Needs, rights, and equity: moral quality in healthcare rationing

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There are two approaches to resolving the growing shortage of resources within healthcare services which are either completely or partly funded by the state. Political campaigns can be waged to increase the size of the budget. Conversely, ways can be found to stretch the existing resources even further. When governments are set against the first, those who manage centrally funded services have grappled with the second. In this context, the question of how best to prioritise or "ration" health care has become the subject of frequent and intense debate. How can the importance of providing quality health care be reconciled with the reality of not having enough resources to meet the needs of the population?

An increasingly common managerial response is to define the problem of scarce resources in utilitarian terms. Accepting that governments will not provide more resources, the question becomes how to create the greatest healthcare "good" for the most people. The answer can take two forms. Firstly, scarce resources should be directed to those needs which can be satisfied most cost effectively – where the most healthcare gain can be achieved for the most people and least money. Secondly, local populations should be able to decide democratically who gets what need satisfied – thereby ensuring the most acceptable satisfaction for most people.

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The advantages of such approaches are clear. On the face of it they offer moral justifications and structural mechanisms for conserving resources through denying or restricting health care to some in order to optimise its benefit to others. Surely, allowing waste and inefficiency in the face of scarcity in health care is morally repugnant, as is the undemocratic refusal to allow the public to decide how limited resources should be distributed. Variations of such arguments are popular among healthcare managers and suggest practical and "hard headed" solutions to the problem of rationing health care.

Unfortunately, such strategies can also lead to health care being denied to those in need. In this paper, an alternative moral theory of rationing health care is offered. It will be argued

that rationing primarily based on criteria of cost effectiveness and public participation is unfair. This is because such criteria are inconsistent with the principle that all humans should have equal rights of access to health care on the basis of equal needs. A more equitable, although still practically feasible, system of rationing will be developed, one in which cost effectiveness and public participation will still have an important role. To simplify the argument, our focus will be on the central funding of hospital care only and on rationing within the National Health Service (NHS) in the United Kingdom. The conclusions drawn will, however, be applicable to centrally funded health care in other countries.

Should cost effectiveness or public participation or both determine who gets what?

Within centrally funded health care, the effectiveness of purchasing – however this may be nationally or locally organised – is often equated with the utilitarian goal of maximising the greatest health gain for the most people. The measure usually proposed as a means of achieving this aim is some variation on the quality adjusted life year (QALY).¹ On the face of it, the aim of QALYs is laudable as they offer an apparently objective comparative indicator for the health gain derived from different types of clinical treatments.

QALYs are constructed through the initial correlation of particular treatments with evidence of their impact on mortality and morbidity (defined, for example, in relation to mobility and pain). Different treatments will be associated with different values of these variables – some treatments doing well on all counts, others on only a few, and some scoring poor results altogether. Once this quantitative information is obtained, the task then becomes to rank the treatments in order of the increased or decreased quality of life which each cluster of scores represents. This is usually done through asking respondents to compare their preferences for different combinations – so much life expectancy with so much pain or so much loss of mobility, for example – with being in a state of perfect health. The values which these preferences show can then be averaged and used to rank the quality of life associated with the cluster of mortality and morbidity scores for each treatment.

In this way, a value can be given to the health gain of each treatment. This value can then be set against the average price of each treatment

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to produce a ratio of cost and effectiveness. If the aim is primarily to maximise health gain as defined by QALYs with the most effective use of scarce resources, treatments can then be funded in the order which offers the greatest potential gain. "League tables" of conditions matched to treatments can then be constructed in the order in which they should be purchased.² For example, with similar techniques, studies have scored hip replacements and pacemaker insertions as better value than home or hospital haemodialysis or kidney transplantation.³

The indicators of the effectiveness of health care which form a part of QALY calculations are potentially useful, despite some well rehearsed methodological problems. It obviously makes sense to avoid wasting scarce health-care resources and there is clearly a need for objective criteria of cost effectiveness. However, the problem of equity emerges as soon as it is suggested that QALYs should be the prime determinant of the levels at which particular treatments are funded or even whether or not some treatments should be resourced at all.^{1 4} Immediately, many of our intuitions about justice and fairness are challenged.

For example, if health gain is primarily defined as the potential for extra years lived, will we not always obtain greater value for money through spending it on younger patients rather than on older patients with curtailed life expectancies? Why not, therefore, drastically reduce health care for elderly people? Similarly, if the focus of health gain is on value for money in increasing mobility and decreasing pain then why not make similar reductions in spending on patients requiring expensive treatment who have debilitating chronic illnesses? Indeed, it would be consistent to argue on these grounds alone that we should allow the 10% of patients who are most sick in all categories to die so that we could use the freed resources more efficiently on the 90% who are less sick!⁵ Such suggestions make us morally recoil but we cannot explain why, if we believe that issues about healthcare rationing can be settled by simple reference to criteria of cost effectiveness, however these may be defined.

