

WHAT IS THE GOOD OF HEALTH CARE?

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ABSTRACT

This paper sets out to discuss what precisely is meant by "benefit" when we talk of the requirement that the health care system concern itself with health gain or with maximising beneficial health care. In particular I argue that in discharging the duty to do what is most beneficial we need to choose between rival conceptions of what is meant by beneficial. One is the patient's conception of benefit and the second is the provider's or funder's conception of benefit. I argue that it is the patient's conception of benefit which is paramount and that if this is followed it commits us to a conception of patient care which must be blind to prognosis in so far as prognosis is thought to bear upon issues of prioritisation or resource allocation.

It is a commonplace that there is the strongest obligation to maximise the benefit obtained by the deployment of public resources for health care. Maximising beneficial health care is rightly perceived by both practitioners and the public, not only as the expression of proper moral and professional concern for patients and indeed for public health, but also as a dimension of political and social responsibility. Maximising beneficial health care is not only *right*, but it is also what we mean by *efficiency* in the delivery of health care.¹

The requirement that "we identify technologies that really work and may represent a beneficial improvement for society as a whole"² is often taken to be synonymous with and expressive of "the need for

¹ See for example Alan Williams, "Economics, Society and Health Care Ethics" in Raanan Gillon, ed. *Principles of Health Care Ethics*, London: John Wiley, 1994, and his "Ethics and Efficiency in the Provision of Health Care" all in J.M. Bell and Susan Mendus Eds. *Philosophy and Medical Welfare*, Cambridge: Cambridge University Press, 1988.

² From a draft document prepared by Franco Sassi, Brian-Abel Smith and Elias Mossialos for The Scientific and Technological Options Assessment unit of the European Parliament (STOA) and presented at a workshop in Brussels on 9th February 1996.

evidence based medicine".³ It is difficult to quarrel with the idea that medicine (or almost anything) should be evidence based. The crucial question however is: "what is the evidence supposed to be evidence of and what conclusions does it mandate?"

To answer such questions we need to examine just how the term 'benefit' is standardly used in assessing health care delivery and ask what exactly 'benefit' is?

WHAT IS BENEFICIAL HEALTH CARE?

Patients rationally want three⁴ things from health care. They want (1) the treatment that will give them maximum life expectancy coupled with (2) the best quality of that life, and (3) naturally they want the best possible opportunity or chance of getting the combination of quantity and quality of life available to them.⁵ So rational patients, in a free market with unlimited resources to purchase for themselves, will select the institution, the personnel and the therapy that will give them the best possible chance of achieving the longest and best quality of life that money can buy.

What's true of patients has also been true of purchasers and to a lesser extent, providers. Just as patients want the best treatments, (that is the treatments which offer the best chance of the best combination of quality and quantity of life) so purchasers, and often providers, naturally tend to want the best patients, that is the patients who have the best chance of the longest and best quality of remission.

There are many different sorts of providers and purchasers, and different levels of provision, and there is often no clear division between them. There are the health carers (doctors, nurses, paramedics etc.) and other providers who are not "hands on" carers; managers at various levels for example. Most of these will not also be purchasers, but some will. In the United Kingdom, for example, many general practitioners will be "fund holders" who will purchase services for their patients from other providers. Despite these complications I will follow recent precedent and call all those providing health care services to patients "providers" even if they are also purchasers.⁶ Then there are the funders of health care provision. These funders range from general managers of hospitals to

³ Ibid. p8.

⁴ Though not necessarily only these three of course.

⁵ While patients want the highest benefit from treatment they can of course only demand "the highest *expected* benefit".

⁶ Patients are of course also often purchasers, whether purchasing private health care for themselves, paying prescription charges for otherwise publicly funded services or purchasing for themselves or a relative services like long-stay geriatric care.

directors of health regions or of the companies which manage hospitals or hospital groups, to ministers and governments. If we were still following recent precedent we would call these "purchasers". However, many patients are also purchasers and I will therefore break with the purchaser/provider terminology and call those who fund or purchase health care on behalf of the general public⁷ "funders". It is difficult to attribute wants or desires in any straightforward way to many of these. Individual health carers often want to be successful, they want to succeed in helping patients. They also often want and seek the challenge of difficult or even seemingly hopeless cases. Equally some hospitals or institutions are also 'centres of excellence' and have specialised in dealing with the hardest cases and in pushing back the frontiers of knowledge and therapy.

I believe that the pressure exerted by the call for 'evidence based medicine' is, at all levels, pressure to select according to outcome. Now this is not of course outcome for the individual patient, but outcome for patients generally or for the health care system. At the level of the individual patient there is seldom disagreement. The patient, as we have noted, wants the best combination of expected quantity and quality of life from treatment, and it is accepted that it is generally unethical to offer less than optimal treatment in this sense.⁸ The crucial question, and the one which concerns us now is not: which treatment to give to a patient, but which patients are to be selected for treatment? In this context, the question that evidence based medicine asks is: what does the evidence tell us about who we should prioritise and who we should treat? This is a question largely directed to that class of funders who distribute or allocate resources, and it is these people or corporations that I shall henceforth mean when I use the term "funders".⁹

Now it is of course natural for providers and funders to want the best patients, just as it is natural for patients to want the best treatments. For one thing, providers and funders who can boast the best survival rates at the best quality of life will be more appealing to patients looking for the best combination of institution and personnel for their treatment. They will also look more impressive to other donors or service funders, such as governments or health insurers. Providers and funders who can do this not only look most efficient,

⁷ As opposed on behalf of to themselves, family or friends.

⁸ Even here the waters are somewhat muddy. There may be conflicting evidence as to which the best treatment is and also there may be reasonable cost constraints. Should a costly therapy be offered to improve a patient's chances of complete remission from say 50% to 55%? Patients usually want any improvement in their chances however small. Providers and purchasers often taken a different view.

