Case conference

.... Strive officiously to keep alive?

The case of a patient with an incurable condition which was bound to deteriorate is discussed in the light of two conceptions of medical care: the first, the traditional one of treating with all the means at the doctor's disposal until death 'wins', the other to 'let go' of his skills for the greater good of the patient and his family. The second course was adopted by the doctor looking after the patient described here after careful consultation with the daughter, who was living in her father's house and willing to look after him as long as was necessary. On the whole the doctor is commended by those contributing to the case conference, although it is recognized that the course of action adopted is still not yet fully accepted in modern society. (Both lay and medical opinion, however, seems to be moving towards that way of thinking.) Susan Thorn's contribution makes the suggestion that in cases where there seems to be a moral or ethical dilemma there might be some kind of counsellor available for those concerned in making the ethical and medical decisions, and in the addendum to the case conference a former general practitioner, now practising as a hospital doctor, points to the two different medical cultures exemplified by the attitudes of American and British doctors.

Case report

Mr A B and his family were well known in the county town in which they lived. For the whole of his life he had involved himself deeply in his local community. He was a teacher at a local school where he worked a great deal to organize hobbies, sports, etc, after hours for the children, and did not confine himself to his official duties. He was an active member of the local cricket club and became its secretary for 10 years before, in his early 50s, it was recognized that he was suffering from the early signs of a presenile dementia. Over the course of three years this popular, extroverted, active man went through the progressive disintegration of personality which accompanies the dementia. He could never understand or accept the reason for his dismissal from the school as he had no insight into his problem. He went through a period of paranoia and aggressiveness in response to this which seemed quite alien to his temperament. He became upset when his views were not accepted at the cricket club committee, and eventually the right to attend was refused, intensifying his distress. He gradually settled, however, into a contented pattern of life as the dementia became more profound. He was a widower, and fortunately had one widowed daughter, living a few houses away, who agreed to come to live in his house to care for him. For about a year he led a peaceful life in this way, pottering in the garden, sitting in the sun, and watching television without comprehension, but some pleasure. He was clearly confused on day-to-day events, could not dress himself, although he valued his appearance, and could not carry out even simple purposeful activities without assistance. He would become confused at meals and when unable to complete a task would appear distressed and cry. He retained his genial personality and enjoyed the presence of visitors although he could not remember their names or who they were, even with quite close friends. It was hard to say whether this was a life of suffering. His daughter felt that he had never fully understood why it was that he had had to leave his school and his cricket club and live a life of relative isolation. She knew that conversation of his past or reminders, such as old photographs, etc, would immediately obviously cause him anguish, with tearfulness and a mood of lethargy and depression which would last for several days. He seemed to bear a burden of a sense of loss which he could not understand.

The choice for doctor and daughter

I had known him as his general practitioner for a year and in that time had witnessed a gradual decline in his capacity to cope with the simple activities of the house. He moved about less, spoke less, and took almost no initiative, although remaining always welcoming and cheerful. He developed 'flu in the early winter with a mild upper respiratory infection which I treated with a five-day course of oxytetracycline. Following this he was never really well and insidiously developed congestive cardiac failure. He appeared in no distress, but was generally weak, unable to get out of bed, and had some orthopnoea so that he was allowed to sleep sitting up. At this point his daughter raised the question of the necessity to treat him other than by measures designed to keep him comfortable. There was no element of self interest in her request. She was a
woman of independent means who was clearly devoted to her father and said she would continue the responsibility of his care for another 10 years if necessary. But she felt that his life had lost its dignity and meaning, that he was aware of his disability, and suffered through the inability to understand it, and that he had always stated his fear of being a burden on his family. We agreed to treat him conservatively. We managed the ankle oedema with supportive bandages and propping up the foot of the bed, gave him a mild sedative at night, and arranged for night nurses so that he would never be left unattended. Over a period of three weeks he gradually became weaker, although at no time in distress from dyspnoea or any other obvious discomfort. At this point his daughter contacted her sister who lives in America and is married to an American physician. She had been writing to her sister that their father was not very well but had not been too explicit. At this point the son-in-law asked specifically about the nature of the illness and its treatment, and when informed that no specific therapy (Digoxin or diuretics) was given for the cardiac failure he rang me from America to question me in detail of my management of this problem. He made it clear that the attitude I held was quite unacceptable to him on principle and that if I did not pursue 'proper treatment' he would 'expose me' and 'make sure your licence to practise medicine is removed'. At this point I consulted one of the senior partners in the practice who had known this family for many years, and he independently assessed the situation after discussing the problem with Mr A B's daughter and agreed with our management. The American medical practitioner then came over with his wife and there ensued two or three very tense interviews with all concerned. He accepted that this father-in-law was suffering no discomfort, was well and meticulously cared for. However, he felt that the withdrawal of Digoxin, diuretics and antibiotics constituted euthanasia, and contacted legal representatives in London. I was told that the matter was to be brought to them to the attention of the General Medical Council. Over the next weekend the patient suddenly deteriorated, becoming feverish and confused. I attended frequently, monitoring the dose of sedation required to minimize his confusion but not to cause excessive drowsiness. He gradually deteriorated and died within 48 hours. His daughter was present almost constantly and felt that her father had had a peaceful and calm end to his life.