In theory, the general public is sometimes appealed to for help with such difficult moral choices. We have seen that traditional formulations of QALYs link cost effectiveness of treatments to a further measure – the ranking by the public of the relative quality of life which they can produce. QALYs aside, it is certainly fashionable to emphasise the moral importance of wider public participation in decision making about rationing health care.⁶ However, there is no reason to believe that local democracy of whatever kind can satisfactorily resolve major moral dilemmas about resource allocation.

Research on the representativeness and rationality of public consultation has shown serious problems in discovering what most people actually believe.⁷ Much will depend on where and when consultation occurs, who speaks, and the terms of reference of the meetings – often completely arbitrary factors.

It has been shown, for example, that the wording of questionnaires can lead to vastly different preferences being expressed.⁸ Thus, given the same evidence, members of "the public" may at different times and places make different decisions about who should get what. In the United Kingdom, for instance, there seems to be considerable variation in public attitudes towards the provision of certain types of treatment. For example, in vitro fertilisation, reversal of sterilisation, and cosmetic surgery seem unpopular in some areas but not others.^{9 10}

Moral intuitions about what is ethically acceptable can also differ between members of the public and between the public and health-care professionals. For example, the state of Oregon created a now famous programme of public consultation to set priorities for state

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provided Medicaid. This is often cited in support of the feasibility of such strategies in rationing medical care. Yet after the first initial consultation, it became clear that some intuitions about treatment priorities endorsed by the public were not subsequently reflected in the decision making of the health professionals running the consultation exercise.¹¹ As one well known commentator has argued:

"There is no reason to believe that a different set of commissioners, reacting to the same community meeting process, would have arrived at a similar ranking of services".¹²

Health authorities in the United Kingdom have ignored local opinion in similar circumstances.¹⁰

These experiences of conflicting moral intuitions suggest that in the face of dramatic scarcity, criteria of cost effectiveness might well be used to discriminate against minorities whose treatments are expensive and offer only slight increases in life expectancy and decreases in morbidity. Indeed, it can be argued that some traditional research into QALYs themselves falls into this category when evaluations of the cost effectiveness of treatments are derived from interviews with people representing the majority who are not seriously or chronically ill. The fact that the wider public might sometimes agree with or initiate such discrimination against minorities undermines arguments for giving it a decisive role in the distribution of healthcare resources. If we have learned anything from recent history it is that the best interests of minorities are not necessarily safe in the hands of majorities. This is of particular concern if the minority in question consists of those too vulnerable through illness to defend themselves.

If neither cost effectiveness nor public participation can ensure justice in the distribution of health care, on what theoretical and practical bases should it take place?

Why is there an equal right to health care based on equal need?

The discussion thus far has relied heavily on moral intuition. We have argued against regarding cost effectiveness or democratic endorsement, or both, as acceptable criteria for rationing health care. Yet this scepticism is based on the prior belief that individuals should have equal access to health care on the basis of equal need – that the distribution of health care *should* be regarded as equitable in these terms. Supporters of centrally funded healthcare provision usually endorse some variation of this idea, arguing that necessary services should be free at the point of access. But can such ideas be founded on more than moral intuition, recognising that such intuitions may wildly differ? The answer is “yes” as can be shown through an analysis of the links between our need for good health and the moral duties which others expect of us and we expect of ourselves.

WHY IS HEALTH A BASIC HUMAN NEED?

Physical and mental health are necessary conditions – they are “needed” – for optimally successful social participation. Without such participation, people have no chance to flourish. We learn who we are and what we can do as people through our interaction with others. To the degree that we are disabled in our potential for such interaction by physical and mental illness then it is not just our immediate health and wellbeing which are threatened. Our future as creative and productive people of whatever kind is correspondingly reduced.¹³ For this reason, we need appropriate medical care – to minimise the serious and sustained disability which some illnesses cause.

Our own physical and mental health will also impact on the productivity and creativity of others. People who are less healthy than they might be cannot help others to flourish. Such help can take various forms – formal and informal education, emotional support, physical security, and engaging in all of those activities which constitute the social environment within which people will live and develop their moral and mental skills. The negative impact of physical and mental illness thus spreads far further than the sick person. Needing people is not optional. We all need other people to be able to make the most of our lives.¹³ Unless they too are healthy, their capacity to help us to do so will be limited.

WHAT IS THE RELATION BETWEEN HEALTH AND GOOD CITIZENSHIP?

All cultures are held together by visions of “the good” which are equated with various moral duties. It is our conformity with specific sets of such duties which identifies us as good citizens of particular cultures. For example, all cultures have moral codes concerning the responsibilities which parents have toward the education of their children. Parents are expected to do their best to conform to these codes, and moral, and where appropriate legal, penalties will be enforced if they do not carry out their duties.