⁹ I shall assume that corporate individuals can have perspectives and preferences.

they are likely to be the most popular: just the recipe for success that every provider and funder wants. However, this syndrome has built into it what we might call "Bob's Logic". The eighteenth century hero of Sheridan's play,¹⁰ Squire Bob Acres, facing a duel with his rival, but wishing above all to come out of it safely, wished the duel to be conducted in a way calculated to make his objectives the most likely of success. Discussing the circumstances with his second, the redoubtable duellist Sir Lucius O'Trigger, he reasoned, with impeccable logic given his measure of a successful outcome, that the duel would be best conducted if the protagonists were a good distance apart: "I tell you, Sir Lucius, the farther he is off, the cooler I shall take my aim". Sir Lucius, who has a different conception of the purpose and point of duelling, scornfully responds: "Faith? then I suppose you would aim at him best of all if he is out of sight!". Bob's logic leads funders to prefer those patients who are the most healthy and the least in need of treatment.

There is an obvious incompatibility between what patients rationally want in providers and funders and what providers and funders rationally want in patients. Whereas patients want the best chance of the best *for themselves*; providers and funders want something rather different. It is probably true that providers for example do share the ethic and the interests of patients to the extent that once they have taken on a patient, they do want and strive to do the best for that patient. However there are two obvious constraints for providers. The first is that they often want to be selective in the patients they take on, and accept for preference the patients who are likely to do well in their terms, that is last longest and recover best. Moreover, having accepted a patient they may still want to select between patients *of theirs* to achieve the same end. Patients, of course, want to be accepted without question or qualification,¹¹ and once accepted, want the best treatment *for themselves*, not the best treatment for the providers, nor the patient body as a whole, nor for society.

It does not follow from the fact that as a patient I want the best chance of the best quantity and quality of life, that I have a moral obligation to defer to patients with a better prognosis than myself, nor does it follow that providers ought to select patients on this basis, nor that doing so is dictated either by deference to patient choice or by justice.

I have argued at length elsewhere,¹² that justice does not require

¹⁰ Sheridan, *The Rivals* Act V Scene III. Oxford University Press, 1968. The play was first performed in 1775.

¹¹ In at least two senses of 'qualification'.

¹² And for over a decade now, see John Harris, "QALYfying The Value of Life", *Journal of Medical Ethics*, September, 1987, 117-123, and also "Double Jeopardy and the Veil of Ignorance" in *The Journal of Medical Ethics*, July 1995.

that we¹³ prioritise patients either on the basis of life expectancy or quality of life, and I will not now repeat those arguments. I want here to examine one aspect of what is commonly meant by "maximising benefit" in this context, namely choosing to prioritise the care of patients who have the best chance of benefitting from treatment.

Although all three things that patients want from health care are part of their prognosis, I shall, for present purposes, refer to a patient's prognosis as their *chance or opportunity* of being able to benefit from treatment and exclude the dimension of a prognosis which has to do with the degree of benefit they can obtain. I am interested, then, in a patient's *chance* of their treatment yielding *some benefit* and I shall further assume that the chance we are talking of is always that of obtaining the maximum degree of benefit available to that particular patient — the maximum remission in terms of length and quality.¹⁴ I shall assume that it is reasonable to express such *chances* as percentages.

The question this paper is going to address then is: ought practitioners and other health care providers, to prioritise patients on the basis of their prognosis, on the basis of their chances of benefitting from health care, and should funders distribute the resources available for health care in the same way? Should the patient with a ninety per cent chance of recovery always¹⁵ be preferred to the patient with a forty per cent chance, if they are in competition for resources for health care?

THE DUTY TO DO WHAT IS MOST BENEFICIAL

The answer to our question turns on choosing between rival conceptions of what is meant by 'beneficial'. For the patient, 'beneficial' means that which will benefit her. The provider and the funder, on the other hand, tend to think of benefit in terms of the size of health improvements, bigger naturally seeming better.¹⁶

Suppose you and I are both patients and rival claimants for treatment. Suppose you have a good chance of a large benefit (long

¹³ "We" here of course means "society" in its public policy on access to care. See also John Harris, *The Value of Life*, Routledge, 1985. and also Harris 1987 (note 12 above).

¹⁴ Of course there are chances within chances and a patient's prognosis may be that she has a certain percentage chance of one outcome and another of a better outcome and still another of a different outcome and so on.

¹⁵ Or even often?

¹⁶ For other thoughts about what "doing the most good" in health care might mean see: John Broome, "Good, fairness and QALYs". Michael Lockwood, "Quality of life and resource allocation" and Alan Williams, "Ethics and Efficiency in the Provision of Health Care" all in J.M. Bell and Susan Mendus, eds. *Philosophy and Medical Welfare*, Cambridge University Press, Cambridge 1988. A recent example occurs in the Report of the Royal College of Physicians, *Setting priorities in the NHS*, September 1995, where they define "need" as "capacity to benefit", the implication being the greater the possible benefit the greater the need thus making it impossible, by definition, to have a great need for a small benefit or a weak need for a great benefit.

remission of good quality of life) and I have a small chance of a small benefit (short remission with poor quality of life). For each of us treatment will offer a better outcome than non-treatment and we both want our chance of benefit. Is it obvious which of us should get priority?

THE PROVIDER'S AND FUNDER'S CONCEPTION OF THE GOOD

There is little doubt that most clinicians most of the time think that their moral obligation is to do the "most good" for their patients. They usually think that this means not only never neglecting those with the best chances of recovery, and where necessary prioritising them,¹⁷ but also and more generally, prioritising patients with the "better prognosis". They are also, of course, concerned with 'spread' — they want to maximise the number of people they can benefit by treatment. However, this conception of what it means to do the most good decidedly embodies a provider's or funder's perspective. Moreover, it embodies a conception of the point and purpose of health care, and hence the good to be done by health care provision, which, while coherent and consistent, is only one such view, and one with important drawbacks. I shall suggest that this 'provider's and funder's conception of the good' denies the legitimate claims of patients and is, in an important sense, unjust.

Before doing so however, just a few more words about what I have called "the provider's and funder's conception of the good" of health care.

