

REITH LECTURES 1980: Unmasking Medicine

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Lecture 4: If I Were You, Mrs B

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In practising medicine doctors routinely make decisions, they make judgments. This much is commonplace. But what sort of judgments or decisions are they? The immediate reply of most people would be that they are judgments based on the technical skill and training of the doctor. I do not agree. Doctors make decisions as to what ought to be done. Some, but only some, of these decisions are matters of technical skill; that is, based on the observation of objective facts and the application of particular skills in the light of such facts. I submit the majority of decisions taken by doctors are not technical. They are, instead, moral and ethical. They are decisions about what ought to be done in the light of certain values. Now, this creates a problem. Doctors claim a special, indeed unique, competence in a particular area—the practice of medicine. So medical judgments, medical decisions, are for them and them alone. But if I am right that it is a fundamental feature of medical practice that doctors are making ethical judgments, it means that ethics, to the extent that they touch on how doctors choose to practise medicine, are something for them and them alone. This is a surprising, and even dangerous notion.

It would normally be accepted that ethical principles, the principles by reference to which we organise our lives and decide what we ought or ought not to do, are not the preserve of any one group. But the doctor may reply that, yes, he does make ethical decisions, but these are medical ethics and so they are properly for doctors alone. This would suggest that there is a realm of ethics unique to medicine and within the unique competence of doctors to determine and apply. My response is that medical ethics are not separate from but part of the general moral and ethical order by which we live. Decisions as to what the doctor ought to do must therefore be tested against the ethical principles of the society. He has no special dispensation to depart from our moral and ethical order. It must be wrong that a doctor, by describing a decision as medical, can claim unique competence to make such a decision, even if it touches the basic values by which we live our lives. For, if doctors claim unique competence it must be something they are uniquely competent to do. But doctors are not uniquely competent to make ethical decisions. They receive no training to prepare them for such a role.

So, put rather bluntly, what I am calling for is a wholesale re-examination of the sphere of alleged competence of the doctor. If you agree with me, as I take you through some examples, that doctors are indeed making ethical decisions in a rather haphazard, idiosyncratic way, then you will want to consider how best we should respond. We may seek to insist that doctors conform to standards and principles set down by all of us. We may suggest that the education of doctors prepare them more appropriately for the decisions they are called on to make. We may be content merely to remind them that they must look over their shoulders from time to time to make sure we approve of what they are doing. In large part, I am sure, doctors will

recognise the truth in what I am suggesting. It's just that they seem to operate on some form of automatic pilot when it comes to matters of ethics. We must gain their attention and provide the correct navigation.

Take the following propositions. You would not, for example, consider the law of homicide, and exceptions to it, to be a matter for doctors alone to decide upon. Nor would you regard it proper for doctors alone to decide when principles of honesty should be observed or waived. Nor would you regard it properly for doctors alone to decide the appropriate conditions for family life. These are all examples of social and political decisions which go to the root of our culture. Would it surprise you then to realise that each is an example of a decision commonly taken by doctors and regarded as uniquely within their competence to make. And, by being uniquely within their competence, it follows that only doctors, and no one else, may properly challenge such a decision.

It is doctors, for example, who decide whether or not to treat a baby born severely disabled. If untreated the baby will usually die, through what may be called benign neglect. There is no mechanic's manual, no technician's guide, which indicates when treatment is justified. Instead, the doctor decides, on the basis of some rough-and-ready calculus of the baby's future quality of life. And I use the cliché 'rough-and-ready', because it captures the quality of the doctor's decision, a decision by rote, which has become a stereotype without need for deliberation. Furthermore, the decision varies with the doctor. There is no agreed course of action even among doctors. In figurative terms, the baby in Barnsley lives, the baby in Bradford dies. And, in the process—if one can play the lawyer for a moment—the law of homicide has its tail twisted. This would not be the first time we have turned a blind eye. But, we should all be given the chance to know and to decide, on the basis of clear and agreed- upon principles.

