

# Epilepsy, economics and ethics

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In this lecture I want to consider some ethical aspects of economic analyses of health and disease. The focus will be on the relations between on the one hand health economics, on the other hand *utilitarian ethics*; i.e. the thesis that maximising the sum total of good in society is the morally right thing to strive for.

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## Utilitarianism:

*In any choice situation, the morally correct choice is to maximise the expected sum of good in society*

(where the "good" can be conceived of as happiness, welfare, QALYs, etc.)

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Epilepsy surgery is chosen as the main example in order to show that an abstract ethical discussion may have concrete implications for epilepsy outcome research. As an introduction, a few elementary facts and distinctions concerning health-economic analyses will be recapitulated. After that, you will be introduced to a certain discussion in the recent philosophical literature, and a thesis about the proper limits of utilitarianism as a decision tool in the allocation of medical resources will be presented. This thesis is then applied to the field of epilepsy surgery.

Let us first have a brief look at some paradigms for economic analysis in medicine. The terminology used here is essentially that of Shorvon 1996.

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*Cost-effectiveness*: cost ~ medical improvement

Typical result: Surgery costs \$X per seizure-free patient.

*Cost-utility*: cost ~ global measure of gain

(Also often referred to as "cost-effectiveness" analysis.)

Typical result: Surgery costs \$X per gained QALY.

*Cost-benefit*: cost ~ monetary measure of gain

Typical result: Surgery costs society \$X and earns \$Y.

Shorvon S, *Models of Economic Appraisals in Epilepsy*. In: **Economic Evaluation of Epilepsy Management** (Pachlato Ch & Beran R G, eds., London 1996).

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A *cost-effectiveness* study (in the strict sense) relates the cost of an intervention to the good that it does, where the good is measured by some objectively defined parameter, usually a medical variable. A typical example would be a comparison of the cost of epilepsy surgery with its outcome, quantified by means of the percentage of patients rendered seizure-free. The disadvantage of such studies is that because of the idiosyncratic outcome parameters, they cannot be meaningfully compared with studies from other fields, say, heart surgery.

Because of the last-mentioned fact, health economists have designed the *cost-utility* study (often also referred to as a kind of "cost-effectiveness" analysis). In an ideal such study, the outcome is measured in terms of its effect on global well-being, or quality of life, or utility, which is supposed to be a common measure of value in any human life. In many medical applications, utility is operationalised as QALYs, quality adjusted life years. The value of living a year with a certain medical condition can be determined by letting a sample of well-informed persons "trade off" such a year against a shorter life with full health (or against a smaller probability than 1 for a year with full health). Hence the QALY does reflect, at least approximately, people's informed preferences about their own lives. There are many well-known problems (of both an empirical and a conceptual nature) involved in the determination of QALYs for different medical states, but these problems are not at issue here.

Recently, some cost-utility studies of epilepsy surgery have been published, and I will take two of them as examples here. Both, by the way, are called "cost-effectiveness" studies by their authors. In a New York study, Langfitt determines the cost per QALY of epilepsy surgery, including evaluations of patients who are then not operated, to \$15.581. In a Pennsylvania study described by King and his co-authors, the corresponding figure is \$27.200 per QALY.

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## ESE-and-surgery cost per QALY:

1. \$ 15.581

Langfitt J, *Cost-effectiveness of anterotemporal lobectomy in medically intractable complex partial epilepsy*. **Epilepsia** 38 (1997), 154-63.

2. \$ 27.200

King J, Sperling M, Justice A & O'Connor M, *A cost-effectiveness analysis of anterior temporal lobectomy for intractable temporal lobe epilepsy*. **Journal of Neurosurgery** 87 (1997), 20-28.

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Part of the difference between the studies can be explained by the fact that King *et al* do not

include that effect on QALYs which is due to many patients having their seizure situation relieved without becoming seizure-free.

