Mind the gap : explanations for the differences in utilities between respondent groups

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Valuing Health: Does Enriching a Scenario Lead to Higher Utilities?

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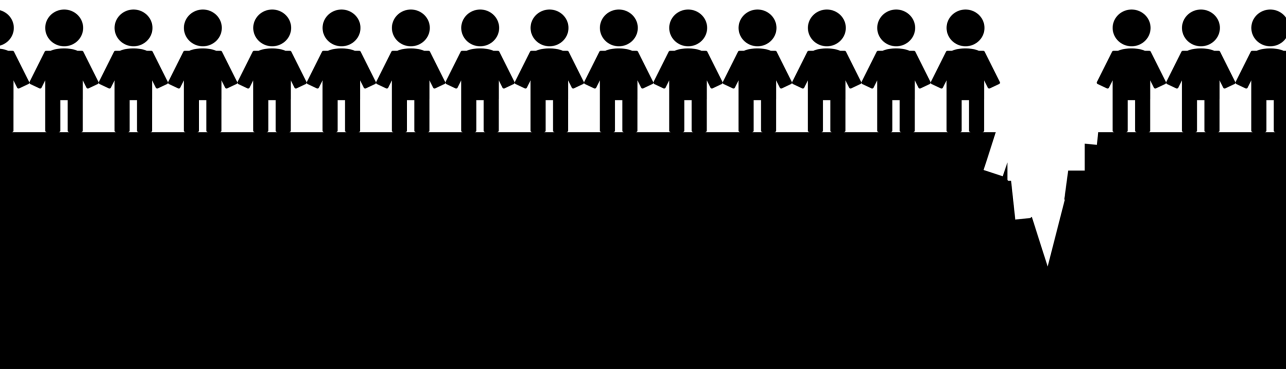

Abstract ***Objectives:*** *Patients have been found to value their own experienced health state higher than an investigator constructed scenario of that health state. The aim of this study was to investigate if patients value their own experienced health state higher than a standard EQ-5D scenario of their health state and if "enriching" this scenario by adding individualized attributes reduces the differences between experienced health and the scenario.* ***Methods:*** *Face-to-face interviews were held with 129 patients with rheumatoid arthritis. Patients were asked to value in a time tradeoff their own experienced health; 6 standard EQ-5D scenarios, of which the 5th (untold to them) represented their own health state; and a standard EQ-5D scenario of their health state (identified as such) enriched with individual attributes.* ***Results:*** *The own experienced health state was not valued differently from the own standard EQ-5D state and was lower compared to the own enriched EQ-5D state of that same health state. An interaction effect was found for health status. Patients with better health did not report different values for their own experienced health compared with their own standard EQ-5D description; their own experienced state was rated lower than their own enriched EQ-5D description. Patients with poor health valued all 3 health states similarly. Surprisingly, utilities for scenarios enriched with exclusively negative individual attributes were not lower than those for the own standard EQ-5D description.* ***Conclusion:*** *The hypothesis that disparities in valuation can be attributed to EQ-5D description being too sparse was not confirmed.*

3.1 Introduction

Utilities of health states are important in health decisions. Health state utilities are used to compare investments in cost of a therapy with the benefits in health. Utilities can be elicited in members of the general public but also in patients. Which group should be used is still a matter of discussion.[16,44] Many studies[16,88] but not all[81] have found valuations of patients to be different from valuations of members of the general public.

Patients are often asked to value their own experienced health state, whereas members of the general public are asked to value descriptions of these health states. Jansen and others[20] found that patients' ratings of their own experienced health state were higher than their valuation of a description of that same health state. The authors explained this difference in rating by hypothesizing that the description of the health state may not have matched the own experienced health state despite an evidence-based development process. Similar results were revealed in a meta-analysis of utilities assigned to prostate cancer.[46] Patients with prostate cancer rated a description of their health lower than their experienced health state.

Valuing a description of a health state instead of valuing an experienced health state might cause differences in the interpretation and integration of the information. These differences in interpretation and integration could result in different utilities.[15] In particular, patients interpret information in light of their experience, whereas healthy participants are limited to the information that is provided in the health state description.

Moreover, descriptions of health states are developed in several ways. Jansen and others[20] developed health state descriptions based on the literature and experiences of physicians and patients. However, others have developed descriptions on the basis of health state classification systems, such as the Health Utilities Index (HUI)[21] and the EuroQol EQ-5D.[89] Dissimilarities in the construction of health state descriptions might lead to different interpretations and valuations as well. In addition, health state descriptions are often framed in negative terms. This leads to a focus on the negative impact of the health state, which might cause healthy participants to overestimate the negative impact of a disease.