The American medical practitioner was in London during this time and refused to attend after the death of Mr A B. He rang me and informed me that all communication between us would now be through our respective lawyers. I waited but heard no more.

Mr A B's daughter, who cared so well for him, at no point questioned the morality of our actions. She was not a church attender, but in the community was recognized as a wise and compassionate person who held Christian beliefs. She felt that her sister had not wished to oppose her husband or make open statements of support, but had constantly made reassuring remarks such as 'doesn't he look peaceful', 'he's so settled', etc. Presented with the same situation again I would not make any other decision.

**Clash between two equally moral beliefs**

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This case demonstrates a clash between two equally moral beliefs: 1) everything possible should be done to prolong life; 2) quality of life is sometimes more important than life itself.

The physician who believes in the first of these precepts simply has to make a technical decision about whether or not treatment with Digoxin and diuretics would prolong this patient's life, whereas one who believes in the second has to take into account other more complex variables.

A value judgment must first of all be made about quality of life, something which is much easier to do when details of the patient's previous life are known personally by the physician. Judgments have also to be made about the patient's and the relatives' wishes. In this case it was the daughter who first raised the issue and we have her hearsay evidence that her father had always feared being a 'burden on the family'. Is hearsay evidence adequate, or should there be a statutory requirement for written evidence of the patient's wishes? Equally, if the daughter had not voiced the issue, should the physician, or would he/she have been justified in managing the problem in the same way without any discussion? Finally the physician has to consider the legal position.

It is possible to envisage three different legal codes being applied to this situation by three different societies or by the same society at different stages in time: 1) everything possible should be done to prolong life; 2) given certain safeguards an individual should, in certain circumstances, have the right to choose whether or not to die; 3) the individual may be sacrificed for the sake of the group.

At present the law favours the first position (a person commits homicide who directly or indirectly by any means causes the death of a human being). In an era when physicians could objectively do little to prolong life this was probably an appropriate definition, but it is doubtful whether homicide is the appropriate description for not instituting or for withdrawing therapy which may prolong life. The second position, which provides for individual autonomy, seems to be one which is increasingly favoured by society. The change in the legal status of suicide and the Californian 'natural
death bill' are two instances in which changes in laws have recognized society's desire to allow individuals more autonomy in this area. The third position is exemplified by the abandonment of elderly relatives by nomadic tribes when they can no longer hunt or keep up with the rest of the group. Our own society, when it chooses not to spend all the money which it might on expensive life-prolonging technical machinery, similarly sacrifices individuals for the sake of the group, and it is impossible to envisage a society in which legal sanctions would be enforced against those who expend money on officiously keeping individuals alive - an extreme view - but perhaps the first position is equally extreme. Both deny individual autonomy: in the first instance the physician uses his armamentarium to keep the patient alive as long as possible without reference to the patient’s wishes; at the other extreme society delegates the task of choosing whom to sacrifice to physicians, in their role as technical experts, and the patient has no right of appeal. The middle ground, despite its difficulties, allows individual autonomy and with this goes the important implication of a dialogue between consumers and providers of medical care.

