

Choosing between cancer patients

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Author's abstract

The leading ethical problem in medical practice for the coming decade is likely to be how to select patients for priority. Criteria for such decision-making in the case of cancer patients are discussed. Clinicians, ethicists and others need to agree guidelines on giving priority to one patient over another when resources are limited, and such criteria need to be approved by society at large. The public must accept that in a non-explicit rationing system, each individual competes with every other. In the case of even more difficult ethical choices, a multidisciplinary national committee is required to advise on decision-making, and its views need to be debated by the general public.

As high-tech procedures proliferate in medical practice, and more elderly people predominate in the population, it is becoming clear that no Western country has the financial resources to provide unlimited medical care to all who need it. Rationing of medical resources is thus unavoidable if a society aims to provide the 'greatest good for the greatest number'. The leading ethical problem in the coming decade is likely to be how to select patients for medical priority. Clinicians and ethicists will have to debate guidelines on which groups of patients should receive priority, who should make the onerous decisions and on what grounds they should be made. But a much more difficult problem in our democratic society will be how best to take account of public opinion in formulating the guidelines.

Doctors who work in a mainly tax-funded health-care system are already faced with a rationing dilemma. While their ethical duty is to do their utmost for the patient whatever the cost, governments set limits to the overall resources allocated to health services. The demand has to be limited in some way and in the UK, this is to a large extent based on people's willingness to accept the queuing system. The onerous responsibility for establishing one's place in the queue is inevitably

passed to the doctor. But the possession of such power makes the doctor's position invidious in the eyes of the patient (1) and he is rightly suspicious of the divided loyalties of the doctor.

Nevertheless, physicians have always rationed their professional time according to the seriousness of the case, and rationing of expensive high-tech resources is inevitable under any health-care system, whether tax-funded or ruled by market forces. The question therefore is not whether it is ethical to ration medical resources, but how to achieve consensus as to the criteria for defining greater need by a patient. Not surprisingly, 'patient need' does not necessarily mean the same thing to different doctors.

Discussion of the criteria used by clinicians for rationing and allocating priorities is difficult, partly because such rationing may not be a conscious process. Thus, some doctors in the UK would claim that they never practise rationing because of limited resources, but only because of different patient need. However, medical management has to be appropriate to the individual patient and a decision may be made in a busy hospital department that it is kinder and wiser to withhold active treatment from a frail, aged patient with advanced cancer: in a less busy department, the same patient might be given active treatment (2). Medical decision-making may therefore be based on subconscious value judgements.

This certainly occurs in the case of renal dialysis where the UK is almost at the bottom of the list among Western countries in its provision, although there is no evidence that the need for such treatment varies between different countries. Faced with an aged patient with multiple diseases, a doctor in the UK may deny dialysis treatment because of greater need by younger patients, although he usually explains his decision on the basis that dialysis is inappropriate in the older patient. A quite different judgement might be made in another Western country or even in a third world country in the case of an important personage or political leader: and as long ago as 1980 Parsons and Lock found great variability in selection criteria even within Britain (3).

In the case of cancer, the decision made by UK doctors in deciding priorities between patients are generally based on two sets of criteria – tumour-related

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assessments and value judgements based on indirect assessments. These two sets of factors will decide the time given by the doctor to the patient for consultation, the place in the queue allocated for admission to a hospital and the duration of that admission, the place in the queue for special investigations and high-tech treatment, the provision of transport facilities or other ancillary services. The two types of patient assessment need to be analysed separately (4).

Tumour-related assessments influencing priority decisions usually include: 1) urgency or life-threatening nature of the patient's symptoms; 2) need for highly skilled supervision, and 3) the doctor's belief that control of symptoms or progress of the disease is likely from the procedure. Because of the uncertainties, the presence of paternalism or prejudice may colour the doctor's presentation to the patient of the alternatives to hospitalisation, investigation or treatment.

Indirect assessments which also influence priority decisions may include a greater variety of factors: 1) Medical state of the patient (including other serious disease which may co-exist) and the likelihood that he or she will be able to resume a life of reasonable quality. But has anyone the right, apart from the patient, to judge whether the patient's quality of life justifies a continued struggle? 2) Age of the patient chronologically. Younger patients are generally given preference on the basis that more years of life are likely to be saved, but this convention is gradually being modified to allow for the patient's 'biological age' – the number of potentially good quality and active years remaining. Particularly among elderly patients, functional status is now considered more important than chronological age in priority decisions. 3) Usefulness to the community. This basis for selection is rarely discussed but until 1973, it was used openly in the USA as a criterion for giving priority in the queue for kidney dialysis. Thus, selection emphasised social class, economic and employment status, educational background and family environment, in addition to age, mental acuity and absence of disease in organs other than the kidney. Using such criteria, a doctor might give greater priority to a highly skilled technician or professional person, on the basis that he might yield more useful years of service to the community than a handicapped or unskilled worker. Again, he might give greater priority to an individual with a young family needing support. 4) Family influences. While the doctor aims to be the 'patient's advocate', he cannot ignore the interests of the family and close friends. Sometimes the wishes of the patient may conflict with those of the family, mainly in cases where the patient may prefer to die in peace while the family is still pressing the doctor for further aggressive attempts to prolong survival. A decision by the doctor to stop active treatment in such a case can result in prolonged resentment by the family after the death of the patient. 5) Inappropriate factors. A doctor may

