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Focus: current issues in medical ethics

Ethical problems in the management of some severely handicapped children

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Author's abstract

This paper examines some of the arguments advanced and acted upon by doctors concerned in decisions about whether severely handicapped patients should live or die. It criticises the view that 'selective treatment' is morally preferable to infanticide and shows how the standard arguments advanced for this preference fail to sustain it. It argues that the self-deception, which is sometimes cited as a sign of humanity in these cases, and which is implicit in the term 'selective treatment' is more dangerous than is the remote chance of brutalisation which is often cited as the danger of active euthanasia.

Selective treatment of severely handicapped children is calculated to result in their deaths. I am thinking particularly of the management of children with severe spina bifida (1). Such a policy has been justified on the hypothesis that it is reasonable to conclude that the child would be better off dead. This paradoxical sounding conclusion means simply that it is judged to be in the child's best interests to die. I am assuming that the children in question are too young, or too severely handicapped, to be themselves consulted. I assume also that this sort of judgment, while difficult to make, is unproblematic in that we can all imagine many cases in which life is so intolerable, so painful, so miserable, so difficult and so utterly without reward, that we would not wish to live such a life and that it is reasonable to suppose that no one would. I assume also that severe spina bifida is such a case.

What is, however, highly problematic, is the judgment that it is morally preferable to withhold treatment from such children so that they die slowly, rather than to kill them quickly and painlessly. Since 'selective treatment' in this context usually means not treating and often not feeding either, I will use the term 'selective non-treatment' to refer to this procedure.

There are many good reasons for abandoning the view that passive euthanasia is either morally preferable or causally more remote than active euthanasia, and I have argued this point at length elsewhere (2). However, many in the medical profession and many relatives of patients accept that selective non-treatment of severely handicapped children is morally preferable to killing and it is worth looking at the reasons that one eminent practitioner in this field has advanced for this view.

In a paper entitled 'Ethical problems in the management of myelomeningocele and hydrocephalus' John Lorber (1) makes out his case for selective non-treatment. Lorber sees clearly that it is in his severe spina bifida patients' interests to die, and his programme of selective non-treatment is calculated to bring about the speedy deaths of the patients. 'It is essential', Lorber emphasises, 'that nothing should be done which might prolong the infant's survival' (3) and that the temptation to operate should be resisted because 'progressive hydrocephalus is an important cause of early death' (4). An early death is of course desirable both to shorten the suffering of those marked for death and so that expensive and scarce resources should not be wastefully employed.

It may seem tendentious to talk of patients 'marked for death' but non-treatment is a death dealing device. If all patients whatsoever were treated as Lorber treats his selected spina bifida children (only fed on demand, given no tube feeding, no oxygen or resuscitation and no antibiotics for infections) (3) and they died, their deaths would be treated at 'best' as resulting from criminal negligence and at worst as culpable homicide. Indeed non-treatment is so effective a killer that Lorber is able to report that 'of the first 41 untreated infants in Sheffield none survived beyond eight months and 60 per cent were dead before they reached one month of age (4).

The tragedy is, of course, that these children or their families should suffer unnecessarily for even one month. Lorber sees this and records that 'It is painful to see such infants gradually fading away over a number of weeks or months when everybody hopes for a speedy end' (5). Lorber's motives are of the highest, he wants to save children and their families as much suffering as in conscience he can,

and he has been courageous in pioneering selective non-treatment which is more economical of suffering and of resources than is the active treatment of severe spina bifida. It is therefore particularly poignant that he believes it right to stop short of killing and particularly worthwhile examining his arguments for so doing.

Although Lorber's paper is ostensibly about the ethical problems of selective non-treatment, he in fact relegates discussion of these to the final page and a half of his paper. After noting 'a major inconsistency and perhaps hypocrisy' (6) in his opposition to active euthanasia Lorber sets out the arguments which he must believe to be strong enough to outweigh charges of hypocrisy and inconsistency and to justify those painful weeks and months which, in this case, represent the moral difference between killing and letting die. His arguments must be such as to pull the moral difference back in favour of selective non-treatment. With such a task before him we must regret that Lorber allots so little space to his discussion of the solution of these ethical problems. We will take the arguments in order.

The argument from brutalisation

This argument has two parts which are stated in two sentences, 'active euthanasia may brutalise the persons who carry it out . . . It would be wrong for a doctor to order his junior or his nurses to carry out such a task if he cannot bring himself to do it (6). To 'brutalise' in this context is I suppose to render individuals more insensitive to the pain and suffering of others and more careless or callous about the value of their lives. Evidence of brutalisation would be very hard to find and Lorber cites none. But what we have to balance here surely is a remote and imponderable danger of sensitive medical staff becoming 'brutalised' to an unknown (but perhaps insignificant) degree, against real and present pain, suffering and distress to the patients, their loving ones, *and* the medical staff who have to preside over their slow demise. We must also take into account the equally probable brutalising effect of taking responsibility for a slow and distressing rather than a quick and painless end. In the absence of any evidence, it is plausible to suppose that the responsibility of bringing about a slow and distressing death would be more rather than less brutalising than would a quick and merciful killing.