Nor is the ethical dilemma limited to new-born babies. It arises each time the doctor decides whether or not to try to resuscitate the person who has attempted suicide. It arises each time the doctor weighs up what to do about his elderly patient who lies paralysed from his latest stroke and now has pneumonia. Should he treat the pneumonia so that the patient may live another couple of weeks or months? Or should he let the pneumonia be the old man's friend, as it used to be?

Now, consider Mrs X. She has cancer. It is decided that the cancer will not respond to treatment and that she will die within a matter of weeks or months. Given that such predictions are at best guesses, the question that then arises in the mind of her doctor is what should he tell her. Should he tell her the truth about her condition or offer some alternative story which is perhaps more optimistic? The assumptions which underlie these questions are obvious. People do not want to die, neither do they want to know they are dying, nor could they tolerate being told they are dying, nor do they know they are dying. Some or even all of these assumptions may be well- founded on occasions but they are unsupported by any evidence. They reflect the anxieties of the healthy. In fact, what surveys there are show that the large majority of patients with, for example, cancer would prefer to know the truth. By contrast, doctors ordinarily choose not to tell. Perhaps the most important assumption underlying the question of what to tell the patient is that it is the doctor who is uniquely qualified to decide what the patient should know.

Of course, once the view is allowed that patients do not want to know the truth, rationalisations can readily be created which serve to justify the position. The notion that the patient does not wish to know soon becomes the patient should not know. One argument commonly used is that the diagnosis is uncertain. But a study published in 1978 demonstrated that uncertainty over diagnosis was not the reason for withholding information, though it was used to justify it. The better explanation for non-communication was uncertainty, not over diagnosis, but over how much each patient wished to know, an uncertainty largely produced by the doctors' own anxieties. The doctors realised that some patients may indeed wish to know the truth but, since without asking they could not know which patients, they managed the problem by not telling anyone. This may have provided the ideal coping mechanism for the doctors. But it meant that only the patient who insisted on the truth and was confident enough to be persistent, got his way.

Another rationalisation resorted to is the so-called therapeutic privilege. This suggests that, as a matter of good medical practice, circumstances exist in which the doctor may withhold information from his patient, if in the exercise of his discretion and judgment it wouldn't be in the best interests of the patient's health to know. This is clearly a device created by doctors to do what is in the best interests of doctors. It may be justified on some occasions but there is no effort to specify these occasions. Everything proceeds on the basis of the particular doctor's judgment. It all boils down to the doctor being good, gentle and kind. It would be nice if all our doctors were like this. But, just in case, can't we have some more certain guarantees that our interests, as defined by us, may be allowed to prevail? The device of the therapeutic privilege pays lip-service to the principles of truth-telling and self-determination, while it creates a discretionary exception which is quite capable of swallowing these principles when the doctor decides the occasion requires it.

If we look beneath these rationalisations we see an ethical principle which is certainly not part of received tradition in analysing the doctor-patient relationship. The traditional view is that the doctor-patient relationship rests on trust or at least on agreement. But what we see is an operational principle defined by the doctor and accepted by us by default, which allows the doctor to suspend the trust or rewrite the agreement when in his view this is appropriate. Of course, if the patient breaks his trust or violates the agreement, there may be dire consequences for him, even to the extent of his forfeiting further care. Not so the doctor. He remains arbiter of the relationship, even to the extent of claiming the privilege of resort to an operational principle which is the precise opposite of traditional ethics. For, it is a basic moral principle of our society that we should tell the truth.

So far, the examples I have referred to are fairly commonplace. We would all have recognised them as typical of medical practice even if we would not all have recognised the ethical nature of the decisions made. It may be that some of you would be content to leave things as they are, despite the far-reaching significance of some of the decisions taken. Well, let me press you a little further. Let me press the point that decisions taken by doctors are of such a nature that a check should exist on the power this grants to them. I want now to look not at specific examples but across a whole area of medical practice, that concerned with reproduction and birth. I want to identify for you the ethical principles by reference to which this area of medicine is practised.

