22nd Plenary Meeting of the Euroqol Group *Edited by K. Stavem*
Oslo, Norway, 2005

COMPARING GENERIC AND DISEASE SPECIFIC HEALTH STATE VALUATIONS BY A LAYMEN PANEL

J.A. Haagsma[1], M.F. Janssen[1], G.J. Bonsel [1,2,3]

[1] Department of Social Science, Academic Medical Center Amsterdam
[2] Department of Public Health, Erasmus MC, University Medical Centre Rotterdam
[3] Institute of Health Policy and Management, Erasmus University Rotterdam

Abstract

Introduction: The objective of this study was to explore the effects of adding disease specific information to generic health state descriptions on health state valuations by a panel of lay people.
Methods: 23 different health states of common diseases were presented for valuation. Each of these health states consisted of a EuroQol6D5L-profile and were presented with and without a disease label and a formalized clinical description of the disease. A panel of lay people (n = 105), recruited from the general public, valued the health states with the Visual Analog Scale (VAS).
Results: For 19 health states, mean VAS values for health states with a disease specific information were numerically lower ('more severe') compared to those without this information ($p < 0,001$), with a mean difference of 0,10 (range: -0,08 to 0,28). The difference in VAS values was greater for less severe diseases. Standard deviations did not differ between health states with and without disease specific information, indicating similar precision.
Conclusions: We found that the panel of lay people valued health states with disease specific information as more severe, especially for mild diseases. This indicates that disease specific health state descriptions contain information about prominent symptoms not reflected in the generic health state, consequently causing a valid shift.

Introduction

Information on the health status of a population is essential input for burden of disease studies and cost-effectiveness analysis of interventions. To quantify population's health status, summary measures of population health may be used, which summarize fatal and non-fatal health outcome into a single number (Field & Gold, 1998). Time lost due to premature mortality can be added to time lost due to morbidity using disability weights. The disability weight reflects the impact of a condition and its value is based on the preferences of a panel of judges stated towards a set of health states (Murray & Acharya, 1997). The preferences towards health states are anchored between 0, indicating indifference between the health state and full health, and 1, indicating indifference between the health state and death. The precise number is commonly referred to as disability weight.

To derive disability weights, several choices have to be made considering the approach to quantify the preferences of the panel of judges (Essink-Bot & Bonsel, 2002). One of these choices regards the description of the health states, which may be described as (1) disease

specific or (2) generic. Disease specific health state descriptions indicate the cause, the specific health effects and the treatment of the condition. In contrast, a generic health description system describes functional health without regard to the underlying condition. A widely used generic health state description system is the EuroQol classification system, which describes health in the dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression (EuroQol-group, 1990).

Generic health state descriptions, like EuroQol health profiles, allow comparison across diseases and interventions. However, disease specific health state descriptions are more sensitive for the detection and quantification of small changes (Patrick & Deyo, 1989). This indicates that disease specific health state descriptions provide information that is not reflected in the generic health states but which matters for health state valuation. This was also found by Stouthard et al. (2000). In their study, Stouthard et al. (2000) combined disease specific information with EuroQol data. They found that health states with a similar EuroQol profile and a different disease label yielded different values. However, because medical experts provided the values, the disease label might have created a mental image of the typical patient, which the medical experts valued rather than the actual information that was presented to them.

Contrary to medical experts, lay people are unfamiliar with most conditions and its consequences. As a result, lay people may be less affected by the information that is provided by the disease label compared with medical experts. To our knowledge the effect of disease specific information on health state valuation of lay people has not yet been examined. The aim of this study was to examine this effect by comparing valuations of generic health states with valuations of disease specific health states by a laymen panel with the Visual Analogue Scale.

Methods

Participants

From a large population sample of 560 lay people we selected 126 people, who were representative for the Dutch population regarding age, sex, education and disease experience.

Health state description

For the description of the generic health state we used and extended version of the EuroQol classification system. This extended version of the EuroQol classification system describes health with five levels of severity in six dimensions: mobility, self-care, usual activities, pain/discomfort, anxiety/depression, and cognition. We presented 19 EuroQol health profiles for valuation. These EuroQol health profiles ranged from mild to severe. The diseases specific health states consisted of a EuroQol health profile and additional disease specific information, like a formalized clinical description of the disease and a visual aid to indicate the location of the condition on the body. In cases of altered physical appearance of the patient due to the condition, we added a picture of the condition to the vignette. In total, we presented 23 disease specific health state descriptions for valuation.

Valuation technique

To assess the health state valuations of the generic and disease specific health states, we used the Visual Analogue Scale (VAS) method conform the EuroQol format. The VAS method requires participants to score the health state on a vertical thermometer graded from 0 (worst imaginable health state) to 100 (best imaginable health state).

