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What is This?

Whose Preferences Count?

PAUL DOLAN

An important consideration when choosing how to allocate health care resources is the improvements in patients' health-related quality of life (HRQoL) that alternative allocations generate. There is considerable debate about whose preferences should be used when measuring and valuing HRQoL. This debate has usually been in terms of whether the values of patients or the general public are the most appropriate. It is argued in this paper that this is a false dichotomy that does not facilitate understanding of empirical evidence. Nor, more importantly, does it address one of the most important issues in the debate about whose preferences count, that is, whether the fact that many people adapt to poor health states should be taken into account when ascribing values to those states. A conceptual framework is developed to facilitate a more fruitful discussion of the issues relating to the question of whose preferences should count. *Key words*: health-related quality of life; patients' preferences; resource allocation; elicitation methods. **(Med Decis Making 1999;19:482–486)**

In determining priorities in health care, an important consideration is the improvements in patients' health-related quality of life (HRQoL) generated by alternative allocations of resources. There is general agreement that individual preferences should play some role in determining what constitutes an improvement in HRQoL. The question is whose preferences?

Values can be elicited from various population subgroups; for example, from health care professionals, from patients currently experiencing a particular condition or health state, from those with experience of the health state either in the past or in caring for others, and from samples of the general public. While the preferences of different populations may be considered more or less appropriate in different contexts, this paper considers the issues surrounding whose preferences should count in the context of allocating resources across different interventions.

While few people recommend that HRQoL should be measured and valued according to the preferences of health care professionals, many consider that it is most appropriate to elicit valuations from those people who are currently experiencing the health states for which values are sought.[1] The argument is that these are the only people who know what it is really like to be in those states and therefore the only ones capable of expressing a "true" preference over different states of health. On the other hand, those without direct experience of the health states, it is argued, cannot accurately predict the impact that the states will have on their HRQoL.

However, the received wisdom is increasingly that the preferences of the general public should be used. Recently, a consensus panel convened by the United States Public Health Service recommended a "reference case" for use in cost–effectiveness analyses in health care.[2] In addition to suggesting that the health-state descriptive system should be generic and that the valuation method should be preference-based, they recommended that the source of values should be a representative sample of the general population. The panel's principal reason for this recommendation was that, since the public bears the costs associated with resource-allocation decisions, they ought also to have some say in the determination of the benefits. Also, it was felt that patient values might be subject to self-interest and strategic biases in ways that the "detached" views of the public would not be.

Public preferences are also considered the most appropriate by those who advocate the "insurance principle," the logic of which is that the preferences used to determine coverage patterns under health insurance plans should be those of the beneficiaries, as determined empirically prior to any need for spe-

cific treatments.[3] In addition, if one of the purposes of the health care system is to reassure the public, then resources should in part be allocated so as to reassure the public that treatment is available to alleviate the health states they fear the most.[4]

Existing Evidence

Empirical evidence is important to this debate, since the implications of using public or patient preferences will differ only if the preferences of the two groups are sufficiently different. Sackett and Torrance[5] reported that home dialysis patients assigned higher values to health states associated with kidney dialysis than did the general public. Boyd et al.[6] found that colostomy patients valued various states of health related to their condition higher than did a healthy population. And Hurst et al.[7] found that patients with rheumatoid arthritis gave higher scores to these states than did a general population sample. But Balaban et al.[8] reported no difference between valuations elicited from rheumatoid arthritis patients and those elicited from a general population sample. And Jenkinson et al.[9] found no difference between how BHP patients valued their health and how the general public valued the same health states.

Therefore, the evidence bearing on this subject is not unambiguous. The results from some studies suggest that patients have higher valuations than the public; the results from others suggest that there is no difference between the preferences of the two groups. The evidence is also mixed regarding the extents to which valuations are influenced by respondents' current health status. Kind and Dolan[10] and Dolan[11] found that those in poorer health generally gave higher values to the same health states. But studies by Llewellyn-Thomas et al.[12] and Hadorn and Uebersax[13] found that respondents' own reported health status did not influence their valuations.

There are a number of explanations for the equivocal results found in these studies. For example, the ways in which health states are described vary enormously across studies (condition-specific descriptions have been used[5,6], as well as different generic measures[7–9]). Similarly, very different methods have been used to value the health states (e.g., visual analog scale,[10,11] standard gamble,[12] and time tradeoff[5]). Therefore, given the plethora of evidence that shows that seemingly subtle changes in question format can often dramatically change the stated preferences of respondents, it is difficult to compare the results from the studies reported here. Additional issues relating to the comparability of the samples are addressed by the following framework.

