Patients’ wants versus patients’ interests

John Wilson  Department of Educational Studies, Oxford University

Author’s abstract

(1) Should we treat other people according to what they want (their own values), or according to what we take their best interests to be? If they have given us no mandate to decide for them, their values should prevail. This applies not only to allowing but also to assisting them to get what they want.

(2) Taking this seriously in medical practice involves a lot of communication between doctor and patient, and a lot of research to establish a typology of patients in respect of their wants. The results would seriously affect doctor-patient relationships and the organisation of general practice and hospital care. It is with this, rather than dramatic ‘moral problems’, that medical ethics should be chiefly concerned.

A: I want here to raise, if not to settle, a question of principle which runs through all our dealings with other people, but is perhaps particularly acute for those whose profession highlights certain choices about human interests. The question is, roughly put, ‘Ought one to give other people the treatment they want, or opt for, or think best for themselves on the one hand, or the treatment oneself thinks best for them on the other? Is it what we take to be their wants that should be the determining criterion, or what we take to be their (best) interests?’ Of course this question can often be avoided: people (patients) often give mandates to other people (doctors), thus empowering them to decide what is best for them; and sometimes a person may be persuaded that what he wants is not in his best interests, so that he comes to want something different. But often the question cannot be avoided.

It is worth noticing that we often display uncertainty here. On the one hand, most of us give our friends the Christmas presents they want, not the ones we think are in their interests: and some parents at least will not only allow their daughters to marry men who (in the parents’ view) will make them unhappy, but even give them a slap-up wedding. On the other hand, many of us would hesitate before allowing, let alone assisting, other people to take drugs, or commit suicide, or run into what we take to be serious danger. J S Mill notoriously got into difficulty when considering whether his principle of non-interference should operate in all cases, even when a person’s wants were (as it might seem to others) clearly irrational, or based on ignorance, or severely damaging to himself; and it is not at all clear, even in the case of the most lucid moral philosophers, for example, Hare (1), which way they would jump.

I come down on the side of wants rather than interests, because it seems to me that wants are logically prior. We live in a world where people have different views about what is good for them (including different philosophical theories about what is good), or different ideas about what their interests are. Certainly they may be mistaken, and it is important that discussion and research take place in order that we may all see our mistakes. Meanwhile, however, we need a principle of procedure. Do we assent to a principle that any person A can treat or deal with any person B in a way which is against what B wants, whenever A thinks this to be against B’s interests? Or do we prefer a principle that allows B to be treated as B wants, always provided that he does not harm other people? Or shall we adopt some kind of compromise, whereby B can have the treatment he wants except in certain specified circumstances (if he wants to kill himself, for instance)?

The interesting thing about this question is that the mere raising of it seems to enforce a particular answer. We ask ‘Do we want . . .’?, and whatever answer we give will be in accord with our wants – even if our wants take the form of wanting other people to override our personal views sometimes (even always), as it were giving them a mandate to do so. The same is true if we put the question as I put it in the first paragraph, ‘Ought one . . .?’ We assume, that is, an initial set-up in which we sit round a table and treat each other as negotiators of equal status: so that the outcome will necessarily be some form of agreement or contract in terms of what we want. Particular views or theories about what anyone’s real interests are, particular ideologies or values, are set aside: if any one view were taken for granted, there would be no true negotiation. Further, there are (I believe) good reasons why a
person ought, if at all possible, to negotiate with his fellow men rather than arrogating the right to treat them in accordance with his own ideology.

There is, however, a distinction between allowing another person to have what he wants and assisting him to do so. Some moral philosophers think this distinction to be morally important: thus Foot (2): 'For while it is not normally permissible to seize an object from a man because he will harm himself with it, it does not follow that there is an obligation to help him to keep such a thing if it is falling out of his reach'. In general we certainly feel more reluctance in assisting than allowing; and this has particular relevance to professions like that of medicine, where it is more usually a matter of assisting. Ought one actually to provide the patient with the drug he craves, or the means to suicide? Many J S Mill type liberals, thoroughly convinced that to deny people what they want (even if it is not in their best interests) is a kind of tyranny, nevertheless draw the line here.

Again we need some kind of general rule; and again my guess is that we would prefer a rule which put some kind of (perhaps more limited) obligation on other people to help us achieve our own ends, even if the ends may be misguided. Certainly we may wish to write some exceptions into the rule: for instance, if we are under some clearly specifiable form of compulsion, such as drug addiction. But in general I think we would side with the parents who give their daughter a proper wedding even if that initiates a disastrous marriage, because that is what we would want if we were in the daughter's shoes. The point is not so much that the marriage cannot be stopped (so that impeding it would be no more than a token gesture of disapproval, a way of keeping the parental hands clean); but rather that genuine love or concern for another person - assuming the person is not a minor, or under some other kind of mandate which gives us the right to decide for him - involves waiving one's own values in favour of his. As with the parents, we can only hope that discussion based on mutual trust, or an appreciation by the person of how much we value her and would be sorry to see her do harm to herself, will cause her to change her mind.