A surgeon is surveying his operating list. He has twenty six patients on it and this week he can get through about half of them. However they have radically different prognoses. All need surgery in the next two or three weeks if they are to have any chance of long term survival. If he operates on A–M, probably all procedures will be successful and at the end of the week he will have thirteen patients well on the way to recovery. If he operates on N–Z however, it is likely that only half the patients will survive, although all have some chance of benefit. At the end of the week he may only have six or seven patients left. The surgeon may reason that he will "do more good" if he has thirteen patients alive at the end of the week rather than six. Is this right?¹⁸

¹⁷ If a clinician is confident that she can treat her entire 'list' of patients satisfactorily then she has no need to think about prioritising.

¹⁸ I have grossly simplified the example of course. I am assuming that all will survive until the end of his next operating session if not treated this week. However there are still many strategies open to the surgeon (including mixed strategies) and many ways of prioritizing the list including "first come first served".

The provider's and funder's conception of the good of health care is essentially a 'public health' conception.¹⁹ It sees the business of health care as maintaining and improving public health or the health of the community. On this conception, health, and the good of promoting health, is a public good and something quite impartial and objective. On this view "a year of healthy life is of equal value no matter who gets it" and the point of health care is to maximise the number of healthy life years the world contains. This is the ethic behind the notorious QALY and I have discussed its defects at length elsewhere,²⁰ but we should remember their salient features because they apply to our present dilemma.

This conception of the good of health care is essentially maximising. It is as much served by a policy of increasing the population of the world as it is by improving the health and life expectancy of the existing population. But even if we confine the scope of 'beneficial effects' to lives in being, there are serious difficulties. The provider's and funder's conception of the good of health care is also inevitably (though not essentially) age biased, in that treating the young successfully inevitably generates more healthy life years after treatment than does treating the old. This provider's conception of the good can also make some claims to justice and impartiality. These claims have two dimensions. By treating the maximization of units of healthy life-time as the objective of health care, rather than concentrating on the health needs and wants of individual people whatever their expectation of quality adjusted lifetime,²¹ this conception claims an impartiality of sorts. However, it is an impartiality that is partial between persons and impartial only between units of lifetime abstractly conceived.²² Secondly it embodies a faith in the justice of a sort of natural lottery of health that is unwarranted. On this view fate has impartially allotted chances of sickness and health and chances of recovery from illness, and doctors work within this given framework. So that if someone is lucky enough to be born healthy, then this in itself is evidence of a just, or at least not unjust, distribution of opportunities.²³ On this view, in prioritising

¹⁹ This is true of the provider's and funder's conception of health care as I have characterised it. While there doubtless are both providers and funders who have different conceptions, their star is not currently in the ascendant, and until their views take centre stage we can ignore them and in so far as their conceptions cohere with the patient's conception of the good they are of course given full expression here.

²⁰ See my "Rationing Life", *The Health and Social Service Journal*, June 1986, "QALYfying the Value of Life", *Journal of Medical Ethics*, September. 1987. 117-123.

²¹ Provided of course that they have some lifetime that is worthwhile to themselves to gain from treatment.

²² See note 12 above.

²³ See Hillel Steiner, *An Essay on Rights*, Oxford: Blackwell Publishers, 1994. Chapters 5, 7 and 8.

those with the best prognosis doctors are merely administering a given distribution of life chances, moreover it is one which favours both public health and the provider's perspective. Since, depending on your 'world view', this distribution has been allotted either randomly by fate, or purposively by one of the Gods, or by natural selection, there is an in-built point, purpose or at least impartiality in the distribution which will not obviously be improved upon by the interference of the health care system.

There is much to be said for this view and I will not attempt a thoroughgoing critique of it here. However it makes some large and unwarranted assumptions and it is as well to be aware of some of its less attractive features.

Two features in particular demand attention. The first is the assumption of the fairness or impartiality of a natural distribution of health. The second is the implicit assumption of the injustice of interfering with such a distribution.

The fairness of a natural distribution of health depends upon the idea that we are all born equal, with equal chances of living to a ripe old age. Illness and accident are, on this view, "bolts from the blue" which might equally affect anyone. We of course know that assumption to be false. Our life and health chances are rigged in advance by our genetic constitution and thereafter affected by a myriad of factors including environment, socio-economic status, occupation, education, and personal and public responsibility for health.²⁴ The genetic part of this complex equation is particularly important because it means that certain individuals and groups are disadvantaged from conception²⁵ and will pass on this disadvantage to their descendants. They are congenitally disadvantaged.

Even if the initial distribution of health were just or impartial, it would not follow that we should not disturb this distribution.²⁶ Indeed every health care provider believes that we should disturb the natural distribution of health or they would have nothing to do. So the question is, if it is right to treat and attempt to cure the sick and thus interfere with the natural lottery of health, why is it right to prioritise the treatment of those with the best prognosis? The answer to this question cannot be that it is right to attempt to maintain a natural distribution of health that we have already conceded the

²⁴ This point is enlarged upon in Margaret Brazier and John Harris "Public Health and Private Lives" in *The Medical Law Review* in press. See also: John Harris and Søren Holm "Is there a moral obligation not to infect others?" in *The British Medical Journal* 7014 volume 311, 1995. 1215–1218.

²⁵ Or possibly from long before. See my *Wonderwoman and Superman*, Oxford: Oxford University Press, 1992. Chapter 3.

²⁶ See Hillel Steiner, *An Essay on Rights*, Oxford: Blackwell Publishers, 1994. Especially Chapters 5, 6 and 7.

rightness of overturning!

The two likeliest ways of justifying the provider's perspective are either in terms of the moral importance of the good that it delivers, or in terms of the consent to such a perspective of all those affected. Before addressing these possible justifications let's look at an alternative perspective, which I shall call, I hope not tendentiously, "the patient's perspective".