Measuring Experience of Illness

Much of the theoretical and empirical literature deals with the question of whose preferences should be used as if the different population groups were mutually exclusive. But the distinction between some groups, particularly between those with and without experience of illness, is very blurred. Recognizing that many people have current or previous experience of illness, directly themselves or through relatives or close friends, and for different durations, may help to focus the debate about whose preferences should count and help explain the equivocal results reported above.

Of course, this presupposes that the type and extent of illness experience an individual has will in some way shape his or her preferences. And, of course, much more empirical evidence is required here. But the whole debate about whose preferences count has taken place against a background in which attributes relating to experience of, or knowledge about, particular health states is assumed to have some direct effect on preferences relating to those states. The same general assumption is made in this paper.

A three-dimensional measure is developed by which to consider the extent to which an individual has experience of a given health state, h_i. The first dimension measures the strength of the relationship that the individual has with the person who is experiencing (or who has experienced) h_i. This ranges from the individual him- or herself to no experience whatsoever and will cover, with varying degrees of association, the person's family and close friends, as well as "indirect" experience (via the media, for example). The second dimension is the time since h_i was experienced. This ranges from now (in which case h_i is currently being experienced) through the most distant memory that the individual has of h_i, to never at all. The third dimension measures the period of time during which h_i has been or was experienced. This ranges from always, representing the whole of the individual's life, to no time at all (it is not clear whether this duration should be measured in absolute terms or as a fraction of the individual's lifetime, or as some weighted average of the two).

This measure of experience of h_i is shown graphically in figure 1. The axes should be seen as categories with ordinal properties. It is possible that the categories on the strength-of-relationship dimension might have a different ordering for some individuals; for example, some people might be closer (in terms of the effect that h_i has on them) to their friends than to their immediate families. The origin represents a current patient who has always been in h_i. Movements away from this point along the x-
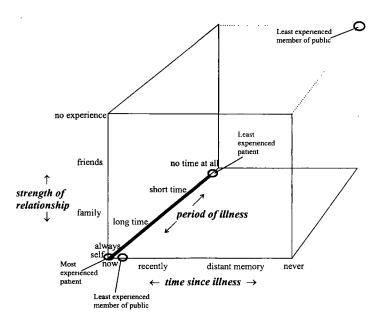
FIGURE 1. Measuring experience of illness. The bold diagonal line refers to all current patients.

axis represent less recent experience of h_i, those along the y-axis represent less personal experience of h_i, and those along the z-axis represent that h_i has been or was experienced for (absolutely or relatively) less time. It is the individual's perceptions regarding these attributes that are relevant here (rather than the actual time since h_i was experienced or the actual time during which h_i was experienced), since it is these perceptions that will determine the value that he or she attaches to h_i.

Note that any one individual can simultaneously be at a number of points on the graph (in effect, one for each person that the individual is "related to" who has experience of h_i). Also note that any one individual can be at multiple points on more than one graph, since each graph will be unique to a given severity of h_i, or possibly a limited range of severities. For example, many people will be located nearer the origin when considering health states that involve mild dysfunction, but fewer will have recent experience of severe disability in themselves or in their families for long periods of time. Therefore, there is likely to be a negative relationship between proximity to the origin and severity of illness.

From this measure, it could be argued that, for any given severity of h_i, the most experienced members of the public are more like patients than they are like the least informed members of the public. This highlights that the general public is a very heterogeneous group in terms of its experience of h_i. And it highlights that patients are a heterogeneous group, too; some will have experienced h_i only recently, while others will have been in h_i for a considerable time.

Measuring Anticipation of Illness

In addition to having current or past experience of h_i, many people are also likely to have given some thought to the possible impact that h_i would have on them (or those close to them), particularly if *they think that* they (or those close to them) are likely to experience h_i sometime in the near future. Therefore, it is also possible to develop a measure that considers the extent to which an individual has anticipated the possible consequences of h_i.

This measure has three dimensions, the first of which is analogous to the "strength of relationship" dimension described above: here, it measures the strength of association that the individual has with person who will or who might experience h_i. However, the same weight does not have to be given to each "category" of relationship in the two measures. In fact, in the anticipation-of-illness measure, it is likely that many people will consider only the impact that h_i might have on themselves and their immediate families. The second dimension measures the *perceived* time until h_i will occur (ranging from immediately to never), and the third dimension measures the *subjective* probability that h_i will occur (clearly ranging from 1 to 0). Again, it is the individual's perceptions regarding time and risk that are relevant here, rather than the objective timing and probability of h_i.

This measure of anticipation of h_i is shown graphically in figure 2. Again, the axes are ordinal. The origin represents an individual who is certain that he or she will experience h_i immediately. Any movement from the origin along the x-axis represents an individual who still is certain about the occurrence of h_i, but at some time in the future; along the y-axis represents an individual who is certain that someone he or she knows is going to experience h_i
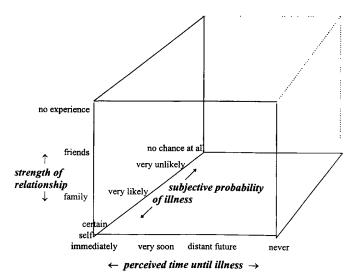

FIGURE 2. Measuring anticipation of illness.

immediately; and along the z-axis represents an individual who believes that he or she has some chance of experiencing h_i immediately.

