The ethical issues involved in decisions to treat or not to treat

This paper has not been reviewed by Dr Longstaff. Please consult him before quoting.

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It will be absolutely no comfort at all to Dr Teo to be reminded that Socrates, condemned for impiety, corrupting the youth and stirring up the established views of the times, came to a rather unfortunate end.

How do professionals think about ethical issues?

I am not going to try to talk about legal issues, but want to expand on some of the points made earlier and to re-frame them a little in terms of some core ethical concepts. Before I do that, let me just put the issue in a broader context: how one might, as a member of a profession, think about such matters? I do that because we have, unfortunately, over the last 15 to 20 years, lost sight of the importance of that concept. We have done so in a world in which the ideology and language of the market have progressively become dominant, pretty much defined by the idea that it is perfectly legitimate for each person to pursue their self-interest and that, if left to the invisible hand of the market, this behaviour will lead to an increase in the stock of common good.

Distinguishing wants from interests

Associated with that idea is a world in which the expression and the meeting of wants is another central concept. This is quite a different world from that in which you, as members of a profession, have voluntarily chosen to participate. When you become a member of a profession, you explicitly reject the doctrine and logic of the market. Whereas the market is the licensing of self-interest, you agree explicitly to act in the spirit of public service, where you place the interests of others before your own. Whereas the market is defined by the meeting of *wants*, members of a profession have to be aligned to, and capable of discerning, the *interests* of those whom they serve. Making the distinction between what people want and what is in their interests is one of the crucial skills brought to bear by members of a profession, as in cases such as have been illustrated by Dr Teo.

The lawyer's pre-eminent duty to the court

Those of you who are lawyers would know that you have a principal and overriding duty to the court, an expression of that duty to act in a spirit of public service. It is a duty you owe to the court before all others, even before that which you might think is owed to your client, and certainly before that which is owed to your profession or to yourself.

The doctor's pre-eminent duty to the patient

Those of you who are doctors, as we have heard, have an overriding duty to act in the interests of your patient, rather than to meet the expectations of the profession or others. You do that because of your duty to society - to act in the spirit of public service. That is the broad context in which I want to pitch this paper. It is larger than just the issue around whether to treat or not to treat.

Some key concepts in Western thought

If we come to that particular set of questions, there are some distinctive concepts which have informed the way in which we think about these questions, at least in the West. I am not expert enough in eastern philosophy to say whether or not these are consistently applied in all cultures, but certainly within our Western tradition, we have all heard some of the concepts which have been mentioned. I will go back to those and articulate them in a slightly different way.

Respect for persons

The first, perhaps core idea, about which Dr Teo spoke, is the notion of the intrinsic dignity of each person, sometimes expressed as 'respect for persons'. In Ethics, what constitutes a person is neither a biological nor a legal fact. It is rather to do with an ethical fact about a person: a person is an individual capable of bearing the full range of attached rights and responsibilities.

The various traditions which give rise to why we accord persons such significance is, in some cases, due to a religious perspective. Some people say that persons enjoy this fundamental dignity because they are made in the image of God. Other people reach that same conclusion without any metaphysical concerns, but particularly look at the human person, for example, as being a kind of being capable of experiencing and exercising reason, and there are philosophical arguments which go from that point.

A choice between two paths

What is important about the notion of persons is that, when we come to some of the tough decisions which have to be made, as pointed out by Dr Teo, we can look at every single individual and try to evaluate their personhood. One of the ways we might to do that, for example, is by looking at their capacity to exercise some kind of informed consent to the things which might be done to them - and I will come back to that in a moment. In some philosophical arguments about this you might find reference to a person who has lost their capacity - in what used to be called a persistent vegetative state, or a traumatic non-responsive state, whatever you want to call it. They are unable to express an opinion,and there are even some questions about the extent to which they are at all aware of their existence and circumstances.

Can 'personhood' be lost?

You might say that some of the basic elements of which personhood is constituted have been lost and it is therefore no longer really relevant to take into account what they would want or could want. Other people - and I think that there is something in this argument - would say that, when we look at human beings, we shouldn't just make a judgement based on their individual circumstances, but there is a reason to look at the kind of class of being to which they belong. They would say that human beings, even in the state where they may be totally unable to exercise some of capacities that we normally associate with personhood, are nonetheless part of the class 'human being' which is, in itself, deserving of a certain kind of dignity.