A cost-utility study can give guidance about the relative benefits derived from two medical interventions, even if they concern different diseases. But it cannot tell us whether, in an absolute sense, the results are worth their costs. Now, both of the mentioned studies do include a comparison with norms concerning acceptable dollar per QALY quotients. King et al quote a proposal by Kaplan & Bush that \$50.000 should be regarded as an acceptance limit, while Langfit quotes tentative Canadian guidelines saying that treatments which cost less than \$19.000 per QALY are almost universally regarded as appropriate ways of using society's resources. How such norms and limits are established is another question which, regrettably, I cannot go into.

In some areas of economic analysis, notably transportation and environment, a form of study called *cost-benefit analysis* has been used. In a cost-benefit analysis, the benefit derived from an intervention is translated into economic terms so as to become commensurable with the cost. In principle, such a translation could be performed by letting people value QALYs in economic terms. There are however many difficult problems involved in this, a major one stemming from the fact that the value of money is not constant between people (money is worth more for poor people). These problems certainly extend beyond the scope of this paper, so let us concentrate on the cost-utility analysis and its central component, the QALY.

In 1995 and 1996, an interesting debate took place in the well-renowned **Journal of Medical Ethics**. The main combatants were two moral philosophers: John Harris of Manchester University, England, and Peter Singer from Monash, Australia. Singer stands for the utilitarian viewpoint, while Harris is outspokenly anti-utilitarian.

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Harris J, *QUALYfying the value of human life*. **Journal of Medical Ethics** 13 (1987), 117-23.

Singer P, McKie J, Kuhse H & Richardson J, *Double jeopardy and the use of QALYs in health care allocations*. **Journal of Medical Ethics** 21 (1995), 144-50.

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Already in 1987, Harris had challenged the use of QALY analysis in medicine, arguing that assessing the effects of medical interventions in terms of quality-adjusted years is unfair towards people who have a low quality of life. To support his point, he constructs the following example. I have simplified it a little to make it more transparent.

Suppose that both of two 30 year old women, Karen and Lisa, have a severe heart condition and are candidates for immediate heart transplantation, but that it is only possible to operate on one of them. Their expected life-length after the transplantation is the same, 40 years. However, 20 years ago Karen suffered from a disastrous car accident which left her with a quality of life permanently only half of Lisa's. Assuming that Lisa's quality of life can be set to 1, Lisa's expected gain from the transplantation is 40 quality adjusted years, while Karen's expected gain is only 20 QALY's.

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### *The case of Karen and Lisa (version 1)*

<b>Subject</b>	<b>QoL before op.</b>	<b>Exp. QoL/LL</b>	<b>QUALY gain</b>
Karen	.5 (last 20 years)	.5/40 years	20
Lisa	1	1/40 years	40

*Utilitarianism: You must choose to operate Lisa*

*Harris: This decision is unfair towards the less well-off*

It is quite clear that a utilitarian would decide the case in favour of Lisa. But this is unfair, says Harris, since it in effect doubles the burden on Karen. Not only is she less well-off before the decision, but she also loses the competition for medical resources. Instead of using the utilitarian, QUALY-maximizing principle, says Harris, we should value Lisa's and Karen's lives equally highly - and toss a coin to decide.

Singer and his co-authors argue against Harris's point in several different ways. One line of argument is highly abstract and seeks to prove by an apriori argument that utilitarianism is a rational view to hold. I will not go into this argument here. Singer's second line of argument is to show that Harris's way of reasoning ? giving equal value to all lives ? yields absurd results in several other examples. And Singer constructs a number of fictional cases to show this. The essence of these cases can be captured by modifying the Karen & Lisa example. Suppose, for example, that Karen and Lisa both have had a high, full quality of life before the transplantation, but that for some medical reason, Karen's life expectancy after the operation is only 20 years while Lisa's is still 40.

