Journal of medical ethics, 1976, 2, 3-7

Focus: Current issues in medical ethics

The Karen Quinlan case: Problems and proposals

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Karen Quinlan, a young American girl, has lain in hospital since 15 April 1975 without any prospect of recovering consciousness. Her breathing is assisted by means of a respirator and she is fed through a tube inserted in her stomach. Her adoptive parents applied to the courts for permission for the respirator to be switched off. The judge refused permission.

Using the Quinlan case as an exemplar, Mr Kennedy analyses the medical points one by one against the legal background. He would like to see established a code of practice to assist doctors in such cases who at present have no legal guidance. A set of rules arising as a consequence of a series of court decisions would be undesirable; rather a code should be drawn up as the result of discussion between the many people concerned and the consensus so arrived at.

Karen Quinlan, aged 21, lies in a coma in St Clare's Hospital, Denville, New Jersey. She was admitted to hospital on the night of 15 April 1975 unconscious and breathing only with difficulty and has not recovered consciousness since. Her weight has dropped from 120 to 60 lb. She lies paralysed with her limbs drawn up to her chest in a fetal position. So rigid are her limbs that she cannot be fed intravenously. Instead, a tube inserted in her stomach provides her with food. An artificial respirator breathes for her through another hole made in her throat from time to time, whenever her own spontaneous breathing ceases as it does until triggered again by the machine. She will never recover consciousness again. She is in what doctors call a 'persistent vegetative state'. Yet she has some residual brain activity in one small sector of the brain. On 11 November it was reported that Judge Robert Muir sitting in the New Jersey Superior Court in Morristown, New Jersey, had after two weeks' reflexion decided that Miss Quinlan's doctors must continue to maintain her on the artificial respirator. He denied the application of her adoptive parents that they be made her legal guardians (she being over 21) and as such be allowed to order the respirator to be disconnected.

The case has aroused enormous interest in the United States and in Great Britain. The issues raised are staggeringly complex and difficult. They are not, however, unfamiliar to doctors. Here and in the United States doctors have for some time faced the sort of problems involved in the Quinlan case and have looked for guidance as to the proper course to take. Guidance, however, has not been readily forthcoming. I write as a lawyer and my purpose is to explore the problem from a medico-legal point of view. Lawyers who should be in a position to give a lead have pointed to the uncertainties and difficulties of the law as an excuse for their inaction. Others have contented themselves with saying that these are medical matters and have shifted the responsibility for decision back to the hapless doctor. They are patently not merely medical matters. Doctors function within a framework of legal and social rules which go beyond the rules of their particular profession and which must also be observed. The truth is, however, that the rules are vague. In each of the problems to be discussed here the doctor finds himself in the unenviable position of being damned if he does anything but equally damned if he does not.

Despite the lack of clear guidance the problems will not go away. Indeed it is likely that the need for a solution will grow more urgent as the technology of modern medicine continues to develop. The amazing rapid advances made, particularly in life-support techniques and the field of transplantation surgery, have thrown up a host of medical, legal, ethical and philosophical problems which society has barely begun to digest let alone deal with adequately.

Three problems raised by the Quinlan case

There are three distinct but interrelated problems which the Quinlan case potentially raises for us in the United Kingdom. They are all of major significance and warrant the maximum public airing in a balanced, dispassionate way outside the confines of the court and the consulting room.

