, like Singer, that this is right. Pope John Paul II said, for example, that donating an organ for transplantation constitutes "the highest act of love for one's neighbor."¹²

Careproviders who don't or can't see this may lose the opportunity to help patients as much as they could. For example, patients may donate an organ and learn that it "failed." Even if this doesn't happen, patients may fear that it will. Either way, careproviders can help. They can point out to patients that there may be a gain that they can't acquire in any other way. The gain cannot compensate for the loss of a "failed" transplant, but there may still be a "silver lining," and it may be most profound. This is that donors may, as a result of having experienced this loss, gain a depth of perspective regarding their life and of living that they simply couldn't have acquired in any other way. They couldn't acquire this, even by trying.

This is stated, perhaps, as clearly as anywhere by Simone Weil. Speaking of her own gain from having had severe headaches she wrote, "I was suffering from splitting headaches; each sound hurt me like a blow. . . . This experience enabled me by analogy to get a better understanding of the possibility of . . . love in the midst of affliction."¹³ This can even happen in response to giving birth to an infant with severe special needs. For example, Barbara Collins is the mother of such a child. She says, "This has given me a sense of what's important. I can't empathize anymore with my friend whose day is ruined because the cleaning lady didn't show up!"¹⁴ Another poignant and compelling example is given by Marianne Rogoff, who has written about her and her husband's life with their daughter Sylvie, who died while still a baby. Sylvie's doctors said just days after she was born that she would be "better off dead,"¹⁵ and Sylvie died several months later. Rogoff writes that she and her husband read the Anne Tyler novel, *The Accidental Tourist*.¹⁶ In the novel, Rogoff relates, "Out of the blue, a victim of random violence, [Macon Leary's] child is killed. Since the death, he is no longer the same man. . . . He blames himself. Macon Leary has to learn how to change, be altered by experience, and transformed."¹⁷ Given these accounts, careproviders may be able to tell patients and donors, that, following a profound loss, they may experience this kind of transformation. But could they say this to a person who would like to donate an organ to a stranger if they believed that the person would like to donate mostly or solely to benefit only him- or herself?

CONCLUSION

My intention in writing this has been to help careproviders avoid the risk that their patients will no longer see them as a refuge of last resort. Second, I hope that careproviders will not contribute to the greater society losing sight of who patients really are, and "lead the way" for society to accurately appreciate the strengths of all patients. Finally, I hope that even when careproviders become engaged in public policy, they can retain a capacity to help the patients as much as they possibly can.

Patients who seek kidneys illegally are, in addition to committing a criminal act, trying to lengthen their lives. Women who seek *in vitro* fertilization, especially those who do this "over and over," may not do it because they are depressed; they may do it *in spite of feeling guilty for not adopting*, because it is more important than anything else in their life could be *to them*. This is also true for women who undergo a vaginoplasty for their husbands, and for men who seek to become women, to better satisfy not only themselves, but their sexual partners. They may do this because this is most important *to them*, and, thus, their quests are worthy of careproviders' respect and support.

Persons who donate an organ, especially to a "stranger," may not do it to benefit themselves; they may, even, be physically and emotionally harmed by donating. Even knowing this, they may continue, nonetheless, *because this is what they believe they should do*. Society can see all these persons as *less* than they are, and what careproviders say about specific groups of patients may significantly influence what persons in society believe. If patients are mislabeled, they may become marginalized; careproviders may have contributed to this result. To help their patients and society most, careproviders must retain a capacity to see the kinds of patients they write about realistically. If they can take patients' most deeply felt needs seriously, they may also be able, clinically, to help them to the greatest extent possible.

NOTES

1. P.L. Berger and T. Luckmann, *The Social Construction of Reality* (New York: Anchor Books, 1966), 170.

2. As one patient who was not having success with IVF said, "The feeling of failure was so painful! It was not only the pain in my body but also a strong assault on my feelings." T. Su and V. Chen, "Transforming Hope: The Lived Experience of Infertile Women Who Terminated Treatment After In Vitro Fertilization Failure," *Journal of Nursing Research* 14, no. 1 (March 2006): 46-54, p. 50.

3. P. Orenstein, *Waiting for Daisy* (New York: Bloomsbury, 2007), 200.

4. W. Shakespeare, "#60," *Shakespearean Sonnets*, ed. B.A. Mowat and P. Werstine (New York: Washington Square Press, 2004), 125.

5. S.G. Boodman, "Cosmetic Surgery's New Frontier," *Washington Post*, Health Section, 6 March 2007, F1, F5. Since this procedure was first recorded in 2005, there have been 793 performed in the U.S. in this year. One physician who "invented or popularized" this procedure has done 3,000 over the past 12 years. Ibid. No doubt there are good reasons careproviders should be concerned about this. One doctor says that there is "absolutely zero scientific literature" that supports this procedure "even doing only what those doctors doing this purport that they do." Another doctor reports that she has treated several women who have had complications resulting from this procedure. This includes painful intercourse. Ibid.

6. Ibid., F5.

7. G.E.M. Anscombe, *Intention* (Oxford: Blackwell, 1963).

8. G. Liguori, et al., "Laparoscopic Mobilization of Neovagina to Assist Secondary Ileal Vaginoplasty in Male-to-Female Transsexuals," *Urology* 66, no. 2 (August 2005): 293-8.

9. R. Coles, *Simone Weil* (Reading, Mass.: Addison-Wesley, 1987), 118; see also E. Panagopoulou, "Emotionally Expressive Coping Reduces Pregnancy Rates in Patients Undergoing In Vitro Fertilization," *Fertility and Sterility* 86, no. 3 (September 2006): 672-7, in which the author suggests, on the basis of data, that this technique that involves distraction and "distancing" may work better for patients who have failed

IVF than these patients "emotional expressing" and working through their grief, p. 676.

10. P. Singer, *Writings on the Ethical Life* (New York: HarperCollins, 2000), see, particularly, 110-3, and 258-9.

11. I. Semeniuk, "How We Tell Right from Wrong," *New Scientist* (3 March 2007): 44-5.

12. M. Banasik, "Living Donor Transplantation — The Real Gift of Life," *Annals of Transplantation* 11, no. 1 (2006): 4-6, p. 5. I think, when contemplating this question of what we should all do for "strangers," of a scene from the movie *Suddenly Last Summer* (1959). Elizabeth Taylor and Montgomery Clift are having dinner in a country club-like setting on one side of a high glass wall. On the other side of this glass wall, outside the country club, are poor persons, crowded against the glass panel. Their faces are jammed and mashed against it as they look in and on those inside. J.L. Mankiewicz, *Suddenly Last Summer* (New York: Columbia Pictures, 1959), movie.

13. Coles, see note 9 above, p. 118.

14. R. Simons, *After the Tears* (San Diego, Calif.: Harcourt Brace Jovanovich, 1987), 79.

15. M. Rogoff, *Sylvie's Life* (Berkeley, Calif.: Zenora Books, 1995), 18.

16. A. Tyler, *The Accidental Tourist* (New York: Knopf, 1985).

17. Rogoff, see note 15 above, p. 87.