Judgement procedure

This study was part of the Mild Diseases and Ailments Study (Bonsel et al., 2003). The Mild Diseases and Ailments Study followed a two step judgement procedure, consisting of a panel meeting and a questionnaire. For each of the panel meetings we invited 18 participants. During the three-hour panelmeeting, the purpose of the study, the EuroQol classification system and the VAS method were explained. Subsequently, the participants valued ten disease specific health states with the VAS, including four disease specific health states from this study. During the valuation of the health states, the participants wrote down their value on a white board and explained how they reached their valuation. The participants were allowed to change their valuations at any time. Three weeks after the panel meeting, the participants received a questionnaire by mail. In this questionnaire, the participants were asked to value 22 disease specific health states and 6 generic health states. We developed ten versions of the questionnaire, which were randomly assigned to the participants.

Data-analysis

The following formula was used to determine the VAS values for the health states:

$$\text{VAS value} = 1 - (\text{VAS}/100)$$

We calculated mean and standard devation for each disease specific and generic health state. Additionally, we calculated the difference between mean VAS values of generic and disease specific health state with the same EuroQol-profile to establish the effect of the disease label.

Furthermore, in order to examine the concordance between mean VAS values of the disease specific and generic health states, we calculated the Spearman correlation coefficient. We did not exclude or transform any data used for the calculation of the VAS values.

Results

Of the 126 lay people we selected, 105 agreed to participate in this study. 51 % of the respondents was male and the average age of the respondents was 49 years old. 99% (n = 104) of the participants that attended the panel meeting completed the questionnaire. It took the participants on average 1 hour and 56 minutes to complete the questionnaire.

Table 1 presents the mean VAS values the participants assigned to the generic and disease specific health states. Regarding the severity of the condition, indicated by the sum score of the EuroQol profile, the participants ranked the generic and disease specific health states logically. To both generic and disease specific health states the participants assigned high VAS values to severe health states and and low VAS values to mild health states. The standard deviations of the VAS values of generic and disease specific health states did not differ, indicating a similar precision. In addition, the Spearman correlation coefficient

between mean generic and disease specific VAS values is 0.94, indicating a similar ranking of the health states.

Table 1. Difference in mean VAS values of disease specific and generic health states (HS)

Disease label	EuroQol	Disease specific HS			Generic HS			Δ
		n	mean	sd	n	mean	sd	
Allergic rhinitis	111211	34	0,27	0,13	14	0,05	0,04	0,22
Eczema	111211	34	0,27	0,17	14	0,05	0,04	0,22
Onychomycosis	111211	103	0,06	0,06	14	0,05	0,04	0,01
Tinea pedis	111211	34	0,14	0,13	14	0,05	0,04	0,09
Acne	111211	34	0,20	0,16	17	0,08	0,07	0,12
Eczema	111211	103	0,36	0,17	17	0,08	0,07	0,28
Stomach complaints	112311	34	0,42	0,15	17	0,19	0,09	0,23
Menopausal symptoms	112321	34	0,33	0,17	18	0,20	0,11	0,14
Eczema	112412	34	0,47	0,12	16	0,51	0,16	-0,03
Vertebral fracture	333311	34	0,66	0,13	17	0,43	0,15	0,23
Multitrauma, stable phase	333221	34	0,55	0,18	18	0,45	0,14	0,10
Larg burn, stable phase	333321	34	0,69	0,15	14	0,47	0,12	0,22
CVA	333323	103	0,80	0,11	17	0,73	0,14	0,06
Brain injury, severe, stable	224333	34	0,80	0,12	16	0,60	0,18	0,21
Large burn, acute phase	334431	34	0,72	0,11	14	0,71	0,16	0,01
Paraplegia, stable phase	544321	103	0,79	0,12	17	0,77	0,14	0,03
Multitrauma, stable	334333	34	0,76	0,14	14	0,70	0,15	0,06
Multitrauma, acute phase	445431	34	0,76	0,12	16	0,78	0,12	-0,02
Brain injury, severe, acute	335334	34	0,90	0,07	16	0,77	0,16	0,13
Paraplegia, acute phase	544431	34	0,81	0,06	18	0,89	0,08	-0,08
Quadriplegia, stable phase	555231	34	0,90	0,06	14	0,83	0,11	0,07
Quadriplegia, acute phase	555431	34	0,87	0,07	16	0,86	0,10	0,01
Multitrauma, acute phase	445434	34	0,86	0,09	16	0,91	0,12	-0,05

* 0 =full health, 1 = worst imaginable health state

For 19 of the 23 health states, mean disease specific VAS values were numerically higher (‘more severe’) compared to mean generic VAS values ($p < 0.001$). The difference in VAS values between generic and disease specific health states ranged from -0.08 to 0.28. The mean difference of the VAS values was 0.10. Especially conditions characterized by altered physical appearance had numerically higher VAS values (range 0.20 to 0.72) compared to similar generic health states (range 0.05 to 0.71). In addition, difference in mean VAS values was greater for less severe diseases. For mild health states, the mean difference in VAS values was 0.17, whereas for severe health states the mean difference in VAS values was 0.02.

