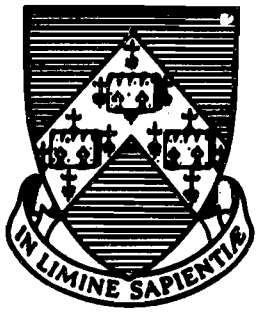

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Health Economics, Priority Setting and Medical Ethics: Implications for Multiple Sclerosis

by
Alan Williams

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Abstract

The need for priority-setting in health care systems has forced us to think more carefully about objectives and opportunity costs. If our objective is the maximisation of the health of the community, for this to be an effective guide to action we have to find some practical way of describing and valuing health, and we have to find out how far various health care activities do actually contribute towards improving people's health as so measured. Although different measures of health place different weights on different dimensions of health, there is general agreement that, to be acceptable, such measures must include changes in life expectancy and changes in patients' quality of life, and the weights used should preferably reflect ordinary people's values.

In the case of unpredictably progressive conditions, such as Multiple Sclerosis, for which there is as yet no scientifically established cure, it might be thought that there is no case that can be made for devoting resources to its treatment, in the face of competition from the highly effective therapies that have been developed for many other conditions. But this is to neglect the many treatments on offer to MS sufferers which will improve the quality of their lives, even though they have no effect on the underlying disease process. But to evaluate their effectiveness requires measures which concentrate on quality-of-life dimensions, and which reflect people's own valuations, and which are not impossibly complex to administer and/or interpret.

The prime candidates for such a role in the MS field are the measures developed by Kurtzke and his collaborators. But they have billions of

possible "cells" in their classification systems, and in their more practicable abbreviated versions they use quite arbitrary weights in order to generate a single index number. It is suggested that if MS is to compete effectively for resources, then these quality-of-life measures need to be drastically simplified, and relative valuations need to be elicited from ordinary people for each such simplified health state, so that a single index number can be generated as a tool for comparing the effectiveness of different interventions. At the same time, one of the standard "generic" measures of quality-of-life should also be used alongside this modified Kurtzke scale, not only for general calibration purposes, but also to facilitate comparisons with the cost-effectiveness of those non-MS interventions which have already been appraised with those "generic" measures.

Although some people still see the encroachment of cost-effectiveness considerations into health care evaluation as a retrograde and even as an unethical matter, it cannot be ethical to impose avoidable sacrifices upon people (especially when these sacrifices are, essentially, unnecessary suffering and/or premature death), and that is what economic evaluation is seeking to prevent. Seen in that light, there can be nothing immoral about becoming more efficient!

HEALTH ECONOMICS, PRIORITY SETTING, AND MEDICAL ETHICS; IMPLICATIONS FOR MULTIPLE SCLEROSIS

I start from the assumption that the objective of the health care system is to maximise the health of the community, given the level of health care provision that has been deemed affordable. Such has been the progress of medical science and medical practice in recent decades that not even the richest countries can now afford to undertake every health care activity that might conceivably do someone some good somewhere sometime. We therefore find ourselves in the paradoxical situation that although as communities we are richer than we have ever been, and have more potentially beneficial activities available to us than ever before, we face increasingly excruciating decisions about priorities in health care, i.e. about which activities we can afford to undertake, and which we have reluctantly to set aside, at least for the time being.

Priority Setting

One implication of this unfortunate situation is that it is no longer sufficient, when making a bid for more resources to be devoted to some activity, to show that that activity is beneficial (i.e. effective). What is now required is a demonstration that that activity is more beneficial than anything else that anyone can do with those same resources (i.e. that it is cost-effective). Politically this is seen as an unpleasant and divisive development, since it sets specialty against specialty and patient against patient in the competition for

resources. It is, however, inevitable, and rather than bemoaning the fact and wishing it would go away, a more constructive response is to face up to the challenge it poses, and adapt our ways of thinking, and our ways of acting, accordingly, but without losing sight of the fundamental objective, which remains that of maximising the health of the community served, within the resource constraints we face.

This requires us first to be clear about what we mean by health. For me this is a straightforward matter at the level of principle (though at the practical level things get rather difficult, as we shall see shortly). The two broad dimensions of health are life expectancy and quality of life. By "quality of life" is meant here quite basic features such as the ability to go about one's normal activities without pain or distress, in other words the rather primitive aspects of living which, when we are healthy, we take for granted, but which suddenly assume great importance when they are compromised by illness or injury.

In thinking about health, economists have found it useful to employ the unifying concept of the QUALITY-ADJUSTED-LIFE-YEAR, or QALY for short. Again the underlying idea is simple in principle, but rather difficult to implement in practice. If by some treatment we can offer people additional years of <u>healthy</u> life expectancy, each such additional year counts as ONE unit, i.e. 1 QALY. But if (as is often the case) the best we can do is offer people additional years of <u>unhealthy</u> life expectancy, then we should rate each such year as being worth less than ONE, according to the relative value attached by people to being, say, chairbound and in moderate pain, compared with being fully mobile and in no pain. This is what the "quality-adjustment" bit of the QALY is all about.

As an example of the way in which this notion can be used to appraise the benefits of a treatment, I will describe briefly how I have used it to estimate the benefits of Coronary Artery Bypass Grafting (compared with drugs) for the treatment of a typical patient with severe angine and left main disease (the most threatening manifestation of that condition). I used Rosser's Classification of Illness States (Table 1) as the basis for my quality-of-life assessment, which, as you see, works with the 2 dimensions of disability and distress, which together generate 29 possible health states that people can be in (in the case of "unconscious" no differentiation between levels of distress seems necessary). There is, of course, a 30th state, "dead", which takes us to the life expectancy dimension of health. For me the great advantage of Rosser's classification is that she derived a valuation matrix (Table 2) to go with it, based on the views of 70 subjects (a mixture of doctors, nurses, patients and healthy people). This matrix provides a set of "quality adjustments" with which to evaluate the various unhealthy states relatively to the state of being healthy (which by convention takes on the value 1) and relatively to being dead (which by convention takes on the value 0). You will note that the median values from Rosser's respondents indicate that 2 states (rated at 0) are regarded as being as bad as being dead, and 2 more (with negative ratings) are regarded as being worse than being dead.

