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

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Focusing illusion, adaptation and EQ-5D Health State Descriptions: The difference between patients and the general public.

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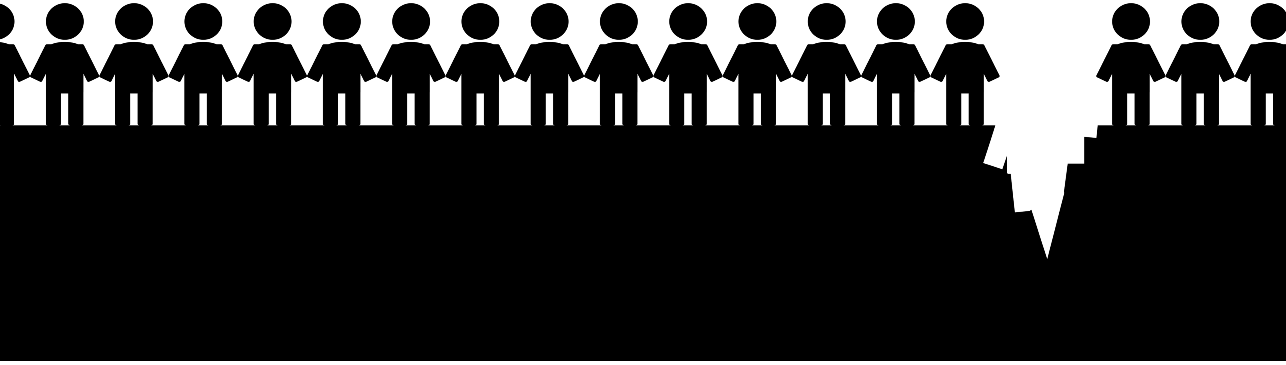


Abstract ***Objectives:***Patients tend to assign higher utilities to health states compared to the general public. Several explanations have been given for this difference including focusing illusion -, caused in part by the We investigated whether patients and the public differ in which dimensions they find important. Furthermore, we compared whether the dimensions named by patients and the public obtained higher rankings of importance compared to the predefined EQ-5D dimensions. Within each nominated dimension we investigated whether the public used a more negative frame compared to patients. In addition, adaptation was investigated by comparing patients with high levels of adaptation and patients with low levels of adaptation. ***Method:*** Data were collected using semistructured interviews among 124 patients with rheumatoid arthritis and 64 members of the public. Participants indicated which aspects are important to them when they think about their life having rheumatoid arthritis and rated the importance of these aspects and of the EQ-5D dimensions. ***Results:*** In contrast to patients, the public named more often aspects related to sports & mobility, leisure activities, and work, and framed these aspects negatively. Compared to self-rated dimensions, the public ranked the EQ-5D dimensions as more important whereas patients found both groups of aspects equally important. Patients who showed higher levels of adaptation did not differ significantly from patients with lower levels. ***Conclusion:*** The public is focussed on life domains that are negatively influenced by the described health state whereas patients are focussed on both the positive and negative aspects of their lives.

4.1 Introduction

In cost-utility analysis, utilities are used to estimate how much better the quality of life is in one health situation or 'state' compared with another. Utilities can be elicited from the public or from patients. For analysis from a societal perspective, it is recommended to use utilities assessed from a representative sample of the general public.[98] In contrast, utilities of patients who have experience with a health state might be more appropriate in clinical decision making and in certain policy decisions.[99] Whose utilities should be used is only relevant if patients and public differ. Literature dealing with this difference is somewhat controversial3 and generally supports the supposition that patients assign higher utilities compared to members of the public.[16, 46, 100]

Several explanations have been given for the difference between patients and the public. Patients typically assign utilities in light of their experiences, whereas members of the public are limited to a description of the health state. Even among patients, it has been shown that utilities for patients' own health are higher than utilities they assign to a description of their own health.[20, 46] When patients give utilities for their own health, a broad range of information can be used, whereas utilities based on health state descriptions are supposedly limited to the information provided.