Yet to say that someone “ought” to do something implies that they “can” do it. If we believe that others should do their best to do what is right – to be a good citizen in the terms defined by our culture – then it follows that they must be physically and mentally able to do so. This point applies equally to our moral expectations of ourselves. We cannot realise our potential to be good citizens in the eyes of others if we are physically and mentally disabled in ways which could be corrected. This will be true in all cultures and for all people who morally identify with them.¹⁴

It logically follows that if we wish to impute moral duties to others then we have no option but to accept that they have the right to appropriate health care to enable them to do their best to be good citizens as we define it, always assuming that we really wish them to be so. And the same applies to others with respect to us. If they wish us to do our best to accept and act on the duties which they morally endorse then they must also respect our right to such care. In this sense, duties and rights go hand in hand. This is not just because they are usually correlated in practice but because without rights, duties are little more than moral abstractions.

WHY IS APPROPRIATE HEALTH CARE A BASIC HUMAN RIGHT?

Hence if we want others to believe that they have a significant moral stake in the culture with which we ourselves identify then we should support their equal right to appropriate health care on the basis of equal need. To provide such resources unequally – or inequitably – will arbitrarily make some individual subjects or groups objectively less able to do their best to do what is expected of them. The inconsistency of such a strategy can only be resolved by a judgement that those who are deprived should receive a commensurate reduction in their moral responsibilities.¹⁵ Yet this step is rarely taken because to do so would show a lack of commitment to the vision of moral good which defined these responsibilities in the first place. It would mean that the good was not really believed to be that good after all.

Moral beliefs are inherently universal. If we really believe that we are right about them then they must apply to everyone equally – in the same way and to the same degree. If we expect that everyone should do what we believe to be right then they must have the necessary physical and mental abilities. Suppose, for example, that we really do believe that parents have a moral responsibility toward the education of their children which they should do their best to implement. How could this be reconciled with doing nothing to help them to minimise disabling physical or mental illness which keep them from doing so? In effect, this would be to say that we take our moral beliefs seriously unless we find it expedient – for whatever reason – not to do so.

In reality, of course, those deprived of the wherewithal to act as good citizens *are* still expected to strive to do so and are condemned

when they do not. This has resulted in the creation of a disenfranchised minority with little personal stake in the moral aspirations of the majority.¹⁶ Thus even if members of the majority choose irrationally to discount the equal right of everyone to health care, it is hardly prudent for them to do so in practice. Although it may be possible to defend themselves against the most obvious expression of the minority's moral alienation – crime and other forms of asocial behaviour – total protection will be impossible.

It is because of the explicit or implicit recognition of arguments like the above that moral intuitions often suggest there is something morally adrift with purely utilitarian criteria for rationing health care. A narrow focus on either cost effectiveness or public acceptability in the rationing of health care can lead to people being denied a necessary condition for becoming and remaining good citizens and as such from fulfilling whatever personal potential they may possess. Moreover, to the degree that we can see the possibility of ourselves being so denied then we will be uneasy about the injustice of distributing centrally funded health care in this way. Therefore, both reason and prudence dictate that people should have an equal right to appropriate health care based on need.

Respecting the right to health care in practice: procedural policies

Those who defend more utilitarian approaches to resource allocation may well respond to the arguments outlined above by raising the general issue of practical feasibility.¹⁷ The scarcity of healthcare resources is a fact of our social and political life, they will say. This means that some people cannot have as many of their needs met as others. Consequently, if we are to continue to respect the right of each person to equal access to appropriate health care on the basis of equal need then we must find a way to reconcile this right with the reality of scarcity – of not being able to meet everyone's needs. This can be done through rationing health care in conformity with seven procedural principles.

(1) HEALTHCARE NEEDS SHOULD BE MET IN PROPORTION TO THEIR DISTRIBUTION WITHIN THE POPULATION

The first step in the just allocation of health care should be an assessment of the needs of the local population. Given our focus on hospital care, "need" is defined here as the requirement for specific clinical intervention to avoid sustained and serious disability. At present, such "needs assessments" are based on various sets of data – extrapolations from previous patterns of clinical provision, national and local mortality and morbidity statistics, specially commissioned studies on specific types of health problems, along with evidence from action groups and other representatives of local populations. The accuracy of needs assessment is of great moral importance. Yet, as is widely agreed, it is difficult to attain.¹⁸

For example, in the absence of dedicated surveys, evidence about general patterns of morbidity is partly derived from mortality statistics. Such extrapolation can disguise variations between geographical locations and social classes. Also, because of their emphasis on acute disease, mortality derived morbidity statistics systematically ignore the extent and types of chronic illness. Previous expenditure on healthcare services is another common

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proxy measure of health need. Yet some care is ineffective and improperly prescribed and other care is effective but inefficiently and inequitably distributed. Extrapolations from data describing either or both will result in a distorted profile of local need. With these and other problems in mind, it is hardly surprising that many healthcare planners and researchers are sceptical of the value of current assessments of need in ensuring a just allocation of welfare.¹⁸

Yet the identification of factors leading to inaccurate needs assessment presupposes that we have a vision of what an accurate assessment would look like and how it should be obtained. Indeed, it is precisely such a vision that is behind current attempts by needs assessors to improve the accuracy and reliability of their work. For the sake of the argument let us accept that improved methods of needs assessment will be available and that they will be able to provide reasonably accurate information about the levels of need for secondary health care within given populations. At their simplest, such assessments will indicate the percentage of the population expected to require treatment for, say, heart disease, kidney disease, orthopaedic problems, psychiatric illness, and so on.