What I then did was to get some Cardiologists and Cardiac Surgeons to estimate the prognosis for a particular category of patient when on drug therapy, not simply in terms of life expectancy, but also in terms of the expected year by year transition from one disability/distress state to another. I then got them to repeat the exercise for the same patient if given a coronary artery

TABLE 1

Rosser's Classification of Illness States

DISABILITY		DISTRESS	
I	No disability	A.	No distress
II	Slight social disability	B.	Mild
III	Severe social disability and/or slight impairment of performance at work Able to do all housework except very heavy tasks	C. D.	Moderate Severe
IV	Choice of work or performance at work very severely limited Housewives and old people able to do light housework only but able to go out shopping		
V	Unable to undertake any paid employment Unable to continue any education Old people confined to home except for escorted outings and short walks and unable to do shopping Housewives able only to perform a few simple tasks		
VI	Confined to chair or to wheelchair or able to move around in the house only with support from an assistant		
VII	Confined to bed		
VIII	Unconscious		

TABLE 2

Rosser's Valuation Matrix: All 70 Respondents

DISABILITY RATING	DISTRESS RATING			
	A (None)	B (Mild)	C (Moderate)	D (Severe)
I (None)	1.000	0.995	0.990	0.967
II (Slight social)	0.990	0.986	0.973	0.932
III (Severe social or slight work	0.980	0.972	0.956	0.912
IV (Work severely limited)	0.964	0.956	0.942	0.870
V (Unable to work)	0.946	0.935	0.900	0.700
VI (Confined to chair)	0.875	0.845	0.680	0.000
VII (Confined to bed	0.677	0.564	0.000	-1.486
VIII (Unconscious)	-1.028	NOT APPLICABLE		

Source: Kind, Rosser and Williams: "Valuation of Quality of Life: Some Psychometric Evidence" in Jones-Lee, M.W. (editor) The Value of Life and Safety, North Holland, 1982.

bypass graft. I then applied the quality-adjustment score from Rosser's valuation matrix to each such described state, and plotted the result as indicated here (in Figure A). The horizontal axis shows life expectancy, the vertical axis quality of life (as measured on the Rosser Scale). The benefits of successful treatment are given by the shaded area. The actual benefit calculation has however also to take into account (i) the probability that the treatment will not work (which it fails to do in 30% of cases), (ii) the perioperative mortality rate (around 3%), as well as (iii) introducing a discount factor to reflect the fact that some of the benefits are rather remote in time. For what it is worth, may I simply say that the benefits in this particular case came out at about two-and-three-quarter QALYs.

By itself that means very little. It acquires more meaning when we take two further steps. The first is to take note of the extra costs of CABG over drug treatment, which in the UK in 1985 (when these calculations were made) was about £2,800, so that the QALYs gained by this treatment for this type of case cost the health service about £1000 each (or about US$ 1600 at current exchange rates). Even in a middle-income country like Britain that is undoubtedly a bargain. But if we now take the second further step and compare that COST-PER-QALY with those obtained by other treatments (Table 3), it acquires still more significance, for it enables us to see where, in any priority rating of health care, a particular treatment ranks. The implication is that, if we are to fulfil our objective of maximising the health of the community with the limited resources at our disposal, we should switch resources into those activities whose cost-per-QALY is low, at the expense of those whose cost-per-QALY is high. Some high cost activities could still be continued as research activities, but in my

Figure A

CASE 1: SEVERE ANGINA: LEFT MAIN DISEASE

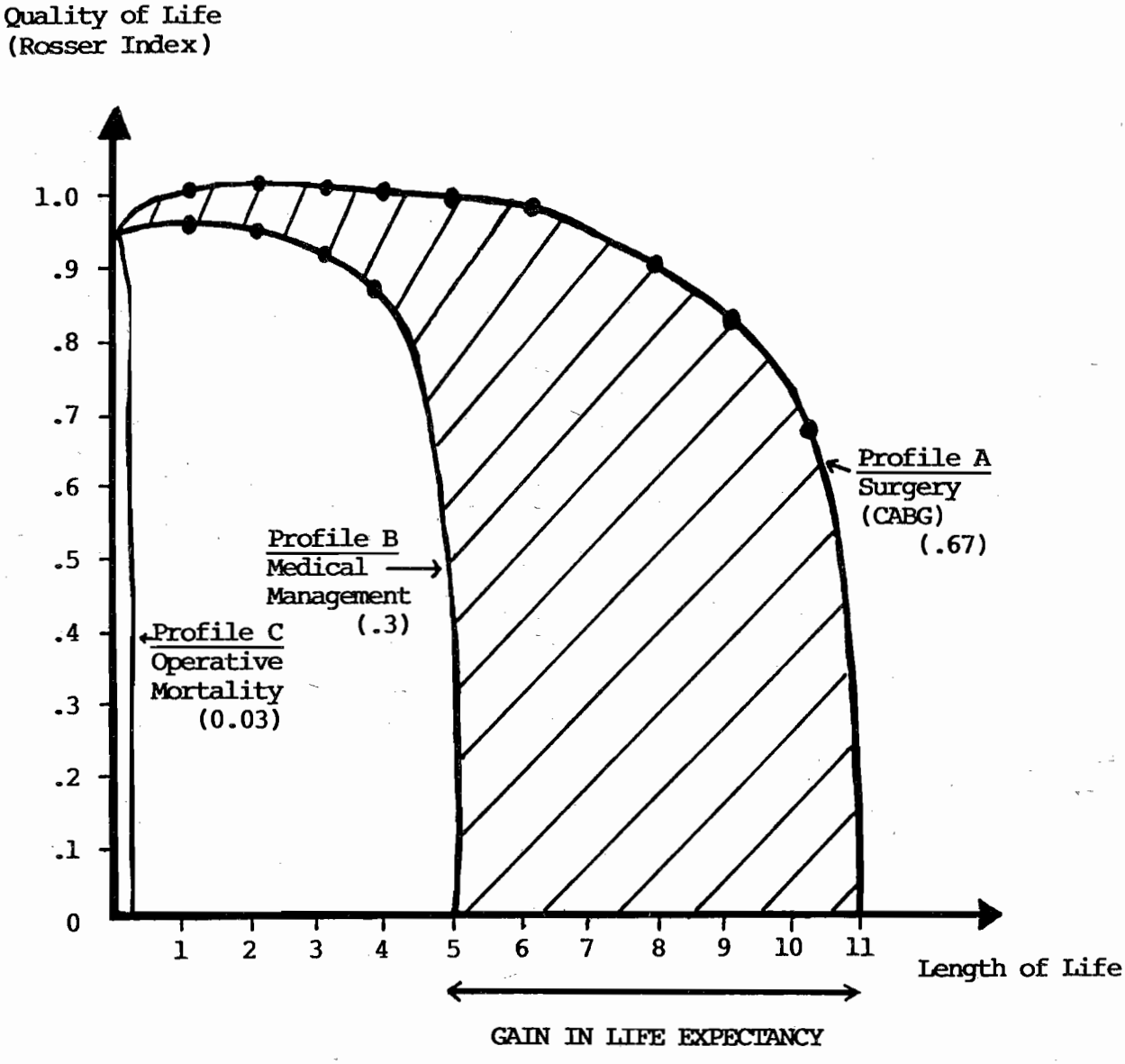


TABLE 3 SOME SELECTED TREATMENTS

RANKED BY COST-PER-QUALITY-ADJUSTED-LIFE YEAR

(£'000 1985 NHS COSTS)

Hospital haemodialysis	15
Heart transplant	8
[UK GNP PER HEAD	5]
CABG for 2VD & moderate angina	4
Kidney transplant	3
Hip replacement	0.8

Source: Williams A (1985).

view not unless they are separately funded, pursued according to carefully reviewed scientific protocols, with full disclosure of data, and evaluated by independent researchers (not by the protagonists themselves!).