Insinga and Fryback[23] asked members of the general public to value a selection of all possible EQ-5D health state descriptions as well as their own experienced health. By chance, several participants' experienced health matched one of the EQ-5D descriptions they had valued. It turned out that ratings of the own experienced

health differed from the ratings of the matching EQ-5D description. Specifically, participants with mild health problems valued their own experienced health lower than the corresponding EQ-5D health state description, whereas patients with moderate health problems estimated their own experienced health higher than the corresponding EQ-5D health state description. The authors concluded that an EQ-5D profile of a health state does not resemble the own experienced health state because it is too sparse and lacks positive aspects.[23] Possibly, EQ-5D descriptions should be enriched to create more resemblance between self-ratings and self-identified EQ-5D ratings.

In cost-utility research, enriched EQ-5D descriptions have already been used to explore preferences for different medication types. Medication-related attributes added to the EQ-5D description induced differences in preferences between treatments.[90] Smith and others[49] suggested that formerly treated patients should rate their past health state more similar to patients than to members of the general public, assuming that differing valuations result from descriptions being sparse and lacking scope. In contrast to their expectations, ratings of formerly treated patients were more similar to the ratings of members of the general public than to the ratings of patients currently undergoing treatment.[49] This finding indicates that providing more detailed information about a health state might still not eliminate patient-public differences.[49] Nevertheless, information that makes the health state description more personal might improve health state descriptions. For instance, Llewellyn-Thomas and others[91] found that with objective health outcomes, individual health state descriptions were better explained than standardized health state descriptions.

The aim of this study was to investigate if patients value their own experienced health state higher than their own standard EQ-5D scenario and if "enriching" this scenario by adding individualized attributes leads to smaller differences between the valuations of the own experienced health and the scenario. To this purpose, patients had to value their own health state in 3 different ways. They valued their own experienced health, a standard EQ-5D description of this health state, and an enriched EQ-5D description of this health state. Based on the findings of Smith and others[49] and Llewelyn-Thomas and others[91] we chose to enrich the own standard EQ-5D description with individual patient attributes instead of giving more detailed but standard information. Considering the results of Insinga and Fryback[23] we expected the valuation of the own standard EQ-5D description in relation to the other valuations to depend on the current health of the patient.

3.2 Methods

3.2.1 Participants and procedures

The sample consisted of patients with rheumatoid arthritis (RA) aged 18 to 76 years old who had visited their treating rheumatologist in the past 6 months. From the database of the Leiden University Medical Center, 300 patients who visited their rheumatologist in the last year were randomly selected. In the selection method, we oversampled men to get an equal male/female distribution because RA is more prevalent in women.

Medical records of the selected patients were assessed for comorbid conditions and true diagnosis of RA. From the 300 selected patients, 50 patients had not been diagnosed with RA, and 7 had comorbid conditions. The remaining 243 eligible patients received information about the survey by mail, including an informed consent form. If patients did not return the informed consent form within 3 weeks, they were called as a reminder. Data were collected using self-report questionnaires and a semistructured interview. The medical ethics committee of the Leiden University Medical Center approved the study protocol.

3.2.2 The interview

Face-to-face interviews were performed by 3 trained interviewers following a strict interview protocol. The interviews took place at the patients' preferred location: at home, in the hospital, or at work. Patients who were interviewed in the hospital came to the hospital; they were not hospitalized at the time of the interview. The interview started with the valuation of each participant's own experienced health of the previous week. This was followed by the EQ-5D questionnaire, a 5-item health-related quality-of-life questionnaire with the dimensions mobility, selfcare, usual activities, pain/discomfort, and anxiety/depression.[89] Patients answered this questionnaire on a 3-point scale: no problems, some problems, and no function at all or, in the case of pain, extreme pain. After this EQ-5D questionnaire, 2 filler questionnaires followed -that is, the Patient Satisfaction Questionnaire[92] and the Rosenberg Self-Esteem Scale[93]- to distract patients' attention from the answers they gave on the EQ-5D questionnaire. In the next part, participants were asked to value[46] standard EQ-5D states. Five of these EQ-5D states were retrieved from previous research with patients with RA, covering the full utility range from 0 to 1 according to the UK tariff.[11] A description of these health states can be found in