THE PATIENT'S PERSPECTIVE OF THE GOOD

Let's start by outlining this alternative conception of what health care provision is for, what ends it serves, in short what good it is. I have suggested that each of us rationally wants for ourselves the best chance we can have of the goods that the health care system can deliver, even if that is a very small chance indeed. Of course this desire will be tempered by the costs to us of delivering such a chance; perhaps in terms of the pain and discomfort of the treatment and the quality of life thereafter. It may also be tempered by the costs to others. Would it be better for those I love if I do not survive in such and such a condition, or would my survival really be worth it if it costs someone else the chance of a better life? My point is not that these are not real considerations for any patient or potential patient, but rather that they are his or her decisions to take. If the patient is entitled to a chance equal to that of any other patient of obtaining beneficial treatment, then it must be up to the patient herself to choose whether or not to forego her own chance of treatment, either in her own interests or in the interests of others or society.

I am treating the entitlement to an equal chance of beneficial health care as a claim, a claim legitimised by a particular theory of equality. That is why only the claimant herself can choose to relinquish her claim. While it may be true that we cannot hope to meet the health care needs of everyone, we can see that everyone's claim to have their health care needs met is given equal weight. Of course this will involve assessing when needs are equally urgent or important, not an easy task, and it does not of course preclude the possibility of deciding that claims cannot be met because they are not equally urgent or equally important. Nor does it preclude denying claims because some fair procedure has chosen between claims in circumstances in which not all claims can be met.²⁷

Clearly, where one person's health care needs are in competition with the equal needs of someone else, then some fair way of choosing between the two rival claimants must be found. A lottery is of course

²⁷ This paper is of course about the question of whether or not a poor prognosis is the sort of consideration that weakens claims to have health care needs met.

very often one such way, another is sometimes a properly conducted waiting list. Where moral claims are equal and not all such claims can be met, there is, by hypothesis, no reason to prefer one claim to another. A method of selection which does not involve a preference must therefore be used. A lottery or the tossing of a coin are methods which allot equal chances to all participants and therefore involve no illicit preference. Of course we must be sure that where lotteries are used this does not simply amount to subjecting the outcome to chance a second and gratuitous time and we must not use random methods whether there is a good moral reason to prefer one candidate to another.²⁸

There are however two other good reasons for accepting that it is up to the claimant to choose whether or not to relinquish this particular sort of legitimate claim. Firstly, because once we permit others to decide who will live and who will die on the basis of the overall good thereby achieved, there is no reason to stop short and confine such decisions to so-called health benefits. I may well rationally (and rightly) believe that compared to the value of your existence, my existence is worthless and that the world would be infinitely the better for your continued survival than for mine. I may even choose to act on this belief and cede my place to you.²⁹ Once we argue, however, that others may rightly make this calculation, and act upon it, we have taken a step that I suggest is unacceptable. Unacceptable not because it is implausible to believe that such calculations can rationally be made, nor because it could not be true that the world would be a better place if certain people survived while others did not; but for two decisive and complementary reasons. They are first, that it is very unlikely that in the long term the world would be better if we routinely selected among people according to some conception of the public interest and institutionalised the power to do so. The second is that it is totally incompatible with a central tenet of both our moral and our political theory. That tenet is that each person matters equally, both morally and politically, and hence justice requires that each be accorded the same concern, respect and

²⁸ I have defended the use of lotteries elsewhere. A similar defence has also recently been mounted by John Broome, although he would almost certainly reject the conclusions and the assumptions of this paper. See John Broome, "Fairness", *Proceedings of the Aristotelian Society* 91 (199–1991) pp. 87–102. On the question of subjecting outcomes to chance gratuitously see Derek Parfit, "Innumerate ethics", *Philosophy and Public Affairs*, Vol 7 No 4 1978, and on reasons for sometimes preferring random selection see John Harris, "The Survival Lottery" in *Philosophy*, January 1975. 81–88. and "EQALYty" in Peter Byrne, ed. *Health, Rights and Resources*, King Edward's Hospital Fund for London 1988. More recently, John Harris, "Double Jeopardy and the Veil of Ignorance", *The Journal of Medical Ethics* July 1995 and "Would Aristotle have played Russian Roulette?", *The Journal of Medical Ethics*, in press. More generally, Barbara Goodwin *Justice by Lottery*, Hemel Hempstead: Harvester, Wheatsheaf, 1992.

²⁹ "You" may be my child, my parent, my mentor, my hero, my leader or literally anyone.

protection as is accorded to any and that society treats all impartially.³⁰

The second reason why only the patient herself can choose to forego her chance of treatment is that if each person matters equally and hence has an equal right to the care and consideration of the health care system of the society of which they are a member, then, arguably, one of the things that follows from this is that each person has the right to have their chance of benefit given equal weight with that of others, whatever that chance may be. If you have a large chance of a large remission and I have a small chance of a small remission, then to treat us as equals, on one plausible conception of equality, is to give us each an equal opportunity of having what is, in effect, our only chance of our life continuing, whatever chance that is. For if those with the better chance are always to be preferred this inevitably creates an aristocracy of the fortunate. Now this might be consistent with equal justice or rights for citizens, if fortune has no favourites. However, it is not only 'common sense' that knows that some people are born lucky.

Interestingly, recent advances in genetics and in particular in genome analysis have confirmed common sense and made this point even more obvious and even more urgent. We have always known that individuals are individual, and that each persons' life chances, whether allotted by nature, nurture or circumstances are inevitably and necessarily different. What has changed is our capacity to acquire foreknowledge of what these chances are, or are likely to be. For not only does each illness or injury have its own prognosis, but each individual, from the identification of her genome, will have her own prognosis. And increasingly these prognoses will be known, actually or potentially.

If we are to allot opportunities for health care according to prognosis it would be irrational and possibly self-defeating to confine that prognosis to a particular illness or injury. For the genes may tell us that although the chances of treatment for this condition are good, the ultimate chances of survival of this individual are poor.

Consistency and rigour in prioritising on the basis of prognosis will imply massive information gathering, storage, retrieval and availability on a whole range of features which, additionally to genome analysis, will include lifestyle, environment, personal preferences, sexuality, gender, 'compliance' and many other features.

Even if we felt there were good moral and political reasons to prioritise on the basis of prognosis, the practical problems of gathering

³⁰ While there are many theories of justice and many attempts at justifying its basic tenets, all (well all that matter) are alike in upholding some version of this principle.

all the necessary information, and the political problems of permitting its gathering, storage and retrieval should give us pause.