To make this system work, with respect to each health care activity we need information on:

(a) its effects on life expectancy

(b) its effects on quality of life

(c) the values attached to different health states

(d) how benefits to different people are to be added together

This last point may generate some surprise, since it is not normally considered explicitly in clinical trials or indeed in most other evaluations of health care activities. For example, one of the commonest indicators of outcome in clinical trials is the survival rate at some designated point in time, e.g. at two years after entry into the trial. But what are the implications of using such a measure to choose between treatments ? They are as follows:

(1) to survive less than 2 years is of no value

(2) having survived 2 years, further survival is of no additional value

(3) it does not matter with what <u>quality</u> of life people survive to 2 years

(4) it does not matter who you are

The only one of these implicit assumptions that is acceptable to me is the last one, and it was on that basis that I did the earlier calculations that I showed you. But if, say, it were felt that benefits to young people should count for more than benefits to old people, or that the parents of young children should get priority over their contemporaries without children, there is no technical problem in incorporating such weights into the calculations, though there may well be considerable problems in eliciting a set of weights that the community would accept as proper in this context.

I did not expect to get much help with that particular problem from any published clinical trial, but I did expect to get help with my other information requirements, namely, the effects of various treatments on life expectancy and quality of life, and how patients valued any such changes. The fruits of my labours have, in general, been disappointing. For instance, some time ago I spent a fascinating weekend going through all the issues of The Lancet published in 1987 to see what outcome measures were used in the reported trials of ostensibly therapeutic activities. I found 93 such trials, the nature of the outcome measures used being as follows:

PHYSIOLOGICAL .....in 84 STUDIES

MORBIDITY.....33.....

MORTALITY.....28.....

QUALITY OF LIFE

using loose criteria.....32.....

using strict criteria.....9.....

28 studies had only physiological measures, and none of the 28 studies which reported survival data calculated the implications for patients' life expectancy. To get the tally of quality-of-life measures up to a reasonable level, I had to include measures such as heartburn and cough frequency, even though in context it seemed that the investigators were really using them as physiological measures. Being rather more stringent, and requiring some more formal and systematic measurement process, left me with only 9 studies, which concentrated on physical functioning(including activities of daily living) and pain/distress. Only one elicited patients preferences or overall evaluation. All in all, not very helpful!

One of the commonest measures of patients' quality of life is Karnofsky's Index (Table 4) which has 11 categories based essentially on physical mobility and selfcare. Its disadvantages, compared with Rosser, are that it has no pain/distress dimension, and the numerical scores are purely conventional and do not pretend to represent the actual views of patients about their relative valuation of each state. In a recent review of all generic measures of this kind (i.e. those not designed for use with a particular condition but intended to be used across a wide range of conditions) Wenger recommended that consideration be given particularly to the five set out in Table 5, which range in complexity and coverage from the Sickness Impact Profile (which takes about half an hour to complete) to the General Health Rating (which takes only a few minutes). So there is really no dearth of candidates for anyone seriously interested in pursuing this line of enquiry, though it has to be said that they each have drawbacks.

TABLE 4 KARNOFSKY PERFORMANCE STATUS INDEX

Definition	%	Criteria
Able to carry on normal activity and to work NO special care needed	100	Normal; no complaints; no evidence or disease
	90	Able to carry on normal activity; minor signs or symptoms of disease
	80	Normal activity with effort; some signs or symptoms of disease
Unable to work. Able to live at home, care for most personal needs	70	Cares for self. Unable to carry on normal activity or to do active work. A varying amount of assistance is needed
	60	Requires occasional assistance, but it able to care for most of his needs
	50	Requires considerable assistance and frequent medical care
Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly	40	Disabled; requires special care and assistance
	30	Severely disabled; hospitalisation is indicated although death not imminent
	20	Very sick; hospitalisation necessary; active supportive treatment necessary
	10	Moribund; fatal processes progressing rapidly
	0	Dead

TABLE 5 WENGER'S SHORT-LIST OF GENERIC MEASURES

(Self Assessed Patient Questionnaires)

Instrument:	No of Items:	Time Required:
SICKNESS IMPACT PROFILE	136	30'
MCMASTER HEALTH INDEX	59	20'
NOTTINGHAM HEALTH PROFILE	45	10'
PSYCHOLOGICAL GENERAL WELLBEING	22	12'
GENERAL HEALTH RATING	29	7'

Source: Wenger NK et al (1984) - Overview, in Wenger NK et al (editors) Assessment of Quality of Life in Clinical Trials of Cardiovascular Therapies, Le Jacq, New York.

Multiple Sclerosis

"What has all this to do with Multiple Sclerosis?" you may be wondering. Well, when invited, as an innocent outsider, to contribute to this conference, what I brought to it was this way of thinking and this experience in other fields of medicine, and as one with no previous exposure to MS I was intrigued to be offered an opportunity to see where you have all got to with these same problems. As a non-medical new entrant, who has only had a chance to scan the literature on MS briefly and cursorily, I expect that I will have missed some relevant and important material. But the great advantage of ignorance, as compared with stupidity, is that it is remediable, and I am sure I am in the right place to have it remedied ! Meanwhile what I propose to do is to see how far I can get, in evaluating the cost-effectiveness of treatments for MS, with the material that has come to hand.

Before doing that, however, I had better declare in general terms what I think I know about the course of MS and its treatment, as gleaned from my background reading, so that if I am labouring under a gross misapprehension about the current state of play you can straighten me out on that too. The three key features about the condition itself appear to be:

(a) the course of the disease is extremely variable

(b) it is especially difficult to predict what course it will take in any particular patient

(c) there is little correlation between the clinical indicators of disease severity and its effects on the life expectancy and quality of life of patients

The three key features about the treatment regimes currently available appear to be:

(i) there is no proven method of influencing the natural history of the disease

(ii) there is no known way of influencing its effect on life expectancy

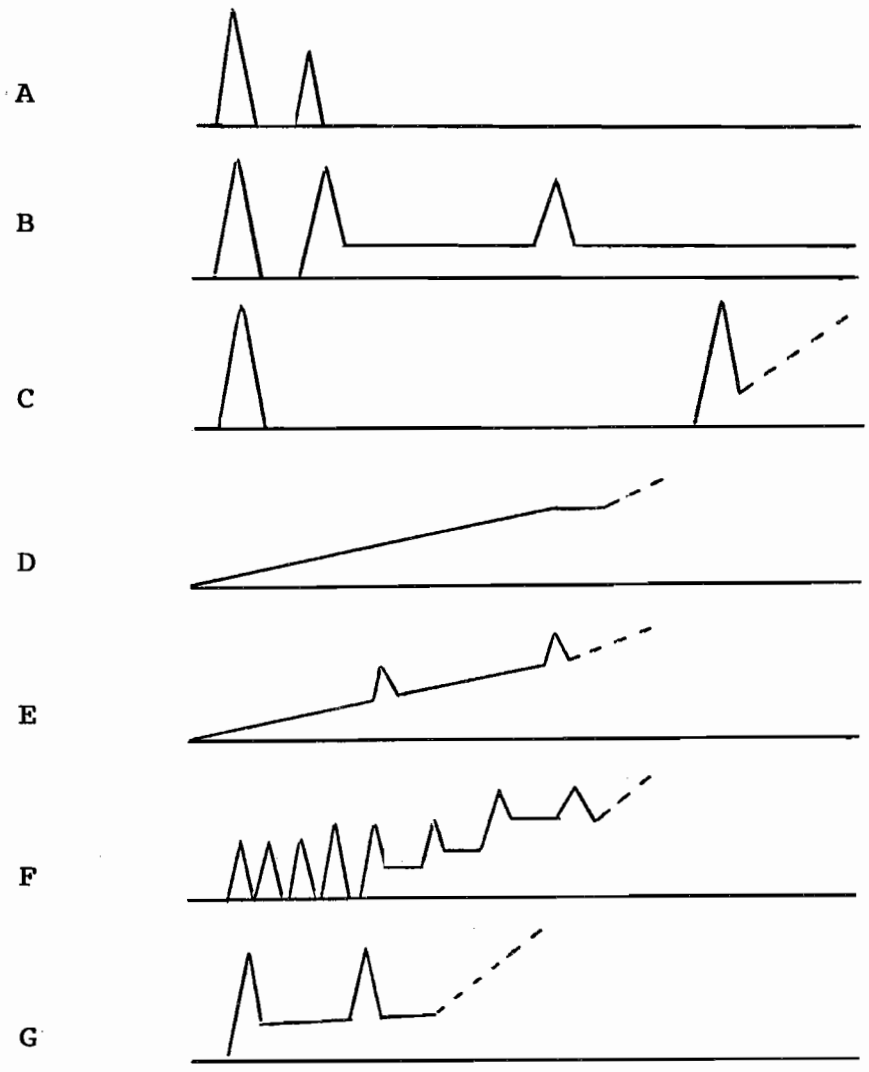
(iii) the major emphasis is therefore upon ameliorating the effects of the condition upon the patient's quality of life