It does not follow from this that either doctors or anyone else who is in a position to help others should be infinitely plastic about giving people what they want. For the principle cuts both ways: if patients have their own wants, values and points of view, so too have doctors: if teenage children, so also their parents. Caring for someone as an equal does not mean that we should put our own wants and points of view on the shelf: it means rather that we have to negotiate these, as equals, with those we care for. Without this reminder the whole notion of responsibility to others is liable to disappear (as, arguably, it is disappearing in a welfare state): for instance, the responsibility of citizens to pull their economic weight in society, to be in a fit state to defend their country, and so on - duties not consistent with drug addiction. These arguments, commonly neglected and weighty enough to cover most of the cases that may worry us, are the ones that really do justice to the equal moral status of human beings: and they are to be sharply distinguished from the un-negotiated deployment of one individual's ideology on others.

B: These are tentative arguments, and deserve much more careful consideration; but if the general conclusion is correct, a number of practical points immediately follow. These can be summarised by saying - what is obvious enough, but rarely happens - that we cannot know what people want or opt for without communicating with them. The man who thinks he knows what is best for another need not communicate: but the man who treats the other as a moral equal, who wants to be fair or just to him, needs to know in detail what the other counts as good or bad. The sheer labour of communicating, and (more commonly) our preference for deploying our own values on other people rather than respecting theirs, make us pay no more than lip-service to human equality: we are not usually willing to do the necessary work.

How does this apply to medical ethics? In a sense, it undercuts a great many of the problems commonly discussed: for if we use the criterion of what people want, then the ethical decisions will be up to them - assisted, of course, by the facts that medical expertise can give to them. Any advice a doctor gives will be given only in the light of what the patient thinks good: it will be of the form 'If you want a long life, then do such-and-such'. But of course the patient may prefer a short life but a merry one, or no life at all: that is up to him, unless he gives the doctor a mandate to decide for him in his best interests.

The application of our criterion to medical ethics lies elsewhere: briefly, in trying to match up medical practice with the wants of different types of patients. Where these wants are clear (as, in the case of simple physical health, they often are) there are no problems except technical ones.

But very often they are not clear. Here are some of the questions we should be asking:

1. How far is it true, and for what sorts of patients, that people under medical treatment like to know what is going on, want to participate in the treatment, and need to see their doctor as a kind of partner? How many people prefer a more authoritarian figure who simply tells them what to do? How many actually like a rather stern figure who sometimes ticks them off? (There is a prevailing fashion for a more 'democratic', less 'authoritarian' style of doctor-patient relationship: this does not seem to be based on any serious enquiry or research. My dentist insists on my 'participating', which means that he asks me awful questions like 'Do you think I should use the grinder or the splinterer at this point?' I prefer to close my eyes and recite poetry until it's all over.)

2. How far does an open, loose and informal style of hospital regime actually suit the wants of patients?
Would some prefer a stricter regime – and if so, which ones? How are we to determine this beforehand? (Another example of a change in fashion not properly researched.)

3. Which patients would prefer to be told, and which patients would prefer not to be told, if they have a terminal illness?

4. Under what conditions would what patients find life intolerable and prefer to be allowed (or assisted) to die?

I hope these examples (there are plenty more) will show that a great deal of work is required: partly by way of establishing a useful typology or classification of patients in terms of the relevant wants, and partly by way of communicating adequately with patients so as to ensure that their wants are known in advance. What actually happens – though this too needs more research – is that particular individuals, and particular climates of opinion or fashion, simply enforce a particular style or way of doing business without regard for individual differences amongst patients, often indeed without regard for their wants at all. This is of course not confined to the medical profession; teachers and parents commonly lack (as all of us do) the flexibility to employ different styles to fit different children in school or at home.

It will also be clear that this aspect of medical ethics (in my judgement, much the most important) cannot be properly dealt with except by person-to-person discussion, often of a fairly sophisticated kind. It cannot – in principle, not just in practice – be packaged or automated, because it turns entirely on trying to find out what particular individuals want and feel. It cannot be done by committees, but only by a doctor who wants to be fair to his patient, and knows that he cannot be fair unless he understands what his patient wants.

Of course this is time-consuming; and it shows the desirability of a system in which the patient has some one person with whom he has a sufficiently close relationship to feel safe about his wants and feelings being known and respected – not just a (any) doctor who can fill in for any other. This has fairly obvious consequences for the way in which health centres, general practice and hospitals are organised, for the mobility of doctors, for the connections between physical and mental health, and many other such matters. Arguably, just as young people badly need some one person (parent, teacher) who will take overall responsibility for their education rather than a shifting population of teachers in oversized schools – someone whose prime expertise is to know them, someone whom they can trust because they are known – so every adult needs a single person to whom he can relate in all matters of health (even if, as of course he must, that person will often send him out to some specialist to solve a particular problem). Without the trust, we cannot get adequate communication: and without the communication, we cannot meet his wants.