1) WHEN IS SOMEONE DEAD

The first problem is the tantalizingly simple question, When is someone dead? Nowhere has the observation that the law regulating the conduct of

doctors has been put under great strain by the development of medical technology in the past 15 years been shown to be more true than as regards the determination of death. The age-old tests of holding a glass to the patient's mouth, as Lear did to Cordelia, or testing the wrist for pulse are no longer valid. The legal view (reflecting this old-fashioned medical notion) that death was the absence of vital functions, ie, breathing and heart beat, is outdated. Hearts are routinely stopped in open-heart surgery and their function is taken over by a machine, yet the patient could not be said to be dead. Victims of serious illness or accidents are placed on artificial respirators which breathe for them permanently (as in the case of polio victims) or until such a time as they can breathe again on their own and no one says they are dead. The old legal rule had to be modified. But what new rule should be adopted and what form – statutory, code of practice or case law – should it take? The debate was given fresh impetus by another of the major technological advances referred to earlier, the transplantation of vital organs salvaged from corpses. Organs are of use only if removed within a short time after death. Thus it becomes of the greatest importance to determine precisely when death should be said to have occurred. Jumping the gun or unseemly haste had to be avoided but a pair of healthy kidneys should not be buried in the ground when they could save the life of someone doomed with kidney failure. Though it cannot be emphasized too much that the issue of death is quite separate from considerations of transplantation and should remain so, there is no doubt that transplant surgery added force to the call for a reconsideration of the legal definition of death.

Prompted by an authoritative paper produced by the Harvard Medical School in 1968,[1] doctors moved towards the view that death must be defined in terms of the destruction of the brain rather than the cessation of breathing or respiration. The term 'brain death' was coined. The argument briefly is as follows. The heart beats if it receives a supply of oxygenated blood and appropriate neural instruction via the autonomic nervous system. The blood is oxygenated if the person breathes. Both the autonomic nervous system and breathing are dependent on the functioning of the brain. They can continue though much of the rest of the brain is destroyed. But if that part of the brain which regulates breathing and the autonomic nervous system, the brain stem, is destroyed the person will never breathe again spontaneously of his own accord nor will his heart beat without artificial assistance, since brain cells do not recover and regenerate. The loss of function is permanent. The important terms are lack of spontaneous breathing and heart beat and the permanence of such lack. A machine can breathe for the patient and the heart can be kept beating. But the machine is ventilating a body without a brain – a corpse. This presence or absence of brain stem activity can be measured by a relatively uncomplicated clinical technique. Finally, it cannot be overemphasized that brain death defined as the inevitable loss of all brain function is not a 'new type of death'. No medical sleight of hand is involved. All that is involved is the development of more appropriate criteria for establishing a medical fact – the death of a person.

Thus a new medical definition emerged with appropriate safeguards and techniques for establishing its existence. The law has responded in different ways in different places. In several European countries and in eight states in the United States, most recently in California, the new medical concept of brain death has been given legislative force in statutes defining death. In some states in the US, most notably Virginia[2], the courts have been asked to endorse the new definition in legal actions involving a decision whether someone had died as a matter of law. In the United Kingdom there has been no legislation nor case law. Instead, as the new definition has gradually gained recognition among the medical profession so the view is coming to be accepted that this should also be the legal definition. Unfortunately, it cannot be stated with certainty that this is the law. Until it is certain, doctors work in a legal vacuum anxious about the legality of decisions they regard as incontrovertibly correct. This state of affairs should not continue. Legislation is a possible answer. In such a fast-moving scientific area there is, however, always the risk that a statute will crystallize or freeze the law at a given stage of medical knowledge and be shown to be defective in the light of further scientific development within a relatively short time. A second possible alternative solution, to wait for a case to present itself before the courts, is undesirable. Doubts are not resolved in the interim and such a crucial issue is left to be decided in the context of a particular set of facts which may not allow an authoritative general ruling to emerge. What, in my view, is needed is for the new concept of brain death to be incorporated into a code of practice worked out by the medical profession after consultation with lawyers, theologians and other interested parties and sanctioned by the Ministry of Health. This would serve as an authoritative statement to be followed by doctors and courts alike and could be kept under review by a permanent standing committee appointed by the Minister.

In the Quinlan case the definition of death does not, despite headlines to the contrary, appear to be involved. Press reports indicate that Miss Quinlan has some brain activity. Clearly she cannot be said to be dead by any Anglo-American standard. If she were the problem would be solved. The dramatic prominence given to the act of switching off the respirator to which so much sensational attention is given would be seen for the irrelevance which it is.