Again, one individual can be at multiple points on the graph; this time, one for each person that he or she is "related to" who the individual expects will be ill at some point in the future. And again, for the reasons noted above, an individual can be at multiple points on more than one graph. Since people will probably think that there is more chance of their experiencing a mild condition, and experiencing it sooner, there is likely to be a negative relationship between proximity to the origin and the severity of h_{ij}, as is the case for the experience-of-illness measure. But, of course, much turns on the subjective probabilities that people attach to different severities of h_i. And it is here that the two measures are likely to be related. For example, an individual who has experience of h_i in his or her family is more likely to think that he or she will personally experience h_i at some time and thus is likely to have given thought to the possible consequences of h_i.

Discussion

The experience-of-illness measure and, perhaps to a lesser extent, the anticipation-of-illness measure developed in this paper could be used to explain why some studies have found differences between patient and public preferences and others have not. There is such heterogeneity within both groups in terms of their experiences of and anticipation of illness and, crucially, in terms of the extents to which they have adapted or would have thought about adapting to a particular health state, that patient and population groups may not be comparable across different studies.

That some studies have found valuations elicited from patients to be higher than those elicited from the public is likely to be explained by the observation that many people in poor health are to some extent able to compensate for it.[14,15] Such adaptation can take many forms, from simply learning to cope with disability to "cognitive dissonance," whereby people deny the true losses associated with their changed circumstances.[16] Of course, a member of the general population is free to consider the adjustments he or she would be likely to make in order to cope with the disability, but the extent to which the individual would do so is questionable.

Therefore, the most important question when choosing whose preferences to use is whether or not it is appropriate to take account of the fact that some people give higher valuations than others in part because they have learned to cope with their disabilities. And it is here that the measures could be used as a conceptual framework within which to discuss the normative issues relating to the question of whose preferences should count.

For those who consider that adaptation is relevant when measuring and valuing HRQoL, there is still the question of *when* to ask patients for their preferences. This is because adaptation to a particular state of health will typically be a gradual and continuous process. At one extreme, a value could be elicited immediately after a patient has entered a given health state, when adaptation is likely to be negligible; at the other extreme, it could be elicited only after the patient has been in that health state for a considerable length of time, after all of his or her "coping mechanisms" are in place.

Therefore, if patient preferences are to be used in resource-allocation decisions, the question is not *whether* adaptation to illness is considered relevant (since it is) but rather *the extent* to which it is considered relevant. The literature has been almost completely silent on this issue, but the experience-of-illness measure developed in this paper provides a conceptual framework within which this discussion could take place. Moreover, given that coping is a gradual process, the measure suggests that those who believe in using patient preferences precisely because they consider adaptation to be a relevant part of the value attached to different levels of HRQoL might consider a member of the general public who had recently been in a poor health state for a considerable length of time to be a more appropriate source of value than a patient who has been in the same state for only a short time.

Both measures developed here raise questions for those who are committed to using the preferences of the general public, or prospective patients. It might be, for example, that the preferences of those who are likely to have given some thought to a particular health state (perhaps because they know somebody who is experiencing it or because they expect to experience it themselves shortly) are considered more suitable than the preferences of those who have given little or no thought to the consequences of that state (perhaps because they have never come into contact with anyone in that state or because they do not expect ever to experience it themselves).

If an adequate consensus can be reached on the answers to these normative questions, then the question becomes one of determining which population groups have the most appropriate level(s) of experience and anticipation of given health states. There may be people who would argue that the preferences of all citizens should be given equal weight. This would mean that the preference of someone who had not given the slightest thought to a particular health state would count for as much

as the preference of someone else who had experienced or anticipated that state. This particular weighting would in many ways make the measures developed here redundant; the objective here would be to elicit the views of a representative sample of the population. But the measures may still be relevant in helping to determine the extent to which representativeness is achieved.

For those who believe in giving greater weight to the preferences of those with experience of illness, the question is about precisely what weights to give to the many different groups located at various points in figure 1 (at the extreme, the values of those located at the origin count for everything and the values of those located anywhere else count for nothing). For those who believe that people do not have to have experience of illness for their preferences to count, the issue is what weights the preferences of the different people located at different points in figure 2 should be given. In any event, the conceptual framework developed here suggests that the issue of whose preferences count is more about the weights that should be given to different degrees of experience and anticipation of illness than it is about whether the preferences of designated groups, such as patients or the public, should be used.

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