If we are to distribute access to health care in the light of prognosis, then health professionals and administrators need to have immediate access to the relevant information at the point of need or claim. To take just one example, in order to prioritise care, the casualty officer in the accident and emergency department must know precisely the general outlook for every casualty she sees, and she must know it immediately. This is not just the prognosis derived from their presenting condition, but that which would be indicated by analysis of their genome (when genome analysis becomes readily available), general health state, details of life style etc. If this were not possible, or were possible and not achieved, huge injustices would occur and reasonable questions would arise as to the legitimacy of making those on whom information happened to be available bear the whole brunt of our attempts to redistribute health care according to this particular conception of a meritocracy of health.

Of course there will be cases where fairly complete information on a particular individual may just happen to be to hand. The justice of acting upon it in these cases would share the justice of a tax system which taxed only those on whom tax relevant information happened to be available, but which had no systematic gathering of information (tax returns etc.) and no investigative, checking or appeals procedures.³¹ Moreover a health care system which penalised people on the basis of information about their general health state and life expectancy, would almost certainly discourage the divulging of health relevant information and would therefore tend to undermine the public health considerations which are often thought to be part of its attraction.

Even if, *per impossibile*, such complete information could be made available there remains the question of whether it would be desirable for other reasons, (which would include privacy and the dangers of abuse), to support such comprehensive information gathering and monitoring.

Before moving on to the problems with the justification of the provider's perspective, there are two further problems with the patient's perspective that need to be addressed. The first is the problem of resource guzzlers, the second has to do with maximization of people treated or lives saved.

³¹ I discuss this point more extensively in my: "Could we hold people responsible for their own adverse health?" in *The Journal of Contemporary Health Law and Policy* Vol. 1 1996. 100-106.

RESOURCE GUZZLERS

It is important to be clear that I am not claiming that each person is entitled to be given their chance of treatment, to have their needs met, whatever this costs others, nor however many others are adversely affected. So that, for example, treating someone with very severe disabilities who can be given small improvement only at vast expense, may involve leaving numbers of others without health care because of the drain on resources that this individual represents. If each person is entitled to have their needs weighed equally with those of others, then wherever giving treatment to *x* means that *y* is denied treatment, this principle is violated, that is, unless some method that gives equal weight to the claims of each is found. However, this is also a problem for those who see the obligation to maximise benefit in terms of treating those who have a good prognosis. For there is no general correlation between chance of benefit and cost of treatment. Those with a good prognosis are as likely to be resource guzzlers as those with a poor prognosis. To re-phrase the example just considered, substituting for the word "small" the word "large", the same point is made: treating someone with very severe disabilities who can be given *large* improvement only at vast expense, may involve leaving numbers of others without health care because of the drain on resources that this individual represents.

This leaves, both for those who believe in prioritising by prognosis and for those who don't, the problem of how to deal justly with those who are especially expensive to treat. This is a large problem and one beyond the scope of this paper. Suffice it to note that it is not obvious that those who are expensive to treat, whether this treatment gives large or small remission, are thereby beyond the pale of our moral concern.³²

MAXIMISING LIVES SAVED

It is not only a tenet of consequentialist philosophy³³ but also arguably one of the requirements of rational morality³⁴ that if each person counts for one and none for more than one, then two count for two and so on. This entails a policy of maximising lives saved. For example, if there are two stricken ships, one with thirteen live crew and one with six, and the lifeboat can only reach one before all are

³² I have said something about this problem in my "More and Better Justice" in Bell and Mendus, eds. 1988 see note 1 above.

³³ See for example Jonathan Glover, *Causing Death and Saving Lives*, Harmondsworth: Penguin, 1977, and John Harris, *Violence and Responsibility*, London: Routledge and Kegan Paul, 1980.

³⁴ See Derek Parfit, "Innumerate Ethics", *Philosophy and Public Affairs*, Vol 7 No 4 1978.

drowned, it should rescue the crew of thirteen rather than that of six.

Now, if we go back to our surgeon's list of twenty six patients, it looks as though we are faced with the same dilemma. If he operates on A–M he will rescue thirteen, if on N–Z, only six; so he should prioritise the group with the best prognosis.

However there is an obvious ambiguity in the Benthamite maxim "each is to count for one and none for more than one". A person counts, not only and not principally, as a life in being, a "life in the bank" so to speak. A person counts as, and because she is, a person. Her life matters, not because it is *a life*, but because it is *someone's life*, because her life is an enterprise in which she has, and takes, an interest. *A person's counting is not the same as counting persons.*³⁵ The fact that each person *counts* — matters morally, is recognised when their moral claims are respected, and as I have argued here, this happens when their chances of continued life are given equal weight with the, necessarily different, chances of anyone else.

So the maximising requirement of consequentialism is met when the claims to chances of continued life, of equal numbers of people, are given equal respect.

There is also a problem about how to individuate claims.³⁶ Einer Elhauge, for example, has argued:

Suppose treating one person's illness will save his life for now, but we can predict that in a year he will require more life-saving treatment to live another year, and the year after that further life-saving treatment to live a third year. On a pure lives-saved test, this would count as saving three lives. Treating this person three times would thus be preferred over using the same resources to give two persons each a single treatment that would extend each of their lives by two years. But this furthers neither the maximization nor the just distribution of utility.³⁷

Elhauge's concluding comment here is surely right, but I am far from persuaded that even on "a pure lives saved test, this would count as saving three lives". All lives require constant saving of this sort. Every necessary meal is a life-saving treatment. We do not refuse someone a meal today because he will need another tomorrow, and so on. A claim to treatment that needs repeating periodically, or is ongoing, (like insulin for diabetes or alopurinol for gout, or a heart pace-maker that works constantly) is like a claim to food or shelter.

³⁵ Or, rather it matter *when* the counting of persons is done, before the surgeon begins operating for example, or in anticipation of the situation when he has finished.