The EQ-5D is widely used to provide health state descriptions. The EQ-5D consists of five dimensions:, mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension is described according to one of three levels of severity: no problems (1), some problems (2) and extreme problems (3). In total the EQ-5D can thus create 243(3^5)theoretically possible health state descriptions.[89] EQ-5D health state descriptions thus consist of five sentences stating the level of problems on the dimensions. Several publications have pointed out that the sparseness of these EQ-5D health state descriptions[23, 90, 101–104] limits their ability to comprehensively describe health states. The sparseness of EQ-5D descriptions is a result of the original purpose of the EQ-5D. The EQ-5D was developed as a non-comprehensive measurement alongside other more detailed measures of Health Related Quality of Life (HRQoL).[105] The five EQ-5D dimensions were selected from a review of existing instruments and tested against the results of a survey on the concepts of health of lay persons.[22] Given the current use of the EQ-5D as a full health state description it has been suggested that the comprehensiveness of the EQ-5D health states should be improved by adding new health state dimensions.[23] Studies investigating the effects of extra dimensions have based the selection of extra dimensions on expert groups and the general public's concepts of health.[102,104] However, by selecting EQ-5D dimensions from lay persons' health concepts, the sparseness of the EQ-5D health state descriptions might inadvertently prompt a focusing illusion in this group.

Focusing illusion is suggested as an important explanation for the difference between health state utilities assigned by patients and the public. When members of the general public are asked to imagine life in a certain health state they will concentrate on the differences between their current health state and the health state to be valued.[26] Life domains influenced by the health state receive disproportional attention, whereas domains that will not be affected are ignored. The public concentrates on the negative aspects of an illness while patients give utilities in light of their experiences in general.

Another explanation suggested for the differences in ratings between patients and the public is the adaptation of patients. When patients experience an illness they will adapt to it by changing their interests and goals and by lowering their expectations for specific dimensions in the future.[18] In contrast, it seems almost impossible for the public to anticipate such adaptation.[38,39] This study investigated focusing illusion and adaptation as explanations for the differences in utilities between patients and the public. We investigated whether patients with rheumatoid arthritis (RA) and members of the general public who were asked to imagine having RA differed in which dimensions they rated as important in their lives. We hypothesize that compared to patients, members of the public are more focussed on dimensions influenced by the illness. Furthermore, we asked participants to name important aspects in their lives and examined whether the dimensions named by patients and the public were given higher rankings of importance compared to the predefined EQ-5D dimensions. Given that the EQ-5D dimensions were based on concepts of lay persons we hypothesize that the EQ-5D will accurately reflect the opinion of the public but not that of patients. Within each named dimension we investigated whether the public used a more negative frame compared to patients. The public may focus on those dimensions for which they would experience limitations after developing an illness, thus leading to negative framing.

Similarly, adaptation was investigated by comparing patients with high levels of adaptation and patients with low levels of adaptation. We investigated if patients with high levels of adaptation named different dimensions compared to patients with low levels of adaptation, if within each subgroup the dimensions named obtained higher importance rankings compared to the predefined EQ-5D dimensions and within each of the dimensions we investigated whether these two groups differed in their framing.

4.2 Methods

4.2.1 Patient subject recruitment

From the patient database of the Leiden University Medical Center, 300 patients aged 18 to 76 years old who had visited their rheumatologist in the past 6 months were identified. Men were oversampled to get an equal distribution of males and females. Medical records of the selected patients were reviewed to confirm the diagnosis of rheumatoid arthritis (RA) and to identify comorbid conditions. Of the 300 identified patients, 50 had not been diagnosed with RA, and 7 had severe comorbid conditions. The remaining 243 eligible potential patient subjects were mailed information about the interview and an informed consent form and asked to return the signed consent form if they were willing to participate. Those who did not return the form within 3 weeks were telephoned once and asked if they were interested, and whether they needed a copy of the survey and consent form mailed to them.

4.2.2 Recruitment of members of the public

Members of the public were recruited through advertisements in local newspapers distributed in Leiden and the surrounding mid-west region of the Netherlands. To meet inclusion criteria, participants had to be between 35 and 76 years old. Those who had RA or whose partner had RA were excluded. Of the 69 people who responded, two were excluded; one of the excluded participants had RA and the other one had a partner who had RA. The 67 individuals who were invited to participate were mailed information about the survey including an informed consent form.

