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Unprincipled QALYs: a response to Cubbon

John Harris *University of Manchester*

Defenders of QALYs persistently and perversely argue from the unexceptionable premise that QALYs (years of quality life-time) are a 'basic human need in all times and places' to the unjustified and dangerous conclusions that they are a defensible and perhaps desirable principle to use in determining the allocation of health care resources.

The nub of the problem may be brought out in the following revealing passage from J E Cubbon's discussion:

'The appeal of QALYs may be brought out by contrast with an alternative position, namely that what is valuable are lives, not life years or their quality. From this point of view society should aim purely and simply to keep the number of deaths to a minimum. It would follow that one should strive to save a baby who can live only another hour of acute suffering just as much as one who will have a happy and fruitful existence for three score years and ten ... . An evaluation of life or lives without regard to actual or potential QALYs seems very incomplete. QALY maximisation on the other hand views QALYs as an essential prerequisite for what we regard as important in our lives (1).

The alternative position to which Cubbon alludes is one defended by me (2) but hardly recognisable from Cubbon's account. I believe, and indeed I believe that most of us believe, that it is lives that are valuable and not life-years. I will for present purposes merely assert this principle but I have defended it in detail elsewhere (3). This principle involves the idea that if each life is valuable then the fewer lost prematurely the better, and that in all but exceptional circumstances we should try and rescue as many people as possible from the threat of death, not simply those who are healthy or happy or both. I don't know whether there is anyone who believes that we should aim 'purely and simply to keep the number of deaths to a minimum', if this means that we should not care about the quality of life of our fellows. We should of course try to protect life and maximise its quality. What we should not do is abandon those whose quality is poor to concentrate on the fortunate. QALYs require us to do precisely this.

Key words

QALYs; quality of life; policy-making.

Cubbon's choice of two babies for comparison is not entirely a happy one. For one thing many would want to distinguish babies, who can have no preferences of their own about continued existence, from those who can and do have such preferences. Moreover, many believe that a baby 'who can only live another hour of acute suffering' should, so far from being rescued, be killed instantly rather than permitted to suffer another second if death is the only means of arresting such acute suffering (4).

There are two separate elements to the QALY and both have their problems, but we should distinguish the nature of the problems. The first is the fact that QALYs value lifetime rather than lives and the second is that they value higher over lower quality of life.

The lifetime view

There is some plausibility to the view that we should prefer, *in extremis*, to maximise lifetime and not simply lives in being. This is the contrast that Cubbon in fact relied on in his example of the two babies. For the fact that one of the babies had only an hour to live does all the work of appealing to our intuitions here. Most people would prefer to save the baby with the life expectancy of 70 years rather than the one with only an hour to live even if both would have healthy lives for the allotted span. The fact that the shorter span is also of worse quality adds nothing to the intuitive preference for rescuing the child who has some reasonable life-expectancy.

However, as we have seen, babies are a special case. Cubbon's appeal to our intuitions would work equally for most people if he had chosen to compare saving the life of a twenty-year-old with an expectation of fifty life-years rather than an eighty-year-old with an expectation say of five more years (5).

QALYs are, however, appealing only in these extreme cases. But this contrast does not recommend the adoption of QALYs as a principle, a moral principle, of resource allocation. For QALYs require that we value life-time (quality equal or adjusted) rather than lives in *all* cases. This means that we would be obliged always and inevitably to maximise life-time rather than lives and to deploy resources accordingly. This is why QALYs are ageist. They direct us to save

the lives of those with greater life-expectancy rather than less and hence to prioritise medical services which have this effect: paediatric rather than geriatric to take just one example. Whenever (quality constant) we could devote resources to someone with greater life-expectancy we should do so. This means not only saving people twenty years old rather than people eighty years old, but rather saving people twenty years old rather than people twenty-two years old and saving twenty-year-old women rather than twenty-year-old men because, other things being equal, they have the greater life expectancy and thus QALYs will be maximised by such a policy (6).

It is far from clear that we would regard such a policy as 'essential for human flourishing and goal attainment'. The unattractiveness of the QALY approach will become even clearer when, with completion of the human genome project, we can in principle know much more reliably the life-expectancy of everyone in the population and so decide at birth whether it will be worthwhile devoting health resources to anyone in particular (7).

The quality of life view

If we now turn to the quality adjustment strand of QALYs we see that this too has its problems. Other things being equal it dictates that we prefer to maximise quality life-time not simply lifetime. This sounds an admirable principle (and it is) if it is applied to individual choice. If there are alternative therapies for me, I want the one which will give me the longest remission coupled with the best quality of life I can achieve. Similarly, a health-service provider faced with rival treatments or treatment centres, should prioritise the treatment or the treatment centre likely to produce the most QALYs *for each patient treated.* Again, and regrettably, the injunction 'maximise QALYs' does not do this; rather it encourages health-care provides to choose, not the treatments but the patients, who will generate the most QALYs. This involves not only ageism and sexism, but also injustice, unfair discrimination and a positively Thatcherite preference for the fortunate.