Autonomy and consent

There are debates about that, with quite differing views. Depending on whether you take the views of Peter Singer on the one hand, or mine on the other, you will find some divergences worth reflecting on. Either way, if we do take seriously the notion of personhood, then autonomy is routinely linked to it, as Dr Teo said. In its application come particular notions around consent in terms of whether or not to treat.

The challenge of the case presented by Dr Teo lies in the fact, as we all know, that not every person, either because of their age or their condition, is capable of expressing informed consent, and yet that is one of the hallmarks we start with. It is when that becomes doubtful that difficulties arise.

When it comes to whether or not to treat, certainly in terms of the ordinary measures which might be brought to bear - and we will come to the extraordinary in a moment - it is entirely relevant whether or not the person will consent for the procedures to be performed. It is not up to the doctor. It is not up to the doctor's colleagues. It is not up to the patient's family to determine for that individual whether or not that procedure should or should not be taken, whether to treat or not to treat.

Cultural variation

Again we should note that there are some cultural specificities in these things. Not every culture invests the individual with the same status as we do. Some cultures would seriously question what I was just saying. They would say that it is, in fact, a community or a family issue. My assertion - that it is up to the individual - is the dominant tradition within which we would operate, but there might be people who would raise questions which we should seriously consider as part of our ethical reflection, not just whether we should tolerate that opinion, but whether there is something in it which needs to be thought about.

I have tried to do that, but still come back to the point where, ultimately, I accord a greater respect to the individual person for some of the reasons I have mentioned.

Ordinary and extraordinary means

Consent is a hallmark, but beyond that, when you come to look at whether to treat or not to treat, there are a couple of other distinctions which need to be borne in mind. There are traditions within medical ethics. Many of you would know these. Whether or not the means you propose to employ in relation to the treatment are

'ordinary' means or 'extraordinary' means; are these things you would do routinely as a matter of course, or are the things you are seeking to bring to bear extraordinary? Dr Teo, in a sense, has been making a case for this. You might say, 'Here is a doctor who wants to employ extraordinary means', but that's not quite the sense in which the term is normally used. 'Extraordinary' doesn't necessarily involve the fact that it is unusual. Rather the notion 'extraordinary means' is often attached to the concept of whether or not it brings an additional kind of burden to be borne by the person for whom the procedure might have been employed.

That is, in fact, not even an absolute in its own terms. The notion of 'extraordinary means' and the burdensome nature of those means can be relative to the condition of the person. For example, what might be a very burdensome procedure for, say, a young person, who in all other respects would seem to have a long life ahead of them, enjoying the full range of decisions they would otherwise care to make, might be burdensome, but relative to the benefit to be secured, might not necessarily represent an extraordinary means in their case. This contrasts, say, with a person very close to the end of life, where the procedure involves a considerable burden compared with the kind of benefit to be secured, where that burden would be far more of a weight to be borne.

The burden to be borne

The notion of 'burden' is relative. This has some bearing on what we consider to be ordinary or extraordinary means. Other factors also come into play. For example, an extraordinary means can be something which is extremely difficult to secure. The mere difficulty of getting it can make it extraordinary, relative to the circumstances in which a person finds themselves.

The New Zealand doctor-patient who came over here was, in one sense, resorting to extraordinary means, having not found a willing surgeon in New Zealand, but knowing that, if he came to Sydney, Dr Teo would be there. Should or shouldn't the patient do it will become relative, as we will see in a moment, to who actually bears the burden of cost. If it is borne entirely by that particular patient, in this case the doctor, then it might be worth bearing, but if the burden were falling on the state or on a whole lot of other people who had to bear the burden of that extraordinary means, then some other consideration might have been necessary.

The concept of futility

The final significant factor in terms of whether or not to treat is another one mentioned by Dr Teo - the concept of futility. Is the intervention futile or is it capable of generating some reasonable outcome? He is absolutely right to draw this crucial distinction. I am called in, from time to time, to hospitals in the public health system to work with patients or doctors, and occasionally by formal institutions like the Public Guardian, to help people think through some of these issues. The notion of futility is central because there is an important distinction between the noble goal we might pursue to prolong life and the alternative which we could bring about with exactly the same technology, namely prolonging the process of dying.

Prolonging life or prolonging the process of dying

This distinction is sometimes absent in the place where you think it really ought to be, namely in the minds of the medical team, who can have this heroic commitment to do whatever is required. It can also be absent in the minds of families and others. Just understanding that distinction would re-frame the situation in a way which might bring about a different sort of outcome.