The questioning of the need ‘to treat other than by measures to keep him comfortable' is not a rare experience, and, at present, the way in which the problem is resolved depends upon the beliefs and values of individual physicians looking after individual patients. The law, perhaps sensing a change in public opinion, appears reluctant to get entangled, and an analogy can possibly be drawn with the decline in prosecutions which began long before attempted suicide ceased to be a criminal offence. The Californian ‘natural death bill' may be the first legal recognition of a change in the status quo. An argument can, however, be made that the necessary rigidity of the law is not an appropriate vehicle for dealing with such sensitive issues, and that informed and sensitive pragmatism achieves a similar result.

Active and passive roles in medical ethical dilemmas
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Where there is both professional and lay uncertainty over a decision concerning management it would seem more appropriate for the doctor and the patient jointly to seek a solution to a complex problem than for the doctor to adopt a more active role with the expectation that the patient (or, as in this case, the relative) will be guided by expert medical advice and adopt a more passive role. The success of such interactions, however, depends on the extent to which the individuals involved are able to identify and appraise the issues and options. How do doctors and lay people learn the questions they should ask themselves? Who identifies them and who arbitrates when there is conflict?

The general practitioner in this case study gives a sensitive description of the patient's deteriorating condition and implies the reasons for his actions. He also describes the way in which the daughter assessed the situation. The first question they would both appear to have asked themselves is, 'Can anything be done to improve the quality of this man's life?' and the second, 'What can be done to ensure that he suffers as little as possible during his life?'. The general practitioner had discussed the question with a senior partner. The daughter, ‘wise and compassionate', obviously had a very good relationship with her doctor. She does not appear to have needed to discuss the question with anyone else. It is important, however, that the patient or friend who feels he has no one to talk to be able to talk to a lay counsellor.

It was interesting that the son-in-law should have felt that his recourse was to the General Medical Council (GMC) and that the general practitioner accepted this.

The GMC's pamphlet 'Professional Conduct and Discipline' (sent to all doctors in the UK in July 1977) quite clearly states: 'The Council is not concerned with errors in diagnosis or treatment' and there is no discussion of the ethical questions raised in this case study.

Family practitioner committees are not concerned with matters of 'clinical judgment'. Appendix D of the Merrison Committee Report1 details the controls on doctors' fitness to practise and states that there can be investigations 'by any local professional committee of a complaint made by a member of the profession against another member', but that 'the number of formal investigations carried out by such committees is small'.

It would be a pity if the only place where such difficult matters could be discussed, regardless of whether they are raised by lay or professional people, was in the court room: my experience of patients who wish to make complaints about their medical care is that they rarely wish to resort to litigation. Time and again, complainants have said that they only want to make sure that what has happened to them does not happen to someone else. It is essential that a mechanism be devised where there can be a fair, speedy and inexpensive assessment of clinical and ethical questions with the least trauma for both doctors and patients. One solution would be to set up medical tribunals on a regional basis with the Ombudsman or his officer as chairman and a professional adviser and lay representatives from outside the region concerned.

We have the opportunity to discuss this now since the Department of Health and Social Security is carrying out a review of procedures for investigating complaints against family practitioner
services and a parliamentary select committee is examining the complaints procedure of the Parliamentary Commissioner for Administration. In the meantime, who is identifying the questions which professional and lay people should be asking themselves about patients such as Mr A B? And how will this information be communicated?

Reference


An example of two different conceptions of the practice of medicine

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One possible way towards a partial understanding of this complex human situation is to see it as a clash of values between two medical practitioners, two different conceptions of how to practise medicine.

If a doctor is trained to see his role preeminently in terms of skills and curing illness, then predictably he will wish to tackle such symptoms and disabilities as can be alleviated with all skills at his command and he will feel guilty and frustrated if unable to do so. Death is felt as a professional failure.