give greater priority to someone with whom he communicates better. 'Personal chemistry' may be responsible for such a situation, while absence of rapport may result from anger, tension or depression in the patient. (These symptoms are only too common in cancer patients as a reaction to the threat posed by the disease). Such factors may lead to greater priority being given to the patient who is always pleasant, co-operative and outwardly compliant. Indeed, some patients are highly manipulative in being able to secure for themselves a higher degree of priority.

Because of the variety of value judgements and clinical assessments involved, it is not surprising that different priorities for care may be given to the same patient by different doctors. A patient with advanced cancer may be regarded as terminal by one doctor and as a candidate for active treatment by another. Each doctor working in isolation stresses his right to allocate his time and skills according to his personal value judgements. But is it right that they should have sole responsibility for such selection? Apart from being an inefficient system subject to idiosyncratic judgements, the decision-making process should reflect the current mores of society. If resources available for the treatment of cancer are to be limited by the state, they should be allocated in a well thought out strategy (5).

To overcome some of the current problems in patient selection, we need to consider the following approaches both in the case of the UK and also in other Western countries with a mainly tax-funded health care system: 1) consensus by doctors on guidelines in the optimal management of different types of cancer at various stages in the disease. We have no such consensus at present. 2) a code of medical practice worked out by a multidisciplinary national committee in the case of specific ethical problems, such as resuscitation procedures in terminal patients or the criteria for allocating scarce medical resources. 3) approval by society of the criteria used daily by doctors for deciding priorities between patients.

Self-regulation by doctors

Physicians in the past have enjoyed a wide range of discretion in choosing treatment for the individual cancer patient. The pressure of scientific and technological advance is however changing clinical freedom, so that cancer treatment is now less governed by personal opinion. Attempts are constantly being made by scientifically-controlled trials to compare the effectiveness of different treatments. However, the results may either be ignored or else regarded by some physicians as a threat to their clinical freedom. And much could be done to broaden criteria for trials especially in measuring quality-of-life outcomes, and, more controversially, to include comparisons of costs of treatments being assessed.

As a first step, we need self-regulation by physicians. This involves formulating specific guidelines which will help to decide whether to hospitalise or not, to

order high-tech tests or not, to engage in aggressive treatment or not. These guidelines need to be based on objective criteria and should not be regarded by the physician as a threat to his autonomy. He will have an incentive to use them – avoidance of inappropriate use of resources should improve the quality of care available for those patients in whom active treatment is appropriate (6).

The problem is that it is difficult to evaluate clinical practice of this type. Medical audit involves critical analysis both of use of resources and quality of outcome for the patient. Measuring use of resources is relatively easy, but who measures the quality of the outcome – the clinician or the patient? For example, a treatment which causes partial reduction in size of a tumour may represent clinical success for the physician but the patient may feel no better for it. On the other hand, patients often declare themselves pleased with a treatment they have received, yet show little evidence of benefit in clinical terms. Quality of outcome is hard to measure. It is therefore difficult to design guidelines which will ensure that scarce or expensive resources are given only to those cancer patients in whom need and likely benefit are greatest. An index of cost-effectiveness has been suggested for assessing the outcome of a health procedure – Quality Adjusted Life Years (QALYs). It takes into account both the expected duration of survival and also its quality. While such a concept may be useful for health planners in choosing between two types of medical procedure, it seems much less appropriate in deciding which patient to treat first when scarce resources are being allocated.

Self-regulation by oncologists could however restrict unnecessary investigations or the use of expensive, new, marginally more useful chemotherapy agents. For the conclusions of consensus meetings to be accepted, they should be sponsored by authoritative professional bodies without vested interests either in stimulating demand (for example pharmaceutical companies) or inhibiting demand (for example governmental departments) (6).

A code of medical practice

We must also work towards a code of medical practice which will protect the individual from inappropriate treatment while, at the same time, maximising the benefit to society of our present resources. A code of medical practice set up by a multidisciplinary national committee might have practical advantages. Whereas a set of guidelines established by medical consensus would have no teeth, ignoring a code of practice from an official body could lead to censure, complaints or litigation against a doctor.

It would also have some advantages for the clinician. He would benefit from attempts by ethicists, sociologists, theologians, even economists, to provide an acceptable code of practice, even if in the final analysis, the buck always stops with the clinician. The burden would be eased by knowing that the clinical management was supported by colleagues and society.

