Baby marrow: ethicists and privacy

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Author's abstract

A family had a child in large part to use its marrow in the hopes of saving the life of an older child afflicted with leukaemia. Public response from medical ethicists was negative. This paper argues that what the family did was not clearly wrong and that the ethicists should not have made public pronouncements calling the morals of the family into question.

When is privacy invaded? What are the responsibilities of ethicists when questioned by the press? These questions came together with the case of the Ayala family.

Abe and Mary Ayala's 17-year-old daughter, Anissa, needed a marrow transplant to survive her leukaemia. The Ayalas had not been able to find a suitable donor. Mrs Ayala became pregnant in the hope that the baby would have the appropriate marrow type (the chances were about one in four). Getting pregnant required that her husband undergo surgery to reverse a vasectomy.

Response was negative. Their doctor said: 'It made me uncomfortable ... It didn't sit well if that was the only reason, to have a child to help another child.' Alex Capron said that having a child for this reason violated a Kantian principle: no one should ever be treated as a means to an end — that each one of us ought to be treated as an end-in-itself (1).

I do not propose that what the Ayalas did was clearly right. I do want to make three suggestions: 1) What the Ayalas did was not clearly wrong; 2) If it was wrong, Kantian grounds will not show it, and 3) The privacy of the Ayalas was invaded by ethicists when they took the Ayalas to task in public. These ethicists violated what should be a canon of behaviour in cases like this one.

What the Ayalas did was not clearly wrong

It is not easy to argue that never having been born (or conceived) is better than some bad life. Cases where the claim might make sense, a life of unmitigatable pain for example, are far from the case of the Ayalas, where the infant is most likely to suffer only brief pain. It is hard to see the grounds for Marissa Eve, (Baby Marrow) or a guardian for her, claiming wrongful life. Even being told that she was conceived to help her older sister, while certainly disconcerting, could hardly be grounds for a wrongful life claim.

Indeed, it is difficult to see exactly who was harmed by what the Ayalas did. Granted there will be pain caused to the infant, but it is transient and the procedure is basically safe. Anissa can only be helped (unless one insists on arguing that giving her hope that may not bear fruit is a harm; but this is an unfair and unrealistic claim). The parents are not harmed, except perhaps for the pain and discomfort associated with pregnancy, labour, birth and the reversal of the vasectomy. But these are hardly, in this case, weighty considerations. Of course, one gets the impression that the ethicists were prompted by their belief that what the Ayalas did was immoral and that if the ethicists did not speak out, then the public might assume that what was done was right. Rather than discuss the role of ethicist as gatekeeper for public morality, I turn to the presupposition that the Ayalas broke some sort of Kantian principle.

Kantian grounds will not show the Ayalas wrong

Action theory seems to have made it reasonably clear that there is no one correct way to describe an action. Part of the reason for this is that often the description of an action requires knowing why it was performed. Given that human motives are notoriously mixed and difficult to determine, describing actions is also difficult. If this is at all reasonable, then it should be just as difficult to know whether an action is an example of using someone merely as a means to an end, since this clearly requires knowing why an action is performed. For example, if I jump into a raging river and save a drowning child, what is the best way to describe what I have done?

I have foolishly risked my life (as Kant might put it, on an inclination). I have heroically saved a life. I have made myself a celebrity.

Under the last description, I may have used the drowning child merely as a means to an end. Why did I save the child? Because it was the right thing to do.
On impulse. Because I wanted the fame.

Which is correct? And, who really knows? It is not always clear just what the motive for any action is; or, whether there is, indeed, just one motive. How exactly does one decide which of many motives, some means/some ends, are primary?

H J Paton in his book, *The Categorical Imperative*, states: ‘To sacrifice one’s life in the performance of duty is not to use oneself merely as a means’ (2). He gives an example to show the distinction between using someone as a means and using someone (or something) *merely* as a means. He points out that when we mail a letter we use the postal workers as means but not simply (or merely) as means, since we believe that they have a duty to perform their services. The stamps we use, however, are used merely as means. Filling out the example just a bit, we can consider the case where I have a duty to mail you a letter. My duty requires that I use the postal service but not merely as a means, since they have a duty to perform their services.

Thus, if saving the life of one’s daughter is a duty and if the only way to save that life is by conceiving a child, later to be used in a certain way, then that conception and the resulting child are not mere means if they can be said to have duties toward, in this case, Anissa. Obviously, neither conceptions nor infants can be said to have duties. It appears then that on Kantian grounds, the Ayalas have done wrong. But Kant cuts even deeper than this. For unless we want to argue that most donors of tissues have duties to donate, we are forced on Kantian grounds to say that when we accept donations we are using donors merely as means. If we want to reject this result of Kantian analysis, having found it counter-intuitive, then we also have to reject its use on the Ayalas.

