

Virtual Mentor

Ethics Journal of the American Medical Association
February 2005, Volume 7, Number 2

Journal Discussion

Values for Resource Allocation Should Expose the Adaptation Process, Not the Outcome

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Ubel PA, Loewenstein G, Jepson C. Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. *Qual Life Res.* 2003;12:599-607.

Menzel P, Dolan O, Richardson J, Olsen JA. The role of adaptation to disability and disease in health state valuation: a preliminary normative analysis. *Soc Sci Med.* 2002;55:2149-2158.

Patients may succeed in reaching high levels of well-being despite chronic illness or impairment because they eventually learn to adapt to their situation. As a result, these patients generally rate their own health higher than the general public rates the health of patients in these circumstances. This phenomenon has attracted the attention of quality-of-life experts like Menzel [1] and Ubel [2], who have explored these differences further. From their analyses, we get a clearer picture of the psychological processes that contribute to the discrepancies between a patient's own health rating and the general public valuations of that patient's health state. An unresolved issue, however, is the question of whose values and rankings are more appropriate to use as the basis of health care allocation—those of patients or those of the general public? It is usually assumed that resource allocation decisions should be guided by societal preferences, because they affect the entire society [3]. However, Menzel and his co-authors questioned the appropriateness of this approach, arguing that if social values fail to anticipate and account for the adaptation process, they are factually mistaken and can misrepresent a patient's quality of life [1]. This raises the question of whether pervasive social values should be considered invalid for use in resource allocation with adapted patient values used instead. In this contribution we make clear our position in the ongoing debate on this matter.

The term “adaptation” refers to the instability of internal standards by which people evaluate certain outcomes or health states. For most people, an improvement in health constitutes an improvement in well-being, and vice versa: loss of functioning decreases quality of life. This is reflected in the way unaffected members of society rank quality of life for less-than-full-health states. Patients without hope for recovery from a particular problem, however, often adapt to that state of health. They learn to cope with their disabilities or lower their expectations in order to achieve a more stable state of well-being. But does this ability to adapt mean that our health care systems should

try less diligently to resolve the health problems of these patients? Contrary to what we believe, Menzel, indeed seems to think so. According to him, a person's contentment with his or her health state—not the health state itself—should be the relevant outcome measure [1]. This idea originates from the moral argument about the worth of an individual life, which objects to stigmatisation of disabled persons' lives as inherently less valuable. Every additional year of life provided for a disabled person, Menzel suggests, should receive the same value as a year lived by a generally healthy person, irrespective of their different health states [1]. Menzel also objects to using quality-of-life values determined by healthy members of the public because their lower quality-of-life estimates for health states of chronically ill patients would imply that life-saving treatments for this group are valued less [1].

We object to Menzel's position, first, because patients' internal "reference points" may turn out to be rather flexible. Patients with no hope for recovery will probably reach an adapted state. If, however, they have the opportunity to improve their health, they will probably recognize and appreciate the capabilities that can be regained after treatment, so, from the reference point of their anticipated improved health state, the perceived value of their current health drops [4]. This so-called "response shift" illustrates the instability of subjects' internal standards of measurement and leads us to conclude that patients give invalid and unreliable values for their own health states when compared to a wider set of (attainable and unattainable) health states. Although we agree that stigmatisation of handicapped persons is unwarranted and that handicapped persons should have equal claim to life-saving treatments, we do not agree that it is appropriate to concentrate on subjective measures of happiness and to ignore real differences in patients' health states. Surely there must be better ways to address the problem of stigmatisation.

The second reason why we disagree with Menzel is that inequalities in health generate inequalities in opportunities, regardless of whether or not these translate into inequalities in happiness [5]. Disabilities reduce a person's opportunities in life and should therefore be considered relevant in the decision-making process that concerns resource allocation. For example, patients with stool problems who are incontinent may regain control over defecation using enemas. However, compared to healthy people, their achievement of continence requires consumption of resources. In this case, time is invested, and perhaps a diet is prescribed to control bowel movements. Time and resources expended in managing one's health cannot be used in pursuit of other goals, resulting in reduced opportunity and choice, and thus making patients less capable than healthy persons to get what they want from life. This capability perspective motivates us to argue that, from a distributive justice point of view, social values, not adapted patient values, should inform resource allocation.

The capability perspective offers an explanation for the discrepancies between patient-derived values and those derived from non-patient members of society. Patient values seem to represent the "state" of being adapted, whereas the values of others may acknowledge that an "act" of adaptation will be required. It is interesting to consider whether other inconsistencies between quality-of-life measures can also be explained by the concept of capability. The capability perspective turns our attention to the

question of how quality of life is accounted for in techniques that elicit preference. According to Verkerk et al, existing measures lack a uniform basis. Some preference elicitation instruments concentrate on contentment with functionings whilst others are also sensitive to the capabilities of the patients [6]. We therefore believe that the debate about values that aim to inform resource allocation should go beyond the question of whose values count; it should also consider the conceptual implications of the process in which values can be generated.

References

1. Menzel P, Dolan P, Richardson J. The role of adaptation to disability and disease in health state valuation: a preliminary normative analysis. *Soc Sci Med*. 2002;55:2149-2158.
2. Ubel PA, Loewenstein G, Jepson C. Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. *Qual Life Res*. 2003;12:599-607.
3. Drummond MF, O'Brien B, Stoddart G, Torrance G, eds. *Methods for the Economic Evaluation of Health Care Programmes*. 2nd Ed. Oxford: Oxford University Press; 1997.
4. Sprangers, MAG. Response-shift bias: a challenge to the assessment of patients' quality of life in cancer clinical trials. *Cancer Treat Rev*. 1996;22(Suppl. A): 55-62.
5. Sen AK. Why health equity? *Health Econ*. 2002;1:659-666.
6. Verkerk M, Busschbach JJV, Karssing ED. Health-related quality-of-life research and the capability approach of Amartya Sen. *Qual Life Res*. 2001; 10:49-55.

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