Literature and medical ethics

Doing harm: living organ donors, clinical research and *The Tenth Man*

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Abstract

This paper examines the ethical difficulties of organ donation from living donors and the problem of causing harm to patients or research subjects at their request. Graham Greene explored morally similar questions in his novella, The Tenth Man.

Medical treatment is often painful, usually unpleasant, and sometimes genuinely harmful. The administration of pain has become a routine part of diagnosis and treatment, from blood-drawings, intravenous lines and lumbar punctures to chemotherapy, limb amputations and involuntary psychiatric confinement. Many doctors are understandably uncomfortable with this part of medicine, even when the patient agrees to it, especially when the harm is permanent or severe. Life may be short and the art long, but the art's most delicate aspect is not to shorten life further, and not to diminish it.

Although medical procedures that harm patients are ordinarily intended to serve the patient's welfare, there are two related exceptions: non-therapeutic clinical research on human subjects, and organ transplantation from living donors. The procedures are related in that living organ donation, at least in its early stages, has been an experimental therapy. They are exceptional in that both human research and living organ donation require people to take risks or undergo harm for the sake of others, rather than for themselves.

The bioethical literature of the past three decades has done a thorough job of exploring the rights of competent patients to refuse treatment, and it has struggled, not always successfully, with the question of when research or other risky procedures are justifiable on patients incompetent to consent. But it has tended to overlook a cluster of questions surrounding the opposite problem: competent people who consent to, or even request, procedures which are risky, painful or harmful. Part of the

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reason for this neglect may be the idiom in which bioethical questions are usually scripted and rehearsed, which is not well suited to the moral backdrop against which these issues are often played out. A vocabulary of rights and autonomy can be inadequate to represent the intimate bonds of family and friends, the delicate balance between sacrifice and self-interest, and the complex, often awkward relationship between doctors and organ donors or research subjects. In a moral framework shaped by respect for patient autonomy, whether or not to undergo risk or harm can come to seem a matter solely for patients to decide. The worries that many doctors feel about exposing willing subjects to harm or great risk can be frustratingly difficult to express.

What I would like to do here is to articulate some of these worries and to take the debate beyond the terms in which it is ordinarily expressed: as a conflict between the principles of beneficence and autonomy. To do this, I draw on Graham Greene's novella about shame and redemption, *The Tenth Man.* I will suggest that the issue of doing harm to willing subjects is more complicated than philosophers often acknowledge. I conclude with some practical recommendations for approaching the problem of patients who willingly expose themselves to harm or risk.

Volunteering to be harmed

Sometimes competent adults volunteer for research or other sorts of medical procedure that are likely to harm them. Sometimes they volunteer for good reasons, other times for bad ones, but in either case a certain proportion of them are well aware of the harms they are risking and freely consent to them. One relatively common example is phase one clinical trials for chemotherapeutic drugs. Phase one trials test a drug's safety, and for chemotherapy they are generally done on patients with incurable cancer. Patients are at first given a small dose of the drug, which is increased until the patients begin to have toxic side-effects. However, with the toxicity comes only an exceedingly small chance of therapeutic benefit; for example, one study put the rate of complete remission at 0.16 per cent, and the likelihood of any objective response at all at less than 5 per cent (1).

While some people see no problem in exposing competent adults to the risk of harm as long as they are informed and willing, many others feel vaguely uneasy about it. In fact, most people can imagine some limit to the degree of risk, and the severity of the harm, to which they would be willing to allow a subject to expose him or herself. Renee Fox reported a dramatic example at a conference sponsored by the University of Utah after the total artificial heart implantation in 1982 (2). Commenting on her experience at Stanford University, Fox said that the Stanford heart transplant team had been contacted by a number of healthy volunteers who wanted to become living heart donors. The volunteers wished to donate their hearts to patients in need, knowing that this meant sacrificing their lives.

William De Vries, the surgeon who performed the first artificial heart implant at Utah, said his team also received a number of calls from healthy volunteers when their surgical team was in the process of selecting a patient for the implant. These volunteers had no medical need for an artificial heart, but nevertheless wanted to volunteer to have one implanted, apparently solely to become test subjects for the sake of medical science. Some of these volunteers were death row inmates. Another was a sixty-year-old woman who had raised her family, and evidently thought this would be a fitting way to end her life.