which brings us back to where I started, namely the measurement and valuation of different states of disability and distress.

The variability of the course of the disease was well illustrated in a diagram (Figure B) published in a 1975 booklet on MS produced by the Office of Health Economics in London, and based on earlier work by McAlpine et al (1972). 7 different patterns are identified, and labelled A to (through) G. To fit these schematic representations into my framework of thought I need to label the vertical axis "Quality of Life" and turn the diagrams upside-down so that Case A now looks like this (Figure C), Case E now looks like this (Figure D), and Case F now looks like this (Figure E). What I then need are the results of studies

Figure B

THE COURSE OF MULTIPLE SCLEROSIS



A. Abrupt onset; few if any relapses after first year; no residual disability
B. Relapses of diminishing frequency and severity; slight residual disability
C. Abrupt onset with good remission followed by long latent phase
D. Slow progression from onset without relapses
E. Slow progression from onset, superimposed relapses, and increasing disability
F. Many short attacks, tending to increase in duration and severity
G. Severe relapses, increasing disability and early death.

Source: McAlpine et al 1972.

Figure C

HYPOTHETICAL CASE A
as a time profile of quality of life

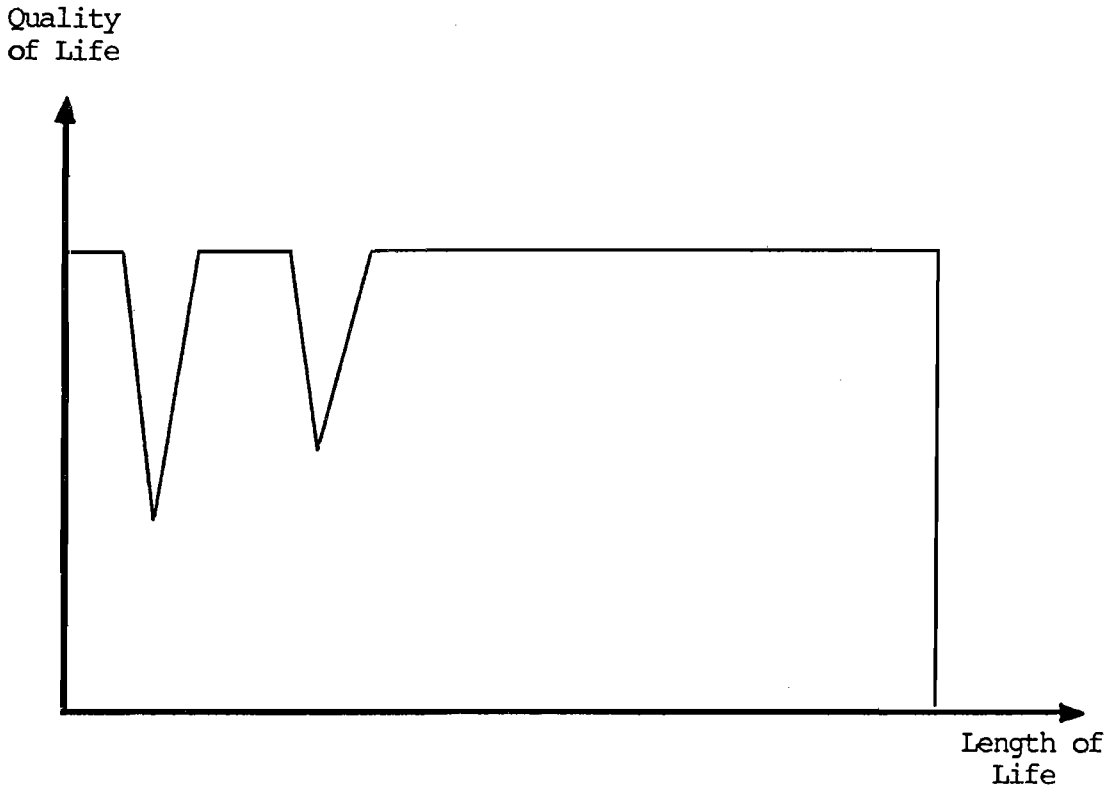


Figure D

HYPOTHETICAL CASE E
as a time profile of quality of life

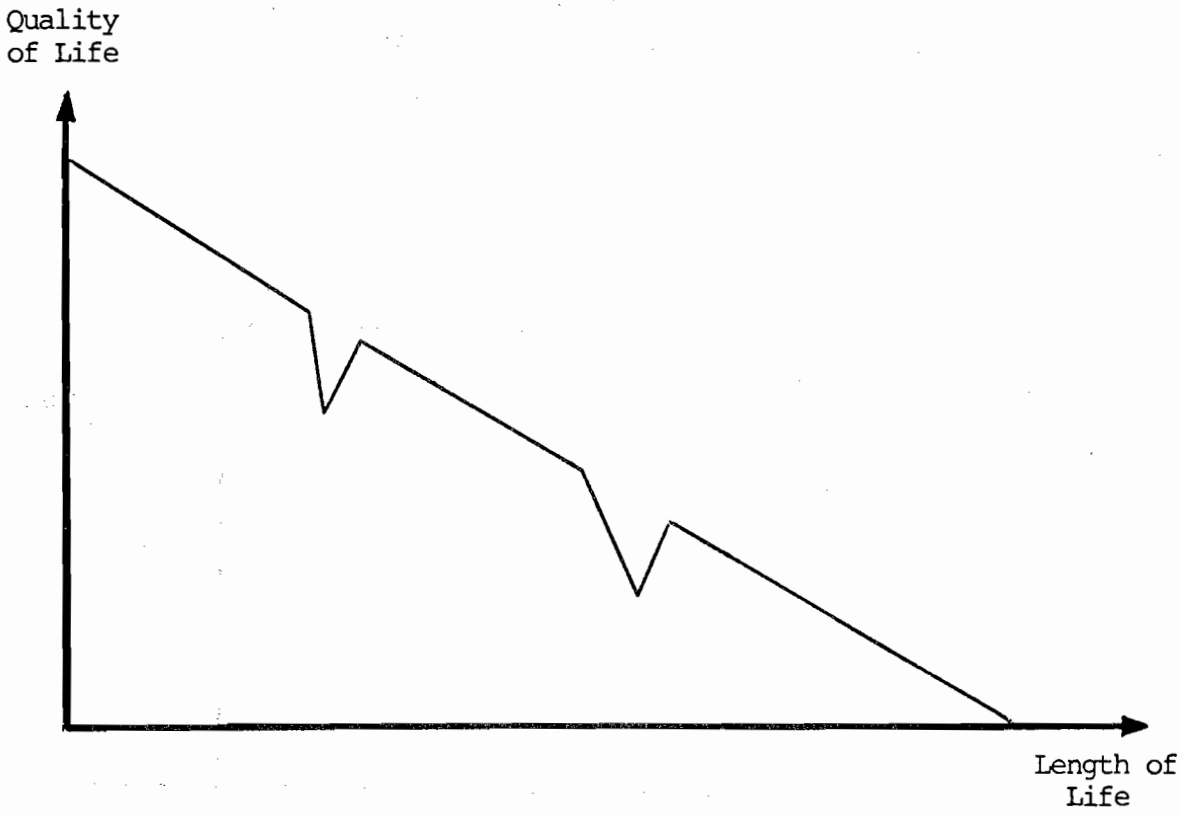
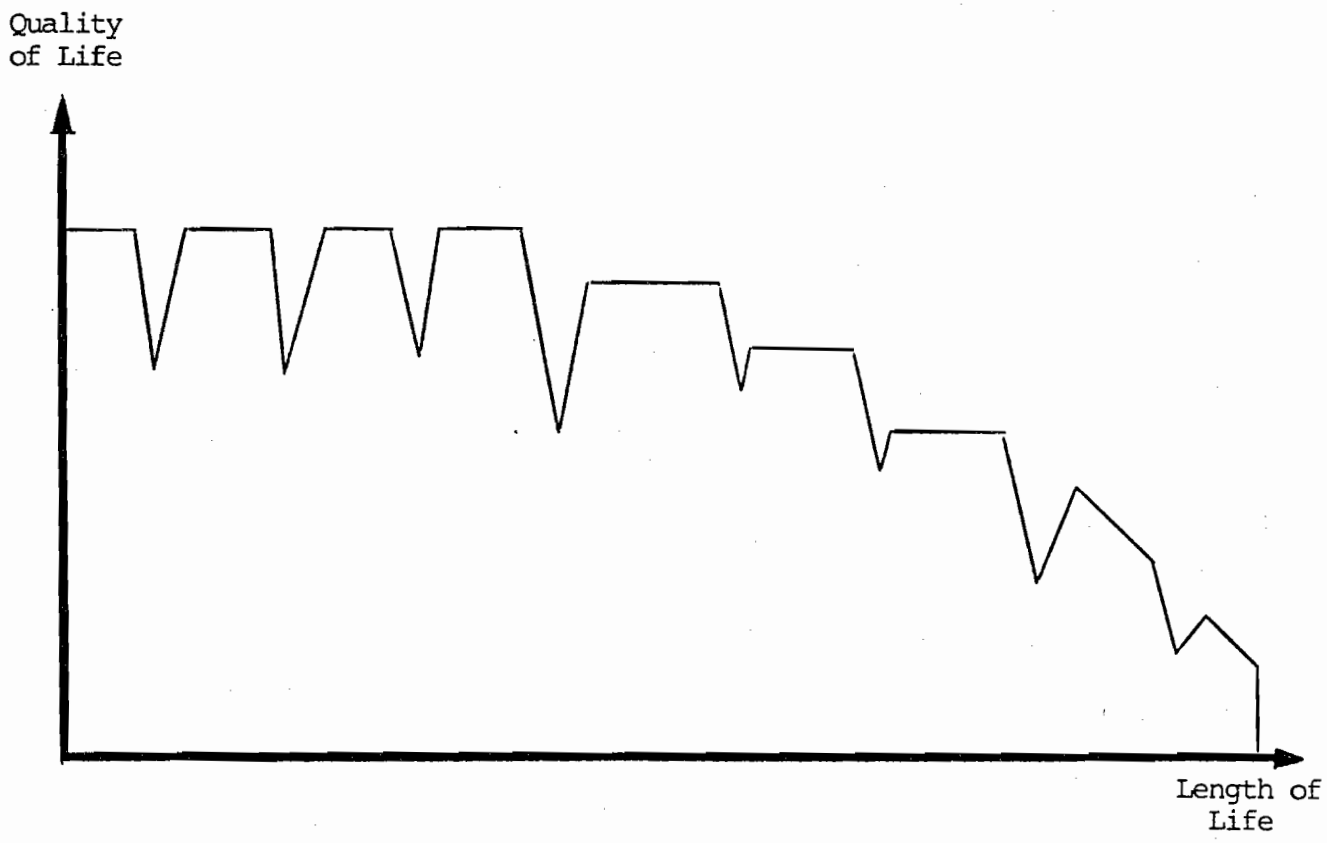