³⁶ See Daniel Callahan, *What Kind of Life: The Limits of Medical Progress*, 1990. 132–134.

³⁷ Einer Elhauge, "Allocating Health Care Morally" in the *California Law Review* Vol 82, No 6, December 1994. 1506.

To say that the person who needs daily treatment has his life saved three hundred and sixty five times a year is no more illuminating than to say the same of the person who needs food every day. The charitable 'soup kitchen' on this view, arguably saves more lives per treatment than the local hospital.³⁸ For this reason, in so far as it is known that repeated treatments will be necessary, they count not as repeatedly saving lives, but as saving one life repeatedly. In so far as further treatments are not foreseen of course, no account can be taken of them.

We must now return to the two issues left unresolved. We recorded that the provider's perspective must be justified in terms of the moral importance of the good that it delivers, or in terms of the consent to such a perspective of all those affected. We have seen that the good that the provider's perspective delivers is far from unproblematic, and that it is at odds with central moral and political tenets of our society. But what if it's what people want?

DO PATIENTS WANT THE PROVIDER'S PERSPECTIVE?

Of course if everybody actually wants it there's no problem. However, anything less than universal actual agreement does pose problems. The first, which I shall record now but not attempt to resolve, is one of the problems of democracy. One sort of consent to adopting what I have called the provider's perspective, could be provided by the ballot box, either in terms of a referendum, or, in terms of an actual or claimed mandate to implement it following a national (or regional) election. We should note that it does not follow from the fact that the majority want it, or that the winning political party has promised it or wants to deliver it, that it is either permissible or ethical. Prior always to the question of what the people want is the question of what they ought to want. But even leaving aside the 'moral veto' on action, there is the question of how democracy and democratic decision making is to be understood.

It is not part of any existing (nor any respectable) theory of democracy that what the people want they are entitled to have. Even if it was decided emphatically in a referendum, or even if the ruling party announced prior to an election that if re-elected it would, say, deny health care to Jews or Blacks, or give such groups automatic low priority in health care, it would not follow that it would be right to implement such a policy. Nor would it be a defensible to say that such a policy was justified because it had the consent of the populace. More

³⁸ Although hospital patients are also given food, the hypothesis here is that those catered for by the soup kitchen would not otherwise have been fed, whereas the hospital patients (or most of them) would have eaten at home if not in hospital.

likely of course and less extreme is that treatment of stigmatising illness like H.I.V. would be given low priority, at least so long as it remained confined to so-called 'at risk' groups.

If we can be clear that people are not morally entitled to have everything they want, then we are free to first assess the moral arguments for and against prioritising by prognosis, rather than trying to pre-empt those arguments by discovering what people want. However, I shall not attempt to argue this point further. At least if it were to be the subject of a referendum, or the platform of a political party, it would (one hopes) be thoroughly debated; and that perhaps would be the occasion to press the point to a conclusion. However, in health care a much more insidious form of 'consent' is often appealed to, and one which apparently neither requires consistency with the will of those whose consent is alleged, nor with the will of the people democratically expressed. It is a constructed, assumed, fictional or theoretical consent to which appeal is made and this we should now briefly examine.

FICTITIOUS CONSENT

There are a number of instances in health care where the patient's consent is appealed to and used, where her actual consent is unobtainable. These are circumstances in which the patient is either unconscious or unable to process the information required to give a valid consent, or is temporarily or permanently lacking the relevant capacity to consent. In such cases terms like "proxy consent", "substituted judgement", "presumed consent" or even "retrospective consent" are used to justify treating a patient. However, not only are these all fictions, but they totally fail as justifications for treating the patient in particular ways.

The reason why it is right to do what presumed consent or substituted judgement seems to suggest in these cases, is simply because treating the patient in the proposed ways is in his best interests and to fail to treat him would be deliberately to harm him. It is the principle that we should do no harm that justifies treating the patient in particular ways. The justification for treatment is not that the patient did consent (which he didn't) nor that he would have, nor that it is safe to presume that he would have, nor that he will when he regains consciousness or competence, but simply that it is the right thing to do, and it is right precisely *because* it is in his best interests. That it is the "best interests" test that is operative is shown by the fact that we do not presume consent to things that are not in the patient's best interests, even where it is clear that he would have consented. We do not infuse known heavy smokers with cigarette smoke while they

are unconscious even where it is reasonable to suppose they would have consented. Nor do we usually give patients in hospital alcoholic beverages or cigarettes, even when they specifically request them.

Of course we do not give beneficial treatments to patients who have refused them, say by advanced directive, because to do so would constitute an assault and a violation of their will. But it is not a violation of someone's will nor an assault to give a treatment they have not refused, the withholding of which would constitute an injury. And the reason it is not a violation, is not because they have consented in some notional or fictional sense, but because it is the right thing to do. And the reason it is the right thing to do is that to fail or omit to do it would injure the patient. It is the infliction of that injury, by act or omission,³⁹ that would constitute the violation or assault. In short, if someone has not indicated clearly that it would be a violation of their will to refrain from injuring them, then we should not injure them.

It is widely held that not only should we not harm people who do not want to be harmed, we also should not harm even those who do want to be harmed, and that this is sufficient reason not to withhold treatment the absence of which would harm. This raises the question of the right to harm oneself. What of the shopkeeper who sells cigarettes?⁴⁰ Two points need to be made here. The first is that the shopkeeper, as we have here suggested, has sufficient moral reason not to sell cigarettes and would not be wrong to refuse to do so regardless of the preferences of his customers. Secondly, the delivery of health care is not straightforwardly like the marketplace, and health professionals have often refused to give 'treatments' they regard as mutilating for example, regardless of the expressed preferences of patients for such treatments.