Ideally, a calculation can then be undertaken to measure the average unit cost of treatment within each category of need for secondary care that has been assessed. The numbers of people estimated to be in each category can then be multiplied by the average unit costs of treatment giving the total potential expenditure required to meet the total need in each category. These sums can then be aggregated to show the expenditure required to meet the total identified secondary healthcare needs of that population.

In the unlikely event that the sum required for this total expenditure is equal to or less than the budget then there is no problem. However, in the real world of centrally funded health care, there is likely to be a significant gap leading to the inevitability of rationing. To make this an equitable process, the budget for each specialty must be reduced by the same proportion. Thus if healthcare provision really is morally driven by the principle of satisfying need and the total amount of money required

is 20% less than the funds available then the allocation to each specialisation must also be reduced by 20%. To do otherwise would be to accept that some people in equal need should not be given equal access to health care simply because of the type of need they have.

Centrally funded healthcare systems remain mixed in their commitment to providing this equality of access. For example, in the United Kingdom, the NHS continues to have an overarching commitment of this kind, funding expensive programmes of transplantation and cancer treatment, despite questionable QALY scores. However, against the background of public support, increasing numbers of health authorities have withdrawn or minimised local funding for in vitro fertilisation, reversal of sterilisation, and cosmetic surgery.¹⁹ Yet it is well known that infertility can be both psychologically and socially disabling for some women and men.²⁰ The same can be said for disfigurement requiring cosmetic surgery.

To the extent that our argument linking needs, rights, and duties is accepted then there is no acceptable moral justification for discrimination against particular types of treatment – against patients with specific clinical categories of disease and disability. Some illnesses will inevitably be more expensive to treat than others, and sometimes with less effect. Some will not find popularity with the public. Yet neither of these criteria can justify the denial or reduction of health care to those in need. Patients with illnesses which are expensive to treat or are unpopular can be just as disabled by them as those whose treatments find public favour. Thus failure to provide services when they are needed is a violation of the rights of individual people – just as it would be, say, to withdraw education from children whose families were held in low esteem by the local population. Because health care must be rationed, it should be done fairly *within rather than between* types of treatments.^{21 22} *Reductions in resources should be spread in equal proportions over all categories of clinical need.*

(2) WITHIN AREAS OF TREATMENT, RESOURCES SHOULD BE PRIORITISED ON THE BASIS OF EXTREMITY OF NEED

The greater the disability caused by illness, the greater the moral entitlement to effective treatment. The right to appropriate health care increases in proportion to the degree to which illness threatens the person's potential to flourish through successful social interaction and reduces their capacity for good citizenship. Risk of death is clearly the greatest possible hazard generating the most immediate claim on available resources. Once dead, an individual can do nothing and claim nothing. The next claim on resources would be immediate risk of serious and irreversible disability. Although acute pain may not be life threatening or permanent, its immediate effects are extremely disabling. Indeed, as such pain may signify disease and can inhibit further clinical investigations of its cause, it too creates an entitlement to early and effective medical treatment.

At the opposite end of the range of urgency are healthcare services which patients may want but which they do not need – “need” being again defined with reference to what is required for a person to optimise their potential for successful social interaction through minimising physical and mental disability. Preferences which are not associated with such requirements have no claim on healthcare resources. An example would be cosmetic surgery for a condition which is marginally distressing but in no way socially disabling. The moral cutting edge of any claim must be the serious and sustained disability that would ensue if it were not met.

That such arguments find public favour is clear from the fact that those with serious illnesses have traditionally been accorded a greater moral claim on available resources than those requiring treatments deemed “elective.”²³ Drawing attention to this fact is not meant as an endorsement of public acceptability alone as a criterion for moral judgement. It is simply to point out how consistent our moral common sense often is with acceptable moral argument.

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Thus the general method of *rationing by triage* should dominate the organisation of waiting lists within the NHS, as it has in other circumstances where scarce healthcare resources have had to be centrally allocated. Dividing patients into those with conditions which are acute, urgent, and elective entails separating them into categories of *moral similarity* of claim on available resources. The principle of allocating healthcare resources according to extremity of need translates into the practice of providing treatment in this order – acute cases seen first, then urgent, and finally elective cases. Of course, the theory of triage requires considerable work, especially on its conceptual coherence and its practical implications for the detailed construction of waiting lists.²⁴ Yet from experience in accident and emergency departments, it is remarkable how willingly most people will wait, *provided* they believe that these general principles are being fairly applied.