4.2.3 Data collection

Data were collected using semistructured interviews and self administered questionnaires. Face-to-face interviews were performed by three trained interviewers. The interview took place at the patient subjects' preferred location: at home, at our department (an office area of the LUMC), or at work. Members of the general public were requested to visit our department. Patient participants who were interviewed at our hospital office were not hospitalized at the time of the interview. In this paper only the part of the interview used to gather the information for this study is described. A full description of the interview can be found elsewhere.[100]

The semistructured interview was slightly different for patients and members of the public. Both groups received the same questions but answered them from a different point of view. Patients were asked to answer questions about their own health during the last week. Members of the public read a health state description of RA (see Appendix C) and were asked to imagine that they had the RA state described, and to thus imagine their previous week with this health state. At any time point during the interview the RA health state description could be reread by the participant.

During the interview, patients and members of the public answered the EQ-5D questionnaire by filling out the level of problems on each of the EQ-5D dimensions for their own health or the health state description, respectively. Next, after some filler questions, patients were asked to name aspects important to their health during the last week, and members of the public were asked the same questions imagining that they had the RA state as described. An open-ended question was asked to elicit up to a maximum of five dimensions. Each of the dimensions named by the participant was summarized to one keyword after consultation with the participant. These keywords were then written down on separate sheets of paper. Subsequently, the five EQ-5D dimensions were also written down on separate sheets. All dimensions were ordered by importance to the participant's life with rheumatoid arthritis (actual or imagined). If aspects were ranked equally important they were put next to each other. The most important dimension was rated as 1, the next one 2, and so on.. If aspects were equally important they received the same importance rating.

After the interview, participants received a questionnaire which they completed at home and returned by mail. For patients this questionnaire included the Illness Cognition Questionnaire (ICQ) to assess adaptation. This questionnaire consists of three scales: hopelessness, benefit finding, and acceptance. Patients rated how much they agreed with 18 statements on a four point Likert scale ranging from 'not at all' to 'completely'. The medical ethics committee of the Leiden University Medical Center approved the study protocol.

4.2.4 Coding

The aspects named by the patients were initially consolidated into 10 dimensions based on often recurring themes in the interviews. Each interviewer independently coded the aspects based on these dimensions. Based on a comparison of the coding, a final coding system was developed. All aspects were recoded by each of the two interviewers, differences were compared, and discrepancies were resolved through discussion and reviewing the audio tapes of the interviews. A full description of the coding system can be found in Appendix D.

The dimensions named by members of the public were coded using the same coding system. Both interviewers coded all aspects. Agreement between the interviewers was substantial, with a Cohen's $\kappa = 0.79$.[106] Divergent evaluations were compared, and discrepancies were again resolved through discussion and reviewing the audio tapes of the taped interviews. All aspects named fitted in one of the dimensions of the coding system. The interviewers also judged independently whether the aspects were framed as positive, negative or neutral, based on the descriptions in the interview schemes. The agreement between these ratings was almost perfect for the dimensions named by patients (Cohen's $\kappa = 0.90$) and moderate for the public (Cohen's $\kappa = 0.51$).[106] Divergent evaluations were compared. By listening to the taped interviews agreement was found.

4.2.5 Analysis of data

1. Do patients and the public differ in which dimensions they find important, in their ranking, or in the framing of the aspects named?

To answer this research question, the number of patients was compared to the number of members of the public that named at least one aspect within a dimension. For each dimension the frequencies were compared by using a χ^2-test. Furthermore the overall importance of all EQ-5D dimensions was compared to the overall importance of all self-named aspects using the Wilcoxon signed rank test. A lower number indicated a higher importance. For this analysis we calculated for each participant the mean rank-order of all EQ-5D dimensions and that of the self-named dimensions. Next, for each of the EQ-5D and self-named dimensions the mean importance was calculated. The mean ranks of the coded dimensions based on the own named aspects were based only on the rank-order of participants who actually named an aspect in this dimension.