For, if she is dead in that her brain is dead, then the machine is ventilating a corpse and switching it off is of no practical significance except to allow her to be buried in peace.

Some would go further than the notion of brain death and argue that a person whose brain stem is undamaged and who thus breathes spontaneously but who has suffered such brain damage as to have permanently and irrecoverably lost consciousness should be regarded as dead. Such persons are often referred to by lawyers as sleeping beauties, or more cruelly as vegetables. Newspaper reporters assigned to the Quinlan case were able to track down the case of Elaine Esposito. She is 41 and has lain in a coma in Tarpon Springs, Florida, for 34 years since she suffered a burst appendix at the age of 6. She cannot speak or move. Her condition is hopeless. She is cared for around the clock by her devoted mother. Unlike Miss Quinlan, however, she can breathe on her own. To say that she is dead is clearly a major step. Death at this point becomes not a matter of medical determination but of philosophical evaluation. Life is seen as consciousness, death as its irrecoverable absence. It would mean sealing the coffin lid on a body whose heart and lungs are still functioning spontaneously. It is a step which few, whether doctors, lawyers or members of the general public, would be prepared to take. It certainly does not represent, nor is it likely to represent, the legal position in the UK.

2) THE SO-CALLED 'RIGHT TO DIE'

The second issue which arises from the Quinlan case is whether someone can demand to be allowed to die – the so-called 'right to die'. The picture comes to mind of a sick and dying person who decides that further treatment is just too much and that he would rather be allowed to die in peace. This does not involve any issue of euthanasia or even suicide,[4] merely the assertion by a dying person of the right to have a final say in what happens to him to avoid the further indignities of tubes and drips, pills and pain. What does the law say on this? Both in the USA and the UK the common law has traditionally guaranteed the adult person of sound mind the right to determine what he should do with himself. Thus, under most circumstances, medical treatment is seen as unlawful unless consented to. When it comes to refusing treatment, however, in the face of death it is less easy to give a categorical answer. In the USA there have been a number of decided cases the balance of which point to the dying patient having the right to refuse treatment.[3] Notwithstanding this, some weeks ago (*Time*, 24 October) it was reported that a 39-year-old woman dying of leukaemia and unable any longer to feed herself was ordered by another New Jersey Court sitting in Newark to submit to being fed by tubes. The court held that there was no constitutional right to die, a phrase echoed in the Quinlan case. It is my view that such a decision is both inhumane and wrong in law and will be overturned if appealed, if for no other reason than that there is no right to invade the privacy of an unwilling patient by forcing treatment on her.

In the UK there is no authoritative guide. Again the unfortunate position exists whereby the doctor must make a decision which obviously could have grave legal ramifications without any legal guidance. It is no surprise that the tendency of doctors is to err on the side of safety and continue treatment even though the patient has refused it. In the striking words of an American expert, doctors are more and more practising 'defensive medicine'[5] in this area, with one eye on their lawyer and another on their insurance policy. Doubts should be dispelled. Once again there is need for a code of practice which would lay down the correct legal position. I take the law to be that an adult of sound mind can validly refuse further treatment and thereafter may be nursed but may not be subjected to any medical interference. Where, however, no such wish has been expressed the doctor is entitled to assume that the patient wishes to be treated. This, it appears, is the ruling on this point in the Quinlan case. Since Miss Quinlan is over 21, no one can make decisions of this kind for her unless authorized to do so. As she was admitted to hospital unconscious, speculation as to whether she would have refused treatment, as was alleged by her adoptive parents, is insufficient reason for overriding the assumption in favour of treatment.

It must be beyond argument that relatives of adult patients should not have the legal authority to refuse further treatment on behalf of the patient. Many might act with the best of intentions but the law must protect those who cannot protect themselves from relatives who might urge the withdrawal of treatment for reasons which were selfish rather than altruistic. If the patient is legally incompetent, however, it remains a matter of lamentable obscurity whether a legal guardian or other relative can in law authorize withdrawal of treatment.[4]

3) WHAT IS THE EXTENT OF THE DOCTOR'S OBLIGATION TO HIS PATIENT?