(3) THOSE IN MORALLY SIMILAR NEED SHOULD HAVE AN EQUAL CHANCE OF ACCESS TO HEALTH CARE

“Fairness” in allocating scarce resources of whatever kind entails more than distribution on the basis of need. Those whose need is acute should be seen first and everyone who is morally similar in these terms should have priority of access to resources. Assuming that a surplus will remain to be distributed to patients with urgent and then elective conditions, a procedure must therefore be developed to ensure that those within each of these categories have an equal chance of receiving

care. This procedure must *randomise* such morally similar competitors for care for the purposes of resource allocation. In other words, there must be a lottery of some kind.²⁵ The problem is that lotteries of the usual kind – everything from tossing coins to drawing lots – are practically inappropriate for the allocation of clinical treatments. Neither clinicians nor patients would tolerate them.

Yet assuming that they really are organised to prioritise those in greatest need, waiting lists can come close to performing this role. The randomisation is achieved because within populations for whom health care is usually provided, the *time* at which and the *seriousness* with which illness develops is to all intents and purposes a matter of chance. When we become ill, we are subject to what is sometimes called the “lottery of life.” Acute illness, for example, is the sort of misfortune which could affect anyone and it is this severity – rather than any personal or social attribute of sufferers – which creates a morally similar entitlement to health care.²⁶

This is of course not to suggest that the timing or extremity of illness is a completely random process. Some groups such as unskilled workers, those who are unemployed, or elderly people will experience higher levels of serious illness than others. Yet even here the distribution of illness between individual people *in these groups* is still random enough for waiting lists to be fair – provided that they are not discriminatory on other grounds.

Thus waiting lists are not in themselves a moral scandal. What is unacceptable is prioritising patients for reasons other than levels of morally similar need dictated by triage. This might be because of their own personal influence or that of their primary or

need for which it is provided – of restoring the ability of recipients to act and interact with others to optimal levels. There can be no right to health care which cannot be shown to be successful in these terms. In circumstances of scarcity, providing ineffective care is wasteful and cannot be morally defended as it diverts healthcare resources from real need satisfaction.

It follows that the decisions of funders of health care should be based on evidence about the effectiveness of services – on their outcomes.²⁹ The use of many therapeutic interventions continues to be founded as much on tradition and public expectation as it is on scientific evidence. Under such circumstances, funders have no choice but to act on the best information available to them. It is therefore their moral duty, along with that of the providers of care, to seek to improve this knowledge base. Thus the current emphasis on clinical audit and evidence based medicine is of ethical as well as practical importance.³⁰ Finally, returning to QALYs, their potential value lies mainly in analysing the comparative cost effectiveness of different treatments for the same conditions. Criticisms offered earlier focused on the potential of QALYs to be used to discriminate against certain types of conditions representing unpopular need.

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secondary clinicians, or both.²⁷ When injustice of this kind is found, the moral consensus among other waiting patients may be seriously undermined. They may no longer wish to be “patient,” especially if they are also critical of the low levels of resources which lie behind their lack of medical treatment. Against the background of scarcity, if the constitution of waiting lists is unfair, the equity of the health-care system itself will be undermined.

(4) SCARCE RESOURCES SHOULD NOT BE PROVIDED FOR INEFFECTIVE HEALTH CARE

If needs are to generate a right to health care then they must be capable of successful satisfaction – the technologies must be available to remove or reduce their associated disabilities. This is why it makes sense to speak of a right to good health care but not to good health. For some people the attainment of good health will be impossible no matter what action is taken.²⁸ It is also why health care which is offered should be capable of meeting the

The link between the right to health care and its potential effectiveness can lead, however, to surprising and uncomfortable results. This is because even when treatment does relieve disability caused by illness, this is not enough in itself to justify a patient’s moral right to it. The improvement must be sustained. Many patients may be able potentially to benefit from a variety of life saving treatments – some of which are highly expensive – without having the right to them. Within intensive care medicine, for example, it is often possible to keep unconscious patients alive a little longer who will still die in the very short term or might live to be so brain damaged that they will never be able to execute another human action. Similar dilemmas about non-treatment are common in the care of neonates and elderly people when there can be enormous pressure from relatives and the public to provide expensive although futile treatments.

Considerable progress has been made on the development of acceptable ethical and legal guidelines for not starting or for withdrawing lifesaving treatment.³¹ As part of the drive toward effective clinical audit and evidence based medicine, it is imperative that there is clarification of the grounds on which such decisions are and should be made. Otherwise, scarcity will again dictate that some treatments

with sustained effectiveness remain unavailable or unjustifiably delayed for those who could benefit.