To investigate framing, we first compared the overall framing between patients and the public. For each participant we summed the positive, negative and neutral codings and divided these by the number of aspects. That is, a participant who named 3 aspects of which two positive and one neutral obtained the value $0.67(\frac{(1+1+0)}{(3)})$. The overall framing value between patients and the public was compared using the median test. Next we calculated for each dimension the number of participants who framed the aspect as positive, negative, or neutral. If participants named more than one aspect with unequal codings in the same dimension this participant was judged as "mixed". For example, if a participant named "I often swim" and "I am not able to walk long distances" both aspects were coded into the dimension sports & mobility with one as positive and one negative. For each dimension the positive and negative frequencies of patients were compared to the frequencies of the public using a χ^2-test. Neutral and mixed were excluded.

2. Do patients with low acceptance of their illness differ from patients with high acceptance in which dimensions they find important, their ranking, or in the framing of the aspects named?

All analyses described above to compare patients and the public were also performed to compare patients with high acceptance of their illness and patients with low acceptance of their illness. Low and high acceptance of the illness was based on a median split of the acceptance scale of the ICQ. Bonferroni correction was used to correct for multiple comparisons where necessary.

4.3 Results

4.3.1 Participants

Of the 243 patients identified, 132 patients agreed to participate in the study (54%). No differences in age or time since diagnosis between responders and non-responders were found. Of the responders, one patient with emotional problems and two patients who were not able to speak and understand Dutch were excluded. Five patients who could not finish the interview due to time or cognitive and concentration problems were excluded from further analyses. In total 124 patients were included in the analyses. The interviews took place at the hospital ($N = 82$), at the patients' home ($N = 41$), or at work ($N = 1$). In total 67 members of the public originally agreed to be interviewed. Two participants canceled the interviews, both due to tight time schedules. All interviews took place at the hospital ($N = 65$).

Table 4.1 and Table 4.2 present the demographic information of the participants. As can be seen from Table 4.2, the health state of patients was less severe than the health state description imagined by members of the public both based on the UK-tariff estimated from the ratings participants gave on the EQ-5D questionnaire. No differences were found on the aspects named and rankings given between patients with different educational levels. Past and/or present significant health

Table 4.1 Participant Characteristics

		Patients ($N = 124$)		Public ($N = 65$)	
		N	(%)	N	(%)
Gender					
	Female	59	(48%)	r50	(77%)
Education[a]					
	Nine years or less	33	(28%)	5	(8%)
	Between 10 and 12 years	65	(52%)	29	(45%)
	13 years or more	24	(19%)	31	(48%)
Children					
	Yes	103	(83%)	49	(75%)
Marital status					
	Married	109	(88%)	37	(57%)
	Divorced/Widow	9	(7%)	13	(20%)
	Single	6	(5%)	8	(12%)
Work Status[a]					
	Fulltime	20	(16%)	7	(11%)
	Part-time	22	(18%)	23	(35%)
	Household/ volunteer/ unemployed	17	(14%)	14	(22%)
	Unable to work	30	(24%)	6	(9%)
	Early retirement	22	(26%)	15	(23%)
	Retirement	2	(2%)	0	(0%)
Illness or disability					
	Yes	No information available		40	(62%)

[a] Numbers do not add up to total sample size due to missing data.

Table 4.2 Participant characteristics; continuous

	Patients ($N = 124$)		Public ($N = 65$)	
	Mean (Range)	SD	Mean (Range)	SD
Age	58(29-75)	10.88	56(38-75)	10.86
Time since diagnose RA (years)	13(2-47)	9.26		
EQ-5D UK-tariff[a]	0.63 ($-0.43 - 1.00$)	0.27	0.53($-0.20 - 0.69$)	0.27

[a] EQ-5D UK-tariff of the health state to be valued

Table 4.3 Members of the public who currently have or previously had significant health problems:

Type of health problem:	N	(%)
Stroke	2	(3%)
Cardiac disease	4	(6%)
Cancer	7	(11%)
Migraine / severe headache	8	(12%)
High blood pressure	11	(17%)
Asthma/ bronchitis etc.	1	(2%)
Severe back problems/ herniated disc	3	(5%)
Parkinson	1	(2%)
Severe problems in joints	4	(6%)
Other	19	(29%)

problems experienced by participants from the general public are depicted in Table 4.3.