Putting Kantian analysis aside and turning to our moral intuitions, isn’t having a child for some reason other than to love it, morally suspect? The following examples suggest that the whole idea of morally evaluating parents in this regard is questionable.

Suppose that my first child has no interest in sports. I am keenly disappointed because above all else, I have wanted a child to be my companion at sporting events of all kinds. I care little, if at all, for other, traditional reasons for having children. In discussing my disappointments with you, I tell you that I have just had my vasectomy reversed and my wife is pregnant just so that I can satisfy this desire to have a companion at sporting events. Such an action is selfish and short-sighted. Indeed, it may backfire. But so long as I can be trusted not to vent disappointment in a brutal manner should the child turn to philosophy instead of sports, it is just not that obvious that I should be characterised as having done anything that is immoral.

Now, just change ‘companion at sporting events’ to championship boxer. (Perhaps the first female champion.)

Thus my child will be put into dangerous situations and will be caused pain with no real choice on my child’s part. Is it now clear that I am immoral? Or, am I just that much more selfish and short-sighted? I do not think that the answer is obvious. If I am right, then the pain caused the Ayala infant (in a situation with less overall danger than boxing) cannot be clearly immoral. Even if in the boxing case I ought to be considered immoral, there are enough differences between it and the Ayala case to cast doubt on whether the Ayalas should be seen as immoral. With the Ayalas, the pain to the infant is transient, the danger limited and the benefit aimed at another, Anissa, who really is in need of help.

Reversing a vasectomy in the hope of creating a great boxer may be far-fetched. But there are many cases of fathers who have raised their sons to follow them into boxing and other sports where there is physical pain and danger. The children are in effect given no choice. Indeed, after a while the children want exactly what the father wants. Again, this sort of child-raising is not clearly immoral.

(In these examples, I am making a rather traditional assumption that an action is clearly immoral if and only if it [a] violates a clear right; [b] causes unnecessary pain, loss of freedom or pleasure, and [c] there is no [reasonable] justification for [a] or [b].)

I conclude that the Kantian principle should not have been used as a weapon against the Ayalas. Moreover, the examples used above are adequate to show that what the Ayalas did, while worth scrutinising, was hardly a clearly immoral act.

**Their privacy was wrongly invaded by ethicists**

Consider a couple having a fight at a restaurant. They are doing it in public and their voices are loud enough to hear if we pay a little attention. So we do. After all, it is human nature to be fascinated by such goings-on, especially when they are making no real effort to keep anyone from hearing. And yet, we would try not to be too obvious in looking and listening. Why? Because we all know that somehow this is a private affair. It is none of our business. (Oddly enough, it would be even less our business if we knew the couple. In part, this accounts for why we feel so embarrassed when friends fight ‘in front of’ us.) It is wrong to strain to listen. If seen, we would feel sheepish, indicating that we would feel that we had violated the privacy of another. If seen, we would be open to the angry comment, ‘What are you looking at?’, indicating that, at least to the couple, we had violated their privacy.

(Another interpretation of this example is that we feel embarrassed for the couple because they have lost self-control and have aired in public what ought to have been kept private. On this interpretation, we have not invaded their privacy. They have made the blunder of going public. If anything, *our* privacy has been invaded by their argument. Even this interpretation will make my point. Despite the fact that our feeling is not embarrassment at listening, we still understand that the argument should be private, and, therefore, not subject to our [however unwilling] scrutiny and evaluation.)
This is a common-sense notion of privacy that we all know should be accorded to certain parts of people's lives. Having an argument is one of them; passionate kissing on the college green is another (we try not to look); defecating is another (again, we try not to look). We are not immoral to listen and to look. But it is wrong and insensitive. We are being voyeurs; not a pleasant appellation.

So it is with the Ayalas. They are in public. (How their case became public is another issue. Whether it really should be considered newsworthy is a question for journalism ethics.) And yet, we (ethicists, certainly) ought to avert our eyes; not from the issues but from them. They should not have been subjected to public moral judgement.

It is important to ask: 'Judgement by whom?' We all can claim to have a right and an obligation to speak out when we feel that an injustice is taking place or about to take place. But the 'we' refers to us as people not as professional ethicists. Can it be that by virtue of being professional ethicists we actually lose some rights? That the answer is yes should not be so surprising.

