and at worst is dismissive of our most basic human rights.

Ms Simms argues repeatedly that 'carers have a right to life'. No one in their right mind would dispute this. In fact, the salient point here is precisely that nobody has ever suggested depriving the carers of their lives, in the way that some people have suggested depriving the newborn handicapped of their lives.

Ms Simms's argument rests upon a false conflation of 'right to life' with 'right to a particular quality of life'. If, as she suggests, it were the case that the parents' right to life was at least equal to, and in immediate conflict with, the child's right to life, then there would indeed be a prima facie case for one of the parties to relinquish that right. If, that is, the child's continued existence was incompatible with the parents' continued existence, then we could at least start to think about who is going to have to die. But I have yet to hear of such a case.

It is indeed scandalous that parents, through lack of governmental and other support, are forced into a 'lifetime of caring' which is truly 'intolerable'. But this is not a matter of life and death, it is a matter of quality of life. They do not thereby have, as carers, lives that are not worth living. Ms Simms is wrong to say this as it would, if true, imply that they have no greater moral claim to life than the same handicapped infants whose projected quality of life renders them vulnerable to killing. They have, as carers, lives which are much poorer in quality than if they were not carers, or if others were involved in the caring. If, that is, governmental policies and public attitudes were different.

I would argue that a right to life is obviously more important than a right to a particular quality of life. It logically presupposes it, in that a given quality of life is unattainable if your life has been taken from you. But I am not arguing here for a simple play-off of rights with the more important ones winning. I am not, that is, arguing that carers ought to put up with present circumstances because their children's right to life is sacrosanct.

The conflict between rights of infants and rights of carers is caused, in the major part, by governmental policies and public attitudes. Ms Simms admits these as important variables in her references to hospital conditions, the difficulties in getting handicapped children adopted, and public spending levels. It is most unfortunate that she appears to acquiesce in these conditions, treating them as factors beyond our control. When faced with harsh impositions and uncaring attitudes which depress the quality of peoples' lives and frustrate their caring impulses, is it better to resolve the impasse by killing people, or by changing those circumstances?

Ms Simms speaks of 'the real world that exists out there'. To deprive the weakest in that world of their most basic rights, on the grounds that a governmental or public attitude has deprived others of totally different rights, is a policy which lacks morality and courage as much as it lacks logical coherence.

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Response to Neale

SIR

Mr Neale argues that the right to life is more important than the right to a reasonable quality of life. I would disagree with this proposition, since the 'life' he talks about in the first instance may be barely more than a vegetable form of existence with hardly any brain function. Several of the severely handicapped young people I saw in the course of my investigation were in this sad and hopeless condition. He argues that it is the duty of their parents to abandon all hope of a normal life of their own in order to sustain such a being, who demands their total and unremitting attention for the foreseeable future as long as he or she remains at home.

I do not think that parents have any such duty nor do I admire those who allow themselves to become a human sacrifice in such a hopeless case. If society as a whole takes Mr Neale's view of the matter, then society has to provide the total and very expensive care in perpetuity that such conditions demand. Society has no moral right to demand that the parents shoulder this burden on its behalf, which is what so often happens at present.

The ugly question of priorities therefore necessarily raises its head. Mr Neale blames 'governmental policies and public attitudes'. Given the dire state of Britain's economy and the stress under which the NHS and the social services labour, it is really fanciful to believe that the large sums of public money needed to give the very severely handicapped and their carers a worthwhile quality of life will be forthcoming in the lifetime of most of us taking part in this correspondence. Most people, as Mr Neale notes, do not appear to believe that maintaining a mockery of life ought to be given priority over returning sick people to health. Far from thinking this deplorable I regard it as sensible and realistic. What is important is that the criteria on which these views about the quality of life of the very severely handicapped are based, should be clearly stated and publicly discussed in a rational way. Doctors should not, as they are sometimes forced to at present, have to make these decisions about life and death hurriedly and under the immediate pressure of lack of resources.

While profoundly disagreeing with Mr Neale on this point, I think he has raised a very important issue. Increasingly the argument in medical ethics on a variety of important matters does seem to be between the Sanctity of Life party versus the Quality of Life party. What both parties need to be honest about is in recognising that there are no longer enough social and medical resources to fulfill all needs and that some will inevitably have to be sacrificed to others. In a recent paper, Dr Andrew Whitelaw wrote:

'Neonatal intensive-care units have the ability to prolong the lives of infants with profound neurological abnormalities, including some who will never enjoy independent meaningful lives. Furthermore, neonatal intensive care is an expensive and scarce resource which is sometimes denied to viable infants because of shortages of nurses or equipment. Against this background, many paediatricians have practised selection in applying high-technology life-support techniques' (1).

My own impression is that the Sanctity of Life party has not yet recognised that in the real world such hard choices do have to be made.