Certainly we can agree that doctors should not order others to do what they themselves cannot in conscience bring themselves to do, and others should not take such 'orders'. But again we are discussing what people ought to do in these cases, and what they feel they can in conscience do will, one hopes, be determined by what, after considering carefully evidence and argument, they think they ought to do.

The argument from lack of consent

'I strongly disagree with active euthanasia' Lorber states, 'especially for babies and children, who cannot possibly ask for it or give their considered consent' (6). Consent is worrying, but it is no more worrying for active euthanasia in the cases under consideration, than it is for selective non-treatment. As we have seen, selective non-treatment is intended to result in death and it does, and those who die cannot possibly ask for it or give their considered consent.

The slippery slope argument

'It would be impossible to formulate legislation, however humane are the intentions, that could not be abused by the unscrupulous. There have been plenty of examples in the past, especially in Hitler's Germany. Few just or compassionate persons would wish to give such a dangerous legal power to any individual or group of people' (5) (6). There are two points that need to be made here. The first is again that Lorber and others already have this power, they decide to act so as to bring about the speedy deaths of their patients and they are very successful. Whatever the dangers of legislation are, it must surely be possible to make them less than those that already exist without specific legislation. The power is awesome but it is already exercised. The second point is about the spectre of Hitler and Nazism. By raising it Lorber invites us to see the difference between active and passive euthanasia as the difference between humane medical practice in a civilised society and the first step on the road to the holocaust. But the Nazi euthanasia programme was nothing like the possibilities we are considering. Under the Nazis euthanasia was simply one way of exterminating those racially or politically beyond moral consideration. And the Nazis were not short of other ways to achieve the same ends. It is precisely because we care about spina bifida children, precisely because we are in no doubt that they matter morally, that we are concerned about what it is in their best interests to do. The spectre of Nazism offers no analogy at all and so only fogs the issues.

We must again remind ourselves that doctors already take decisions which result in death with no legal or publicly debated safeguards. If we do not cry 'Nazism' it is simply because we know there is no analogy and we know that all concerned are concerned only about the welfare of their patients. But if we fear even the slimmest chance of abuse, we should take care that all decisions in these areas are taken in the open with the widest possible public debate and scrutiny. One way to ensure this would be to legalise non-voluntary euthanasia only for those patients who were incapable of consenting and only where death was clearly in their best interests.

We could then build into the legislation whatever safeguards and criteria we wished.

The last door argument

The argument here is that active euthanasia closes the last door on an individual's life whereas 'No treatment with normal nursing care is a safeguard against wrong diagnosis . . . If an infant's condition is not as grave as was thought, he will live and he can then be given optimal care . . .' (5). But this on Lorber's own account of the treatment is not necessarily true. If a child selected for non-treatment contracts an infection and dies because it is not given antibiotics or, if it requires resuscitation which is not given and it dies, there will be no opportunity to discover whether the diagnosis was wrong or not. So this 'safeguard' is hit and miss at best. If the child *per* almost *impossibile* lives, we may find reason to say the diagnosis was wrong, but if the child dies we cannot say the diagnosis was right unless the non-treatment played *no role at all* in the death, for otherwise the diagnosis is self-fulfilling. Whether closing a particular door on life chances is closing the last door will be a question of fact in each case. If the child dies of an untreated infection then the withholding of the antibiotic drugs was in fact the closing of the last door, just as the administering of a lethal injection would be.

There can be surely no doubt that active and passive procedures which are both consciously designed to result in death and which do equally result in death are both forms of euthanasia. The crucial question must surely be: are there any reasons against the advocacy of active euthanasia in these cases which are of sufficient moral weight to tip the scales in favour of an alternative which involves weeks and possibly months of the very suffering that the alternative was embarked upon to minimise?

The argument from self-deception

One argument that is sometimes advanced is the suggestion that parents and relatives of severely handicapped children would not accept or consent to anything resembling killing, and so if doctors are to be able to recommend what they see as the most humane course, such a recommendation or, if that is too strong a term, such a possible course of treatment, would be useless if it were always rejected by those whose consent is judged necessary (7). But this, even if true, should not prevent us from seeing clearly what is the most humane course of action and advocating its acceptance. Unless we do so those concerned will continue to deceive themselves as to the reality of what they are doing, or consenting to have done, and will continue to choose a programme which involves weeks and months of avoidable suffering. And we should be clear that it is self-deception unless it can be unequivocally demonstrated that one procedure is of different moral quality from the other. The only palpable differences demonstrated by Lorber are that non-treatment takes longer to bring about death than would active euthanasia and is minimally less certain to result in death. Both these features seem to count against rather than in favour of selective non-treatment given the reasons which justify its being undertaken at all.