These fundamental ideas are all extremely relevant factors: the intrinsic dignity of persons; respect for persons, giving rise to the importance of their ability to consent or to the importance of their consent; notions of ordinary and extraordinary means related to concepts of burden; and whether or not futility exists in what you propose to do, based on that distinction between prolonging life and prolonging the process of dying.

True dilemmas

Of course, not every situation presents itself as neatly packaged as that. Dr Teo made an important point we should never lose sight of, namely, that life could be pretty simple. We don't really have too much difficulty, most of us, in deciding between right and wrong, good or bad. Those come pretty easily to us. The decisions which truly tax us are when it is 'right versus right', 'good versus good', when there is an ineradicable degree of uncertainty introduced into the decision - which is what makes for a dilemma. That's what a dilemma is. It is when you are being pulled in opposite directions. These things can be complicated, when any of the factors I have been alluding to have been brought into question.

For example, the five-year-old on a ventilator, unable to express a view - probably in any case of questionable capacity because of her age - or to make an informed decision on her own behalf, immediately introduced into the equation the fact that others, whether parents or a public guardian, will be starting to express views about the child's interests.

Of course, it cannot always be assumed that even the parents would necessarily be acting in the best interests of the child. All of us, as human beings, can be overwhelmed by our own emotional needs, our grief, our sense of loss. We can cling on to people, even if our better selves in some sense would reach a different decision, which is why it is important that members of a profession be able to discern interests rather than just wants.

Distinguishing the medical wants from the patient's real interests

When it comes to medical issues, the wants which might be expressed and their difference from interests, are around some non-trivial issues. If I were a medical practitioner and any of you were diabetic and said to me, 'Simon, I want a big block of chocolate', I would have no problem at all saying, 'Look, I know what you want, you have clearly expressed it, but I also have to tell you it is not in your interests that I should give it to you, and I am not going to be involved in your project of securing it.' When it comes to the more difficult issues, distinguishing between a want and an interest can be much more difficult. 'I want to live', or a family saying on behalf of a person who can't speak for themselves, 'I want you to operate or not to operate'. The mere expression of a want has to be separated for some more mature sense of what the person's real interests might be.

Those interests can include notions of the integrity of the person. Sometimes bodily integrity will be at stake. For example, certain procedures, whether to continue with ventilation or to put a feeding tube into the stomach (a percutaneous endoscopic gastrostomy [PEG] tube), or whether or not to maintain it - these are relevant considerations because they involve some burden, because they can be affected by questions to do with futility and things of that kind.

The role of suffering

That's the general picture. The trouble with this, if more trouble is needed, is that there are some fundamental philosophical splits which occur when you start to put all of these elements together. For example, if we are trying to work out what one ought to do, which is the central question of ethics in relation to a particular patient, and we start to think, for example, around concepts of suffering - and suffering, in every tradition that I know of, is an evil. There is no religion or culture I know of which celebrates suffering as a thing which is good in and of itself. It might be something which, if it can't be avoided, provides an opportunity to grow.

You might tell me that there are some people who think that suffering is good, but that would be pretty much outside the normal experience of human beings. If suffering is an evil, and we are looking at some of these decisions about whether or not to treat, the question becomes, 'Whose suffering?' 'Whose?' is a relevant consideration.

Whose suffering?

At this point, some of the key philosophical channels of argument start to diverge. For example, utilitarianism, a form of consequentialism, whether in its purest form - associated with somebody like Jeremy Bentham, or in its more modern form - with people like Peter Singer, who is a 'preference' utilitarian. What a utilitarian would say, in principle, is that every single person should be counted as equal, that I count no more than anybody else in this room and that nobody in this room counts any less than anybody else in any part of the world, and that, in terms of making a decision about what is right to do, we should be involved in some kind of calculation of the course of action which would, if we take it in its purest form, increase pleasure and minimise pain, increase well-being and minimise suffering.

In that way, if we had the mind of God or some universal calculator, we could add up and subtract all of these pain points or sufferings versus well-being points, and come up with a conclusion which would generate the answer as to the right thing to do. On that basis, we might to start to take into exactly equal consideration, not just the patient, but also the members of the multi-disciplinary team who have a particular interest in a certain kind of procedure being done or not being done. I don't want to judge for or against on those things, or because of consideration for the family members, or for a whole lot of others who might be affected by the decision that we might make.

Strictly speaking, if you are a utilitarian, when you weigh up all the pluses, if you like, with the family and what they want, and with the multi-disciplinary team, then you might say that there are enough pluses to counteract any negatives you put into the calculation associated with the particular person who has to have the decision made for them where they cannot speak for themselves about whether they should be treated or not treated. Just remember the *caveat*: I would be put in a privileged position relative to the individual in all but maybe a few exceptional cases.