(5) LIFESTYLE SHOULD NOT DETERMINE ACCESS TO HEALTH CARE

It has become fashionable to suggest that one way of dealing with the shortage of healthcare resources is to deny them to patients whose deliberate actions are causally implicated in their illnesses. Should those who have sacrificed short term gratification to look after their health be given priority over those who have not? Arguments of this kind seem to be even stronger when a patient's lifestyle continues to compromise the effectiveness of available treatments. In a situation of abundant healthcare resources, we might not have to contemplate such discrimination. However, in the face of scarcity, we do have to consider whether or not it is morally justifiable.³²

Arguments of this kind imply for instance that non-smokers should have priority over smokers in allocating treatment for vascular disease, including coronary bypass. Indeed, some clinicians have refused to offer bypass surgery to any smokers at all.³³ Equally, "individual responsibility" has been included in lists of rationing criteria drawn up by some health authorities and even national governments.³⁴

Health professionals have no moral obligation to provide treatments which are futile. We have seen that to do so would be wrong in circumstances where the consequence might be to deny effective treatments to others who could benefit. Yet it would be equally wrong to assume that all people have the same ability to act in their own best interests and that they can be held equally responsible for self harm. There are a range of educational, psychological, and social factors which mean that such abilities can vary widely. The large literature on compliance in medical treatment makes this point forcefully.³⁵ Among other things, it indicates how complex self destructive health behaviour can be and how clinicians themselves can be implicated in it – for example, through not providing clear information to their patients or not sustaining their trust.

Let us assume, for example, that two people are competing for a treatment which can have some benefit to both, albeit less for the person who has made damaging choices of lifestyle in the past. Accepting that people should be responsible for their actions does not necessarily dictate that the person who made healthy choices should be treated. This would only follow if the two had been equally able to choose the healthy option.

People who have damaged themselves may come from a background of disadvantage. Because of aspects of their socialisation and emotionality over which they have no control, they may not have the same ability to protect their own interests as someone from a more informed and supportive social environment. Moreover, many will not have the material resources to acquire the goods and services

necessary for an optimally healthy life.³⁶ The apparent moral virtue of someone from a personally empowering environment who makes the "right" decisions cannot therefore be allowed to trump the apparent moral turpitude of someone from a personally undermining environment who makes the "wrong" decisions.

Rarely is enough known about patients to judge the degree of their control over lifestyle.

Under most circumstances, therefore, rationing on the basis of lifestyle cannot be morally justified and should not figure in funding strategies for health care. The moral eye should remain clearly on the ball of human need, always provided that proposed treatments are not futile and will relieve disability. The spectre of clinicians becoming judges of lifestyle opens up the possibility for a wide range of personal prejudice in the allocation of healthcare resources which it is in no one's interest to promote. One clinician might feel strongly about smokers, another about obesity, another about alcohol, another about dangerous sporting activity – the slippery slope seems endless and has no clear moral justification.

(6) RATIONALITY SHOULD BE OPTIMISED IN THE ALLOCATION OF SCARCE HEALTH CARE

Even if we assume that all of the principles discussed thus far are incorporated into the allocation policies of the funder, the just allocation of healthcare resources does not automatically follow. Just as the fairness of waiting lists can become distorted by vested clinical interest, the same triumph of contingency over reason can occur in the decisions of those responsible for interpreting how these policies should be put into practice.

Rules do not interpret themselves; they must be applied to particular problems after deliberation about their most appropriate interpretation. Healthcare planners should not be thought of as ciphers who can be absolved of responsibility to optimise the rationality of their own debates. Success or failure in formulating and acting on equitable funding policies will be a reflection of their collective commitment to achieve this goal.

Of course, health planners are constrained by a range of external factors over which they have no control. These can detract from, if not completely obscure, rational decision making. In the United Kingdom, for example, the government has imposed national guidelines setting targets for health service performance which may not accurately reflect the particular needs of local populations.³⁷ Similarly, "internal markets" – with all their problems – are becoming more and more fashionable within centrally funded systems. Despite the rhetoric about the virtues of competition, the reality is that funders cannot escape their responsibilities to sustain the long term economic and

clinical viability of key healthcare providers whose services they "purchase". Yet the purchasing decisions required to do so may be congruent neither with the satisfaction of local patterns of need nor with criteria of competitiveness. Finally, as governments make little new money available to central funders, they have little freedom to increase service provision in general or to shift funds to meet newly discovered need.³⁸

It is not just external factors which can lead to irrational policies and decisions. The internal organisation and membership of planning organisations can also distort rational deliberation and limit the equity of decision making. Sometimes patterns of political power within organisations act to reinforce policies which are linked more to the interests and obsessions of specific persons or groups than to equitable healthcare rationing.³⁹ When there is a distorted pattern of expenditure which cannot be justified with respect to external constraints and does not reflect manifest local need, it can often be explained by the presence of a champion whose institutional power or dominating personality, or both, makes rational debate extremely difficult.

There is often little that funders can do about outside political pressures to make inequitable decisions about rationing. However, there is no excuse *within* such organisations for not exposing arguments about rationing and equity to critical scrutiny to root out factual error and logical inconsistency. Equally, there should be a commitment not to suppress ideas because of their unpopularity or their political origins. To facilitate such processes, funders should endorse a clear statement of policy concerning equity in purchasing to which all employees are expected to adhere in their work as well as defining the principles of rational communication which they should observe in so doing.