References


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Funeral service

SIR

Your readers may be interested to hear of the funeral service arranged jointly by the University of Dundee Chaplaincy and the Department of Anatomy.

This service is attended by relatives
of those whose bodies have been donated for the cause of medical education and research and by first-year medical and dental students.

For many students this is the first occasion when they encounter the personal grief that surrounds bereavement. It also provides an occasion for the bereaved to be present at a funeral service which, because of the donation, they were unable to attend at the time of the death. The therapeutic value of an event such as a funeral (when people formally 'let go' of the dead person) is already well documented.

The funeral takes place in the modern university chapel. The relatives are seated. Staff and students occupy remaining seats and then stand four or five people deep around the walls.

The funeral constitutes a formal committal ‘to the elements’ of the deceased and is within the Christian tradition. One unlabelled coffin is brought into the university chapel for the service and a ‘roll of honour’ of those bodies going to the crematorium is read. Any donor who had specified there should be no Christian service after his or her death would have his or her wishes respected.

Hymns and prayers are selected to emphasise the theme of thanksgiving with the positive aspects of the donation being stressed. Ushers are selected from amongst the students, who will have had their Anatomy end-of-year examination either the previous afternoon or the same morning.

At the service itself many students are emotionally moved. Its immediate benefit in confronting them with the human reality of death is self-evident. Further, as the occasion when many of them come face to face with the reality of bereaved relatives its long-term significance must not be minimised. Relatives, also very moved by the occasion, always express considerable gratitude for the funeral.

Tea and coffee are served after the service in the chaplaincy and the chaplains and Anatomy Department staff circulate amongst the bereaved relatives. The Anatomy Department’s Book of Remembrance is passed around the relatives. We consider detail such as this vitally important in the university’s personal contact with the community in which it exists.

We know of similar funeral services in Aberdeen and St Andrews. Our experience of the event as a vital part of medical and dental formation in Dundee gives us the confidence to recommend it to other institutions so that its value may become more widely understood and its practice more widely shared.

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Jacob and his name: a lesson in the ethics of responsibility

May
The story of Jacob, a name meaning deceiver, and his pretence to be his brother for an inheritance. is one of the oldest stories of the Western world (1) and may still provide a timely lesson for the necessity to take responsibility for what we are and what we do. After presenting himself as his brother Esau and receiving his brother’s blessing, Jacob fled to live for two decades with his-mother’s brother. When he returned home and stopped by the stream Jacob kissed an angel who asked him his name; Jacob replied, ‘My name is Jacob’. The angel renamed him Israel and shortly Esau received his brother back. Jacob’s pretence only provided short-term gain and a longer period of loss, though it culminated in reunion and realisation (2).

Russell has stated: ‘The importance of precepts such as the Ten Commandments lies in the fact that they give simple rules, obedience to which will in almost all cases have better consequences than disobedience; and the justification of the rules is not wholly independent of consequences’ (3).

Jacob did not have the benefit of the Ten Commandments (4), only of his conscience: a situation in which many physicians must find themselves in an era of a fast-changing medical technology. Furthermore, rules cannot cover all exigencies that arise, and it is then necessary to fall back upon the decision of an individual conscience, the results of which can only be judged later. An example of this is presented by Veatch: ‘Another ethical principle in addition to justice and promise-keeping that many formalists hold to be independent of consequences is that of truth-telling. As with the other principles, utilitarians argue that truth-telling is an operational principle designed to guarantee maximum benefit. When truth-telling does more harm than good . . . there is no obligation to tell the truth . . . telling the dying patient of his condition can be cruel and therefore wrong’ (5).

The decision at the bedside often remains an individual one. In Jacob’s case, we know he was acting from self-interest for which he faced a period of atonement.

From Jacob’s story and the Ten Commandments we come to the teachings of Christ. As Garrison has put it:

‘The chief glory of medieval medicine was undoubtedly in the organisation of hospitals and sick-nursing, which had its origins in the teachings of Christ . . . the spirit of antiquity toward sickness and misfortune was not one of compassion, and the credit of ministering to human suffering on an extended scale belongs to Christianity’ (6).

‘For the law was given by Moses, but grace and truth came by Jesus Christ’ (7).

The teachings of Christ reflect the lesson of Jacob: that it is individual action with its consequences in conscience that provide the foundation for both the development and application of ethical laws. The physician at the bedside must follow not only established ethical sanctions, but often must act and abide by all individual decision.

Addendum: Following the completion and sending of this letter, I am in receipt of Dr Michael J Newton’s article in the December issue of this journal, Moral dilemmas in surgical training: intent and the case for ethical ambiguity. Our paths have crossed, for our thinking is neither dissimilar nor mutually exclusive. I hope the readers of this journal will find the ideas presented stimulating enough to engage in reply.

References
(1) Genesis 27, 32.
(2) Watkins K G: From a letter to me outlining a sermon he had given.
(4) Exodus 20.
(7) John 1: 17.