

Health Resource Rationing

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Health care is uniquely important. Modern medicine has been extremely successful in discovering new kinds of health care and improving the old kinds. But medical innovations have come at increasingly high prices. The cost both of the best health care, and even moderately good health care, is rising much faster than our ability to pay for it. This creates a problem. If a society wishes to provide health care to its citizens, some form of rationing has become a necessity.

The very idea of health care rationing is objectionable to many people. Citizens of the United States are especially opposed. This is partly because the U. S. has no universal health care system. The two national health programs (Medicare and Medicaid) cover only 26% of the population, those who are elderly, poor, or significantly disabled. Health care for the remaining 74% is left to the marketplace. This is seen as desirably by many, who believe that a free market will to assure freedom of choice in health care. But the effect of this “free market rationing” by the year 2002 was that 15% of the population – over 43 million people – had no health insurance at all, and that number is increasing. Some public system involving rationing is likely to be required in the future. It is already used in the U. S. national systems and in private Health Maintenance Organizations, so even U.S. citizens will have to get used to the idea. Most other developed countries have universal health care programs. Because rationing decisions are always made within these, the concept is seen as less objectionable.

Health care rationing is a genuine necessity within any publicly funded system. It is easy to argue that national health care systems are underfunded. Nevertheless, the funds that would be necessary to purchase unlimited health care for everyone are beyond any nation’s capacity. Increases in funding can produce better health care, but not unlimited health care. If health care must be limited, then both fairness and efficiency demand that it must also be rationed in some way. We should spend health care funds *wisely*, so that expensive procedures are only funded when they are worth the expenditure in comparison to other procedures. This follows from the fact that an expenditure on any

one patient reduces the funds available to other patients. But we should also spend funds *fairly*, so that everyone gets a just share of the benefits of the system. Crafting a health care rationing system that is both efficient and fair is a tremendously complex process. But it is also a necessity.

Both the efficiency and the fairness of a system of health care rationing are difficult to establish. The simplest programs are easy to apply, but they have serious moral flaws. These flaws have been recognized, and attempts have been made to circumvent them. One group of people is especially vulnerable to disadvantage from rationing systems: people with impairments and chronic illnesses. Even systems that are intended to fairly and efficiently distribute health care resources can discriminate quite seriously against disabled people, as we shall see. This discrimination results from questionable moral assumptions about the goals of health care, from questionable factual assumptions about quality of life, and even from disagreements about the nature of disability itself.

Conflicts between the medical community and the disability rights community are almost inevitable, for one simple reason. The medical community considers disability to be a medical problem, to be solved (if at all) by medical means. The disability rights community considers disability to be a social problem, to be remedied by social changes that make environments more accessible and integrate disabled people with the rest of society. These activists consider disabled people to be similar to an ethnic minority, harmed by discrimination from mainstream society. The so-called “medical model” of disability is a basic assumption of the medical community, but a misconception according to disability rights activists. This is one source of conflict over the relation between disability and health care policy.

One might think that statistical analyses of health care efficiency would result in simple statistical facts, not in moral problems. But statistical analyses often begin with hidden assumptions that infect their outcomes. One early analysis of health care efficiency was called cost-benefit analysis (CBA). The goal was to determine the costs of nationally funded health care in terms of its impact on economic productivity. The analysis indicated that health care expenditures on workers who were young, productive, and highly paid would repay the costs by increased productivity. But other expenditures

didn't produce the same payback. Health care for unemployed and elderly people was a bad investment. The use of these results to prioritize public health care was immediately recognized as unfair. The moral goal of health care is not only to maximize the nation's economic production, but to make its citizens healthier whatever their economic contribution.

It is not difficult to calculate the relative cost effectiveness of different treatments when they are aimed at producing the same outcome. The calculation of the cost-effectiveness of certain screening tests for colon cancer, for example, is merely the cost of one test multiplied by the number of such tests it would take to detect a single tumor. This kind of analysis can lead to useful results. But this kind of analysis, alone, cannot compare different kinds of outcomes; it cannot compare treatments that extend life with those that control pain, or improve function. A way had to be found to compare the different health-related outcomes with each other. This would allow cost-effectiveness analysis to be applied to *health itself*, instead of being limited to individual kinds of outcomes. It would also remove the unfairness of CBA's focus on the economic consequences of health. The health of unemployed and elderly people would receive equal consideration as that of high wage earners. This was surely a moral improvement. But how can one measure *health itself*? The concept has proven surprisingly problematic.