You may not as easily recognise the decisions which are taken as being part of traditional doctoring. They seem far more clearly for us to take rather than leave to the doctor alone. Perhaps when you have heard what I suggest you will be more prepared to accept my thesis, that doctors are involved in making decisions which are more than technical. They are ethical decisions about us. They closely affect our lives. They are made without reference to agreed principles. They invest great power in the doctor. And they are regarded, at least by doctors, as uniquely within their competence to make such that their power is not easily checked.

So, let's turn to medical practice concerned with reproduction and birth. Let me quickly suggest some of the contexts in which medicine is involved, and in which decisions are made by doctors. Obviously there is abortion. Then there is the treatment of severely handicapped newly born babies which I have already mentioned. Then there is the screening of pregnant mothers and foetuses to identify deviations from the chosen norm. There is the provision of genetic counselling to parents to help those who may bear a disabled child make their decision whether or not to have a child. There is medicine aimed at inducing fertility—for example, artificial insemination and, most recently, in vitro fertilisation—the so-called test-tube baby. And there is contraception, which includes, of course, sterilisation. On careful analysis, decisions taken by doctors in these areas of medicine, despite the superficial differences, can be shown to rest upon certain underlying common assumptions which are ethical in nature. I suggest, furthermore, that these common ethical assumptions are unstated, unarticulated and certainly unremarked, because it is probably not appreciated by doctors or lay people that they are being made. Yet when they are identified they can be shown to be of very great significance, reflecting and affecting as they do our approach to childbearing, child-rearing and the value of life. You may well wish to consider who it is who should decide whether you are fit to raise children. Consider what Professor Henry Miller of Newcastle Medical School once wrote, that final decisions on such matters as planned parenthood rest often with parents, but, 'the trouble is, of course, that the parents from whom difficult decisions are most likely to be required are all too often drawn from the most feckless sections of the population'.

The first assumption I would identify is that some are more fit than others for childbearing and child-raising, with the implication that the unfit should not bear or raise children. But, if we were to attempt abstractly to devise a set of criteria of fitness to be a parent, I doubt if we would get very far. Clearly, what is at the heart of the assumption is a concern for the potential child. Yet there is an extraordinary ambivalence in how this concern is demonstrated. On the one hand, it seems to be reflected in a doctor's decision to sterilise the mentally retarded girl before she can get pregnant and bear a child whose future may be less than happy. And the decision by doctors to offer artificial insemination only to stable married couples who have passed some sort of parental fitness test seems to express the same concern for the welfare of future children. Equally, the latest reproductive technology of in vitro fertilisation will be offered by the doctors concerned only to couples who have passed the same parental fitness test. Parenthood is to be encouraged, indeed facilitated, but only in certain circumstances. It is to be prevented in others. The guiding criterion is concern for future children.

But the ambivalence creeps in when the same doctor refuses to perform an abortion, just as much a medical practice in the area of reproduction as are the others. Where is the concern for the future child there? Or where is it, when he refuses contraceptives to a girl under 16. The doctor doubtless regards her as unfit to be a mother, to bring a child into the world, but his decision not to prescribe contraceptive pills may well have precisely this effect. In these two cases the ethical principle of fitness to be a parent which previously guided the doctor seems lost, though arguably it is more than appropriately applied here. Instead, he seems to be operating on another ethical principle, that a woman ought to bear the child conceived. Whether it is in the child's best interest to be born is suddenly of less importance. It is almost as if the child is seen as punishment, that it is no more than is deserved.