It might be thought that few people would approve of very dangerous cardiovascular research on healthy subjects, much less heart transplants from living donors. Yet in a moral framework whose dominant principle is respect for individual autonomy, doubts about harmful procedures are difficult to defend. The volunteers are competent and their sacrifices would clearly help people in need. We allow patients to refuse procedures, even when a refusal will be harmful. So when they request harmful procedures, why shouldn't we agree to perform them? John Harris, who professes to see no problem with such procedures, puts the case simply: 'Should I be permitted voluntarily to donate a vital organ like the heart? Again, if I know what I am doing then I do not see why I should not give my life to save that of another if that is what I want to do' (3).

The Tenth Man

Graham Greene's novella, *The Tenth Man*, is a subtle reminder that self-sacrifice is often more morally complicated than it seems (4). It tells the story of a French lawyer, Chavel, who is jailed by the Nazis during World War II. Chavel has been rounded up by the police for reasons unknown and

imprisoned in a cell with twenty-nine other men. Most of the men are poor, below Chavel's station in life, and this fact increases Chavel's agitation about his plight.

After a number of months a guard enters the cell and tells the prisoners that there have been some murders in the town by the resistance movement. As a result, the commanders have ordered that one man out of every ten in the camp is to be shot. In a day's time, three of the thirty prisoners in Chavel's cell will be executed. The prisoners themselves must choose which three.

The prisoners decide to draw lots, and Chavel is among the three marked to die. Unlike the other condemned men, Chavel panics. He alone among the prisoners is a wealthy man, and fear-stricken, he begins to offer all his wealth and belongings to the other prisoners, if only one of them will change places with him. To the astonishment of all, one man accepts the offer. Michel Janvier says that if Chavel will sign over his house and all his wealth to him, so that he can in turn leave it to his impoverished mother and sister, he will take Chavel's place before the firing squad. He and Chavel draw up a will, and the next day, Janvier is shot.

This exchange takes place in only the first chapter of the book, but it is the story's defining event. The exchange was freely agreed by both men and witnessed by the other prisoners. Yet even though the deal was freely made, we know that Chavel was wrong to make it. Even though we might admire Janvier for sacrificing his life in order to provide for his mother and sister, we know that Chavel was wrong to take advantage of Janvier's selflessness.

Chavel knows this as well, and his actions torment him. *The Tenth Man* is a book about guilt and shame, and its plot turns on Chavel's efforts to purge himself of the guilt that he feels about bartering for his life. After the Nazis fall and Chavel is freed from prison, he is celebrating in a bar when he sees his face in a water decanter.

'It is the face of failure. It was odd, he thought, that one failure of nerve had ingrained the face as deeply as a tramp's, but, of course, he had the objectivity to tell himself, it wasn't one failure; it was a whole lifetime of preparation for the event. An artist paints his picture not in a few hours but in all the years of experience before he takes up the brush, and it is the same with failure' (4).

Harm and autonomy

Our ordinary moral and political vocabulary makes it natural to think of exchanges involving harm, such as the exchange made by Janvier and Chavel, as questions primarily of rights, freedom and fairness. Yet very often our private reservations about harmful practices bear only a tangential relationship to these questions. That this is so can be seen in the awkward terms in which contemporary debates about harmful practices are often played out: whether people have a 'right' to act altruistically, or whether a research subject's 'freedom' is compromised by payment. In *The Tenth Man*, a prisoner objects to the deal struck by Chavel and Janvier on the grounds that it is not fair. But argued in these terms, his legitimate moral concerns are bound to be frustrated. As Janvier angrily replies: 'Why isn't it fair to let me do what I want? You'd all be rich men if you could, but you haven't the spunk. I see my chance and I take it. Fair, of course, it's fair. I'm going to die a rich man and anyone who thinks it isn't fair can rot' (4).

In a debate shaped by concepts like these, taking part in a harmful medical procedure or research protocol comes to be seen primarily as a matter of individual autonomy. Genuine worries about exposing a subject to harm are channelled into a debate about freedom of choice. When a surgical team at the University of Chicago transplanted a liver lobe from a living mother to her daughter with biliary atresia in 1989, critics of the procedure said that to offer a mother the chance to donate a liver lobe to her daughter was 'coercive', that no parent could refuse the offer (5). The bonds between parent and child are so tight, it was said, that they constrict a parent's ability to make a free choice about risking the chance of harm.