The first step in measuring *health itself* was the recognition that the goal of health care was not only to extend lives, but also to make lives better. The relief of pain and discomfort, and the improvement and maintenance of function are legitimate goals of health care even if lives are not lengthened. Life-extension and life-improvement were seen to be distinct dimensions of health care. In order to compare two distinct dimensions of health, a measure had to be constructed that incorporated them both. Some amount of life extension must be seen to be comparable to some amount of life improvement. This would be possible if *health itself* were seen to be the product of multiplying the *length* of life produced by a medical treatment (the longer the better) by the *quality* of the life produced (the better the better). But now we see another problem. One of those goals is easily measurable but the other is not. Length of life is simply a number of years. But how does one measure the "goodness" of life?

In the 1970s this problem led to the coinage of the expression “quality of life” (QOL). The expression rapidly became a buzzword. But it is important to remember its origin. Even though *quality of life* has entered ordinary language, it retains its specialized meaning among those who deal with health care rationing systems. In ordinary speech, quality of life refers to the subjective satisfaction and fulfillment that an individual experiences. But in its original technical sense, quality of life refers to *everything except life extension* that is a beneficial outcome of health care. Subjective satisfaction is irrelevant. The technical concept is quite problematic, as we will see. One its ironies is that the technical term *quality of life* was invented only because of the need for *quantification*. Health care economists had to be able to quantify – to measure, count, add up, and compare – the valuable outcomes of health care. For the purposes of health care rationing, quality of life is a quantity.

With QOL understood as a quantity, an amount of goodness, health care economists believed that they could calculate the total amount of *health itself* in an individual or in a population. Total health is a length of time multiplied by the quality of life (QOL) during that time. The Quality Adjusted Life Year became the standard measure of total health. Numerical comparisons can now be made. One QALY is one year of life at its maximum quality (set at 1.0 by convention), or two years of life at the QOL of 0.5, or four years of life at the value of 0.25. The number of individuals involved does not matter: four years of one person’s life at a given QOL is equivalent to two years of two people’s lives at the same QOL. Health care can now be rationed with the help of objective measures. A system called cost-utility analysis (CUA) was devised by applying cost-effectiveness analysis to the production of QALYs. (“Utility” is a term used by economists and philosophers to designate an amount of welfare or happiness. In the case of CUA, utility is measured in quality-adjusted life years.)

To illustrate the use of CUA in health care policy, imagine a decision between two programs of life extending treatment. Program A and Program B have the same costs, the same size patient groups (say 1000 patients) and each program extends the lives of its patients for one year. The patient group for Program A has the highest possible QOL of 1.0. The group for Program B has a lower QOL of 0.8. Which program should be funded? Clearly Program A. It produces 1000 QALYs (1000 people with a one-year life

extension at 1.0 QOL) while Program B only produces 800 QALYs. A greater amount of *health itself* is purchased for the same price. Cost-utility analysis shows that the QALYs produced by Program B cost 1.25 times as much as those produced by Program A. Given this choice, it would be a financial waste to fund Program B.

We are very close to the point at which health care rationing discriminates against people with permanent impairments or chronic illnesses. One further step is needed, and it is almost always taken. It is this: People with impairments are determined to have a lower QOL than nondisabled people merely because of their impairments. The overall goal of maximizing QALYs implies that, under certain circumstances, people whose QOL is permanently low will receive a lower priority for certain kinds of health care than people whose QOL is high. This won't happen in every circumstance, of course. If two individuals with different QOLs contract a disease that lowers each of their life qualities an equal amount, then the treatment for the disease would result in the same QOL increase for each person, whatever their baseline QOL. Because each treatment results in the same increase, they have an equal priority for treatment even though they began at different QOLs. But consider life-saving treatments. Saving the life of a person with a high QOL produces a larger number of QALYs than an otherwise similar person who has a permanent impairment (and therefore a lower QOL). For treatments like these, disabled people will have a lower priority for health care than otherwise similar nondisabled people.