Not only do we not need the concept of implied or assumed or proxy consent, because it literally does no work; we do not need it because it misleads us as to the character and meaning of our actions. Jeremy Bentham was rightly scathing of fictional consents. He remarked:

In English law, fiction is a syphilis, which runs in every vein, and carries into every part of the system the principle of rottenness . . . Fiction of use to justice? Exactly as swindling is to trade . . . It affords presumptive and conclusive evidence of moral turpitude in those by whom it was invented and first employed.⁴¹

³⁹ I argued against the relevance of the moral distinction between acts and omissions in my *Violence and Responsibility*, Routledge & Kegan Paul 1980. This irrelevance has recently and belatedly been recognised by the highest court in the United Kingdom. See Lord Mustill's judgement in [*Airedale NHS Trust v. Bland*, [1993] 1 All England Rep. 821 H.L.]

⁴⁰ Raanan Gillon suggested this example to me.

⁴¹ Quoted in Steiner (1994) page 258.

EX ANTE CONSENT

Many discussions of consent in contemporary bioethics rely on arguments produced over twenty years ago by John Rawls⁴² to provide a theoretical justification for relying on mythical *ex ante* consent.⁴³ The structure of the argument is familiar but I will provide a skeleton reminder so that it is clear at least how this author understands the argument. The argument turns on what rational egoists, choosing a policy of resource allocation for health care, would choose for themselves from behind a veil of ignorance which concealed from them their own future health state and health care needs. Whatever they would obviously choose they may, so the argument goes, be safely presumed to have consented to.

Einer Elhauge, in an excellent and comprehensive recent review of the ethics of health care allocation⁴⁴ re-presents this argument, and while noting many difficulties, gives it cautious approval.⁴⁵ It is worth quoting Elhauge because he repeats a mistake made by many in the interpretation of the features which give Rawls' framework such plausibility as it has.

Talking of "John Rawls, and others who go behind some variation of a veil of ignorance" Elhauge remarks:

One need merely conclude that behind this veil (or suspension of health knowledge) we would agree to forgo care in the event we are born with certain difficult-to-treat conditions because the expected benefits of that care are exceeded by the expected costs in resources that could instead service our needs in the far more likely event that we are born without those conditions.⁴⁶

Elhauge asks: "if the consent is hypothetical, why shouldn't we go back before birth and even conception, at least in the sense of excluding knowledge of health problems acquired after that point?" and comments that Rawls effectively does go back to this point.⁴⁷

There are very good reasons why a veil of ignorance model will not allow regression before conception at least where such regression means that the veil of ignorance not only conceals features of identity,

⁴² John Rawls, *A Theory of Justice*, Cambridge Mass: Harvard University Press, 1971.

⁴³ See for example Paul Menzel, *Strong Medicine: The Ethical Rationing of Health Care*, New York: Oxford University Press, 1990, and Peter Singer, John McKie, Helga Kuhse, and Jeff Richardson. "Double Jeopardy and the use of QALYs in Health Care Allocation" and John Harris "Double Jeopardy and the Veil of Ignorance" both in *The Journal of Medical Ethics*, July 1995. This paper outlines arguments similar to those developed here on the scope of conclusions which can be drawn from Rawls' veil of ignorance.

⁴⁴ Elhauge 1994. 1449–1544.

⁴⁵ Elhauge 1994. 1540.

⁴⁶ Elhauge 1994. 1536.

⁴⁷ Elhauge 1994. 1536.

but actually *precedes* identity.⁴⁸ There are a number of reasons for this. In the first place, before someone has an identity there is literally no one whose consent can even be presumed. The point is that the plausibility of the veil of ignorance device is that it imagines rational egoists deciding *for themselves* under conditions of ignorance. By hypothesis they want to further *their own* interests, but don't know how to do so because they don't know what *their* interests are. The safety of implying consent relies upon an appeal to self interest. Where there's no self there can be no self interest.

Choosing what it would be acceptable to do to myself is quite different from choosing what might be acceptably done to others. Where the presumed consent precedes identity, one is effectively deciding, not what should happen to oneself, nor to existing people, but rather one is deciding what sorts of future people there should be. The difference is the same as the difference between deciding what a just policy towards existing people with disability might be and deciding (if we had the technology say) whether we ought to ensure that people be conceived without disabilities in the future.⁴⁹ There is all the difference in the world between deciding whether or not particular kinds of existing people should go on living, and deciding whether or not particular future people should be brought into being.

The plausibility of Rawls and other uses of the veil of ignorance, is that those behind it have a *personal and prudential ex ante reason*⁵⁰ for accepting certain outcomes, not an *altruistic* reason. As Elhauge suggests, we have a rational and prudential motive for choosing the plan that could "service our needs in the far more likely event that we are born without those conditions". But it has to be far more likely that *we* are born in such and such a condition, otherwise we lack a motive to consent that is derivable from the veil of ignorance device.

The veil of ignorance appeals to the self interest of rational egoists. That's why Rawls stipulated that his choosers had to be both. So choosers behind the veil of ignorance have no reason to choose one distributive principle over another, *unless they have reason to believe that they themselves are more likely than not to benefit* (or at least not lose) by the choice. So that even if we know that in a given population the

⁴⁸ I have suggested that in certain circumstances identity may precede conception. But these are somewhat esoteric and are not relevant to the present discussion. See my *Wonderwoman and Superman*, Oxford: Oxford University Press, 1992. Chapter 3. I discuss related issues somewhat more briefly in my "Double Jeopardy and the Veil of Ignorance" in *The Journal of Medical Ethics*, July 1995, and in my "Would Aristotle have played Russian Roulette?", *The Journal of Medical Ethics* in press.

⁴⁹ See my "Should we attempt to eradicate disability" in *Public Understanding of Science* 4 (1995) 233-242.

⁵⁰ See my "Would Aristotle have played Russian Roulette?", in *The Journal of Medical Ethics*, in press.

incidence of a particular condition is low, we will not know, in Elhauge's words, whether "the far more likely event [will be that] we are born without those conditions" unless we know our genetic history. The percentage incidence of a condition in a population will not reveal my personal chances of succumbing unless the condition occurs completely randomly. Moreover *my* chances of succumbing to a given condition which is genetically influenced, (and it is increasingly clear that most health conditions are), will be entirely unrelated to its incidence in the population, so long as the human genome is not constructed randomly at conception, which of course it is not.

