

Correspondence

Informed dissent

SIR

To continue my prolonged debate with Madeleine Simms on informed dissent, may we assume from her letter in the December 1986 issue that, in defence of a particular, unspecified quality of life, it is legitimate to kill anyone who stands in our way? Or are the parents of handicapped children the only ones who should be accorded this 'right'.

Surely there are other groups whose life-style is threatened by the need or duty to care for someone else, and if we were to allow killing to solve every such problem, we would probably all be potential victims. This is a particularly dangerous and greasy slippery slope, I think.

In order to be consistent and ethically sound, we would have to decide just how threatening a person must be to a specified life-style before, in the absence of alternatives or mitigating factors, we may justify killing. The right of an individual not to be killed would then depend not on any intrinsic or conferred right to life, but potentially upon the most trivial of external factors.

For instance, I am confined to a wheelchair and unable to stand. If I am in a building with an inaccessible bathroom, how many times have I a 'right' to expect others to carry me there before I become an intolerable burden to them, and therefore a suitable candidate for death? Are architects then to be the final arbiters of life and death for those like me?

If the answer to inadequate facilities for the handicapped is to kill them, then we must presumably also kill those currently suffering in inadequate institutions, as well as immediately dispatching victims of illness or accident. We then, *ipso facto*, remove any real need for institutions, but we also remove all semblance of a 'welfare state'. The weak, vulnerable and ill

would then be entitled to a quick and possibly painless death, not to treatment or rehabilitation.

There are, I think, two ways to approach the nightmare world Ms Simms paints of overburdened carers and handicapped children 'languishing in institutions'. The first is to accept that this sad state of affairs cannot or will not be changed, and thereby to justify killing anyone who is 'burdensome' to someone else.

The second is to acknowledge that we are all in fact interdependent and all rely on others in certain circumstances. I believe Ms Simms is right in saying that mothers should insist that society - starting with the medical profession - should be made aware of the problems they face, and be required to function in the 'real world' of practical solutions. But if we are to retain our legal and social framework, designed to protect the weakest and most vulnerable, we need to avoid both professional 'tunnel vision' and the injustice of killing the weakest to protect the strongest. In doing this, the right to life, rather than the quality of life, must take precedence.

We need then to decide on a solution which will be durable, consistent and applicable in all situations. If all those perceived as burdensome may be killed, and such decisions are supported by government policies, then we begin to approach very closely the Nazi solution of Hadamar hospital, where those designated 'economic lumber' were eliminated 'for the public good'.

If only some of them may be killed, who will decide which - parents? doctors? architects? politicians? If we chose this course, irrelevant factors such as access, aesthetic preference and interpretation of individual or collective responsibility would have to play a part in determining who was to live or die.

On the other hand, if we decide neither of these approaches is acceptable, and none may be killed, we

must all ultimately share the duty to care. This is already done in the case of healthy children whose parents cannot or will not cope with them. If adoption cannot be arranged, the State assumes collective responsibility for them, and they are cared for at our expense. The same should also be true for handicapped children though, as with the healthy, we should first take all possible steps to enable the parents to keep them, if at all possible. Ultimately though for any child we need to acknowledge that while the 'quality of life' may be poorer if we assume the collective responsibility of institutional care, the right to life takes precedence over any such subjective considerations.

Claiming that our desirable quality of life can be achieved only by sentencing others to death is to live in a false, blindfolded bliss of violently acquired and desperately fragile happiness. This may be Madeleine Simms's idea of a 'life worth living'. It is not mine.

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Informed dissent: a further response

SIR

In a moral climate where an increasing number of people seem to be adopting an uncaring attitude towards those less fortunate than themselves, it is always heartening to hear the likes of Madeleine Simms attempting to further the interests of those who are currently forced to look after handicapped relatives ('Informed dissent', JME Dec 1986). However, several serious errors in her argument need to be corrected if we are not to fall into a moral confusion which at best is wasteful of resources,

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 Simm'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 cause. 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 furtively 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

- (1) Whitelaw A. Death as an option in neonatal intensive care. *Lancet* 1986; 2: 328-331.

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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