This version of CUA is beginning to sound like CBA, with its focus on economic outcomes. Instead of discriminating against non-wage-earners, we discriminate against people who have a low QOL. One would think that the same objections would apply. Many non-wage-earners have a lower quality of life than wage earners, and so would be disadvantaged by a QOL-based CUA just as much as by the old income-based analysis. Presumably many poor people, elderly people, lonely people, and people who have lost a loved one have a low QOL, and so would also be subject to discrimination. Shouldn't fairness dictate that health care not discriminate against these groups of people? Should all sad people be classified in the same category as disabled people, and have their access to health care reduced by their low quality of life? Is health care only for happy people?

Not according to the actual rationing systems that have been developed. Advocates of the CUA analyses are not interested in maximizing overall quality of life, in the ordinary sense of the subjective enjoyment or fulfillment that individuals experience in their lives. Keep in mind the original purpose of the concept of QOL. It was meant to quantify non-life-extending health care so that it could be compared and traded-off with life-extending health care. Unhappiness-causing characteristics like poverty and loneliness are not treated by the health care system. So they are ignored by CUA advocates. The term “health-related quality of life” (HrQOL) is now used to call attention to this difference. CUA advocates insist that disability is health related, and insist that loneliness and poverty are not. So a person whose life is made unhappy by disability receives a lower priority for health care. But a person whose life is made unhappy by widowhood or unemployment does not. All sadnesses are not equal.

But are these generalizations even true? Are the lives of people with impairments significantly lower than nondisabled people? It depends on whom you ask. When people with impairments are asked about their lives, they report a QOL only slightly lower than that reported by nondisabled people about their own QOL. But when nondisabled people are asked about the QOL of disabled people, they report (or estimate, or guess) that it is extremely low. Even more paradoxically, health care workers have a lower estimate of the QOL of disabled people than does the general public. Gary Albrecht and Patrick Devlieger have reviewed the literature on this paradox.

So the question arises: whose reports should be used in the rationing system? Should we incorporate the high QOL reports of disabled people themselves, or the low reports that are given of disabled lives by nondisabled commentators? Biomedical ethicists have shown a strong tendency to trust only the nondisabled reports (or, more likely, their own intuitions). They dismiss the reports of disabled people as a mere lowering of personal standards. On the other hand, social psychologists have known of this discrepancy for much longer than the ethicists. Psychologists like Daniel Kahneman and his colleagues have taken the reports of disabled people seriously. The phenomenon fits into other psychological knowledge about how people find happiness in life. Ask yourself this: How happy would you be a year after you won a fortune in a lottery? You probably expect that you would be extremely happy. But the empirical facts don't fit your

prediction. After an initial exultation, lottery winners almost always return to their original level of life satisfaction. The same happens with most people who experience major difficulties, whether from disability or the loss of a loved one. Nondisabled commentators *expect* that disability would cause them to have permanently low QOL, and lottery winning permanently high QOL. Both expectations are mistaken. This implies that people who are living with impairments (and those who are living with lottery fortunes) are the best judges of their own QOL. The contrary assessments of the non-disabled public, biomedical ethicists, and health care economists are clouded by a prejudice well known to psychological researchers.

So there is good empirical reason to doubt that the lives of most people with impairments have much less subjective satisfaction or fulfillment than the lives of nondisabled people. Insistence that they do would be seen as mere bigotry by disability rights advocates. But the CUA advocates have an additional argument to use in support of the lower QOL of people with impairments. They claim that it is logically incoherent to accept reports of high QOL from disabled people.

According to the principles of cost-utility analysis (CUA), logical consistency requires us to link any expenditures dedicated to cures and prevention of a given condition with the quality of life of a person who lives with that condition. If Condition A is regarded as extremely mild then Condition A will have a low priority placed on it for purposes of prevention or cure, and people who live with Condition A will have a very high QOL. Conversely, if Condition B is one that is very important to cure and prevent, then a life with Condition B must involve a seriously reduced QOL. For example, if you consider it important to spend health care funds to prevent or cure blindness, then you are logically required to believe that people who are blind have a low QOL. If they didn't, then why should we devote health care funds to prevent or cure blindness? The mere fact that we want to prevent disabilities logically implies that disabled people have a low QOL. What they report about their own QOL has no relevance to the matter.