As Ronald Dworkin has effectively shown,⁵¹ where there is an independent argument for the morality or justice of a particular distribution or outcome *that* is the sufficient reason for implementing it. We do not need to resort to the veil of ignorance device. If there are such good independent arguments for excluding the care of those with difficult or expensive to treat conditions, let's see them. I have argued elsewhere that there are unlikely to be such arguments because of the instability of notions like "difficult to treat" and "expensive". Most conditions start out as both, and as knowledge is gained from *trying to treat them* and as treatments come on stream and economies of scale may be achieved, the picture usually changes. We cannot, at any rate, have personal or prudential reasons for accepting decisions that will not affect us because we do not (and will never) exist to be affected by them.

The residual reasons for accepting presumed consent are so weak as to be scarcely plausible. Elhauge himself notes that "presumed consent lacks the moral force of actual consent", but doesn't articulate what moral force is left to it. He notes, following Dworkin, that any "presumption that an individual would have consented to the denial of treatment will almost surely conflict with the individual's present views (now that she is ill) about what she would have consented to in the past".⁵² Whether or not *this* is true, it will certainly conflict with her present views about what is in her present interests!

In discussing the implausibility of enforcing antecedent interests in the name of consent, Ronald Dworkin uses an interesting illustration that is germane here. He asks us to imagine something like the following scenario. If I possess a lottery ticket which I bought for one pound, it may be in my interests antecedently to the draw, to sell the ticket to you for one hundred pounds. However once the draw has

⁵¹ See Ronald Dworkin *Taking Rights Seriously* Duckworth, London, 1977. Chapter 6.

⁵² See Ronald Dworkin, *Taking Rights Seriously* Chapter 6, for an excellent account of why enforcing what might have been in one's antecedent interests, cannot be justified on that argument alone when it is not in fact in one's actual interests.

taken place and I have won a million pounds, it cannot be just for you to force me to surrender the ticket for one hundred pounds *even if it is true that I would have consented to sell it to you for that sum had you asked me antecedently to the draw*.⁵³ So even judgements about antecedent interests which are conceded, by the relevant agent, to be entirely accurate, provide no adequate reason for enforcing decisions which are not in an agent's actual interests.

The natural lottery of health, which we reviewed above, is surely like this. Even if it were true that I would have consented to a particular distribution of health resources before I know what I need, it does not follow that it would be fair to enforce that particular distribution on me when I know it is not in my actual interests. There may, as Dworkin notes, be a plausible independent argument for the justice of such a distribution, but it cannot be based on presumptions of consent based on judgements about antecedent interests.

CONCLUSION

I have suggested that one plausible view of the point and purpose of health care requires that each patient is entitled to have his or her benefit considered as of an importance equal to the chance of any other person, however small the chance and however small the benefit, so long as there is some chance of a benefit. Of course, as we have seen, like benefits must be compared with like, life saving treatments generally preferred to life enhancing ones and so on.

The patient must of course want her chance of that benefit and continue to want it knowing the costs to herself and others of supplying it. There are no objections that I can see to patients sharing the responsibility of the amount of health resources they take, so long as they remain free to maintain their claim to equal chance of benefit. If the patient continues to want her chance of benefit when she knows the costs to others of having it, then I believe she is entitled to that equal chance and this should apply to all treatments however 'cost effective' in traditional terms. How the costs to others of supplying a particular benefit to someone are calculated and presented is of course a matter of huge controversy.⁵⁴ If this controversy cannot be resolved in a way that would make the foregoing stipulations possible to

⁵³ That is behind a veil of ignorance about the outcome of the lottery.

⁵⁴ See for example: John M. Stanley: "The Appleton Consensus: Suggested International Guidelines for Decisions to Forego Medical Treatment" in *The Journal of Medical Ethics* 129, 133 1989 and Daniel Callahan *What Kind of Life: The Limits of Medical Progress*, 1990, and Alan Williams "Priority Setting in Public and Private Health Care" in *Journal of Health Economics*, 173 1988. Margaret Brazier has made a similar point in her "Rights and Health Care" in R. Blackburn, ed. *Rights to Citizenship*, London: Mansell, 1993.

implement, perhaps this shows that the dilemmas of implementing the patient's perspective are less real than many would have us believe.

In this paper I have argued that there is an alternative perspective from which to view the requirements of a just allocation of health care resources. This perspective is one that does justice to the claims of each individual on the health care system of which they are a part, and looks at health care from the perspective of their likely wants at the time of need. We have looked in some detail at the idea of the good done or to be done by the health care system and analysed different conceptions of the point and purpose of health care. From this it emerges that what I have called 'the patient's perspective' plausibly "does as much good" on at least one defensible conception of what this phrase might mean, as its rivals. While it is true that funders and providers might legitimately wish to take into account the amount of benefit that their money and/or efforts will provide, discounted by the probability of that benefit being achieved. I have argued that there is another perspective to consider and another interpretation of what 'benefit' legitimately means.

To the patient, the benefit to be derived from the health care system is the benefit of having their needs met, and while no one is entitled to have their own needs met whatever the cost, I have argued that each is entitled to equal consideration of their needs and that needs do not vary in proportion to the chance of their being satisfied, nor for that matter in proportion to the degree to which they can be satisfied.

Most importantly, the policy enshrined in the patient's perspective is the policy patients are most likely *actually* to want for themselves, and those they care about, when facing treatment options. I have argued that conceptions of what patients should want, or would want, or might have wanted in the past, or in some mythical scenario, are either illegitimate constructs, or must give way to real and present wants. This we know even without assistance from the arguments rehearsed earlier. People are entitled to change their minds. The same reasons that people may revise their 'last will and testament' and that no defenders of the use of advanced directives or 'living wills' would prevent these being overturned by present autonomous preferences, hold good and prevent people being bound by hypothetical, presumed or constructed consents.

The conclusion to be drawn is that neither clinicians nor the health care system should prioritise by prognosis and that some fair method of distribution is required. By 'fair' is meant of course one that does not *de jure* or *de facto* treat some patients, some rival claimants for care, as more valuable or more important than others.

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