Equally, to minimise the possibility of irrationality at the level of local policy formation, standing national bodies should be created with the specific purpose of generating and reviewing policies of equitable healthcare rationing.⁴⁰ Provided that their constitutions are sufficiently representative of public interests and relevant professional expertise, such bodies could help further to clarify and make explicit acceptable moral criteria for

policy makers – would result in more rational resource allocation at both local and national levels.

(7) THE PUBLIC SHOULD ADVISE BUT NOT DETERMINE POLICY CONCERNING THE ALLOCATION OF HEALTH CARE

We have argued thus far that the preferences of any local population about the allocation of scarce health resources are in themselves of little moral importance. What is of moral relevance are the reasons given for the preferences. The wishes of majorities may embody serious moral mistakes. The ethical principles developed here are justified by conceptual and empirical argument and not by the anticipated results of any opinion poll. Thus the only rational grounds for rejecting them should be the detection of logical or factual error. For example, reason and evidence alone should determine whether or not we accept the argument that it would be unjust to deny expensive life saving treatment to an incompetent patient who seems to be permanently, devastatingly, and irreversibly brain damaged.

Such a position does not, however, entail ignoring beliefs held in the wider community about the equitable allocation of healthcare resources. In different ways and to different extents, public opinion will set the boundaries within democracies for what is and is not politically feasible. Thus the public must be consulted and there is every reason to assume that many of the moral principles outlined so far would find favour. More importantly perhaps, it would be impossible to optimise the rationality of decision making based on these principles without consultation with appropriate representatives of local populations.⁴¹ This should be done in the following ways.

Better needs assessment

As levels of need and associated disabilities should morally drive decisions about who gets what health care, standard epidemiological tools for their assessment are of crucial importance. Yet we have seen that existing techniques are crude, especially in the measurement of morbidity. As a result, many conclusions about local need are based on little more than the extrapolation of findings from earlier research which may or may not have been done on the populations to which it is now being applied.⁴²

Further research involving the participation of local people is clearly required both to establish how health problems are distributed and how these impact personally upon those affected. It may be, for example, that the degree of disability associated with certain illnesses differs according to class, sex, race, or occupation, and a range of other factors. If we accept that it is the degree of actual or potential disability rather than illness itself which establishes an individual's claim on resources, it follows that different people with the same illness may not be able to claim the same level of support. Such issues cannot be resolved

... funders should endorse a clear statement of policy concerning equity in purchasing ...

the allocation of scarce resources. Policies developed centrally in this way could then be regularly compared with those arrived at more locally. The aim would be to make explicit the reasoning behind rationing decisions and the degree to which they were able to withstand critical scrutiny. Such comparisons – and the debates among and between central and local

without the active participation of those involved, along with their carers, relatives, and friends.⁴³

Better audit and research

Even when reliable information is available about local levels of need, we still require accurate assessments of potential services to establish exactly what types of health care the need is really for. We have already stressed the importance of evidence based strategies for the cure, management, and prevention of illness. But what is sometimes underestimated is the degree of public commitment required to evaluate both existing and experimental treatments. Such research should be regarded as a form of public consultation which can at times make considerable demands on those who agree to participate. The same point applies to the larger numbers of people who are consulted in studies designed to assess the impact of strategies for health promotion. Evidence based health care would not be possible without the active involvement of members of the public and it is important to acknowledge their active contribution.⁴⁴

Better defence of patients' rights

There is more to the provision of a morally acceptable standard of health care than treatment or prevention which has been shown to be effective. Patients and the public are often just as concerned with the quality of the professional and personal relations within which health care is delivered. The upsurge of interest in and concern about ethical and legal issues in medicine is a reflection of this concern. Increasingly, patients have strong beliefs about their right to exercise autonomy over treatment options and the communication of private information which they have disclosed in the course of their medical encounter. These rights are now taken seriously by the professional organisations concerned with ensuring a high standard of clinical care. Their violation is also the subject of a significant proportion of formal complaints about individual clinicians.⁴⁵ The participation of the public is thus vital in monitoring abuses of rights in clinical practice.

More equitable purchasing

The public should also be consulted about the ways in which funders undertake their responsibilities to purchase and distribute resources. The discussion thus far has highlighted a range of ways in which funders may act unjustly, discriminating against vulnerable minorities with minimal political voice. Equally, funders are charged with implementing the health policies of central government – decisions which may themselves have discriminatory effects. Whether it be an individual patient or group unjustifiably refused access to care or the potentially unjust closure of health care facilities, the public has a crucial part to play in drawing attention to the facts and their consequences.

