Case Conference

A 42 year old woman, with a teenage family - a son aged 18 years, daughter aged 16 years, and son aged 14 years - is admitted acutely to the Intensive Care Unit deeply unconscious with a severe brain haemorrhage. The brain death protocol confirms brain death. The husband is then approached with regard to the possibility of his wife being a multi-organ donor (heart, liver, kidneys and corneas).

In the ensuing family conference, the husband mentioned that as a family they had discussed the question of organ donation when the eldest son obtained his driver's licence. Both he and his wife were very happy with the concept of organ donation should a tragic event happen to either one of them. Therefore given that his wife is dead, the opportunity for part of her to be used to give other individuals a chance of life would be acceptable. It may also allow the family to use this positive aspect as a way of dealing with part of their grief.

However, the 16 year old daughter, who is quite naturally very distraught, is opposed to this. She does not want anybody to "open up her mother". Although she had previously agreed with the concept of organ donation when the family had discussed it at home, she could not cope with it now.

COMMENTARY 1

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The husband and wife, "were very happy with the concept of organ donation should a tragic event happen to either one of them", and the 16 year old daughter "had previously agreed with the concept ... when the family had discussed it at home".

However, now that the tragic event has come to pass, the daughter is distraught, and does not want anybody to "open up her mother".

Concerns like this occur with most grieving families. They need to be recognised and accepted by professionals. Empathetic counselling, and the provision of information is needed, whether or not the potential donor has given permission during life. The issues need to be addressed with as much concern for survivors' grieving as with the acquisition of organs for transplantation. Proper care of the grieving family will usually fulfil both objectives.

In this example, the tragic event confronts the husband of the potential donor with a dilemma. For him, not only would organ donation "be acceptable", it may also allow him to use this in a positive way, to deal with part of the grief. On the face of the information given however, unless his daughter's concerns can be alleviated, her grief might be made worse, and she may blame her father for that. On the other hand, the counselling process might help the daughter to foresee that her refusal now, might later be a matter of regret for her, as well as for her father.

The interviewer needs to be sensitive to these aspects of donation, and many others. It is not unusual, for example, for survivors of potential donors to perceive the patient's treatment as inadequate. "If only there had been traffic lights, if only the ambulance had arrived sooner ..." and many similar regrets, require an opportunity for expression, discussion, and acceptance.

The interviewer needs to summarise the chain of events, reactions and feelings elucidated by open-ended questions, to get the information here provided in the case study, and work through whatever issues arise.

Often, there will be little understanding of the meaning of brain death, revealed by questions such as "will my mother feel anything?". Since the daughter's concerns seem to revolve around "opening her mother up", we need to know whether she fears pain, or disfigurement for the donor. The significance of brain death, and the procedures followed if permission is given, need explanation.

The explanation should be couched in language appropriate to those concerned. "The mother that you knew and loved is dead, because the brain is dead. The heart is still beating and the skin is warm, because the machine is doing the breathing. When the brain is dead there can be no thoughts or feelings - no prospect for survival even of the rest of the body. If you believe in such things - the spirit has departed from the body".

To fulfil your mother's wishes, the body would be taken to the operating theatre, and the organs removed at a surgical operation conducted with all the care and respect of any operation. When that was done, the machine would be stopped, and the body released to the undertaker, to be cremated or buried". (It is assumed here that since the diagnosis is known a post-mortem examination is not required.)

When the family seems well informed and have had adequate opportunity to ask questions, they should be given time in private to discuss their position, and to ask further questions if they wish.

By a process of this kind the realities should become clear to all concerned. Because the potential donor is brain dead, with no prospect of recovery, the ventilator will be stopped, whether or not organ donation is to occur. If organ donation is to proceed, the ventilator will be stopped when that has been done, otherwise it will be stopped in the intensive care unit.