appendix B. Unknown to the patients, the sixth health state was their own standard EQ-5D state of the previous week, as indicated in the EQ-5D questionnaire. The computer retrieved the answers of the patient earlier in the interview and created the own standard EQ-5D state for this patient. All standard EQ-5D states were randomly presented except for the patient's own standard EQ-5D state, which was always presented as the 5th state. The description of the patient's own standard EQ-5D state was similar to that of the other standard EQ-5D health states. Patients were not informed that it was their own standard EQ-5D health state. If 1 of the 5 preselected EQ-5D states happened to be the same as the own standard EQ-5D state, this state was replaced automatically with the EQ-5D state that should have been presented in the 6th place.

After valuing their own experienced health and the 6 EQ-5D descriptions, patients answered an open-ended question asking them to indicate attributes important to the own experienced health state. The interviewer entered these attributes in the computer. It was impossible to add a full description of each attribute; consequently, a key word was used. The interviewer and the patient together created suitable key words for each of the individual attributes. Only key words on which the patient agreed were used. These individual attributes were then combined with the patient's own standard EQ-5D state of the previous week to create an own enriched EQ-5D state. On the computer screen, the description of the own enriched EQ-5D state was shown with the individual attributes represented beneath the 5 standard attributes. It was made clear to the patients that the order in which the attributes were presented was arbitrary and that it was up to the patients how important the attributes were to them. Furthermore, patients were told that the description as stated on the computer fit their own health state.

If this were not clear, the interviewer explained how this description was created and made sure that the patient understood that it was his or her own health state. After the valuation of this own enriched EQ-5D state, patients indicated their level of functioning on the individual attributes that they had named before as important to their quality of life of the previous week. To rate this functioning, we used the same scale as was used in the EQ-5D questionnaire. Patients stated if they had no problems, some problems, or were not able to perform an individual attribute. At the end of the interview, all patients were asked whether they had recognized among the 6 EQ-5D states their own standard EQ-5D state that described their own health state. A general overview of the different elements of the interview is shown in (Figure 3.1).

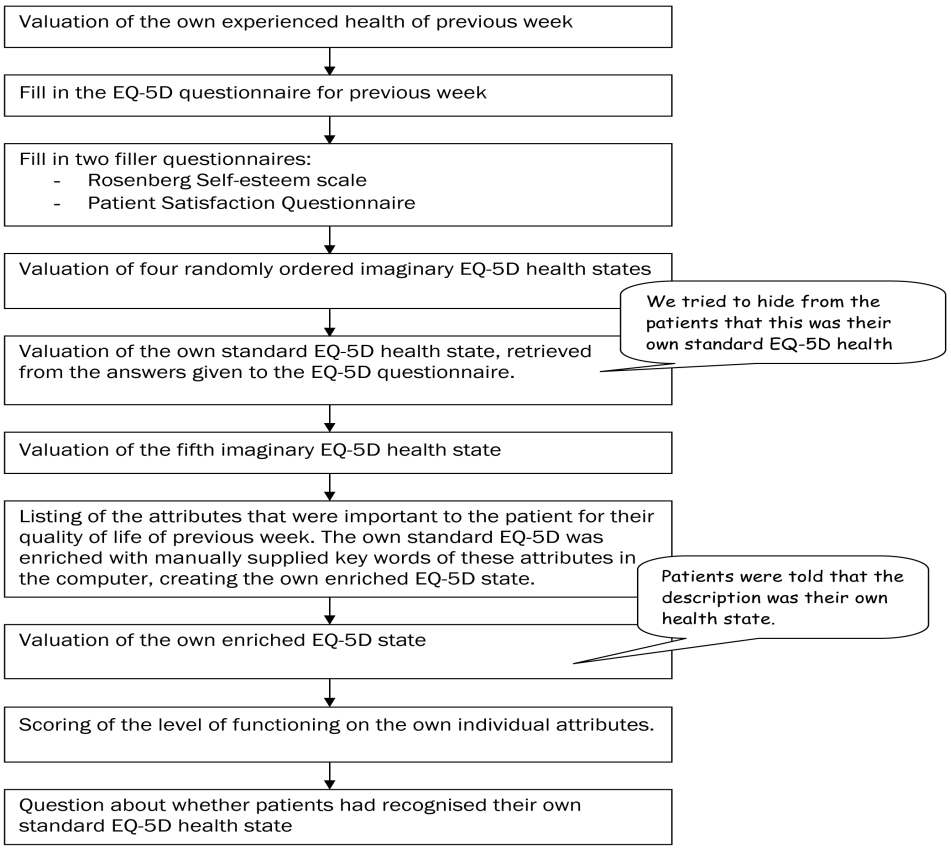

Figure 3.1 The interview process.