4.3.2 Patients vs. Public

1. Do patients and the public differ in which dimensions they find important, their ranking, or in the framing of the aspects named?

Table 4.4 shows the frequencies and percentages of participants who named at least one aspect in a dimension. Patients named significantly more often aspects in the dimension illnesses not RA-related ($\chi^2(1) = 15.25; p < 0.005$), and less often in sports and mobility ($\chi^2(1) = 9.67; p < 0.005$), and work ($\chi^2(1) = 8.01; p < 0.005$) compared to the public. The significance level was corrected for the number of tests,

Table 4.4 Number of aspects named in each dimension by patients and public

	Frequency and percentage dimension named:			
	Patient %	(N)	General public %	(N)
Physical inconvenience RA-related	77	(96)	66	(43)
Illness/inconvenience not RA-related	23	(29)	2	(1)$^\sharp$
Family	38	(47)	20	(13)*
Other social contacts	23	(28)	19	(12)
Emotions/Worries	40	(50)	31	(20)
Sports/Mobility	27	(33)	49	(32)$^\sharp$
Leisure activities	23	(28)	37	(24)*
Work	26	(32)	46	(30)$^\sharp$
Broad every day life	30	(37)	26	(17)
Other	20	(25)	19	(12)

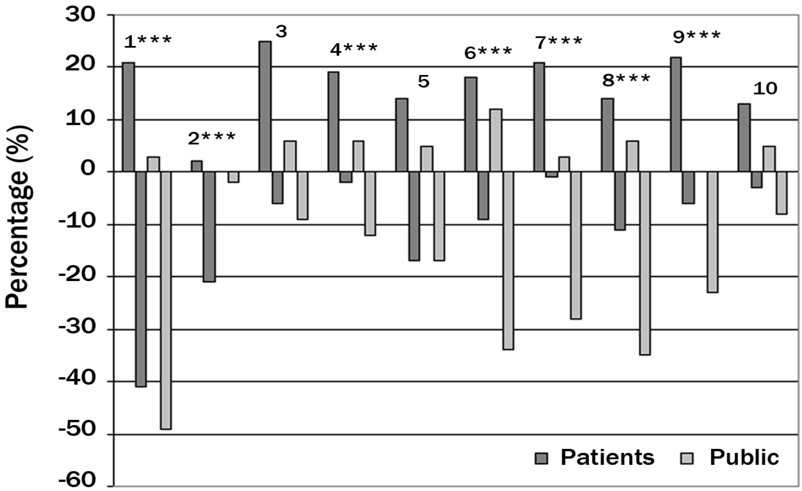
$^*p < 0.05, ^\sharp p < 0.005$

resulting in a corrected level of $p < 0.005$.

The mean rank-order of EQ-5D dimensions was not different from the rank-order of self-named dimensions in patients ($mean = 3.47(1.24)$ vs. mean $= 3.26(1.19)$; $z = -1.64, p = 0.101$). By contrast, members of the public rated the EQ-5D dimensions as more important compared to the self-named dimensions (mean $= 3.30(0.99)$ vs. mean $= 4.01(1.42); z = -3.32, p = 0.001$). Table 4.5 shows the importance of each of the EQ-5D dimensions and self-named dimensions for patients and public; a lower number indicates greater importance. The mean reported is based on the rank-order of participants who named a dimension in this category. Consequently this mean is supported by only a sub-sample of participants (Table 4.4) making it impossible to statistically test the difference between the two respondent groups. Overall, the public framed the aspects more negatively compared to the patients (median framing value of the public = -0.75 vs. median of the patients = 0.00; $\chi^2(1) = 23.92, p < 0.005$).

Figure 4.1 shows the negatively and positively framed aspects for each of the dimensions separately; neutral aspects were excluded. The χ^2 tests shows that for almost all dimensions patients framed their aspects more positively, except for the dimensions family, emotions & worries, and other. Again we used a corrected significance level of $p < 0.005$.

Figure 4.1 Percentage dimensions named by patients and public divided in positive and negative



The negatively and positively framed aspects for each of the dimensions separately; neutral aspects were excluded.