Two examples will illustrate this. Imagine twin sisters, one is disabled from birth with a painful condition that is untreatable and leaves her chair-bound. The other is perfectly healthy. By the time they reach their twenties the disabled sister has, through much effort and resolution, carved out for herself a life she finds worthwhile despite its restricted nature and the pain she experiences. Both are then involved in a motor accident and require the same expensive treatment which will restore each to the conditon she was in before. If resources are scarce (and of course it is an article of faith with QALY advocates that resources are necessarily scarce) QALYs dictate that the healthy sister gets priority and this may mean that she will be the only one of the two to be treated. Having been born fortunate her fortune will be rewarded by the QALY principle. Her sister, having once been unfortunate will have further misfortune heaped upon her.

It's no good Cubbon stipulating, as he does, that QALYs should only sparingly be applied in such clinical decision-making. The theoretical issue is whether or not valuing QALYs rather than persons is coherent with other important pillars of our popular morality such as our conceptions of justice and moral responsibility. That this must be so is illustrated by Cubbon's own use of a clinical example, the two babies, in defending his approach.

Suppose next that a complete but expensive cure is found for a disabling and often terminal genetic condition which affects a minority ethnic group and usually strikes from age fifty onwards. Because of the late onset and the expense it is not very QALY-efficient to treat compared with rival claimants to resources. QALYs dictate that this group be left untreated.

I believe, and have argued at length elsewhere, that each person has an equal claim upon the health resources of the world and in particular those of his/her own society: that no individual or group or type of individual has a more valuable life or a greater claim to life-saving resources than any other. This is part of the claim that all people are entitled to treatment as equals. Indeed, I believe with Hobbes and many other political theorists, that any nation State's claim to the allegiance of its citizens is contingent upon it being willing and able to protect the lives and liberties of its citizens. In the absence of plausible threats of foreign domination, the greatest threat to the life and liberty of the citizens of most democracies comes from threats to health. A society that says particular citizens, whether individually identifiable in advance or not, will not be so protected has effectively declared such individuals to be outlaws – outside the protection of the State – and forfeited its claim to their allegiance.

Cubbon is of course right when he says that the difference between this view and those of the defenders of QALYs is 'a fundamental ethical one and cannot be conclusively settled by argument'. He is right in a sense. He acknowledges that 'what can be done is to adduce considerations in support of one or other of them'.

The considerations I adduce are that QALYs will appeal only to those who are content that we as a society say to some individuals and some groups of people identifiable by the diseases or conditions from which they suffer: 'We will not help you or your kind, your lives are less valuable than those of other citizens, it is simply not worth our even attempting to rescue you'.

The sting of discrimination

Recognising this unsavoury tendency of QALYs Cubbon adduces two considerations in mitigation. 'Discrimination loses some of its sting if those who are less favourably treated are not members of a clearly defined group with a corporate sense' and such people 'feel much less affinity for one another than members of ethnic minorities'.

I am at a loss to understand the supposed force of the first point. The QALY-impoverished, like the poor, are an identifiable group, though one with a shifting membership. Whether or not they have a corporate identity seems entirely irrelevant to the question of the morality of how they are treated, though of course it may affect the political power they are able to wield. But, as the emergence of other victims' support groups shows, nothing builds corporate identity and a sense of solidarity faster than unjust discrimination – which disposes of the second supposed morally relevant difference.

Triage

Cubbon points to a policy of triage in time of war as a shining example and he asks: 'Is there a good reason why the criterion for deciding on priorities should really be different in peacetime?' The answer of course depends upon how triage is defined, but as Cubbon defines it the answer to his question is surely an unequivocal 'yes'. In Cubbon's triage 'priority is given to those needing a quick, straightforward life-saving operation and anyone with multiple wounds for whom little can be done may ... be left to die. This policy may often be motivated by the need to return as many men as possible to the front-line, but it will produce incomparably more QALYs than the selection of patients on a more equitable basis ...'.

This passage certainly and accurately presents the rival moral viewpoints at issue here. Since Cubbon invites a peacetime analogy, the most likely expression of a QALY-motivated health policy is as one designed to get the productive back to work and leave the useless to suffer and die.

We must surely remember that war is different. The hypothesis justifying triage in time of war is that failure to win the war will mean that more innocent people will ultimately suffer and die and more injustice be done. Wars must be won so that the civilised and civilising values of peace may be restored. Among those values is surely the idea that each person matters and that no one should be discarded because his or her productive life is over or nearing its end. Echoing Hobbes again, triage and QALYs are part of the philosophy of permanent war in which the good guys are the fortunate for whom long and healthy life-expectancy can be cheaply provided. The enemy are those unfortunates who stand between the fortunate and their survival by daring to make rival claims on our concern and our resources.

Faith in QALYs

In trying to mitigate the obvious unattractiveness of QALYs Cubbon argues that doctors should not use them in ordinary clinical encounters with patients because 'the bundles of rules followed by doctors in clinical situations ... produce more QALYs overall than would be the case if they were universally replaced by the principle that everything should always be done to maximise QALYs'. Cubbon rightly believes that using QALYs to discriminate between patients would undermine the doctor-patient relationship. He doesn't however consider the possibility that a public policy based on QALYs might, for analogous reasons, undermine public confidence in and respect for government and health-policy makers. But more important, it is simply an article of faith that avoiding QALYs in clinical situations will in fact maximise QALYs overall. If QALYs represent a defensible (even mandatory) way of allocating resources then we surely should use them everywhere and rely on education of the sort Cubbon goes in for, to convince people that this is right and fair.