All health states were valued using a time tradeoff (TTO). Patients rated how many years (x) of their remaining life expectancy (y), derived from Dutch life expectancy tables [17], they were willing to trade to obtain perfect health. Utility was calculated as $\frac{y-x}{y}$. The computer program Ci3[94] was used to elicit the utilities based on a pingpong search procedure. On the computer screen, a short description of perfect health and the health state to be valued were presented. Perfect health was described as full well-being, physically, psychologically, and regarding social activities. While completing the TTOs, patients were asked to think aloud.

After the interview, patients were asked to complete the Health Assessment Questionnaire (HAQ)[95] at home and to return it by mail. The HAQ is a 24-item

disease-specific health questionnaire. Patients reported the number of problems they perceived in performing several daily activities and whether they had to use devices for these activities. The total HAQ score was used in this study as an indicator of the patients' health status, with higher scores indicating worse functioning.

3.2.3 Data analysis

Prior to the main analyses, all variables were examined for uni- and multivariate outliers, linearity, and normality. Missing data were excluded listwise. Differences between valuations were analyzed using within-subjects analysis of variance (ANOVA). Using the Bonferroni pairwise comparison, post hoc contrasts were performed to investigate the valuations of the own experienced health, own standard EQ-5D, and own enriched EQ-5D pairwise. On the basis of statements made during the think-aloud procedure and the open-ended question, patients were divided into 2 groups depending on whether they had recognized their own standard EQ-5D state. To investigate if recognizing the own standard EQ-5D influenced the valuation of this health state, we performed a $t - test$.

Two interviewers judged independently whether the individual attributes named in the open question used to enrich the own standard EQ-5D states were positive, negative, or neutral. The agreement between the ratings of the interviewers was good (Cohen's $\kappa = 0.90$). Divergent evaluations were compared, and agreement was found through listening to the taped interview and by discussion. We expected the valuation of patients' own enriched EQ-5D to be higher when this description was made more positive compared to their own standard EQ-5D.

Inversely, we expected the valuation of the own enriched EQ-5D to be lower compared to the own standard EQ-5D when adding the individual attributes made this description more negative. Examples of negative attributes were pain, fatigue, and mobility; examples of positive attributes were grandchildren, good emotional functioning, and leisure activities. Naturally, the positive effect of the positive attributes would only hold if patients stated to have no problems on this attribute. Similarly, the negative effect would only hold if patients stated to have some problems or were not able to perform the attribute. To determine this valence of the attributes, we analyzed each attribute for the number of problems that patients stated to have with that particular attribute: no problems, some problems, or unable to perform. Only positively evaluated attributes with no problems were judged to add positive information, and negatively evaluated attributes with some problems or unable to perform were judged as negative added information. For example,

when patients named their partner as an additional attribute, this was expected to increase the valuation of the enriched EQ-5D health state only if the patient stated that he or she had no problems with his or her partner. If the patient reported having some or severe problems with his or her partner, we could not be sure if the enriched EQ-5D would become more positive by adding the partner as an additional attribute. The effect of added attributes on the valuation of the health state was assessed with descriptive statistics and a paired sample $t-$test. Finally, ANOVA was used to assess if current health influenced the relative valuations of the 3 health states, with current health based on the dichotomized total HAQ score.

3.3 Results

A total of 132 patients of 243 patients approved the interview, a response rate of 54%. Of these responders, 1 patient with emotional problems and 2 patients who were not able to speak and understand Dutch were excluded. No differences in age and time since diagnosis between responders and nonresponders were found. Data of 2 participants created multivariate outliers and were excluded from further analyses; Mahalanobis distance, $F(3) = 31.07$ and $F(3) = 18.05$. All variables met the assumptions for linearity and normality, except for the variables "own experienced health," "own standard EQ-5D," and "own enriched EQ-5D." Because we found similar results with nonparametric tests as with parametric tests, we decided to present the results of the parametric tests. These tests give more information and made it possible to test an interaction effect.

The interviews took place at the patients' preferred location: at the hospital ($N = 82$), at the respondent's home ($N = 44$), or at work ($N = 1$). Patients were not hospitalized at the time of the interview. The interview took 1.5 to 2 hours. Patients interviewed at home had on average more health problems based on the HAQ total score than patients interviewed in the hospital. Table 3.1 presents the demographic information of the 127 respondents who were included.