Discussion

In this study we found that the panel of lay people assigned numerically higher (‘more severe’) VAS values to disease specific health states compared with generic health states. The precision of the VAS values assigned to generic and disease specific health states was similar. This suggests that adding disease specific information to the health state description causes a shift in the VAS values.

It is inevitable that describing health with a generic description system results in information loss. With the six dimensions of the EuroQol classification system, disease specific symptoms

like altered physical appearance cannot be described. However, altered physical appearance is a prominent symptom of certain diseases and injuries and it imposes a significant burden upon the patient (Newell, 1999; Rumsey & Clarke, 2004). Several studies showed that patients with an altered psysical appearance have a significantly decreased health related quality of life (Lubeck, 1998, Fauerbach et al., 2000; Rumsey & Clarke, 2004). For health state valuation, information on altered physical appaerance of the patient proves to be equally important. The results of this study show that in conditions characterized by altered physical appearance, mean difference in VAS values between generic and disease specific health states increased almost twofold compared with mean difference in VAS values of the other health states.

Surprisingly, we found a greater difference in VAS values between minor generic and disease specific health states. This indicates that especially in minor diseases, the disease specific description contains information on prominent symptoms not reflected in the generic description. The minor diseases as well as their consequences may be easy to imagine for lay participants, especially since the minor disease were common, occurring frequently in the Dutch population. The severe diseases valued in this study occur less frequently and are therefore less familiar to lay people. This unfamiliarity in addition to the difficulty for healthy participants to imagine the impact of the severe conditions may have caused the participants to particularly use the added EuroQol data in their valuation of the disease specific health states. In contrast, in the valuations of minor disease specific health states, the laymen panel may have valued the disease specific symptoms rather than the added EuroQol data, causing a greater difference in VAS values between minor generic and disease specific health states.

The difference in VAS values assigned to minor generic and disease specific health states may also be explained by the valuation technique. In this study, we used the VAS to elicit the preferences of lay people for the generic and disease specific health states. The VAS, however, is not choice based and therefore argued to be unable to capture the strength of the preferences for health states (Brazier et al., 1999). In contrast to the VAS, choice based valuation techniques, like the time trade-off, have a threshold below which participants refuse to trade-off anything. Because the VAS lacks such a threshold, the values participants assign to minor health states with the VAS may overestimate the difference between minor conditions. We assume that the differences in values assigned to minor generic and disease specific health states are smaller when preferences are elicited with a choice based valuation technique. This, however, remains to be investigated.

In summary, we conclude that lay people value disease specific health states as more severe compared to generic health states. The difference in health state valuation is greater with minor health states and health states that affect the physical appearance of the patient. This indicates that disease specific health state descriptions that contain information about prominent symptoms not reflected in the generic health state cause a shift in VAS health state valuations.

References

Bonsel GJ, Janssen MF, Birnie E. Mild Diseases and Ailments Study (MiDAS). Ziektelastbepaling van 27 vermoedelijke 'lichte' ziekten ten behoeve van rationele beperking van het geneesmiddelenpakket. Amsterdam: Afdeling Sociale Geneeskunde, AMC, 2003.

Brazier J, Deverill M, Green C, Harper R, Booth A. A review of the use of health status measures in economic evaluation. Journal of Health Services Research and Policy 1999; 4: 174-184.

Essink-Bot, ML, Bonsel GJ. How to derive disability weights. In: Summary measures of population Health. Concepts, ethics, measurement and applications. World Health Organization, Geneve, 2002.

EuroQol - a new facility for measurement of health-related quality of life. Health Policy 1990 16: 199-208.

Fauerbach JA, Heinberg LJ, Lawrence JW, Munster AM, Palombo DA, Richter D, Spence RJ, Stevens SS, Ware L, Muehlberger T. Effect of early body image dissatisfaction on subsequent psychological and physical adjustment after disfiguring injury. Psychosom Med 2000; 62(4): 576-82.

Field MJ, Gold GM (eds). Summarizing population health: directions of the development and application of population health metric. Institute of Medicine, Washington, D.C. National Academy Press, 1998.

Lubeck DP. Measuring health-related quality of life in onychomycosis. J Am Acad Dermatol 1998; 38: S64-8.

Murray CJ, Acharya AK. Understanding DALYs. Journal of Health Economics 1997; 16: 703-730.

Newell RJ. Altered body image: a fear-avoidance model of psycho-social difficulties following disfigurement. J Adv Nurs 1999; 30(5):1230-8.

Patrick DL, Deyo RA. Generic and disease-specific measures in assessing health status and quality of life. Med Care 1989; 27(3 Suppl): S217-32.

Rumsey N., Clarke A., White P., Wyn-Williams M. & Garlick W. (2004) Altered body image: auditing the appearance related concerns of people with visible disfigurement. Journal of Advanced Nursing, 48 (5) 1-11.

Stouthard, MEA, Essink-Bot ML, Bonsel, GJ, on behalf of the DDW Group. Disability weights for diseases in the Netherlands. European Journal of Public Health 2000; 10:24-30.