In such circumstances, it is also the duty of planners both to consult the public and to aid

and advise its representatives about the most appropriate and effective means of making their case. Again, without such consultation, the rationality of decision making – and therefore its moral status – will be compromised. The public may not always be right. However, members of local communities possess a wealth of what can be termed experiential understanding which is crucial in trying to establish what is right.⁴¹

Equity and the national politics of resource allocation

An assumption has been made throughout this discussion which is found in practically all of the literature on the ethics of resource allocation: that the pool of national resources available for health care is a more or less constant percentage of gross national product. It has been argued that if this were managed in conformity with the substantive and procedural moral principles outlined above, it could eliminate or reduce a proportion of physical and mental illness which remains untreated. However, if extra funding for health care can be found and similarly managed then a much greater proportion of needs could be met. This fact is too often ignored in debates about healthcare rationing.

Because of what is sometimes described as the infinite demand for health care, counter-arguments maintain that increasing the percentage of gross national product on health care is a pointless gesture. Yet this conclusion is avoided once a clear distinction is made between objective needs and subjective preferences. We have seen that the fact that a patient wants, or a clinician prefers to provide, treatments of a certain kind are of no moral consequence in themselves. There should be evidence that patients are obviously disabled by their unmet needs and that the proposed treatments are likely to work effectively to reduce their disabilities. Only under such circumstances, can increased expenditure be morally justified.

There is every reason to believe, for example, that if Britain spent roughly the same percentage of gross national product as many other countries in the European Union on the satisfaction of the objective need for health care, a much higher percentage of disability than at present could be reduced or eliminated.⁴⁶ There can be no stronger moral argument for increasing spending on health care than this. The fact that some objective need might still continue to be unmet or some inefficiency might still remain in the system of healthcare delivery does nothing to reduce the force of this argument.

There are two other arguments which provide superficial support for the belief in an infinite demand. The first is that as medical technology develops the ability to improve or remove disability, the more potentially unmet the need for it will be. The second is that as elderly people make up an increasing percentage of the overall population the need for health care will continue to spiral. At best, all that either argument does is to show the

undoubtedly correct thesis that demand for health care is growing and that we must plan resource allocation to meet it.

As far as the first argument is concerned, extrapolations of future demand for increases in healthcare resources are based on evidence of past rates of growth in technological innovation and life expectancy. These are questionable – at least in the context of the developed countries. On the one hand, the development of some healthcare technologies has been neither need nor evidence based. The evolution of medical technology which is really capable of satisfying healthcare need has been accompanied by unnecessary waste on an enormous scale. Provided that steps are taken to minimise such waste, they can help to balance genuine increases in need to which effective innovation will lead.⁴⁷

The second argument states that given the general increase in life expectancy, spending on health care for elderly people will obviously continue to grow. However, its rate of growth can be reduced by more accurate needs assessment; by more effective prevention through integrated primary, secondary, and community care; and by the general acceptance of consistent and coherent guidelines which would rule out the provision of futile and often very expensive life saving treatment.⁴⁸ There is no room for agism in morally justified rationing.

In short, more healthcare resources will be required to meet existing need and to cater for the future increases in need which will doubtless occur. However, if we focus on acute and urgent clinical needs, there is no reason to believe that these increases will be infinite. Indeed, provided that expenditure is always properly evaluated for effectiveness then the same conclusion also holds for a wide range of elective needs. Especially during the difficult transition to more evidence based clinical care, in which some ineffectiveness is inevitable, we should not lose sight of the fact that underfunding as well as inefficiency can undermine the moral foundations of centrally funded health care.

It is not the purpose of this paper to decide where extra money should come from. Debates about increased funding should not lose sight of the fact that the moral worth of any nation can be judged by the way in which its citizens respect the rights of those most vulnerable and in need.

Conclusion

In its summary of the conclusions and recommendations of its recent House of Commons report on priority setting within the NHS, the Health Committee maintains: "... we need an honest and realistic set of explicit, well understood ethical principles at national level to guide the NHS into the next century." On the same page, the committee then surprisingly claims: "There is no such thing as a correct set of priorities, or even a correct way of setting priorities."⁴⁹ This paper has rejected this second statement through developing and defending just such a set of moral principles.

Allocation of health care strictly based on criteria of cost effectiveness and local democracy is shown to be incompatible with the equal right of all people to appropriate health care. The existence of this right has been morally justified and seven principles of good practice shown to be consistent with it. Healthcare resources should be allocated:

- To meet need in proportion to its distribution within the population
- According to moral similarity based on extremity of need
- So that there is equality of access among those whose need is morally similar
- To exclude ineffective health care
- Without taking lifestyle into account
- According to rational patterns of decision making
- With the advice, but not necessarily the consent, of the public.

The practical implications of each of these principles have been outlined. The result is a model of equitable purchasing for secondary care which takes seriously the right of each person to the health care which they require to reach their potential. The ways in which this same model can be applied to other aspects of healthcare rationing – for example, more specific purchasing practices within the internal market and the distribution of resources between primary and secondary care – will be the subject of future research.

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