While this criticism expresses some legitimate worries, it is aimed in the wrong direction. The most worrying part of living organ donation is not freedom of choice, though there is certainly the possibility of subtle coercion in such a situation. The worrying part is the chance of harm to a healthy donor: the liver transplant procedure was a new one, the risks potentially minimal but in many respects unknown (6). That these worries about self-chosen risks should emerge disguised as concerns about free choice - the idea that a parent is *coerced* by her love for and moral obligations towards her child - says something about the central place the ethic of autonomy holds in our culture. Yet the fact is that no one would have thought to call such a choice coercive if no risk of harm were involved.

While debates over rights and freedom should not be ignored, they do not quite get at the real source of Chavel's shame, nor at what is most troubling about subjects who volunteer for harmful procedures or research protocols. An exchange can be made fairly and freely, yet still fail to be admirable or Chavel's actions were honourable. Certainly understandable; they were the actions of a desperate man, who grasped frantically at the only possible chance of surviving his imprisonment. But they were also the actions of a coward, a man who took advantage of his wealth and another man's selflessness in order to save his own skin. A person who attempted such an exchange might well be

justified in demanding that no one prevent him from making it, but as Adam Smith remarks of this type of situation, '[N]o man, I imagine, who had gone through an adventure of this kind would be fond of telling the story' (7).

Benefit from harm

To get at what is troubling about a person who knowingly and willingly consents to a harmful medical procedure, it is necessary to look not simply at the person making the decision to participate, but beyond him to the other people involved in and affected by the exchange. In many ordinary, nonmedical cases, if a person chooses to risk his life or health, we feel that this is ultimately his decision to make. Miners, police officers and soldiers all take risks, often very dangerous ones. Our highest admiration, in fact, is reserved for those rare people who risk or even sacrifice themselves for the sake of others.

But while we honour self-sacrifice, we would rightly criticize a person like Chavel, who willingly *took advantage of* another person's sacrifice. And this is what is hard to avoid in many harmful medical procedures: a person who stands to gain from a volunteer's selflessness. Altruistic acts benefit other people, both directly, as with an organ recipient, and indirectly, as with the clinical researcher whose reputation is made through the fruits of his research. And while it might be admirable to risk harm to oneself, it is not admirable to encourage another person to risk harm to himself for one's own benefit (8).

The most obvious example is organ donation from living donors - of kidneys, bone marrow, and more recently, liver lobes and lungs. Though the risks associated with each of these procedures vary considerably, from very little to unknown, they are all undertaken for the good of a recipient who, unless he or she is a child, has presumably agreed to be a recipient. Accepting a sacrifice of great magnitude is not mere passive acquiescence, devoid of any moral import. If I allow someone else to risk his life or health for my sake, I am endorsing his self-sacrifice and agreeing to profit by it (9). Now, of course, if the risk to the donor were very small, as in the case of bone marrow transplantation, and the alternative were death, an offer like this would be difficult to refuse, and accepting it would surely be justified. But what if the risk were very high? What would we think of a person who would take advantage of a donor's willingness to take life-threatening risks? What would we think of a person who would accept a heart from a living donor?

Unless the circumstances were extraordinary, most of us would think very badly indeed of a person who would agree to, and take advantage of, a sacrifice of this magnitude. Like Chavel's, his would be an act of failure: a failure of courage, a lapse of moral nerve. Chavel is ashamed because his hour came; he had the chance to behave honourably; and he betrayed himself. Like Conrad's Lord Jim, he was faced with a moral test and he floundered. If an ailing patient were to take advantage of a healthy donor's voluntary self-sacrifice, it might well be understandable, but it would not be morally admirable. It would not be the sort of behaviour that we would aspire to and want to encourage.

