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Justifying terminal care by 'retrospective quality-adjusted life-years'

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ABSTRACT

A lot of medical procedures can be justified in terms of the number of quality-adjusted life-years (QALYs) they can be expected to generate; that is, the number of extra years that the procedure will provide, with the quality of life during those extra years factored in. QALYs are a crude tool, but good enough for many decisions. Notoriously, however, they cannot justify spending any money on terminal care (and indeed on older people in general). In this paper I suggest a different way of construing 'quality' (as meaningfulness rather than physical comfort) and 'life' (as both backward-looking and forward-looking), so that the terminal patient's efforts to find meaning in his life could in principle generate plenty of 'retrospective QALYs' to justify funding.

Quality-adjusted life-years (QALYs) are now well-established in medicine and in health policy. Given scarce resources, they offer a way of rationally justifying one course of action over another, when there are strong cases to be made for both but it is impossible to choose both. So if patient A needs procedure X and patient B needs procedure Y, and if both procedures are equally likely to be successful, an estimate can be generated for the number of extra years of life that A will get after coming through X, and how much better those years will be than in his pre-operative state, and this estimate can be compared to the corollary for B. Because of the uncertainty of the calculations, only a wide discrepancy between the two estimates can sufficiently justify choosing the best one.

QALYs have been criticised in many ways. Notoriously, heart transplants are difficult to justify using QALYs because of the sheer costs and risks involved. QALYs would seem to allow the young to hold the old to ransom. Indeed, the estimates might end up recommending that the entire budget of the NHS be spent on anti-smoking campaigns and hip replacements. Nevertheless, as *one* among other decision-making criteria it remains arguably the least worst when faced with the persistent and recurring dilemmas of healthcare allocation. One expense that is very hard to justify in QALY terms seems to be terminal care. Analgesics and antibiotics are often cheap enough, and therefore justifiable enough, but they only go so far in improving quality and generating new life years. Hospital-funded entertainment and social programmes also make an affordable but only short-term difference. High-quality nursing care can become expensive and so will run into QALY problems very quickly, and more expensive medical interventions would seem too close to futility.

In this paper I want to suggest a way that terminal care can in principle be justified in QALY terms, but it will require a refinement of the definition of the QALY, and indeed a refinement of the definition of 'quality' and 'life'. The essence of my proposal is that good terminal care allows the patient to discover greater meaning in his past life, that this greater meaning is another kind of quality, and that the increase in rediscovered meaningful years can be measured backwards rather than forwards. As such, a life that can be re-evaluated may *acquire* plenty of QALYs during the reflection process, provided that there is enough time and comfort and care. I am not proposing a precise system of *measuring* those QALYs, however; all I am arguing for is the principle.

First let us examine quality. In normal discussions of health, quality of life refers to basic physical comfort, as well as such things as mood, perceptual ability, mobility, clarity of thought, alertness and so on. Obviously both physical and mental aspects of life are relevant here, and sometimes there will have to be a trade-off. The surgical removal of a malignant prostate, for example, improves the quality of life by reducing the threat but may also reduce it by causing impotence: nevertheless, when the risks are spelled out, most patients would consider it a small price to pay. In addition, if the patient understands the risks and freely consents to the procedure, then the very autonomy of his choice also contributes to the quality of the outcome—even if the outcome turns out badly.

It is worth comparing this medical definition with the definition used in ordinary life. After all, no patient wants to be in hospital; the aim of every hospital visit is to allow the patient to resume their previous life, with as much of the quality of that life—understood in their ordinary non-medical terms—as possible. To say that someone has a good quality of life, I suggest, refers most often to something that provides an intelligible source of rich meaning in his life. A person's profession, for example, can be challenging, constructive, varied, fascinating; the person can come to identify strongly with the job, to the point where he will want to succeed in it even if its instrumental benefits (the deadly trio of fame, power and money) wane. And even if a person's family can be a source of frustration, worry and expense, they can *at the same time* be a deep source of confidence and rootedness. I am therefore taking a more Aristotelian conception of meaningfulness as having to do with 'flourishing' (the usual translation of the ancient Greek word *eudaemonia*), and I am contrasting it with the notion of 'mere happiness'.