### *The case of Karen and Lisa (version 2)*

<b>Subject</b>	<b>QoL before op.</b>	<b>Exp. QoL/LL</b>	<b>QUALY gain</b>
Karen	1	1/20 years	20
Lisa	1	1/40 years	40

*Singer et al: It is evidently not unfair to choose Lisa here.*

So, Lisa expects 40 QUALYs from the transplantation, and Karen expects 20. Singer would say that the self-evident choice is to treat Lisa. No unfairness is implicated by such a decision. From such fictional cases, and from the abstract argument which I mentioned earlier, Singer concludes that utilitarianism and maximization of expected QUALYs is, after all, the proper rule to use for resource allocations in medicine.

I will not follow out all the intricacies of the ensuing discussion, since it is enough for my purposes to emphasise two points.

(1) The first one is that Harris, in his argumentation, relies heavily on a principle of *equal rights to life*, for all human beings irrespectively of their quality of life and expected remaining lifetime. In the following, I will avoid debating this principle and only discuss choices between treatment alternatives which do *not* differentially affect life expectancy. But it should be mentioned that the principle of equal rights to life, or something like it, seems to be a well-entrenched moral principle among people in general. In a recent, Norwegian willingness-to-pay study of three alternative medical services, where the participants were informed about the expected benefits of the alternatives, people revealed a *ten times* higher willingness to pay, in terms of Norske Kroner per QUALY, for a life-saving helicopter service than for an extension of a quality-of-life enhancing hip surgery program!

### *Willingness to pay for 3 different programmes*

	Ambulance	Surgery	Hip repl.
WTP/year	316	306	232
QUALY gain	150	200	1125
WTP/QUALY	2	1.5	0.2

Olsen J A & Donaldson C, *Helicopters, hearts and hips: using willingness to pay to set priorities for public sector health care programmes*. **Social Science and Medicine** 46 (1998), 1-12.

Legislators and decision makers who want to promulgate a policy of QUALY maximisation in medicine must certainly respect such public opinions. It is quite another matter whether these opinions can be supported by rational arguments.

(2) The second thing to note about Harris's argument is that his main example involves a principle of *compensatory justice*, which, in turn, can be seen as a special case of a more general *equity* (or equality) principle. Remember that in the original version of the Karen & Lisa case, Karen has suffered for 20 years from the consequences of the car accident, while Lisa has had a good life. Hence, it can be argued, it is fair to compensate Karen for her past suffering rather than to give even more to Lisa. In other words, by choosing to transplant Karen's heart the sum total over time of good in Karen's and Lisa's respective lives become *more equal* than if one had chosen to transplant Lisa's heart. It is important to note that this element of compensatory justice is lacking from the modified Karen & Nina case, in which Singer argues that QUALY maximisation is self-evidently right. Here, the assumption was that Karen and Lisa were equally well-off up til now, so nobody has to be compensated for anything.

As just noted, the principle of compensatory justice can be seen as a special case of a more general principle of equity. In many decisions concerning resource allocations, another application of the principle of equity is possible. Suppose, for a final fictional example, that Karen's and Lisa's pre-operative lives were equally good overall but that last week, Karen fell victim of the disabling traffic accident. Let us also imagine that in this case, the heart operation is not life-saving but only quality-of-life preserving. Lisa's quality of life will be 1

with the operation instead of 0.7 without it, while Karen's (because of the accident) will be 0.6 with the operation and only 0.4 without it.

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### *The case of Karen and Lisa (version 3)*

<b>Subject</b>	<b>QoL before op.</b>	<b>Exp. QoL/LL wo and w op.</b>	<b>QUALY gain</b>
Karen	.6 (but most of her life, 1)	wo: .4/40 years w: .6/40 years	8
Lisa	1 (but .6 for a week at age 7)	wo: .7/40 years w: 1/40 years	12

*Comment: Compensatory justice is not relevant here, only prospective fairness.*

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The expected gain for Lisa is greater than the one for Karen, but is it right to choose Lisa for heart surgery? Many would say that "prospective" equity considerations, referring to a comparison of Karen's and Lisa's expected quality of life without an operation, dictate that we do the other way round.