This point also helps to explain why we often feel very differently about a person who donates an organ to a family member. Chavel's life was saved through a bargain struck with a stranger, and we rightly feel that he was wrong to take advantage of Janvier's unusual wishes. But relationships between family members are coloured by very different moral and emotional hues. Here talk of rights, obligations, respect and freedom gives way more naturally to talk of gratitude, grudges, devotion and kinship. If a father wishes to donate an organ to a child, or a sister to a brother, we can immediately understand the wish. It arises out of love. And accepting a gesture of love, even if it involves the risk of harm to the giver, is profoundly different from paying someone to harm himself, or even from endorsing self-harm from a stranger. When a person is faced with serious illness, we expect her family to respond, and we can identify with the impulse to undergo whatever risks or harms are necessary to help the loved one. It is a legitimate question, of course, whether or not a person who truly loves another could in good conscience allow that person to take great risks for him. But we can understand and approve of the relationship out of which such an offer and acceptance might take place. If a person offers to risk his life for a stranger, even if we admire him we feel the need for him to explain why he is willing to take such grave risks. But if a sister offers to risk her life for her brother, the explanation 'because he is my brother' will suffice.

For related reasons, it seems less problematic for a small child to be the recipient of an organ from a living donor than it is for an adult. Since a small child has no choice in the matter, unlike an adult, he cannot endorse or agree with a donor's decision to undergo risk or harm. Thus there is no worry that the recipient might be taking advantage of the donor.

It must be remembered that decisions about risking harmful procedures are always made within a web of social relationships: between family members, between strangers, between clinician and patient, researcher and subject. The nature of those relationships affects the moral standing of the decisions, as I have pointed out, but the reverse is also true: what sort of decisions we allow or encourage affects the nature of the social relationships. For example, it may be admirable for a person to place another person's interests above his own, but for doctors to encourage or endorse such decisions by their patients might undermine the already endangered assumption that doctors put the interests of their patients first. This would probably change significantly the relationship between doctors and patients. Even those of us who resent being told by doctors how we should behave might be wary of doctors who had no qualms about doing significant harm to their patients for the benefit of someone else.

Paying for organs

The nature of the doctor-patient relationship would probably also be altered if we were to commercialise the transfer of human organs, though just how it would be altered is not easy to predict. Organ transplantation is a practice in which a relatively small proportion of people ever take part, and it fits into our cultural landscape rather awkwardly. Both the language we use to describe the prelude to organ transplantation and our customary ways of proceeding suggest that we have begun thinking of the practice, however tentatively, as a variation on gift-giving (10). We speak of 'donating' organs; promotional campaigns encourage potential blood donors to 'give the gift of life'.

However, the anthropology of a practice is altered by the exchange of money for what would otherwise be undertaken for reasons of affection, charity or duty. We make important distinctions between favours and services, gifts and merchandise (11). To put a price on organs and sell them alters, in a rather uncomfortable way, both the way we think of the organs themselves and the relationship between the organ donor and the recipient. The donor becomes a vendor, the recipient a customer, the organ a commodity, and the relationship a contract. Many doctors would be uncomfortable with this commercialized version of transplantation, even those who doubt that generosity can meet the demand for organs.

The Tenth Man also reminds us that few decisions affect only the person who makes them. Chavel eventually takes a job under an assumed name as a handyman at his old estate, which is now owned by Janvier's sister and mother. There he realizes how much his exchange has hurt Janvier's sister, who despises the unknown man whose bargaining led to her brother's death. She wonders how Janvier could have ever thought that she and her mother would have preferred the wealth they have inherited to his life.

That a person's decision to harm himself deeply affects a circle of people far beyond him seems so obvious a part of ordinary life that it seems almost trite to emphasize it here, but a recognition of this point is often strangely absent in philosophical writing. To emphasize the broader effects of a person's actions is not, of course, to deny that a person's liberty rights entitle him to harm himself if he wishes. It is rather to point out that these actions often extract a heavy toll on those who love and care about the agent, and that for this reason, they are not ethically uncomplicated. If I pay another person to harm himself for my sake, or if I agree to use him in a risky research protocol, I must recognize that my actions might very likely damage his family and friends very much. And even while I might defend that person's right to make the decision to harm himself, I would feel very awkward trying to defend myself against the criticism of his family and friends, whose resentment most of us could readily understand.

Finally, it is important to realize that the doctor is not a mere instrument of the patient's wishes. Analyses of living organ donation and risky clinical research are often simplified needlessly by a failure to acknowledge outright that the doctor is also a moral agent who should be held accountable for his actions. If a patient undergoes a harmful procedure, the moral responsibility for that action does not belong to the patient alone; it is shared by the doctor who performs it. Thus a doctor is in the position of deciding not simply whether a subject's choice is reasonable or morally justifiable, but whether *he* is morally justified in helping the subject accomplish it.