Mere happiness, as I understand it, is a purely mental state, often a fleeting one, that need have nothing to do with the objective circumstances that generate healthy meaning: one can be merely happy by rolling stones up hills all day (like Sisyphus), playing video games or taking crack cocaine, but we would hardly recommend these activities to one's children as a source of meaningfulness. Clearly there will be room for disagreement among people, and there will be many activities that might be on the borderline of meaningful (I've never really seen the point of mountain-climbing, for example). But I am confident we can avoid complete relativism if we reflect on the fact that we do make distinctions between more and less meaningful lives when *worrying* about significant others such as our children. The genuine relativist, if there is such a person, would have to be able to look his child in the eye and say "do whatever you want; I'm serious, *whatever* you want".

QALYs are essentially about the future, and for most decisions in healthcare, this is right and proper: of course we want the patient to be better from now on. Similarly, it is plausible to think that any discussion of quality of life involving meaningfulness should be just as future-oriented. After all, who *wouldn't* want their future to be more meaningful than their present or past? However, the concept of meaningfulness draws the subject not only toward the future but to the past as well. Certainly we want to lead more meaningful lives in the future, but often this meaningfulness will be defined in terms of the past. Sometimes a better understanding of the past is a condition for making good choices about the future.

If I am young and I identify strongly with my country, say, and I want to devote my life to my country and to continuously improve my ability to serve my country, this is based on a source of meaning that lies in my past—at the very least, the fact that I was born and raised in that country, or that my parents also served that country, or that the national symbols and traditions of a fondly remembered youth were now under threat from outside. As such, I will evaluate possible futures against standards and criteria that were already set up before the present search for a more meaningful life (ie, comparing option A against option B to see which will allow me to more effectively serve my country) gets underway. And the process of articulating the comparison of A against B will bring more aspects of the past—more aspects of my identification with my country—into sharper relief.

This is not to suggest that I cannot reflect on these core values, nor that I cannot abandon them in time; but such reflection and abandonment will always be carried out against a relatively fixed background of *other* core values originating in my past. I cannot stray too far from where I have come from, for otherwise I would risk self-alienation: the loss of a coherent narrative thread through a *single* life, my life. It is certainly coherent for me to lose interest in serving my country because I came to see my country as having performed shameful acts, or because I came to see the whole world as my 'country'. Such changes of core values are exactly the sort of thing one can fruitfully reflect upon at the end of one's biological life. Even the recognition and regret that one went wrong at a particular fork in the road can be fruitful if it is part of understanding the whole.

This leads to my refinement of the concept of 'life'; for it is at the end of biological life that a more personal, narrative conception of a life comes to the fore. Instead of 'life', the crude abstract concept used in QALY calculations, what I become interested in is *my* life.

From this comes the notion of a life that is lived forward, but understood backward, as Kierkegaard famously put it. While the

facts of the past are 'frozen', the significance of those facts in my present understanding of my life are not, and demand constant re-evaluation. The same event—a defiant insult to my father when I was 15—might look courageous at 25 and cowardly at 45. The day I met my future wife will be remembered as wonderful on our wedding day, as catastrophic in the divorce courts and perhaps as bittersweet a few years later.

Importantly, these sorts of changes are not random or arbitrary. A past act does not become courageous simply because I declare it to be so; I have an obligation to be true to the past as much as I have to be true to the present. My memories still need to cohere (i) with each other, (ii) with documentary evidence such as photographs and train tickets, (iii) with basic patterns of human behaviour, and (iv) above all with *other* people's memories. But there will still be multiple significances of a particular act that are each sufficiently coherent in the above ways—and sometimes it might be not at all clear to me, the reflecting subject. Maybe I will have to sleep on it, to discuss it with a friend, or read up on it. As with so many of our decisions about the future, we may muddle through as best we can, and be wrong about lots of things: but the notion of 'being true' and of 'wrong' still structure the whole autobiographical enquiry. However much we disagree with another person's recollection of an event, or with the significance that they claim to discover in that event, we must resist the urge to eliminate the disagreement by declaring that 'anything goes'.