$***p < 0.005$

1 Physical inconvenience RA-related
2 Illness/inconvenience not RA-related
3 Family
4 Other social contacts
5 Emotions/Worries
6 Sports/Mobility
7 Leisure activities
8 Work
9 Broad every day life
10 Other

Table 4.5 Importance of EQ-5D dimensions and self-named dimensions for patients and public

	Mean(SD) Rank-Order[a]	
	Patient	Public
EuroQol Mobility	2.92(1.70)	3.62(1.99)
EuroQol Self-Care	3.56(2.16)	3.29(2.16)
EuroQol Usual activities	3.12(1.88)	3.19(1.77)
EuroQol Pain/Discomfort	3.98(2.27)	3.21(1.67)
EuroQol Anxiety/Depression	3.81(2.42)	3.19(2.19)
Physical inconvenience RA-related	3.44(1.72)	3.13(1.68)
Illness/inconvenience not RA-related	4.02(2.21)	4.00(NA)
Family	2.51(1.52)	3.31(1.70)
Other social contacts	3.79(1.85)	3.82(2.14)
Emotions/Worries	3.23(1.87)	3.63(2.42)
Sports/Mobility	3.32(1.77)	4.32(2.20)
Leisure activities	3.52(1.69)	5.20(2.05)
Work	3.97(2.24)	4.67(2.22)
Broad every day life	3.00(1.90)	5.06(1.95)
Other	3.64(1.98)	3.33(1.87)

[a] lower number indicates greater importance

2. Do patients with low acceptance of their illness differ from patients with high acceptance in which dimensions they find important or in the framing of the aspects named?

No differences were found between these patient groups in the frequency of dimensions named. For patients with low acceptance the mean rank-order of EQ-5D dimensions (3.47 (1.27)) was similar to the mean rank-order of own named dimensions (3.35(1.12)), ($z = -0.51; p = 0.61$). However, patients with high acceptance tended to rank the self-named dimensions slightly more important compared to the EQ-5D dimensions ($mean = 3.22(1.27)$ vs. $mean = 3.48(1.23); z = -1.82, p = 0.07$). Aspects named by the patients with high acceptance were framed more positively (median = 0.27) than those named by the patients with low acceptance (median $=-0.20$), ($\chi^2(1) = 6.57, p < 0.01$). However the framing within each dimension did not differ.

4.4 Discussion

Most studies show that patients assign higher health state utilities compared to members of the public.[16] We studied explanations for this difference. Support was found for the focusing illusion of the public. The findings underpin the hypothesis that the public is focused on life domains influenced by a health state: the public concentrated on not being able to perform work, leisure activities, and sports anymore. Alternatively, these findings could also be explained by adaptation of patients. Patients in this study were less concerned about not being able to work or play sports. A possible explanation is that they have learned to live without these activities and have found new life goals.

The overall framing of aspects important to patients was neutral, whereas a positive frame might have been expected. In the discussion about whose utilities should be used it is argued that patients overestimate their well-being, leading to a positive bias.[107] Patients might be unrealistically optimistic about their situation[108] and avoid complaining about their situation.[107] However, our results tentatively show that patients do not positively exaggerate their life domains. This is in line with Riis et al[107] who found no evidence that patients overestimate their mood. Possibly patients have a better picture about life in a certain health state, resulting in more accurate estimations. However, we have to take into account that the results are limited to patients with rheumatoid arthritis. It could be that these patients are less able to adapt to their illness. Rheumatoid arthritis is a disabling and often progressive disease, with varying symptoms and which is characterized by pain and deformity of the joints. There is evidence that pain is a symptom to which people only adapt to in a limited way.[109, 110]

To compare the effect of acceptance, patients with high acceptance were compared to patients with low acceptance. For all research questions a difference was seen between patients with high and low acceptance, but the effect was not strong. Patients who had better accepted their illness framed their aspects slightly more positively than patients who had a lower acceptance.