This alters the doctor's perspective in at least two important ways. First, as a moral agent, the doctor must ask not simply whether a change in a given state of affairs would be morally better, as a detached observer might ask, but whether or not he should become the agent of that change. Answers to these two questions need not be the same. If I were faced with a dying person in intractable pain who wanted to be a heart donor, I might well judge that all things considered, it would be better if he were to die. But this does not mean that I would be willing to kill him, or that I believe that I (or anyone) would be morally justified in doing so. It is an essential part of our notion of agency that we distinguish between that which we do and that which merely happens. It is not at all unreasonable for a doctor to think that it would be good for an event to take place but bad for him to bring it about.

To take another, slightly different example: opponents of a market trade in human organs often argue that an organ-market would exploit the poor, who would be tempted to alleviate their poverty at great risk to their health. Market defenders respond that the harms a poor person chooses to undergo should be a matter for that person himself to decide. A poor person might well think that it is better to be without a kidney than without money. But if I am the surgeon faced with doing the transplantation, this argument may still not win me over. Because even if I agree that the choice of harms should be up to the poor person himself, and that his choice to donate a kidney for money is reasonable, the fact is that I would not be responsible for his being poor, but I would be responsible for his being without a kidney. Greene makes this point in *The Tenth Man*. What torments Chavel is not a mere event, the death of Janvier, but the fact that he, Chavel, is at least partly morally responsible for bringing that death about.

The second important way in which the doctor's perspective differs from that of a patient or a detached observer is in the balance of harms and interests that he must weigh. A potential organ donor or research subject must decide whether to weigh the interests of other people over his own. To do so would be admirable, and not to do so would still be understandable. However, the doctor is looking at a different sort of balance. He must weigh not his own interests, but the interests of one person against another: in the case of organ transplantation, the interests of a potential donor against the interests of a recipient; or in the case of non-therapeutic clinical research, the interests of a potential research subject against the potential beneficiaries of the research. This shifts the moral balance of the problem in an important way, because while we admire the person who undergoes harm to himself for the sake of another, we do not necessarily admire the person who inflicts harm on one person for the sake of another. And the latter is what the doctor must do (12).

Conclusion

How should these points shape the way we approach policy decisions on procedures that involve the likelihood of significant harm to patients? First, there is a legitimate distinction to be drawn between *allowing* a person to risk harm to himself and *encouraging* it. So, for example, even if we acknowledge the argument that a person has a right to risk harm to herself and that her action would benefit others, it does not follow that a system is justified which encourages people to harm themselves. Substantial payment to organ donors or volunteers for dangerous research arguably crosses the line between allowing and encouraging.

Second, there is obviously a difference between choosing to risk harm to oneself and choosing to aid another person in risking it. It is partly for this reason that we might admire a person who chose to risk his life or health for the sake of others, but at the same time criticize the doctor or researcher who exposed him to that risk (12). It is not unreasonable, then, for doctors to be reluctant to expose willing subjects to the risk of harm, even while acknowledging the legitimacy of a system which allows subjects to take great risks. In fact, we might be justifiably suspicious of the character of a doctor who had no such reservations.

Third, it is important to acknowledge outright that when a person chooses to risk harm to himself, very often he is risking harm to others as well. When a person suffers, those who love him suffer, and when a person dies, he is missed. Any decision to encourage or assist a person who is willing to undergo a risky or harmful procedure must take into account these broader effects. (Of course, these effects touch the circle of people surrounding the potential *beneficiary* as well as those surrounding the person taking the risk.)

Fourth, at least part of the reason why we have reservations about patients who volunteer to be harmed is the possibility that other people might be taking advantage of the volunteer's selflessness organ recipients taking advantage of donors, researchers taking advantage of volunteers, and so on. For this reason, any system of practices in which people are likely to be harmed should be set up in ways that minimize this possibility. Of course, there is a sense in which any person who benefits from such a system is taking advantage of those who contribute to it, but it is possible to draw some limits. For example, it would be better to have a system of living organ transplantation in which nobody is able to make a financial profit from the procedure, including transplant surgeons and organ procurement agencies. This would limit incentives for anyone to encourage potential donors to take risks.

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