

NICE discrimination

It's not NICE to discriminate

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NICE must not say people are not worth treating

The National Institute for Health and Clinical Excellence (NICE) has proposed that drugs for the treatment of dementia be banned to National Health Service (NHS) patients on the grounds that their cost is too high and “outside the range of cost effectiveness that might be considered appropriate for the NHS”.¹

This is despite NICE’s admission that these drugs are effective in the treatment of Alzheimer’s disease and despite NICE having approved even more expensive treatments. The effect is that thousands of Alzheimer’s patients will be denied the only treatment available. It is difficult to think of this as anything but wickedness or folly or more likely both. At the same time, and with no apparent sense of irony, NICE has launched a public consultation document³ on its guidelines on social value judgments. As we shall see these guidelines are ethically illiterate as well as socially divisive.

Assuming permanently scarce resources it is clearly crucial that such healthcare resources as are available are not wasted. This point is often made in terms of cost effectiveness and it is argued, not implausibly, that to talk of cost effectiveness implies that we are able to measure just how cost effective each treatment is. To do so of course we need a standard of measurement. NICE has adopted the ubiquitous, but justly infamous QALY, the Quality Adjusted Life Year.

The QALY combines life expectancy after treatment with measures of the expected quality of that life. There are two ways in which QALYS can be used. They might be used to determine which of rival therapies to give to a particular patient or which procedure to use to treat a particular condition, in short which of two different treatments is the more cost effective, better for patients, better for society. QALYs are also used, however, to determine not which of rival treatments to give a particular patient or group of patients, but whether or not to offer any treatment at all to some patients, or whether to offer a particular treatment to some patients even when no alternatives are preferred.

In the case of the Alzheimer’s treatments it is clear that it is not the drugs that have been judged not to be cost effective when compared to rival treatments, it is the patients who are being condemned as not cost effective to society. Why are these patients not cost effective to treat? The only answer must be that they are not worth helping. If it was simply on the basis of cost alone, if we simply cannot afford these drugs, that would be one thing, but NICE has said the drugs are not cost effective in QALY terms. That means that the amount of better life expectancy they provide to these patients is not worth having for society (it is certainly worth having for the patients and those who care for them—ask any of these patients, their families, or their doctors). Why not, what would make these patients worth treating? This is the nasty and unacceptable face of both QALYs and of NICE who together dictate that people who can only be given short periods of improved life (the old or the very ill or those for whom there are as yet only moderately effective treatments) are simply not worth bothering about. NICE cannot claim it cannot fund these treatments because that would mean depriving other, by hypothesis, more deserving or needy patients of treatment because NICE does not review all other options and prioritise according to a conception either of medical priority or desert. QALY measures do of course generate data on other treatments for other patients but not in terms of medical priority, desert or need. NICE, however, does not compare these Alzheimer’s patients with other patients or patients groups whose treatments they do fund and ask themselves, which plausibly should have greater priority or greater claim on the community’s resources or compassion.

EFFICIENCY

Efficiency in the delivery of health care is often defined in terms of maximising

¹I first wrote about the inequities and iniquities of QALYs in 1987.²

beneficial health care or in terms of the maximisation of health outcomes, and cost effectiveness is seen as a dimension of efficiency since it is allegedly an efficient use of resources. These styles of definition of efficiency simply beg the question at issue. This question is: what is the *good*, the benefit to be delivered by health care—what is the efficient use of resources supposed to achieve? They beg the question because they imply that the greater the health gain per treatment, the greater the efficiency of that treatment. However, the question of which is the most efficient or cost effective treatment for this patient or condition is simply not the same question as the question: which patients or groups of patients is it efficient or beneficial to treat. This is because there is an equivocation over the meaning of “beneficial” in the two contexts and a problem about inevitably incompatible ways of quantifying *size of benefit*.