The third issue which arises is the one which was central to the Quinlan case. It is certainly the most intractable and difficult to resolve, involving considerations of morals, ethics and religion as well as law and medicine. Also, it is the most disturbing feature of the decision in the Quinlan case. The issue is, What is the extent of the doctor's obligation to his patient? Must he go on treating a patient who is at death's door with all the enormous panoply of technological resources at his disposal or can he at some stage desist from further treatment and let the patient die? Traditionally the doctor's duty has

been defined as being to preserve life and, when that is no longer possible, to ease pain and suffering. This is, however, a vague and uncertain guide. What should a doctor do when an octogenarian riddled with cancer develops pneumonia? Should he give penicillin or leave him to die in peace? What should a doctor do in the Quinlan type of case when the patient is irretrievably unconscious but is able to breathe spontaneously with help from a respirator from time to time? Must he continue respiration for weeks, months or even years? Again the doctor seeks guidance. He has every right to expect that there be some certainty in the law as to what his obligations are. If no such certainty exists it is inevitable that his decisions will be attended by apprehension as to the possible legal consequences of his taking a particular course of action. This is clearly undesirable. A doctor should be free to deal with this problem, already disturbing enough, without being concerned with issues of legal responsibility. Sadly the law offers no guidance. The famous words of the Victorian poet Clough

> Thou shallst not kill, but needst not strive
> Officiously to keep alive

are often repeated as representing a guideline, but even if they reflect the law their vagueness undermines their usefulness. One thing is clear. A doctor may not kill his patient by any conduct which is intended to accelerate death, for instance by injecting him with a lethal overdose of drugs. Even this assertion is not entirely free from doubt since the case of Dr Bodkin Adams in 1958 decided that a doctor may give drugs which he knows will hasten death if his primary aim was the relief of pain. But if he may not kill his patient and he cannot cure him, what must the doctor do? Perhaps the only widely accepted guideline is that laid down by Pope Pius XII in 1957 in a speech to anaesthetists.[6] Doctors, he said, were obliged to continue with 'ordinary' measures but were not obliged to carry out 'extraordinary' measures. The latter he defined not in terms of what a doctor would regard as extraordinary or non-standard procedures, a definition which would change as developments occurred, but rather as whatever 'cannot be obtained or used without excessive expense, pain or other inconvenience for the patient or for others, or which, if used, would not offer a reasonable hope of benefit to the patient.' This guide, though still vague, has much to recommend it as a starting point. It does not, however, have the force of law. Two leading English law commentators speak of the doctor's obligation to continue treatment as ceasing when it is clearly useless to continue and the treatment has become a burden[7, 8]. Though of great persuasive force this equally is not necessarily the view a court would take of the law. In my opinion, coupled with that of Pius XII, these views correctly state the law and should be the basis for determining the extent of the doctor's legal duty to his patient. If adopted, it would mean that a terminally ill patient must receive food, nursing care and other aspects of ordinary treatment, but a doctor need not indulge in heroic but ultimately hopeless measures to delay the onset of death. Indeed, if it were the accepted rule, to continue treatment in hopeless cases would not only be an unjustified waste of resources, but would also be unethical and might allow the inference that the doctor was regarding his patient as an experimental guinea pig on whom measures no longer medically justified in the particular case could be practised and perfected. The case of General Franco perhaps offered a good example!

But, until a firm set of legal rules is established the doctor will continue to hestitate. His position is again unenviable. If he discontinues treatment the doubtful state of the law could induce a relative or other interested party to bring a legal action alleging that the patient's death was due to the doctor's neglect. If he continues treatment he causes further anguish to family and friends, expends valuable resources of time and money on a hopeless case and may expose his patient to further distress and pain.