There is, in effect, a complicated intermingling of a whole set of principles or, some would say, prejudices or biases. On the one hand, there is a policy of eugenics, seeking the right parents. But, on the other hand, there is a policy of retribution whereby children must be brought into the world regardless. And these policies are completely within the power of doctors to operate. As one writer points out, it is clear that in the case, for example, of abortion, doctors operate a system of screening of women which has nothing at all to do with the legal requirements. Single women seem to be divided into 'the girl who made a mistake' and 'the bad girl'. Women have to be very careful in their management of their relationship with their doctor. If the good girl is suitably contrite she gets her abortion. The bad girl doesn't. It would only encourage her to be promiscuous. The ethics involved are crude and contradictory. Yet they pass unstated and unchallenged, as part of the practice of reproductive medicine. - We happily leave it all to the doctors and shouldn't be surprised at the idiosyncratic and contradictory principles which emerge.

Another ethical assumption which underlies medical thinking and practice concerned with reproduction and birth is that a baby should not be born or, if born, should not be encouraged to live, if the quality of life the child would enjoy falls below a certain standard. Of course, the first observation is that what amounts to a minimum quality of life is not set out anywhere. Indeed, if one attempted to do so, the opposition and the hostility which would greet the attempt would swiftly dissuade others. Yet I am suggesting this principle, inarticulate and idiosyncratic as it may be, is one of the most significant guiding principles in this area of medical practice. Once again, the alleged motive is concern for the child. We can see this clearly in the practice of selective treatment of severely handicapped newly born babies. The most severely handicapped do not receive surgery or antibiotics and are encouraged to die peacefully, or, to use the words of Dr John Lorber, one of the most famous specialists, the babies are not encouraged to live. This same concern for the child is also reflected in the law and practice of abortion, where there is less than the usual opposition when abortion on the grounds that the child will be genetically severely handicapped is raised. Furthermore, the modern practice of screening pregnant mothers is posited on this assumption, that it would not be in the interests of the child or mother if a genetically disabled child were born.

And we have witnessed in tandem with the enormous development of the field of genetics in the past two decades the appearance of genetic counselling. There can't be much doubt that in genetic counselling, too, this same assumption operates. Of course, the theory is that the mother should be given the information and then left to make up

her own mind. The role of the doctor involved is that of a neutral purveyor of facts rather than directing her towards any particular decision. I doubt if this distinction is real, since no presentation of facts is value-free and the so-called neutral party can always, by the facts he chooses to relay and the emphasis he places upon them, manipulate effectively the decision arrived at. Consider for a moment the following. The father is a drunkard and probably has syphilis. The mother has tuberculosis. They have had one child, it died after only six days. The mother is pregnant with her second child. Imagine that the parents are willing to have an abortion if so advised or counselled. When a teacher gave these facts to his class in medical school, most students voted in favour of abortion. The teacher then broke the news. The second child was Ludwig van Beethoven. It is hard not to be bowled over by such a remarkable example. None the less, few would suggest that this ethical assumption concerning a minimum quality of life is wholly wrong or ought to be abandoned. But, quite apart from its clear lack of definition, it is important to notice the eugenic tone which underlies it.

There is perhaps some moral danger in following a path which has it that the handicapped should not be born. Though we all want healthy children, health, as we know, is a term which defies easy definition and who is to say along what point of the scale of handicap a baby's life would not be worth living? Furthermore, such a pursuit of the handicap-free child might inevitably make us less tolerant of that child who, for whatever reason, is not caught by the screening process. Is such a child to face a future as a freak or a reject, shunned because such children are just not born like that any more?

Again, there is some ambivalence in medical attitude and practice in this context. Those doctors who refuse to perform an abortion in which the child is genetically disabled also claim that they are concerned only with the child's best interests. But to them there is no minimum quality to a child's life. Only in such a way, they seem to argue, can we remain a caring society rather than a selfish and narcissistic one which only wants babies if they are made in the right image. Existence is all, a view shared by those doctors who advocate that severely handicapped newly born babies should be helped to live rather than encouraged to die. But even these doctors might perform an abortion for a girl who had been horribly raped or draw the line at treating the most severely handicapped newly born baby. So their position is not free from ambivalence.