Figure E

HYPOTHETICAL CASE F
as a time profile of quality of life

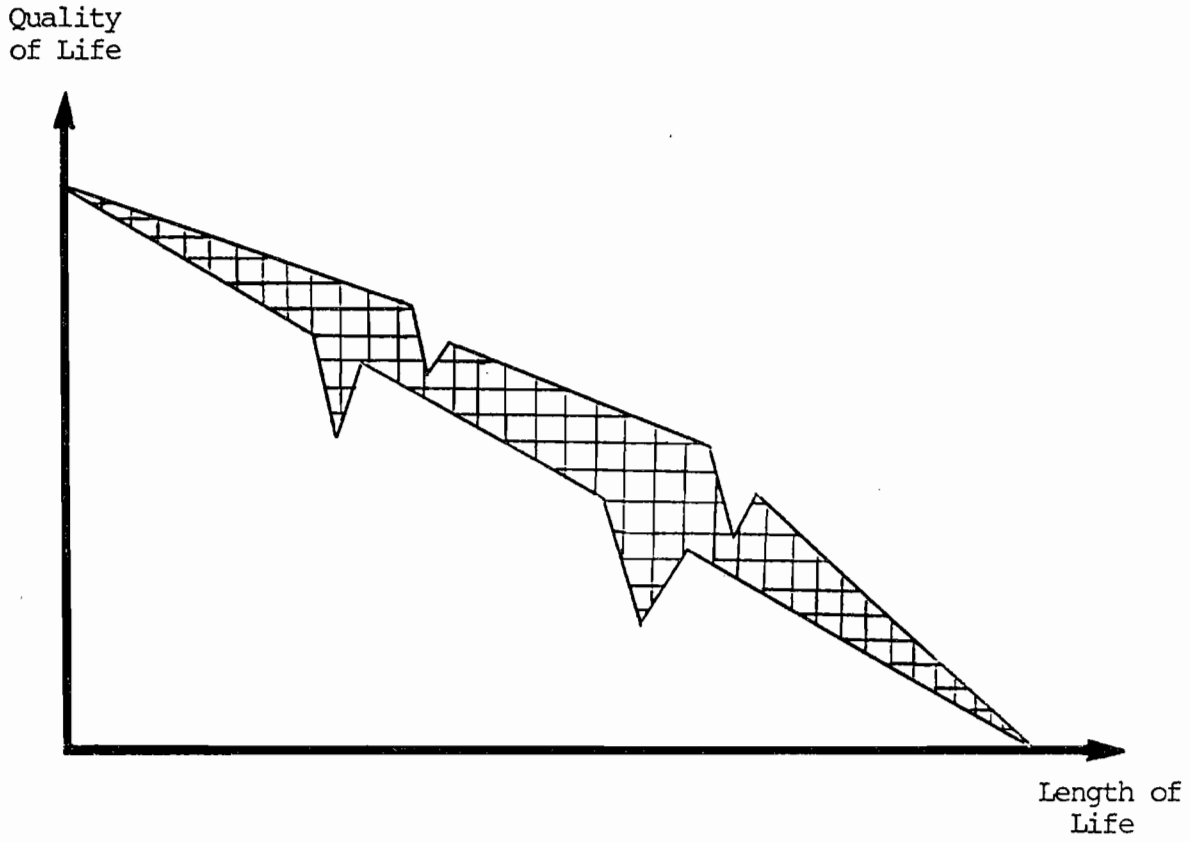


evaluating various treatments for MS, showing that treatment improves things in some such way as indicated here (Figure F), where I have used Case E as the base point for purposes of illustration, and the benefits are indicated by the shaded area. I should perhaps add that in my world the term "treatment" has a very wide meaning, and can include not only things like drugs, surgery, remedial therapy and counselling, but also the provision of mobility aids, home adaptations, domestic help, and even just simply giving patients more information ! Notice that in the case I have illustrated I have not assumed any effect of treatment on life expectancy, and the disease is still progressive, so my framework of thought does not depend on breaking out of the present limitations facing the treatment of MS in order to identify potentially beneficial activities. Any treatment which improved people's capacity to get on with their normal activities, or which reduced anxiety and distress, would get a positive rating on my scale. If, in addition, I knew what each treatment cost, I could calculate a cost-per-QALY (as with my earlier Angina case) and put MS treatments into my league table.

But I have not been able to do this, and I think it would be worth spending the next few minutes considering why. The main problem is the approach which has been adopted to measuring quality of life. The earliest study I found which contained readily useable data on both life expectancy and quality of life dates back to 1950, when Ipsen reported his findings on a cohort of 1000 MS patients in the Boston area. I will here concentrate only on the females, who outnumbered the males in his study population (and had a slightly better prognosis). He distinguished only three categories of quality of life (though that was not the terminology he used), and these three categories were: Working, Ambulatory, and

Figure F

Time Profile of Hypothetical Treatment Benefits
(based on Case E)



Bedridden. If these are given the weights 1.5, 4.5, and 8.5 respectively (which is roughly what they would get on Kurtzke's Disability Scale, of which more anon), it is possible to derive the profile shown in Figure G. In this diagram Kurtzke's scale (which runs from 0 to 10, with 0 the best and 10 the worst) is inverted and used on the vertical axis as an index of quality of life (just as Rosser's Index was used earlier). As in my earlier diagrams, life expectancy is measured along the horizontal axis. But that was 40 years ago, where have we got to today?

Well, as far as I can see, not a lot further in the particular respects that interest me. We do of course have much more detailed classification schemes for grading disability, mostly due, it appears, to the work of Kurtzke and his colleagues. But when these more sophisticated scales are used, for instance by Goodkin and others in a recently published survey of 425 MS patients, and processed as described earlier with respect to Ipsen's work, we get a very similar picture (Figure H) to the earlier one, though since these recent data refer only to survivors we get a rather more optimistic picture on the right-hand side of the diagram (i.e. for disease duration in excess of 20 years).

Kurtzke's thorough work is obviously central and influential, and its latest product, the Incapacity Scale of 1987, was developed from earlier work which Granger had done relating to the Barthel Index. Kurtzke's stated objectives are both ambitious and farsighted, and are as follows:

1. To cover the major aspects of social functioning
2. To provide some quantification of each type of functional loss

Figure G

A Time Profile of Quality of Life
(based on Ipsen's Data)