Whether one family member should be able to prevent organ donation, when the potential donor has given permission in life, is a question which is often raised. It would be unusual, in our experience for this to happen, provided adequate information is given and understood. However, if the situation does arise, after adequate counselling, then this interviewer would be inclined to advise against organ donation. Transplantation

depends in a unique way on the co-operation and support of the community. Every aspect of cadaver donation should be handled with scrupulous care, lest this trust be threatened.

In civilised societies, transplantation is a very special gift, which enriches the society. Anything which alters the gift status, such as financial reward, or serious objections from a close relative (like a Will that is challenged) is a threat to the continuation of these very special transactions.

COMMENTARY 2

Dr Alastair Gunn

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In this case, which I am assuming is a Pakeha family, there are just two possible outcomes - either the woman's organs are made available for donation or they are not. Donation will respect her choice, is acceptable to the husband and two of the children, and may save the life or sight of up to six people. However, it is unacceptable to the daughter, and will cause her unbearable misery, at least for a period; perhaps there is also a risk of some long-term damage to her mental or emotional stability. If the family insists that donation go ahead, they may later feel guilty at having overridden their daughter's wishes - what if she were to be permanently affected or even attempt suicide? Not donating will avoid these consequences but at the price of going against the wishes of the woman and the rest of her family and denying opportunities to potential recipients. There is also a risk that later on the daughter may herself feel guilty at having not respected her mother's wishes and at having denied the chance of sight or life to others.

As I have presented the issues so far, it seems that we are invited to choose between a variety of possible future scenarios. Some elements are relatively predictable, in particular the availability of potential recipients and their prognosis. The emotional and psychological outcomes suggested for the girl and her family are, however, much more speculative. How can we choose, in an atmosphere of such uncertainty?

One thing we can suggest is that the decision be delayed as long as possible, in the hope that either the daughter will accept the donation - surely the best result - or the rest of the family will change their mind. But the woman can't be kept on the ventilator for long: her organs will deteriorate, potential recipients will die, someone else will need the facilities, the hospital (public, I assume) will refuse to bear the cost, the staff will protest at keeping a brain-dead person in the Unit, and the family will be trapped and unable to get back to a normal life. So unless efforts at persuasion are successful - and they might be just as likely to be counter-productive - we seem to be struck with a true dilemma, in which there is no acceptable solution.

But wait a moment: who is the "we" in the last sentence? A serious drawback of the case study method is that it invites us to adopt an impossible position: first, to consider a situation from the perspective of each of those involved, and second, to decide what should happen as if one somehow did not have a perspective. But I doubt if we can truly share another person's perspective, especially on the basis of the very limited amount of knowledge made available. To begin to understand a person we have to develop a personal acquaintance with them, or at least to read a book length case study by a gifted novelist. It is much more difficult to see things through the eyes of a succession of characters (one of whom is dead) and *then* to adopt a god-like or Solomonic position in order to decide between them.

When I discussed this case with some of my students, several suggested that the family had unwittingly got itself into this situation, because they had clearly not discussed what was to happen if one or more of them changed their minds. I think that it is expecting too much for a family to cover every possibility. But it is certainly reasonable to expect a hospital to have clear policies about cases like these, in order to reduce the number of ethical problems that occur rather than waiting for them to happen and then trying to sort them out - a point I repeatedly emphasise in my course on professional and business ethics. For instance, it may have a policy of going ahead whenever there is clear and recent evidence that the deceased person wished to donate, and that all members of the family agree. Such a policy would need a careful definition of "family", allowing for differing culturally based concepts.

In preparing my comments on this case I asked my wife and teenage children what they thought. They all strongly took the view that it is up to each person to decide what happens to their body after death, including the choice between cremation and burial as well as organ donation. I'm not so sure. It is the living, not the dead who have to recover from a sudden death. Still, I would personally hope that if I were to die suddenly, my family would feel able to follow my wishes to be an organ donor. The best procedure, in my view, is for the hospital to explain its policy on family consent to organ donations, provide the family with whatever support and professional help they need, and let them try to reach a consensus.