These issues concerning a minimum quality of life are profoundly difficult. What is striking is that despite their significance they are not widely discussed. They are resolved in the consulting-room and debated, if at all, in the medical journals. But, as you have seen, the ethical assumption that there is a certain minimum quality of life, is unclear. The counter-principle that there is no minimum quality of life co-exists with it, again with no clear meaning or clue as to when one rather than the other should operate, producing ambivalence and contradiction.

A third ethical assumption, I suggest, is that a child has a certain worth, socially and economically, and should be conceived or born only if it would qualify as worth it. This is most evident in the case of abortion, when a doctor may find himself asked to certify that the birth of a child will be a detriment to the existing family's health. Here the word 'health' can be manipulated if need be to include the threat to the health of

existing children represented by additional competition for the available resources of the family. Here, the underlying concern may be, as in the other cases, for the child about to be born, that he is better off not born. But there seems to be an equal concern for those children already born. Those who oppose abortion are particularly concerned about the extent to which this criterion is capable of being manipulated. It means that the decision whether a child should be born may be made to depend on the social convenience of the birth. But to argue otherwise is to say that the child should be born even though it would not be welcome. Despite the complexity of the argument and the conflict of principles we can once again find doctors making decisions, giving advice, as if what was involved was a mere matter of technical expertise. Any ethical analysis which is indulged in is rudimentary at best and not exposed to wider scrutiny. Indeed, recently, doctors specialising in the field of genetics have found themselves more and more parlayed into these ethical difficulties. Through the development of foetal screening they have been able to discover more and more about the foetus so as to aid the parents in deciding what course to take. Now comes the problem. What if a doctor knows that Mr and Mrs X want desperately to have a baby boy. In the course of routine screening, he discovers the foetus Mrs X is carrying is healthy but a female. Doctors have got themselves into a considerable lather about whether or not the parents should be told this, when it is likely, in our chosen hypothesis, that the mother will then have the foetus aborted.

The doctor may not regard the information as relevant to any decision the parents may wish to make. But, by defining what is relevant, the doctor is already making the ethical decision that only certain information should be revealed and that he should be the sole judge of this. To lie, to withhold the information or to reveal it; each is equally repugnant to many doctors. This is, if you will, another example of the dilemmas medical technology brings in its wake. We must, it is clear, flush out these ethical problems associated with medicine at the beginning of life. They affect our future, they are ours to resolve.

So let me tie up the various threads of my argument. We have seen how decisions made by doctors are ethical in nature, calling for careful analysis. There is no evidence that such analysis is engaged in. If, for instance, you look to the recently revised Handbook of Medical Ethics produced by the British Medical Association for wise words and advice, you will be disappointed. For example, the section on the treatment of severely handicapped children ends in the ringing phrase, 'the doctor must find a just and humane solution for the infant and the family'. So far, so good, but just what is a just solution? To argue, as some doctors do, that 'we learn on the job', is to support some notion of education by osmosis, or to say that they perpetuate, unconsidered, the views of their predecessors or to admit that they receive no education at all in ethics.

We should expect not only some regularity if not uniformity in the decisions arrived at but also some conformity between these decisions and those which the rest of us might take. We should also expect that doctors have some educational grounding in ethical analysis. To suggest this last crucial point is to invite scorn. 'There is no room in the curriculum. We don't want to clutter up our timetable with well-meaning Sunday school exercises.' My response is that much greater stress must be laid on the humanities during a doctor's training. Ethics must be a central course, taught not by some superannuated elder statesman nor by the latest medical star in the firmament,

but by an outsider, someone who is not deafened by the rhetoric of medicine. Medical schools must simply be dragged back into our world and out of their hermetically sealed cocoon in which we are counters with which the game of life is played. The principles by reference to which doctors act must be the product of general discussion and debate. We must take over. It may be that, in large part, we as laymen would endorse many of the decisions taken by doctors. But it is over-weening hubris to deny us the opportunity to consider them first and to insist, and I repeat insist, on occasion that our views rather than theirs prevail.