If the millionaire and the beggar both lose *all they have*, on one way of thinking about the loss, each has suffered the same degree of loss, each has lost everything. On another, each has suffered a different quantity of loss measured by the total sum lost. There is no straightforward way of reconciling these different approaches to the assessment of loss. If we are searching for an equitable approach to loss, it is not obvious that we should devote resources allocated to loss minimisation to ensuring that the millionaire is protected rather than the pauper. The same is true of health gain. Even if it is agreed that resources devoted to health care are resources devoted to minimising the loss of health or maximising the health gain, it cannot be demonstrated that the person who stands to lose more life years if they die prematurely, stands to suffer a *greater loss* than the person who has less life expectancy. Nor can it be shown that the measure of health gain must equate to the number of life years, quality adjusted or not, which flow from treatment.ⁱⁱ

This is, however, just what NICE does claim for QALYs.

If you and I are competitors for treatment and I will have a better health outcome from treatment than you, but the treatment offers to each of us the chance of a health gain that is significant and important to us, automatically preferring to satisfy my needs rather than yours, seems unfair. Why should

ⁱⁱI argued this in detail in an article published in the BMJ in 1997.⁴

Abbreviations: NHS, National Health Service; NICE, National Institute for Health and Clinical Excellence; QALY, Quality Adjusted Life Year

my life or health be judged more worth saving or preserving because I am healthier or younger, or because there are more effective treatments for my condition, (even though the treatments available for your condition—as in the Alzheimer’s case, are still valuable, and worth having) rather than because I am more intelligent say, or more useful?

In the press statement (NICE press statement, NICE consultation on social value judgments, 6 May 2005) accompanying the NICE consultation document, Andrew Dillon, NICE’s chief executive, makes age discrimination in some circumstances a point of pride.

NICE has made judgments that take age into account in the past. For example our guideline on fertility treatment recommends that IVF should be made available to women between 23–39 as treatment is most likely to be effective in this age range

This is manifestly untrue since there is no evidence that younger women would not benefit. Inevitably, however, given that such judgments are based on the fallacious QALY reasoning, Dillon’s claim begs the question. Dillon’s claim is only plausible if the good to be delivered in the case of IVF is a maximised “take home baby rate” for society. If on the other hand the good that IVF offers to patients is a significant chance of pregnancy, when without IVF there would be little or none, then NICE and the NHS should offer this chance to as many such women as possible not simply to those most likely to give birth as a result. The chance to succeed may be valuable independently of the probability of success so long there is some reasonable such probability. We need a national debate on the question of what *good*, what benefit, the NHS is there to deliver. Among the candidates are: equal opportunity of benefiting from a publicly funded health care system for all citizens or the NICE option, the largest possible health gain (quality adjusted) for society. Dillon’s backing of “the treatment most likely to be effective” sounds as though it is choosing between different treatments, but in fact of course it is choosing between patients, and in a way that inevitably favours the easiest to treat. This sort of “prioritising by prognosis” generally favours the least sick, the easiest (and often the cheapest) to treat, and the youngest and fittest, although of course there may be particular cases in which this is not true.

Discussing age discrimination, NICE’s new guidelines assert (recommenda-

tion 6): “where age is an indicator of benefit or risk, age discrimination is appropriate”. This sounds fine; it implies that where the old are especially vulnerable they will get priority. This formulation and the expectation it seems to create are, however, grossly misleading since QALYs dictate that benefit is proportionate to life expectancy and it follows that other things being equal the younger or those with greater life expectancy will (or should if QALYs are consistently applied) almost always be prioritised.^{2,5} Just three paragraphs later, however, (recommendation 9) NICE says: “there is no case for discrimination on racial (ethnic) grounds either deliberately or inadvertently, in any NICE guidance”. This is sheer hypocrisy! The reason for outlawing race discrimination must be that it is clearly perceived by all to be absolutely morally unacceptable; and yet the same holds for age discrimination as for race discrimination. Both race and age are in some circumstances “indicators of benefit or risk”, some ethnic groups are at greater risk of certain genetic conditions than others, for example. Either both types of discrimination warrant execration as unjust or both should be celebrated as justifiable discrimination on QALY grounds and therefore required to fulfil NICE purposes.