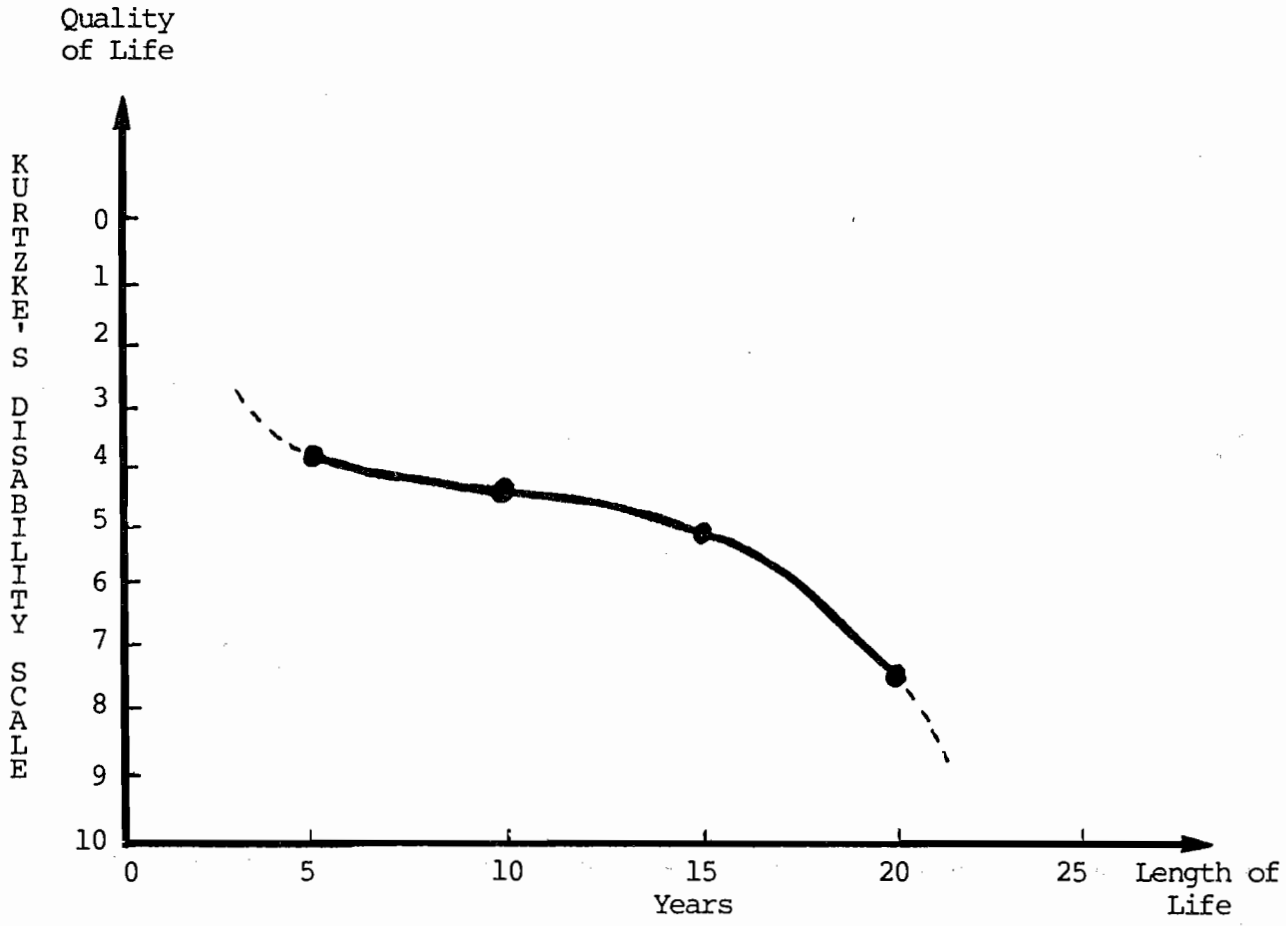
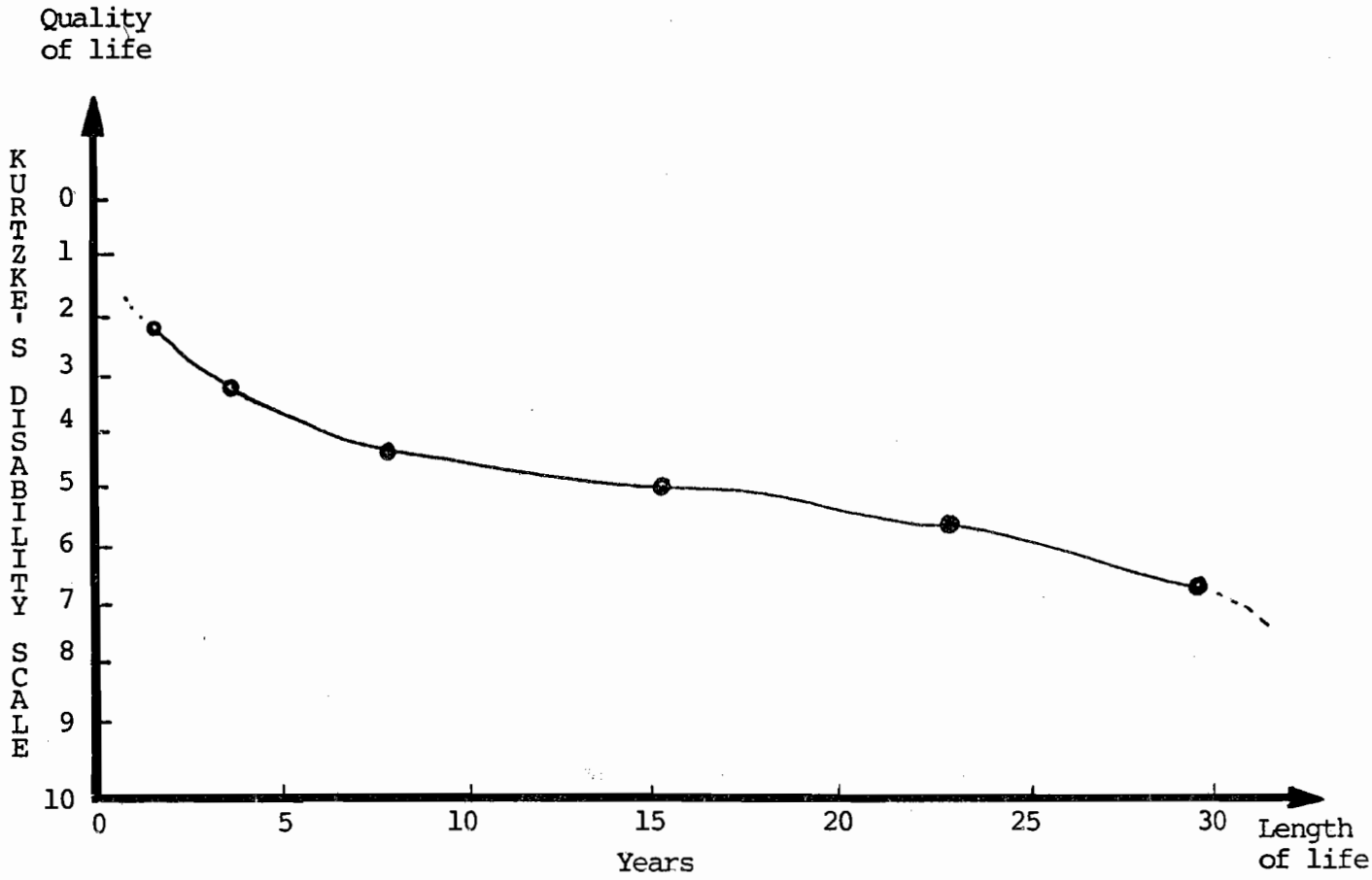


Figure H

A Time Profile of Quality of Life
(based on Goodkin's Data)



3. To permit a composite or profile of functional skills

4. To be simple and clear enough not to be a burden in application

5. To be acceptable to different people in different settings

He goes on to comment that

> "If successful, such a scale would also be of direct value for recording the continuum of care, as well as for the socioeconomic planners whose charge it is to provide needed services for the disabled and their families."

Although I am not actually one of these socioeconomic planners, from my academic ivory tower it is their standpoint I try to empathise with, and it is from that standpoint that my comments flow. Kurtzke's Incapacity Scale covers no less than 16 dimensions of life (Table 6), each of which is to be graded from 0 to 4 (in ascending order of disability). The problem is that such a complex rating system generates more than 150 billion different possible health states (compared with Rosser's 29), and although not all of them will be encountered in practice, its effective use as a 16-dimensional profile of health in evaluative studies remains to be demonstrated, and must be problematical in view of the very large number of cells in his classification scheme. Anticipating this problem, he suggests that the data be condensed by computing an overall score (which would have a range from 0 to 64), with low scores being good and high scores being bad. This unweighted sum is acknowledged to be a "first approximation" to a true overall rating, and the system is really being advocated as "a minimal record of disability that could be applied easily and

TABLE 6 ITEMS COVERED IN KURTZKE'S INCAPACITY SCALE

Stair climbing	Bladder function	Vision
Ambulation	Bathing	Speech and hearing
Chair/bed transfer	Dressing	Physical problems
Toilet transfer	Grooming	Societal role
Bowel function	Feeding	Fatigability

Psychic (mood and mentation) function

uniformly in many clinical settings". I am in no position to pass judgment on its merits in that respect, but as an overall rating of the severity of the impact of MS on people's lives it suffers from the fundamental drawback that these scores are essentially arbitrary, representing at best a rank ordering of states within each of the 16 dimensions individually. These scores do not represent the relative goodness or badness of being in each of the 150 billion different 16-dimensional composite health states, as perceived by the patients themselves. This is a very serious drawback from my viewpoint, because I want my "quality adjustment" rating to reflect people's actual relative valuations, and it is not a drawback that can readily be overcome by getting a group of MS patients to engage on such a rating exercise, for with 150 billion (or even with just 150) states to be rated relatively to being healthy and relatively to being dead this is an impossible logistic task. Somewhere between Kurtzke's 150 billion and Ipsen's 3 there has to be a happy medium somewhere, but I have not found it. Any suggestions?