Setting out the obligation of a doctor in a Quinlan situation

There is a clear case to be made for setting out in as much detail as is appropriate the obligations of the doctor who finds himself in this situation. Again, the question arises of who should decide and what form the decision should take. It must be beyond argument that however the doctor's duty is defined it is not merely a matter for doctors to decide among themselves. The greatest possible range of opinion should be sought. Once a view emerged which commanded general acceptance it should, in my opinion, take the form once again of a code of practice. Such a code could be made subject to constant review by an established body and breach of it could be regarded as a branch of professional ethics warranting sanction from the General Medical Council. Clearly any code which incorporated such practice would of necessity contain stringent provisions to guarantee that the determination that the case was hopeless was medically sound. The requirement that it be made by at least two doctors, one of whom was a consultant neurologist, would meet this point and would follow the current suggested practice to be used in determining death where organs are to be removed for transplant purposes[9].

A code of practice

It is wholly undesirable that the law should be set down as a consequence of a series of court decisions. The last thing which is wanted is for the duty to be set down piecemeal as the result of decided cases.

The absence of proper guidance until a case was taken to court, the time and cost involved in arriving at a final decision and the fact that a set of rules of conduct could not easily be culled from one or even several decisions are just some of the arguments against leaving the matter for determination by the courts.

The Quinlan case serves as a timely reminder that there is an urgent need for a code. There is an urgent need for a full-scale campaign to educate doctors as to their obligations, not only to avoid all the distress of a case such as the Quinlan case, but also to allay the unwarranted but very real fears of doctors and patients alike, both of whom, unaware of the precise limits of proper conduct, view the management of terminal illness with alarm.

The treatment of Miss Quinlan

If, in the absence of a code, the law is as I suggest: that a doctor is obliged in the case of hopeless, terminal cases to do no more than administer such treatment as will maintain the *status quo* but is not obliged to intervene if the patient goes into decline, what result does this produce in the Quinlan case? At the outset it is crucial that the problem should not be seen in terms of the over-simple but headline-catching act of 'pulling the plug' or 'switching off the machine'. This is not and should not be seen as a definitive step. It is merely a stage in ascertaining the true character of the patient's condition. While a respirator is being used the capacity of the brain to take over breathing spontaneously cannot be measured. In Miss Quinlan's case the use of the respirator is undoubtedly an extraordinary measure. In terms of effecting any form of therapy it is useless. Under such circumstances, if the uselessness of the treatment in terms of there being no recognizable prospect of recovery were established, the doctor would be legally entitled to discontinue using it. In Miss Quinlan's case it means she would be left to breathe for herself. If she then failed to do so successfully and went into decline the doctor would be under no duty to intervene; indeed he would be ethically obliged to stand aside and let death take its course.

Can the Quinlan case judgment be critized?

The inevitable conclusion is that Judge Muir's decision is open to criticism. First, he is reported as saying that whether Miss Quinlan should be removed from the respirator was a wholly medical decision. This cannot be so, for insofar as it calls for an assessment of complex philosophical, ethical and legal as well as medical issues, it cannot be left to doctors alone. Indeed they do not want to bear the responsibility alone. Second, I have attempted to show that it cannot be right to require a doctor to continue hopeless 'treatment' for an indefinite period. It is to be hoped that the decision is appealed and reversed on this point.

The need for a code of practice in Britain

As I said at the outset these problems are immensely difficult. What we have seen is that the law, though I have tried to state it accurately, is lamentably unclear in an area where clarity and certainty should be the fundamental right of the citizen. The Quinlan case should provoke us into action. We should call for a workable code of practice. If we do not take this opportunity we shall have our own Quinlan case here in the UK. Doctors already make decisions such as those I have discussed every day up and down the country. We can choose whether we want them to make under-the-counter deals with death, with no legal check or guidance, or whether we want to give them a guide discussed by and acceptable to the population at large.

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