3.3.1 Valuations of own experienced health state

Table 3.2 shows the means and standard deviations of the 3 health state valuations. We found small differences among the ratings of the 3 health states: own experienced health state, the own standard EQ-5D, and the own enriched EQ-5D, $F(2, 242) = 3.83, p = 0.03$. Post hoc analyses showed that this effect resulted principally from the patient's own experienced health state scoring somewhat lower

Table 3.1 Patient Characteristics ($N = 127$)

	Mean	SD	N	(%)
Age	58	11		
Gender				
Female			61	(48%)
Education[a]				
Nine years or less			38	(30%)
Between 10 and 12 years			62	(49%)
13 years or more			24	(19%)
Children				
Yes			61	(48%)
Marital status				
Married			38	(30%)
Divorced/Widow			62	(49%)
Single			24	(19%)

[a]Numbers do not add up to 127 due to missing data.

than the patient's own enriched EQ-5D state ($p = 0.03$). No significant differences were found between the ratings of the patient's own experienced health state and the patient's own standard EQ-5D state description or between the standard and the own enriched EQ-5D state descriptions.

Table 3.2 Means and SD of the valuations the different health states

($N = 122$)	Mean	SD
Own experienced health state	0.79	0.23
Own standard EQ-5D state[a]	0.81	0.25
Own enriched EQ-5D state	0.83	0.22

[a]No differences in the valuations of the own standard EQ-5D state were found between patients who had versus who had not recognized their own standard EQ-5D state, $t(123) = 0.651, p = 0.51$.

Table 3.3 Means and SD of the valuation of the different health state descriptions according to the severity of the patients' current health.

	Patients $HAQ \geq 0.94^b$ ($N = 59$)		Patients $HAQ < 0.94^b$ ($N = 62$)	
	Mean	SD	Mean	SD
Own experienced health state	0.75	0.26	0.83	0.20
Own standard EQ-5D state	0.74	0.29	0.88	0.18
Own enriched EQ-5D state	0.76	0.27	0.90	0.14

[b]Higher HAQ scores indicate worse functioning.

3.3.2 Differences in ratings between patients based on the severity of their current health state

To investigate the effect of the patients' current health, we performed a median split based on the HAQ total score ($0.00 - 0.94$ vs. $0.95 - 3.00$). There were no differences in gender or age between the 2 groups. When the dichotomous HAQ score was added to the ANOVA for the different valuations, a trend was found for an interaction, $F(2, 238) = 2.5, p = 0.09$. Table 3.3 shows the means and standard deviations of the 3 health state valuations for the 2 groups.

The effect seen in the total group turned out to occur only in patients in better health. There was a small difference between the ratings of the 3 health states, $F(3, 183) = 7.94, p < 0.01$. Bonferroni pairwise comparisons showed that this difference resulted principally from the lower valuation of the own experienced health state than the valuation of the own enriched EQ-5D state description ($p = 0.01$). Patients in poorer health rated the 3 health state descriptions as similar, $F(2, 116) = 0.55, p = 0.55$.

3.3.3 Own enriched EQ-5D state description

To the open-ended question, most patients named both positive as well as negative attributes ($N = 96; 76\%$). Fourteen (11%) patients named exclusively positive attributes, and 16(13%) named exclusively negative attributes. Patients who named exclusively positive attributes indeed gave slightly higher valuations to their own enriched EQ-5D state ($mean = 0.92, SD = 0.13$) compared to their own standard EQ-5D state ($mean = 0.90, SD = 0.15$); however, this difference was not statistically significant, $t(13) = 0.03, p = 0.11$. Contrary to our expectations,

patients who named exclusively negative attributes similarly did not rate their own enriched EQ-5D state lower than the standard EQ-5D state description ($mean = 0.79, SD = 0.23$ vs. $mean = 0.76, SD = 0.26$).