Similarly, defenders of QALYs often say that QALYs are only intended to be used at the margin to determine the allocation of *extra* resources. But if they are right and fair at the margin then they are right and fair at the centre.

QALYs and policy

Cubbon ends by arguing that if the context within which QALY maximisation has a role to play is properly delineated, some of the objections fall away. However Cubbon delineates the most objectionable sphere for QALYs, namely as a tool for directing policy decisions about resource allocation rather than in dealing with individual patients.

This area is the most objectionable because rather than using QALYs to measure outputs of health care or as evidence in the choice of rival *therapies* they are used to determine which groups of patients will get priority and hence, often, which will get any treatment at all.

The two reasons Cubbon gives for this are the following:

'1) In a modern society the planning of services will always mean that some groups of people will deliberately be deprived of benefits.
2) Those affected by policies will not generally be known as individuals to those formulating them.'

The first reason sounds bland enough until you consider that we are not in fact talking of people being deprived of benefits – we are talking of people being deprived of life. Cubbon realises this of course and he is right to judge that such decisions may sometimes be inevitable. The moral choice is between a QALY policy which has no interest in minimising the numbers of individuals who will be victims and an alternative which accepts that it is the highest priority to minimise the number of such victims. Moreover, where such deaths are unavoidable, we must ensure that the moral reasons for causing such deaths as do occur are of sufficient weight to justify such a terrible consequence and that in so far as the victims are a matter of choice, that choice is not exercised unjustly.

The virtue of objectivity

Cubbon's second reason has to do with the supposed objectivity (not justice) of policy decisions and he is

much exercised with the supposed virtue of not knowing the personal identity of those whose deaths you are determining.

'The people who would benefit from [QALYs] will mostly not be known to policy makers .... According to criteria similar to those which defined the Rawlsian Original Position, [maximising QALYs] will, therefore, have a measure of objectivity.'

But such Rawlsian objectivity as QALY maximisation possesses does nothing to make QALYs respectable and it is important to understand why. Rawls's famous 'Original Position' and the 'veil of ignorance' behind which it hides is often quoted in support of particular styles of policy-making and almost always misleadingly.

Rawls imagines people deciding the rules which will determine the nature of society behind a veil of ignorance which denies them any knowledge which they could use to advance their own interests whether personal or impersonal. One idea behind such a model of decision-making is that because those making the decisions do not know who in particular will be affected by the policies they decide upon, they have no motive for making things better for one sort of person rather than another. A criticism that is often levelled against the Original Position is that people deciding under conditions of such radical uncertainty might choose a society divided between slaves and slave-owners, gambling that when the veil of ignorance was lifted they would be amongst the lucky slave-owners. Such a choice would be objective in the sense in which Cubbon uses that term, but this does little to recommend it as part of a defensible social policy.

Rawls had hoped that the Original Position would demonstrate the justice of the two principles that he believed rational self-interested people would choose under radical uncertainty. It is the supposed connection between the Original Position and such principles that recommends the Original Positon (8). One of the principles supposedly generated by the Original Position is that inequalities in such things as power, wealth, income and other resources are impermissible except in so far as they work to *the absolute benefit of the least well-off members of society*. It is in part the supposition that the Original Position generates such a fair and humane principle that recommends it as a model of a possible machine for generating just principles.

QALYs unfortunately have the exact opposite effect since they work to the absolute detriment of the least well-off. The worst-off members of any society are surely those with the worst quality of life coupled with the shortest life-expectancy. Rawls insisted that no one should be able to further his or her own welfare unless the effect of this was also to increase welfare for the least well-off. In so far as such a principle has appeal as a just method of resource allocation it rules out the use of QALYs.

John Harris is Professor of Applied Philosophy and Research Director of The Centre for Social Ethics and Policy, University of Manchester.

References and notes

(1) Cubbon J E. The principle of QALY maximisation as the basis for allocating health care resources. *Journal of medical ethics* 1991; 17: 181–184.

(2) See my QALYfying the value of life in the *Journal of medical ethics* 1987; 13: 117–123, and my More and better justice in Bell J M, Mendus S, eds. *Philosophy and medical welfare*. Cambridge: Cambridge University Press, 1988.

(3) See my *The value of life*. London: Routledge and Kegan Paul, 1985.

(4) See my Ethical problems in the management of some severely handicapped children in the *Journal of medical ethics* 1981; 7: 117–120.

(5) Not for me however. See reference (3), ch 5, in which I argue against the ageism implicit in such intuitive preferences while admitting their strong appeal.

(6) Hence QALYs are also sexist.

(7) I discuss such problems in detail in my *Wonderwoman and superman: the ethics of human biotechnology*, Oxford: Oxford University Press, to be published early in 1992.

(8) See Ronald Dworkin's account of this in his *Taking rights seriously*. London: Duckworth, 1977: ch 6.