If the use of existing MS-specific instruments (in their current or simplified form) proves not to be a viable way forward, then an alternative strategy might be to use one of the generic measures I mentioned earlier, alongside whatever MS-specific measures are required for detailed clinical purposes. I found some studies which have gone part of the way down this road. For instance, Harper et al (1986) have systematically compared part of the McMaster Health Index with Kurtzke's Disability scale and found a strong and significant correlation. But Kurtzke's Disability scale correlated poorly with other indices of emotional and mental state, a defect which might conceivably be rectified with the new Incapacity scale. A more promising line of advance

seems to be offered by Zeldow and Pavlou (1988) who in their study of 81 patients attending an outpatient clinic used (amongst other measures) one of the generic measures on Wenger's short-list, the Sickness Impact Profile, or SIP, which, you may recall, was the most complex and time-consuming one of the five listed. It covers 12 domains (see Table 7) and generates two subscores (for Physical Health and for Psychosocial Health) as well as an overall rating, and its weights do reflect people's judgments about the relative seriousness of being in the different states (Bergner 1988). They see such broad-ranging generic scales as changing the focus of interest from narrow neurological or psychological parameters to the broader concerns that patients have about the impact of the disease upon their lives. A similar conclusion is drawn by Robinson (1987) from his review of 23 clinical trials in the field of MS, and he strongly advocates the use of more "subjective" measures, such as the SIP, as a way of enhancing the purely clinical data which currently dominates such trials (his findings in this respect being similar to mine with the studies in the Lancet in 1987).

Personally, I think it would be very useful to relate Kurtzke's Incapacity Scale systematically to some generic measure such as the SIP, but at the same time to try to simplify it by finding out which of its features are the salient ones in patients' own perceptions of their quality of life, and then carry out more systematic psychometric work to establish the relative values attached to this smaller subset of states. We would then be able to proceed with evaluative work of the kind I am advocating, using this properly valued index as the measure of quality of life on my vertical axis, and, together with the

TABLE 7 ITEMS COVERED IN THE SICKNESS IMPACT PROFILE

SUBGROUP PHYSICAL:	SUBGROUP PSYCHOSOCIAL:	OTHER:
Ambulation	Social interaction	Sleep and rest
Mobility	Communication	Home management
Body care and movement	Alertness	Eating
	Emotional behaviour	Work
		Recreation and pastimes

TOTAL: Sum of all 12 individual items

other data I mentioned, facilitating the calculation of QALYs as the overall measure of the effectiveness of a treatment.

Costs and Medical Ethics

This brings me finally to the important shift of emphasis from measuring effectiveness (in QALY terms) to measuring cost-effectiveness (in cost-per-QALY terms). I have found no study in the MS field which attempts to do this. The closest thing that I have come across is a pilot study (with only 20 patients) by Feigenson and others published in 1981, which was concerned with the cost-effectiveness of MS rehabilitation. It was a before-and-after study, with no control group, so it was seriously flawed as a scientific design. To measure effectiveness they used an "MS Functional Profile" which had been developed by the same authors for use on stroke patients. It has 20 broad dimensions, and numerous subdimensions, and has the remarkable property of generating more than 3 times as many logically possible states as Kurtzke's Incapacity scale (500 billion compared with 150 billion), and it shares with Kurtzke's scale all of the drawbacks I mentioned earlier, but I won't go all through that again! The cost data used in the study were the usual conventional average costs of the various service activities, and they concluded that rehabilitation services were very cost-effective, a conclusion that must be regarded as non-proven in the light of the study design and the small number of patients. So the field is really still wide open for anyone wishing to have a go.

But I suspect that there will be some amongst you who really disapprove of the introduction of economic considerations of the sort I have been advocating into priority setting in medicine, believing that letting costs influence clinical decisions or policies is simply unethical. If you are one of these people, my concluding comments are directed to you.....the others may switch off at this point if they feel so inclined, for the worst is over.

A particularly sharply worded protest along these lines appeared in the New England Journal of Medicine in 1980. Here is an extract:

> "Of late an increasing number of papers in this and other journals have been concerned with the `cost-effectiveness' of diagnostic and therapeutic procedures. Inherent in these articles is the view that choices will be predicated not only on the basis of strictly clinical considerations but also on economic considerations as they may affect the patient, the hospital, and society. It is my contention that such considerations are not germane to ethical medical practice..... A physician who changes his or her way of practising medicine because of cost rather than purely medical considerations has indeed embarked on the `slippery slope' of compromised ethics and waffled priorities"

That is a tough act to follow, and I am not proposing to chase all the hares that have been set running. My earlier review of the work done on assessing the progress of patients with MS seems to me to highlight the difficulties involved in trying to distinguish between "strictly clinical considerations"

and other impacts on the lives of patients and on the lives of their relatives and friends (who are the people who constitute "society"), but this is no place to pursue that line of argument any further. I will concentrate on the central issue of whether it is ethical for doctors (and presumably all others involved in patient care) to take costs into account when choosing a course of action

The key to resolving this conflict is to recognise the distinction between "costs" and "expenditures". Expenditures occur when in order to get something we want we have to part with money. In this process we compete with other people who also want these same things. The person who actually gets the thing thereby deprives some other person of it. So the true cost of me getting what I want is the sense of deprivation felt by the person who hoped to get it but didn't. The spending of money is merely a mechanism for deciding who gets what at whose expense. Accountants are concerned about the money. Economists are concerned about who gets the real resources, and who bears the consequent sacrifice. To an economist "what will it cost?" means "what will we have to sacrifice?", and this may be very different from "how much money will we have to part with?" So if someone says to me that they must have something no matter what it costs, I take them to mean that they must have it no matter what sacrifices have to be made. And it is always easier to make such statements if the costs (or sacrifices) are going to be borne by somebody else!

Transferring that little homily back into the field of medical practice. anyone who says that no account should be paid to costs is really saying that no account should be paid to the sacrifices imposed on others. I cannot see on what ethical grounds one can ignore the adverse consequences of your actions on

other people. You can do so on bureaucratic or legalistic grounds, of course, by saying "they are not my responsibility", but we all know into what an ethical morass that line of defence leads. The word we normally use to describe people who behave without regard to the costs of their actions is "fanatical", not "ethical", and I think fanaticism is just as dangerous in medicine as it is in other walks of life. So I conclude that a caring, responsible and ethical person has to take costs into account. Indeed, it is unethical not to do so!

As I said at the outset, I have assumed that our shared objective is to maximise the health of the community we serve, given the resource constraints we face. Doing so efficiently means not doing things whose costs exceed their benefits. After my little homily you will surely have no difficulty in translating that statement into "being efficient means not doing things if the sacrifices entailed outweigh the benefits gained". No one should have any ethical problems in subscribing to that guiding principle, and it is precisely that guiding principle which underlies the Cost-per-Qaly criterion for setting priorities in health care. So I am hoping that there is now no-one left who has any ethical qualms about going down the road I have signposted. After all, there is nothing immoral about becoming more efficient!

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