If I see that you are limping, I might say: 'You ought to see Dr Smith. She is a fine orthopaedist'. But if Dr Smith were to see you limping and say: 'You ought to see me, I'm a fine orthopaedist,' we would certainly wonder about the good sense of the fine doctor. It is expected that students will recommend professors they think have done a good job. Now imagine a professor saying (or even implying): 'Take my course, I'm so much better than my colleagues'. Such professors (they exist) are considered, at best, egotistical, where this is a negative comment. None of this is meant to imply that the comments by the imagined doctor and professor are immoral. Rather, the point is that some things, in some contexts, just should not be said (probably in these two cases because they are unprofessional).

Saying that rights are lost might be too strong. Rather, it is that the profession by its nature requires a degree of common-sense and sensitivity such that sometimes forbearance is the course to be taken. But when and how?

Recent history may help decide.

When some babies were getting liver transplants because of television appearances by their parents, the situation was decried. But no ethicist criticised the parents for taking advantage of the system to help their children. When Baby Fae got a chimp heart, the ethics of the procedure was dissected. But no ethicist attacked the morality of the parents. When heart transplants are discussed, no one impugns the morality of the patient or family for taking advantage of the medical and social system.

The Ayalas also took advantage of the system. When transplant registries failed them, Mr Ayala had a vasectomy reversed and helped start a pregnancy in order, at least, to have a better chance for a marrow transplant for their daughter. There is a temptation to say that the difference is in the treatment the infant will get, none of it to its benefit. But, in the cases of transplants, where one family gets a liver as a result of a television appearance, another family does not get that liver. That is, there is harm to others in both sorts of cases. However, it would appear that the harm to others, given the relative safety of marrow aspiration, is worse in the transplant cases.

Ethicists should have treated the Ayalas in the same manner as the parents of children needing livers and hearts. The discussion should not have focussed on the morality of the Ayalas' actions.

How might the Ayala case have been discussed? One could have emphasised the question: 'What are legitimate reasons for having a baby?' a question which has no simple answer; thereby leaving it an open question whether the Ayalas should be considered blameworthy. Shifting to questions such as, 'Why was it so difficult to find a donor?' or 'Does impeding death justify actions which might seem otherwise morally questionable?' would also have avoided putting the blame squarely on the Ayalas.

Three final notes: law, the press and doctors

The law, at least in the United States, has no real say in the Baby Marrow case. Women are allowed to choose to abort fetuses. Prospective parents, who are not adopting, are not required to show that they will be good parents. Nor are prospective parents required to show they are conceiving future children only out of love. While some people feel pregnant women ought to be incarcerated rather than allowed to risk the health of their fetuses with drugs, courts have yet to make this a clear standard. (A court in the state of Michigan recently ruled that 'a woman [who took cocaine while pregnant] should not stand trial for delivering cocaine to her newborn son through the umbilical cord'...(3.)

The courts do have an interest in protecting the welfare of children. This is done in a variety of ways; from child abuse laws to child labour laws. Yet no one has claimed that the Ayalas have done anything as heinous as violate child abuse laws.

Regarding the press, suppose we agreed the Ayala's case was so newsworthy that they should lose their right to privacy. It still would not follow that professional ethicists would then gain the right to make public moral judgements on the Ayalas. Notice also that the argument against ethicists making public moral judgements on the Ayalas may not apply to those who report them; or to those who solicit them. That is, none of the arguments here undercut freedom of the press.

Whether doctors should make public their moral judgements of their patients' medically related decisions is a question different from whether ethicists may do so. One of the obvious differences is that often doctors are not strangers to their patients, whereas, usually, the ethicist is. Whether such public statements by doctors violate some sense of confidentiality is an interesting question, but not one I shall pursue here.

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Clearly, however, as this paper shows, ethicists may publicly judge other ethicists.

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References


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News and notes

GMC statement about the treatment of patients on the basis of clinical need

'The General Medical Council reiterates the principle that a doctor should always seek to give priority to the investigation and treatment of patients solely on clinical need.'

This statement forms part of guidance that the General Medical Council has decided to issue to all doctors following a debate on access to health care. It will be incorporated into the council's publication Professional Conduct and Discipline: Fitness to Practise, commonly referred to as the blue book.

The council also accepted a report from the Standards Committee concerning guidance to doctors on professional issues relating to access to health care and other related matters. This will be published shortly.
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