Now, at least for cases in which the different results of alternative medical intervention only concern the quality of life and not its quantity, it seems to me that a compromise position between Harris and Singer is both possible and rational. If no element of compensatory justice, nor any other equity concern, is involved, as in the second Karen & Lisa case above, simple QUALY maximisation is allowable. If, however, one of the participants has been considerably less well-off earlier in life, there should be a trade-off between the expected benefit and the previous deficit so that only a fairly large difference in added QUALYs can tip the balance in favour of the person who is better off from the beginning. Similarly, any prospective inequality, i.e. any future inequality which results from the intervention, should be weighted in.

Many different compromise standpoints are possible depending on what is, according to one's moral standpoint, a "fair" balance of the utilitarian principle against these two aspects of equity. Here is also the proper place to note that most so-called egalitarians (including the present author) would not let a difference in well-being between two subjects count for much if both of them are very well-off. This standpoint means that inequality *as such* is not the target, only inequality which implies a bad life for the worse-off.

Let us now have a look at the relevance for epileptology of the Singer-Harris discussion. I will outline just one situation, out of very many, in which compensatory justice and

prospective equity could come into play and change a decision of resource allocation for epilepsy.

The population of patients which, potentially, could benefit from epilepsy surgery is, as we all know, heterogeneous, and the patients have varying prognosis. For example, patients for whom there is reason to expect that their partial complex seizures are due to a circumscribed, unilateral temporal focus will probably benefit substantially from an epilepsy surgery evaluation, while the expected gain is lower in those cases where there are signs of more extensive brain damage and perhaps multifocality. At the same time, the not-so-good-prognosis patients are often less well off from the beginning than the good-prognosis ones. This is partly due to the fact that extensive brain damage is often accompanied *both* by a low quality of life and by a low expected gain from an epilepsy surgery evaluation.

For the sake of argument, let us assume that the the expected cost per gained QUALY for a certain not-so-good prognosis patient is twice that of a good-prognosis patient, say \$ 40.000 as against \$ 20.000.

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### *A fictive choice in Epilepsy Surgery Evaluation*

	QoL	Exp. gain	Cost/QUALY
Patient 1	.5	.1	\$ 40.000
Patient 2	.7	.2	\$ 20.000

*Comment: "Efficient use of resources" (utilitarianism) dictates that we should choose patient 2. But is this fair?*

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Imagine that because of economic restrictions, we are forced to prioritise between these two and let only one of them have a surgery evaluation. At first look, this prioritising task may seem simple indeed: Take the line of action which produces the greatest net benefit, which means choosing Patient 2. But supposing, as we did above, that Patient 1 is less well-off from the beginning (and not only *less* well-off, but really *bad* off; cf what just I said about egalitarianism), couldn't that be a sufficient reason for turning the table and spend the resources on her? Note that both compensatory justice and prospective equity come into play here. The not-so-good surgery candidate has suffered more during her lifetime, and although the gain she expects from the operation is smaller than that which the good-prognosis patient can expect, it is also a gain from a much lower expected level. So, are we really doing the right thing if we prioritise operating the good-prognosis patient?

I do not want to resolve this issue in a dogmatic way by trying to tell you which moral principle is the correct one. Instead I just conclude that it is essential for proper decision-making concerning resource allocation in medicine that fundamental moral principles are brought to light and discussed. The problem of the proper methodology for settling the big theoretical questions which any such discussion actualises is not within the scope of this paper. Instead I will summarise my main points by quoting another recent paper.

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Ethics is typically not considered in economic analyses. However, ethical and economic aspects are not easy to separate. One fundamental difficulty is that the foundations of the economic analysis are ethically biased towards utilitarianism. In the choice between different health care allocations both economic and ethical aspects must be considered. If this ethical bias inherent in economic theories is not recognised, the choice could be dubious from an ethical point of view.

Malmgren K, Hedström A, Granqvist R, Malmgren H & Ben-Menachem E, *Cost analysis of epilepsy surgery and of vigabatrin treatment in patients with refractory partial epilepsy. Epilepsy Research* **25** (1996), 199-207.

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