Nurses and other professionals would also be happier if their representatives had participated in formulating such codes of practice. Finally, the public would be less suspicious of the divided loyalties of doctors, if there existed an official body at which lay people could influence the way medicine is practised (7,8).

In spite of its inherent dangers to professionals, there may even be a need for a permanent independent body whose function would be to review ethical dilemmas in medical practice and to draw up approved codes of practice. Such a body could supervise changes in practice and decide which problems required reassessment. It could be asked by the government or the medical profession to examine specific problems as they arose, whether of ethics or medical practice. It would receive evidence from interested bodies, issue public reports and submit codes of practice to professionals. At present, such a centralised decision-making body would be regarded with great suspicion.

A danger of a formal code of practice is that it might lead doctors to practise defensive medicine with an eye on the lawyer standing behind the patient's shoulder. But doctors differ in their perception of the threat of litigation. One doctor's defensive medicine might be another's good practice in that it involves greater caution in diagnosis or treatment. (True defensive medicine implies that a doctor departs from proper professional practice not for the benefit of the patient but in order to protect himself.)

Society must approve the basis for priorities

In handling the ethical problems involved in rationing scarce medical resources, society hides behind its doctors. In a mainly tax-funded health care service, most doctors reluctantly accept that they are involved in a restrictive or rationing process, although their ethical duty to the patient is in conflict with this. The public must similarly accept that in a non-explicit rationing system, each patient competes with every other. If one patient receives twice the allotted time, another patient must receive less time and usually a lower standard of care. The same principle applies to other medical resources in short supply.

Society should openly acknowledge the justification for such rationing decisions and approve guidelines for allocating priorities. But most governments would regard it as political suicide to discuss such guidelines openly. A recent crisis of funding at the prestigious Cancer Institute in Stockholm led to the proposal that patients over the age of 70 with certain types of advanced cancer might be removed from the waiting list for radiation therapy in order to expedite treatment in younger patients. The public outcry led to immediate withdrawal of the proposal.

The doctor can help to establish the value and role of each medical procedure in terms of scientific validity. Ethicists and others can suggest guidelines on how to allocate priority on non-medical or social grounds. But the public must accept that unless society is prepared to make sacrifices to make *complete* medical care

available on demand to all, each individual is competing with his neighbour. This is an unpalatable truth from which patients and their relatives are being shielded. Politicians refuse to spell out this limitation of a mainly tax-funded health service and as a result, this gives the public debate 'an aura of fantasy' (9).

An outspoken chairman of a regional health authority in the UK suggested a few years ago that as public expectations and doctors' ability to treat were rising faster than the resources which governments could supply, we had to accept that selection of patients for priority should depend on their 'personal attributes'. Included among these were whether they were breadwinners and the number of their dependants, whether they could cope with the financial and social after-effects of their treatment, their home circumstances and the number of years of active life the procedure would give them (9).

He stressed that such criteria were already being used daily by doctors in deciding priority for certain patients. He gave it as his opinion that if the reasons for rationing decisions were more clearly understood, people would understand why they were being given greater or lesser priority, while doctors would be less liable to the criticisms which sometimes followed the harder decisions. It is important to examine this democratisation of the rationing process.

A recent study questioned randomly-selected members of the UK public as to how they would choose between patients of different ages presenting with the same life-threatening illness (10). Whereas practically all chose children in preference to older patients, choices were less certain between a two-year-old versus an eight-year-old, and a 35-year-old versus a 60-year-old. The study was described as an 'attempt to bring true democracy into health service decision-making' and it was suggested that similar surveys might be made with regard to the influence of sex, social class, marital status etc on receiving priority in the allocation of scarce health resources.

The study raises the question of whether democratisation of decision-making means that every individual's opinion is equally valid or whether some opinions are more informed and perhaps therefore more valuable than others. The assumption that the study of random opinion samples of this type represents democratisation of decision-making is challenged by Lamb (11). He claims that true democratisation can come only from 'informed decisions, rational argument and avoidance of prejudice'. He also points out that an individual faced

with a priority decision involving a close relative might express a quite different choice from that which he has expressed in an opinion survey. Finally, it needs to be pointed out that choices are rarely as simple as the one presented in the survey. In clinical practice one may have to choose between using the same resources either for prolonging the life of a child by a few years or for offering long-term control in a 40-year-old.

If we assume that clinicians, theologians, ethicists, economists, lawyers, administrators, patient groups etc can make the most informed decisions, how should consensus guidelines which they have formulated be submitted to the public for approval? Is there a democratic threshold – a level which most people can accept – or would society find an attempt to set a value on each human life as being too awful to contemplate? Many of my colleagues also find the topic unpleasant to contemplate but as doctors, we cannot indulge in the luxury of being able to sweep it under the carpet. The topic needs a full and frank debate out in the open.

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