Understanding the past significance of the important events that comprise my life reaches a climax on my death bed. We spend so much of our time leaning forward into the future that it becomes the first moment when we can *fully* take stock of what our life is—has been—about. I stress the word 'fully'. Most of us will already have had plenty of intimations of our own mortality long before the death bed, and most of us will have taken stock on various traumatic occasions during our lives. But on each of these occasions the stock-taking still has a forward-looking component; "I want to discover what my life amounts to *so far* so that I can plan the rest of it". "This divorce is pretty bad, but I'm not going to let it kill me". This means that we cannot take full stock of our lives because there are still events to come that may change the contours of the whole. If I take stock now, and congratulate myself on the success of a life-long project, that project could still unravel in my remaining years, and lead to a very different stock-taking on my deathbed. And just the opposite may be true: while I might survey my past 40 years in despair, I might find the final view from 70 to have been marked much more by hope.

Most people, of course, will be at least dismayed by the terminal diagnosis, especially if they were relatively young or relatively healthy. And such people need time to come to terms with their decline and with the certainty of death. There are all the practical details to sort out: properly resigning from one's various commitments and roles, making difficult decisions about inheritance both before and after death, putting one's affairs in order with the help of a close friend or relative, and of course saying goodbye. But on top of all this will be the need for time and room to think about the whole adventure that has been one's own life, to face unpleasant facts and mistakes, to get over the insults and injuries from others, to acknowledge the wrongs one has perpetrated on others. And this voyage of self-discovery might lead to further efforts to make amends with long-lost acquaintances.

What I want to argue is that this business of re-examination of one's life is not merely an organisational exercise, but a creative one. It is not merely recollection but re-configuration. Inevitably, during the days and nights of thought and discussion with others

Ethics

there will be new perspectives on the old events, new attitudes taken in place of previously hardened ones, and above all new understandings of the patterns and relationships between the events. All this novelty, I suggest, *constitutes* new life-years, and life-years of very high quality in terms of deepening the meaning of a particular life. The longer the life in question, and the better the memory, the more high-quality life-years will be gained from the death-bed exercise. As such, there is an important misunderstanding of my position that I should warn against: I am not saying that the *process* of end-of-life reflection is valuable and that this value should be introduced into QALY calculations; rather, I am saying that the patient's *life*—as discovered and constructed during reflection—is what is valuable.

I'm not sure whether such life-years could be *measured* in a sufficiently objective way that could satisfy the financial planners. And I certainly don't think that the death-bed achievements could be compared between people. So what I am arguing for is a presumption in favour of increased funding to terminal care and hospices based on the contribution to the new high-quality life-years generated. This is not an empirical point, and not testable by empirical evidence; instead, it is a direct appeal to the reader's intuitions.

Again, the death bed process can go wrong in all sorts of ways. It might lead to bitterness, self-pity and depression: "so many healthy years of life I was given, and I just blew it, I just blew it". Or it might lead to gross self-aggrandisement or self-delusion. Or new conflicts might develop with relatives when the inheritance starts being discussed. Or the dying process might be too quick for proper understanding, or too slow to prevent undignified boredom. Above all, some people might not be interested in reflecting on their lives at all, either because they have never been reflective people or because they just want to get it over with. There will always be limits to what can be

achieved with a patient on their death bed precisely because they have nothing left to lose; and those limits and those patients obviously have to be respected. But I suggest that some of them would appreciate greater opportunity and support for reflection. It is worth stressing that some negative experiences of reflection can be important to go through, for example remorse. In such a case there is a sense in which the patient *should* suffer lucidly on his death bed, in order to pass through that suffering.

In fact, my suggestion would go even further, in order to counteract some of the risks that might arise from solitary reflection, or on the contrary from reflection distracted by family discord. Room should be made in the new budget for a new type of healthcare professional to be made available, the 'life counsellor', a cross between the priest and the psychotherapist and the family therapist. All three existing professions are limited in what they can offer. The priest couches his assistance in theological terms that are not only of limited benefit to the non-believer, but also involve essential reference to an afterlife; the life counsellor would make it clear to the non-believing patients that he was not offering them anything beyond death. Most psychotherapists and family therapists have patients who are physically well, and the therapists' job is to help them deal with the future. Even when the future is relatively constrained by disability or by life expectancy, the therapist will try to give the patient reasons to live. But life counsellors would help the patient deal with the past, explore it, come to terms with it and would help the family members to help the patient. Ultimately they would seek to allow the patient to take ownership of his death, to give the patient reasons to die, that is, reasons to think of this as the right time to die.

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