If a doctor sees his role as having an important interpersonal element, then in a situation like this one he may have to ‘let go’ of a skill for the greater good of a patient and his family. Caring may be more important than curing. How do you measure the greater good?

The striking difference between the care of the dying in an ordinary hospital and a hospice seems to me to depend upon two different value systems: whether preeminence is given to the treatment of patients or the treatment of disease. These are processes to be distinguished but not separated. Pursuit of the treatment of disease may lead a doctor into the situation where prolongation of life quantitatively becomes inhuman. (I would agree that this is such a case.) On the other hand the patient’s general practitioner is invited by the daughter to consider matters of quality of life (his life had lost its dignity and meaning etc) and what are the criteria of what it means to be human? What is the ‘greater good’? How officious is officious?

I would agree that a sense of worthlessness and meaninglessness is a form of living death. I also think that interpersonal communion is one of the things that makes life human – we tend to speak of those who are unable to do this as ‘vegetables’. The use of such words means that a doctor is being asked to abandon his objectivity (if you think objectivity is possible) and deliberately to make an act of subjective identification with another person: an act of imagination. As a student I was taught in a situation of this kind to think how I would act if it was my own father, or mother, or child, or myself... and to do to others what I would that they should do to me. But this still turns up different answers based on our different value systems. (Perhaps this case history could be used by a patient to test out a prospective doctor who would be likely to treat him along the lines of his own value system.)

The doctor from the USA who appears on the scene like a meteorite is a familiar figure. He is usually a relative, comes from a distance, and has no immediate ‘care’ responsibility. He criticizes those who are bearing the burden of care, then disappears in a shower of sparks leaving everyone feeling guilty that they are not doing enough. He is born of the social value system which holds that ‘death is the worst thing that can happen to a man’ and is threatened deeply by beliefs such as that it is possible to ‘die’ while still existing. or that there is a life through death.

In this case the patient’s general practitioner manages the case on values which are shared by the daughter but which are not generally acceptable in society. This takes courage. Medicine – in the way this general practitioner is practising it – is seen to be practised within the wider context of personal care. Medicine is in fact a paraprofession and not the other way round. It is the context of care which makes sense of medical skills and indeed it is only personal care which can save medicine and machines from becoming agents of dehumanization.

Thus the difference between the two doctors seems to me to be that the patient’s general practitioner pays attention to the context and practises medicine in a more holistic way with the context of care offered by the daughter and himself. The doctor from outside responds to the situation on a transatlantic phone, and even when he crosses the Atlantic he is still as far away from the human situation as if he’d never left home: the context is ignored.

What a pity the case did not go to the GMC – it would have made splendid common law.

Addendum

The doctor presenting the case

In my report on the problems encountered over the death of a patient of mine with presenile dementia, I reported my thoughts as they occurred at the time, and the influence they had over the course of this man’s treatment. The main problem encountered was the resistance, vigorously expressed...
of this man's son-in-law (an American physician) to the concept of 'conservative management'. At the time I had attributed his aggressive manner to guilt arising from the fact that he had done little to help in the earlier burden of care and support, so was full of criticism when he came over from the USA to a dying man's bedside.

Since this time, owing to a change in direction of my own career, I have come in contact with several postgraduate American physicians in various specialities. I was interested to see that in similar situations their instinct was always to pursue all medical care to the fullest extent possible (Digoxin, diuretics, antibiotics, oxygen, etc) and the concept of 'conservative management' only applied to a decision whether or not to use a ventilator. These 'uninvolved' physicians seemed shocked that on occasion in this country simple medication would be withheld if a decision had been made not to interfere with the process of nature in order to let a terminal patient die in peace without unnecessary prolongation of the illness. How much their attitude was conditioned by a fear of litigation, rather than a primary assessment of the ethics involved, was difficult for me to determine. It could well have been that the aggression I encountered from this man's son-in-law was not a guilt reaction, but a genuine cultural difference in attitude to the extent to which a physician is entitled to withhold medical treatment.