ALL PEOPLE ARE EQUAL REGARDLESS OF THEIR QALY SCORE

Patients rationally want the treatment that will give them maximum life expectancy coupled with the best quality of that life; but perhaps above all they want the best possible opportunity or chance of getting the combination of quantity and quality of life available to them given their personal health status. Each citizen surely has an equal claim on the protection of the community as expressed by its public healthcare system and this means that each is entitled to an equal chance of having their, necessarily individual and personal and hence different, health needs respected by any publicly funded healthcare system.

Surely the principle governing any distribution of public resources must be equality: surely each is entitled to the same concern, respect, and protection as is accorded to any. People are equal and equally worth treating or saving and equality is not health status dependent. When we say all are equal we exclude discrimination on the basis of all the usual suspects: race, gender, religion, and so on. The moral principle outlawing discrimination protects (or should protect) all persons equally.

People’s lives and fundamental interests should be given equal weight regardless of race, creed, colour gender, age, life expectancy, or quality of life so long as that quality of life is worth having for the person whose life it is.

As the judge, Mars Jones J, said in a famous judgment:

However gravely ill a man may be...he is entitled in our law to every hour...that God has granted him. That hour or hours may be the most precious and most important hours of a man’s life. There may be business to transact, gifts to be given, forgiveness to be made, 101 bits of unfinished business, which have to be concluded.⁶

THE AGE-INDIFFERENCE PRINCIPLE

We surely need to reaffirm a principle of age or life expectancy or quality of life indifference when selecting whom to treat.

An individual’s entitlement to the concern, respect, and protection of the community does not vary with age or life expectancy or with their quality of life.ⁱⁱⁱ

Clearly this principle asserts that: each person is entitled to the same concern, respect, and protection of society as is accorded to any other person in the community. The principle of equality has the advantage of very wide appeal and acceptance, and versions of it are enshrined in many national constitutions throughout the world—for example, those of the United States of America and France and in various declarations of human rights, including the Human Rights Act, the Universal Declaration of Human Rights (articles 1 and 2), and the European Convention on Human Rights, (especially articles 2 and 14).^{iv}

Such a principle is implied by so much that governments of all complexions have supported in the United Kingdom that it is the more amazing and the more scandalous that NICE has chosen so flagrantly to flout it.

ⁱⁱⁱI first articulated this principle in a chapter in *Textbook of Geriatric Medicine and Gerontology*. Its present name, however, the age-indifference principle, was suggested by a member of the working party established by the international charity, Age Concern, to investigate attitudes and values in relation to ageing.⁷

^{iv} See also an article by Simona Giordano in a recent issue of the *Cambridge Quarterly of Healthcare Ethics*⁸ and for more sources see Elizabeth S Anderson’s paper in *Ethics*.⁹

The age-indifference principle reminds us that the principle of equality applies as much in the face of discrimination on the basis of chronological age or life expectancy or quality of life as it does to discrimination on the basis of gender, race, and other arbitrary features.

The point is of course not only to protect the lives and fundamental interests of individuals, but the assertion of their claim to equality, (to equal dignity, and to the equal protection of the community in which they live). This is not only an issue of justice and respect for persons; it is also an issue of community and civility. These values are part of clinical excellence as much as the narrow and discriminatory values exemplified by the QALY and by NICE.

Where people live in a community that values individuals differentially according to the success of their lives or quality and predicted length of their lives, this is highly likely to have a disastrous effect on their sense of personal worth and their sense of

security. Where people are frightened not only of suffering injury or illness, or of possessing genes, which will likely shorten their life expectancy, or are already coping with the deleterious effects of these; but are also frightened that because of these disadvantages they will be denied the only effective treatment available then this is surely likely to have a divisive and corrosive effect on a sense of community.

NICE should not be in the business of evaluating patients rather than treatments; to do so is contrary to basic morality and contrary to human rights. If society simply cannot afford a particular treatment that is one thing, but to adopt a metric of cost effectiveness that lacks compassion, and discriminates against the old, those with diminished life expectancy, the very ill, or those whose individual circumstances mean they will get less than ideal benefit from treatment, is a perversion of science as well as of morality.

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