3.4 Discussion

In this study, we investigated if patients valued their own experienced health state higher than an EQ-5D scenario describing their health state and if enriching this scenario by adding individualized attributes led to smaller differences between the valuations of the own experienced health and the scenario. Contrary to our hypotheses, the own experienced health state was not valued differently from the own standard EQ-5D state and was found to be lower when compared to the own enriched EQ-5D state of that same health state. We found an indication of an interaction between one's current health and valuations. Patients in relatively good health rated the own standard EQ-5D state description somewhat higher than their own experienced health but not statistically significantly, whereas we did not see differences for patients with poorer health. These findings are in line with the results of Insinga and Fryback.[23] These authors suggested that when individuals rate their own experienced health, they might consider minor decrements in 1 or more of the 5 EQ-5D dimensions that fall between "no problems" and "some problems" or that patients consider health decrements within attributes not specified by the EQ-5D dimensions. Likewise, in our study, patients with better health might have thought about minor problems when they valued their own experienced health.

By enriching the own standard EQ-5D state, we expected to make the description and, as a result, also the valuation more similar to the own experienced health state. However, the own standard EQ-5D states were also valued higher than the own experienced health by patients with better health. We can only speculate about this unexpected finding. Perhaps framing of the question about the own experienced health caused the difference between the valuations. Specifically, in the introduction of the own experienced health state at the beginning of the interview, patients were asked to think about their previous week, particularly about their physical, social, and emotional health in that week. In this introduction, the last week was emphasized, and as a result, patients with better health might have been provoked to think about minor problems of the previous week. In the open-ended question, following the 6 standard EQ-5D valuations, patients were asked to name the most important attributes relating to their own health state of the previous week. First, thinking

about the "most important aspects" might have overshadowed the minor problems patients thought about earlier. Second, patients might have become more aware of the positive aspects of their lives. The latter question was asked after patients had valued 5 health states that were for patients in relatively good health who were most often worse than their own health. Lacey and others[96] showed that health states are valued differently when context information is added. Their participants rated a severe health state more severe in a context of other less severe health states and rated a mild health state more mildly in a context of other more severe health states.

In our study, patients valued their own standard EQ-5D state and the own enriched EQ-5D after they had valued 4 other health states. We did so to create a situation where patients would not easily recognize their own standard EQ-5D state. To reduce a context effect of the other health states on the valuation of the EQ-5D states, however, we varied the sequence in which the health states were presented randomly, whereas in the study of Lacey and others,[43] patients viewed the health states in order from most severe to least severe, and patients were asked to view all health states first before they rated them. We believe that a context effect, if any were present in our study, would not have strongly influenced patients' valuations because preselected EQ-5D states showed no order effect. That is, a health state presented first was not valued differently from a health state presented last [a] , even though the valuation of the enriched EQ-5D health state might have been influenced by the earlier 5 states for patients with better health. They might have recognized that their health state was not as bad as the other 5 health states, which could have led to a higher valuation of their own enriched EQ-5D health state. The finding that this effect was only seen in patients in better health may point toward such a contrast effect. For this group of patients, the states were more likely to be worse than the own health state. The fact that their own experienced health was always presented at the beginning of the interview might have had a negative effect on the valuation of this health state. We felt this to be inevitable because we wished to avoid having EQ-5D information to influence patients' valuations of their own experienced health state.

Another finding in this study was that even when exclusively negative attributes were added, the own enriched EQ-5D state was not valued lower than the own

[a]The mean (0.69[0.28]) of the first presented health state did not differ from the mean (0.69[0.28]) presented last. Because of the randomization, all health states appeared an approximately equal number of times in each place. This made it possible to calculate the mean valuation of all health states presented in the first place and to compare this with the mean valuation of a health state presented in the last place.

standard EQ-5D. Because this result was based on valuations of only 16 patients, this finding has to be viewed with caution. However, if there is some ground for this finding, it might have been caused by a so-called status quo bias; people tend to value health states higher when they "own" that health state.[15] In economic decision making, studies have revealed that people value goods more highly when they own these goods.[28,29] People thus seem to prefer what they know, which may result in a preference for own health above an unknown health state. In our study, when patients were valuing the own enriched EQ-5D health state, they were told that it was their own health, in contrast to when they were valuing the own standard EQ-5D description of their own health. Although we found significant differences, they are small compared to the minimal importance difference (MID) for the EQ-5D. Walters and Brazier[97] revealed a mean MID of 0.074(−0.011 to 0.140) for the EQ-5D with secondary analyses on 11 studies. However, the aim of this study was to understand why health states are valued differently. In future studies, it would be interesting to investigate the consequences of such differences for cost utility analyses.

3.5 Conclusion

Only limited support was found for the contention that the EQ-5D state description might be too sparse. It remains uncertain if including personal information with a health state description will make hypothetical health states valued more similarly to experienced health state ratings.