Indeed self-deception is sometimes advanced as itself constituting the moral difference between active and passive euthanasia. The argument here is that it is only because the medical staff and the relatives of the children are able to protect themselves from full awareness of what they are doing that they are able to bring themselves to do what they judge to be morally required by the circumstances. Here the idea that they are only 'letting nature take its course' allows them to distance themselves from the death of the child and fit their part in events more comfortably into their conception of the medical role (8).

The 'course of nature'

There is a terrible irony here in that the whole practice of medicine might be described as a comprehensive attempt to frustrate the course of nature, of which disease is after all a part, and to prevent 'nature' from killing people in its usual extravagant fashion. There is undoubtedly a widespread, but equally undoubtedly, an irrational respect for what is natural or part of the course of nature. Famines, floods, droughts, storms are all natural and all disastrous. We only, and rightly, want the natural when it is good for us. What is natural is morally inert and progress dependent. It was only natural for people to die of infected wounds before antibiotics were available and it is only natural for spina bifida children to die if their condition is inoperable, but it is not natural if they are selected for non-treatment, when with full treatment they would live.

It is also perhaps worth emphasising that if we were ever to feel confident that the right thing is for the child to die in these circumstances then we should face the decision under its most stark and 'non-distanced' description. One might say that there is a moral requirement that in matters of such importance where the lives of others are at stake, we should be absolutely sure that we have faced squarely the full import of what we are doing. Whereas if we disguise the facts from ourselves and others by various distancing strategies, we may permanently shield ourselves both from full awareness of what we are about and from the possibility of thinking through all the implications of such consequential decisions.

Ordinary and extraordinary treatment

An argument that has appealed particularly to Catholic theology involves putting moral weight on the distinction between ordinary and extraordinary treatment (9). Extraordinary treatment is not obligatory and its extraordinariness consists in its involving great costs, pain or inconvenience, or in being a great burden to the patient or others, without a reasonable hope that the treatment will be successful. Almost all the terms of this distinction cry out for analysis, but where resources are not scarce and not competed for by needier or worthier patients, it seems that the crucial issue is whether just staying alive is a 'success'. So long as it is reasonable to suppose that it is, and to suppose this I think we must judge it to be in the patients' interests to live, then it seems difficult to justify the withholding of even extraordinary treatment. For to come to the conclusion that it is in the patients' interests to live we must believe that the pain, costs, inconvenience and burdensomeness of treatment to the patients are compensated for by their being alive. And so if it is in the patients' interests to live it would require a very strong accumulation of pain, distress, costs or whatever to *others* or to society, to justify the patients' being sacrificed to secure their, or society's, freedom from such burdens.

It comes down to this: unless it is clearly in the patients' own best interests to die, then we cannot be justified in bringing about their death by either active euthanasia or by selective non-treatment, unless we can show either that something more important than their lives can be gained by their demise, or that their lives are somehow less important than other human lives and so permissibly sacrificeable to protect values less significant than human life. This may well be true of young children whether handicapped or not. There is a good case for treating young children as having much the same sort of status as a fetus and for thinking about questions of their life or death in much the same way that we think about the permissibility of abortion. That however is another argument (10), (11). At least we can see that the extraordinariness of the treatment required does not play a role in the determination of these issues.

We can also see that the corollary is true, that if it is in the patients' own best interests to die and, as with handicapped children, they cannot be asked whether or not they accept this assessment, then we can conclude that it would be right to bring about their deaths. If this is so then to do this by selective non-treatment is worse than to do so by quick and painless killing. Worse because it inevitably involves more of the very pain and distress, which made an end to life desirable in the first place. Worse also because it may involve both a self-deception and a, perhaps unwitting, deception of others which prevents a clear view of, and so clear judgments about, what is happening.

References

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Commentary 1 and reply

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Dr Harris's article is a very interesting contribution to the ethical aspects of treating severely handicapped infants. Like so many 'lay' people without any personal experience of the conditions we discuss he naturally looks at the situation from a very different angle from those of professionals caring for such children, of the parents, and of the children themselves once they are old enough to recognise their own condition adequately.

Dr Harris also lives in a vacuum which excludes the practicalities of solving or attempting to solve a desperately difficult stiuation. He may well be right in his implied recommendation that active euthanasia, that is, 'mercy killing', is a more humane, quicker and more logical solution than selective non-treatment—another name for letting nature take her own course. Nevertheless, it would be wrong to assume as he seems to assume that active euthanasia would be less traumatic, either to parents or to professional staff who may be expected to carry this out. The killing may be quick and painless, but the aftermath of thoughts and guilt complexes in the parents and persons involved is likely to be much worse than caring for the baby in a humane way until it dies. There is no question of self-deception or hypocrisy here. Furthermore, though many parents do express a wish, when their infant is very handicapped, that the doctor should put an end to the life painlessly, this is illegal and I would strongly disagree with any suggestion that we