This appearance of logical necessity is a consequence of the assumptions behind CUA accounts of rationing. CUA presupposes a utilitarian moral theory. Utilitarianism asserts that morality is a matter of the production of *consequences*: the rightness of an act is the amount of happiness it produces. A well-known shortcoming of utilitarianism is

that it is unable to account for certain moral intuitions involving fairness, justice, and rights. Utilitarianism often seems to give the correct moral answers only when one assumes that no pre-existing rights are involved in the question. CUA advocates make this assumption. The purpose of health care rationing is to maximize the amount of *health itself* that is created by the rationing system. No individual has any particular right to health, or to health care. The only claim that any citizen has on health care comes from that citizen's ability to convert the expenditure of health care funds into high amounts of HrQOL. Citizens who can "reimburse" health care expenditures with high HrQOL will receive health care. Those who cannot, will not. The status of an individual person within this system is merely to represent a potential health outcome, a contribution to the overall sum of *health itself*.

The utilitarianism behind CUA presupposes that that the maximization of HrQOL is the categorical goal of health care, and therefore of health care rationing. But this assumption is challenged by many biomedical ethicists, and independently by the general public. Tom Beauchamp and James Childress have reviewed the ethicists' critiques. Peter Ubel and Erik Nord have conducted studies on how the general public perceives the importance of various kinds of health care. Ordinary citizens consider the strict application of pure CUA analysis to be unfair, and would prefer systems that would actually produce a lower HrQOL than the maximum. For example, they would spend more funds on extremely ill patients than would be justified by CUA analysis. This "rule of rescue" requires that funds be spent on extremely ill patients even when the costs of their treatment are unlikely to be compensated by large improvements in their QOL. Ordinary citizens are also reluctant to give nondisabled people a higher priority than disabled people for life saving treatments *even though they believe* that disabled people have a lower QOL. So the prejudice of the general public against the high QOL of disabled people seems to be compensated by their refusal to go along with CUA in its implication that disabled people should have a lower priority for health care than their nondisabled peers.

The utilitarianism of CUA is inconsistent with the concerns for fairness that are expressed by many biomedical ethicists and the general public. It is unclear which values will be reflected in future rationing schemes. With respect to life-saving measures at

least, the general public seems to consider people with impairments to be similar to ethnic minorities – disadvantaged groups that should be protected from further discrimination. This matches nicely with the views of disability rights advocates. But the assumption that disability implies low QOL is shared by the general public and by CUA advocates. The artificial notion of HrQOL is potentially hazardous to disability rights. HrQOL is a special form of quality of life that links disability and health care. But it artificially separates disability from other life experiences that can cause unhappiness – experiences like sudden unemployment and the loss of a loved one. It reinforces the deep prejudice that the disadvantages of disability are a special curse from nature itself. A person's biology (not an inaccessible environment) is the cause of the person's unhappiness. This is merely a modernized reincarnation of the same old stigma that disability has always held. Unlike other causes of sadness that can be accommodated and learned from, disability is seen to be a permanent loss of life's goodness.

An important principle of the disability rights movement is the exact opposite. The disadvantages of disability arise not from biology but from social arrangements, such as inaccessible environments. Technical rationing concepts like the HrQOL misrepresent the causes of disadvantage for disabled people. Even if disabled people are able to resist the loss of access to health care that would result from a CUA rationing system, they may be equally harmed by the assumption (shared by biomedical policy makers and the general public) that they "by definition" have a lower QOL than their nondisabled peers. If this were true, then improvements to environmental accessibility could benefit them only in small ways. Why bother trying to improve the life of a person who "by definition" has a low quality of life anyway? If the technical concept of HrQOL reinforces the public's belief that disability is unavoidably associated with a low quality of life, it may undercut the disability rights arguments for greater inclusion and more accessible environments.

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