My suspicion is that in medical practice, as indeed in most other forms of person-to-person relationships, we have become obsessed with ‘moral problems’ (which are, in any case, ultimately not our business): problems of life and death, embryos, abortion and so forth. These problems are dramatic, and our earnest and high-minded reflections and discussions on them persuade us that we are ‘caring’, serious and conscientious. In fact they act as conscience-money, distracting us from the more pedestrian but more important task of trying to find out what other people want in order to play fair with them. Nine times out of ten, in almost any personal relationship, we prefer either to carry on in our own autistic style or else to agonise over ‘how to treat’ some other person: when what we ought to do is simply to ask him and talk to him (which includes listening).

A good deal of research needs to be done on the techniques of discussion designed to establish what a person’s views and values are: most contemporary research is far too large-scale and pre-packaged to do the job properly (3). It requires sensitivity and a thorough grasp of concepts and language: the discussion often turns out to be more like a Socratic dialogue than trying to get someone to answer a questionnaire. Much might be gained if doctors themselves were clearer about the different options that patients might want to take up (as in the examples I gave earlier): that is, essentially, about the different styles and approaches that different people prefer.

It is far more complicated than just finding out, for instance, whether a woman prefers ‘natural’ or other kinds of childbirth: more complicated even than distinguishing those patients that have puritanical views about being ill (they feel guilty about it and dislike ‘troubling’ the doctor) from those who run for help even when it is not strictly necessary.

C: There is, finally, a problem that I can do no more than mention here. My suggestion has been, in effect, that what we are willing to do for others should be a matter of negotiation in terms of our respective wants: a kind of contract-making between one person and another (doctor and patient), rather than the imposition of values by either party. But unfortunately there is no reason to believe that all parties would agree to the same kind of contract. Thus the laws of the land represent, or ought to represent, some sort of mutual deal which incorporates the values of all citizens; and whilst to some extent this is true – most people do not want to be assaulted, or stolen from, or defrauded – it cannot do justice to variations in individual wants, because for purposes of practical administration it has to be the same for all. Similarly, though doctor-patient deals may be generalisable over a wide area, there is no reason to suppose that any single deal would be acceptable to all doctors and all patients (for instance, in respect of euthanasia or drugs).

I suspect that quite a lot of the (usually unmerited) distrust of orthodox medical practice – as evidenced by ‘alternative medicine’, for instance – arises from this cause. It is not so much that people think orthodox
medicine to be in some absolute sense 'wrong', but rather that they think their own wants and values to be disregarded because of what one might call professional or administrative pressure – that is, the (understandable) desire to maintain some single set of standards which will apply to all medical practice. Certainly abuses have to be guarded against: but here again, in the light of what I have said, what is to count as 'abuse' must be negotiated rather than presumed. The position with psychotherapy is much looser: patients often make very different deals (overt or tacit) with different brands of therapists, and there seems nothing wrong with that. Perhaps this is something that could be extended into the area of physical health. But in order to get clear about the possible types of contract which could reasonably be offered, both doctors and patients would have to be clearer than I, at least, would claim to be about what their wants and values actually are. There is an interesting comparison here with marriage: many people nowadays do not go along with many versions of public and official marriage contracts, and attempt to negotiate something with their partner which better represents the wants of the two parties. Here the wants, fears and other emotions of human beings are even more obscure than they are in regard to health; but that, fortunately, is outside the scope of this paper.

John Wilson is Lecturer in Educational Studies and Fellow of Mansfield College, Oxford and the author of various books on moral education and philosophy. He has been Director of the Farmington Trust Research Unit, Oxford, Lecturer in Philosophy at Sussex University, Professor of Religious Knowledge at Toronto University and Second Master at The King’s School, Canterbury.

References


Obituary

Sir Desmond Pond

Sir Desmond Pond, who died on 29 June at the age of 66, has a special place in the development of the study of medical ethics in the UK. In the early days of the London Medical Group he gave detailed help in identifying appropriate lecturers, not only psychiatrists, thus ensuring a high academic standard for the programme of lectures and symposia. He served on the Consultative Council of the London Medical Group from 1968 to 1976, and was a member of the Governing Body of the Institute of Medical Ethics and the Editorial Board of the Journal of Medical Ethics at the time of his death.

For the past two years he was chairman of a working party, appointed by the Institute and funded by the Nuffield Foundation, on methods of teaching medical ethics to medical students. Although he was unable to attend the final meeting, he had approved previously the working party’s recommendations, which will be published later this year as the Pond Report on Teaching Medical Ethics.