Not everyone is a utilitarian

Of course, in the world of ethics, not everybody is a utilitarian. Not everybody is a consequentialist. There is a whole stream of philosophical argument which says that it is entirely wrong to judge things by consequences, that there are some things that are just absolutely right or absolutely wrong. One part of that stream of argument would accord the dignity of the person which I started with, that is, the situation of that particular individual about whom the treatment decision has to be made, as a priority above all others.

The doctor's role as 'advocate'

They would not even get into calculating pleasure or pain. That's when you, the doctor, if you are not a utilitarian and you see yourself as having to discern interests and perhaps, to use Dr Teo's language, to be an advocate, might find yourself having to make a decision because you don't judge things according to consequences in the kind of calculation I mentioned, but where you stand aside from the general opinion held by a vast number of people about what ought to be done.

I cannot tonight resolve this age-old question between utilitarians and non-consequentialists of one kind or another, except to say there are some interesting lines of argument which are not for this sort of session to explore.

Arguing 'past' one another

I just highlight the difficulty that, even with people who are acting with goodwill, they might not even realise sometimes that you can have two groups of people equally committed to the professional ideal I described, equally committed to doing what is good and right, but who might not realise that they are arguing past each other, because one is coming from a utilitarian or consequentialist perspective and the other is not, and they keep on arguing, without ever seeing this distinction.

One last issue: the calculations about whether to treat or not to treat that I have been presenting to you so far have only had some relatively narrow considerations, that is, I have said that there is a certain primacy accorded to the individual. I would argue their ability, as an autonomous person, to consent to treatment or decide not to be treated. Where they can't do that, there might then be a discussion about others who are affected, and I have talked particularly about families. I think the views of people in the multi-disciplinary team are worth taking into account, although it is always, I think you are right to point out, a kind of group think.

Unthinking custom, tradition and practice

The great enemy of ethics, as you would all know, is not the greedy or dishonest person. The major challenge to ethics in any organisation or society is the baleful effects of unthinking custom and practice. That's the real thing which challenges ethics. It is when you escape Socrates' question, 'What ought one to do?', by never asking it and instead retreating into what everybody does, or 'That's just the way we do things around here'. That's the great enemy of ethics, so reflective practice, the examined life, constantly requires us to ask, 'What ought one to do?'. That doesn't mean to say that the fact that you are iconoclastic makes you right, but those who would simply assert a position 'because that's the way it is done' or 'that's the consensus', might be on shaky ground. Even there I have a narrow sort of consideration.

The dilemma of limited resources

The last part I want to turn to, in terms of whom to treat and not to treat, is to look at some broader and some challenging issues. For example, if we have limited resources available, to what extent do we apply principles of triage in making decisions about who is treated or not treated? It happens all the time. It can happen in heavy nights in Royal North Shore's Accident and Emergency, where there simply might not be enough beds and resources are stretched. It certainly happens in other critical moments where we can imagine terrible disasters where decisions of this kind have to be made.

Do we take into account the quality of life likely to be secured by the intervention? Do we, for example, treat the 25-year-old, as opposed to the 75-year-old if a choice has to be made? They might be talented individuals with families who love them, but do we take into account, as a relevant consideration, something like the life they have yet to live, as opposed to the life they have lived? Do we make an assessment about that? Do we want our doctors to do this?

Diverting scarce resources to self-inflicted maladies

Do we take into account people who might have contributed to the position in which they find themselves? There is a taxi driver whose services I have used for more than a decade. He has brain tumours. He told me about those before telling me that the primary was in his lungs and that he is a smoker. Has he contributed, in some sense, to the condition in which he now finds himself? When the neurosurgeon sees that the primary is in

the lung and that it has metastasised to the brain, and when he has a limited amount of operating time and limited resources, should that be taken into account or should he be indifferent to it? Let's not fool ourselves, it is not as if there is an endless pot of gold to be doled out for health care, given the other requirements we have for education and roads and a whole lot of other things. Should that man's smoking history, the fact that they did it voluntarily, be taken into account?

Does society make the decision? Should we leave it to doctors to make that decision? Do we leave it to family members? On what basis should we do so?

Conclusion

Hopefully this has provided something of a framework in which to think about the problem. I am sure I won't have clarified it all completely, because you will be divided in your own opinions about some of those key concepts. But those are the major concepts I think we need to resolve in terms of making the practical decisions about whether to treat or not to treat.