In contrast to the hypothesis that patients think more about their life in general we found that 77% of the patients still named one or more aspects of physical (in)convenience related to RA. This can be explained by the context of the study. Patients were invited to participate in a study investigating quality of life of patients with RA and answered several questions related to RA and their health before answering the open ended question about their most important aspects. It may be that the context of the study, the introduction, and the previous questions made information about RA easily accessible in the minds of the patients.[111,112] Along the same line, the answers given by members of the public may have been guided by the domains provided in the health state description.

Another explanation for the difference between patients and members of the public was the sparseness of the health state descriptions, such as in the EQ-5D. When compared to the self-named dimensions we found that according to the public the EQ-5D dimensions were ranked as more important. This suggests that the EQ-5D dimensions indeed give a good reflection of the most important dimensions to be included in a health state description according to the public. In contrast, patients found their self-named dimensions equally important as the EQ-5D dimensions. For patients the EQ-5D dimensions might not be complete, other dimensions are also important in creating comprehensive health state descriptions. A tentative suggestion can be made for adding information about family. As illustrated in Table 4, this dimension might be expected to be more important than the EQ-5D dimensions. Our findings suggest that patients find an EQ-5D health state description too sparse and information about family should be added. More research among patients is necessary to further investigate this finding.

Our findings were based on an open-ended question asking participants to name the most important aspects without referring to the predefined EQ-5D dimensions. Naturally, had we asked patients and the public which dimensions they found important in addition to the five EQ-5D dimensions, we might have obtained different results. We were afraid that if we referred to the EQ-5D dimensions, participants would have focussed on naming similar dimensions. Further, it was decided not to code the aspects into the predefined EQ-5D dimensions but to use a new coding system. EQ-5D dimensions can be interpreted in a very broad as well as in a narrow way. For instance, one can suggest that aspects related to family and friends are mentioned by the dimension "daily activities" whereas someone else might think that family and friends are not per se part of an activity. To determine if the self-named aspects correspond to the EQ-5D dimensions, more information would be necessary about how the participants interpreted the EQ-5D dimensions. For instance, broad everyday life might be expected to come under EQ-5D self-care or usual activities, but most often aspects named in this dimension were hard to distinguish. Often participants mentioned aspects such as "Generally I am able to do what other people would do on a typical day." This can come under the EQ-5D dimension self-care but also under the dimension usual activities. When asked, participants did not make a clear distinction.

In our sample 62% of members of the public had experience with an illness. Experience with an illness may have influenced our findings.[17] Yet from a societal perspective it is suggested that a representative sample of the general public should be assessed for cost-utility analyses. This does not exclude people with current or previous health problems. When we compared the number of participants with significant health problems with the number of the Dutch population[113] we did not find major differences. Our sample seems to be a good representation of the Dutch population.

Patients and members of the public differed on some demographic characteristics. A major difference between the patients and the public was that in the sample of patients more participants were married. However, both members of the public and patients named family an equal number of times as an important domain. Another difference was seen in that more patients were unable to work, compared to members of the public. Post hoc analyses on work status showed that people who were able to work more often named aspects related to this dimension. This suggests that activities that have taken up most time in one's previous week come to mind more easily. However, participants unable to work, mostly patients, seem to have changed their focus. Participants able to work mentioned not being able to work as an important limitation, whereas participants who actually were not able to work did not mention work at all. Finally patients had fewer years of education than members of the public, but no effect was found on aspects named by education level.

In this study patients were asked to think about their own health whereas members of the public were asked to imagine a health state description. Although this is in line with research in cost-utility analysis, it leads to differences in perception of health state severity and to variance between patients and public. In this study the average health state of patients was less severe than the health state description imagined by members of the public based on UK- EQ-5D tariff scores. However, given that the majority of patients were not able to work or had problems with sports/mobility but did not focus on these dimensions of life, we expect the influence of the severity of the health state to be minor.

In conclusion, regarding the EQ-5D health state descriptions, our findings indicate that patients find an EQ-5D health state description sparse. More research among patients is necessary. Regarding focusing illusion we found that the public is focused on life domains that are negatively influenced by the health state whereas patients are focused both on the negative and the positive aspects of their lives. Consequently, patients' picture of life in a health state might give a better reflection of reality. To what extent patients had accepted their illness did not have a strong influence on what aspects patients found important.