The construction of health state utilities

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Abstract

The time trade-off (TTO) is an important method to elicit health state utilities. As all methods to elicit utilities do, it suffers from biases. Additionally, providing a health state with a label (e.g. cancer) has been known to possibly influence utilities. The purpose of this study is to obtain a better understanding of how TTO utilities are constructed and to discuss how biases and labeling may influence patient and public values. The first experiment used qualitative data to explore biases and themes that influence TTO utilities. Forty-five respondents valued six rheumatoid arthritis (RA) health states using a TTO, while thinking aloud. We found evidence of the biases scale compatibility and loss aversion. Qualitative data showed that respondents considered themes such as anticipated adaptation, life goals, and maximal endurable time. Effects of these themes on TTO utilities are discussed. Labeling of the health states appeared to influence utilities. In a second experiment, therefore, 84 respondents divided into two groups valued six RA health states either labeled or not labeled. Labeled health states were valued higher than unlabeled ones were. Labeling may have the effect that healthy subjects, like patients, do not use the whole utility continuum. Labeling a health state may lower discrepancies between patient and public estimates of quality of life.

Introduction

The Time trade-off (TTO) is an important method to elicit health state utilities that are used in cost-utility analysis (10). The TTO assesses the period in good health that is equivalent to a period in bad health. Several studies have presented empirical evidence demonstrating that TTO utilities better reflect individual preferences for health than standard gamble (SG) utilities, due to biases in the latter method (6;34;63). Nevertheless, some biases are known to influence TTO utilities as well. The most well known biases that affect TTO utilities are scale compatibility, utility curvature, and loss aversion (6). These biases play a role in the differences in utilities found between patients and the general public. These differences are the topic of active debate and research (53;64;65), and we will argue that part of these differences may be explained by loss aversion.

Scale compatibility refers to the finding that the higher the compatibility of a characteristic is with the response scale that is used, the more attention and weight an individual will give to that characteristic (6;13). The TTO response scale is in years and, thus, the duration of the state is likely to receive more attention than the health status. Consequently, scale compatibility will lead to higher utilities as people are reluctant to give up life years. The bias of utility curvature results from the assumption underlying the TTO that the utility for life years is linear. For most people this assumption is incorrect, as nearby years are valued more than remote years. Because remote years are more easily traded in the TTO method, this leads to lower utilities (6). Loss aversion refers to the finding that people are more sensitive to losses than they are to gains (11). In other words, the location of the reference point, or point of view, in the TTO is relevant to determine which outcome is perceived as a loss. Bleichrodt argued that the impaired health state is used as the reference point. The

TTO asks how many life years a person is willing to give up in order to *regain* optimal health. Thus life years are viewed as losses, leading to higher TTO utilities (6). Individual differences have indeed been found due to the point of view of the individual that values a health state, and these will likely be related to loss aversion (53;66;67). The differences in utilities between the general public and patients have mostly been attributed to psychological processes that patients have experienced, e.g. adaptation to and/or coping with a health state. Another explanation may be a different reference point. If the reference point for patients is the health state to be valued, whereas for a healthy person it is the state of good health, the bias loss aversion will operate differently for the two groups.

Another factor that may influence utilities and that, strictly speaking, is not a bias, is labeling. A study by Gerard et al. showed a shift in valuation that was partly due to the label 'cancer' that was given to the description (65). They argued that the possible connotations of the word 'cancer' could have led to lower valuation than was the case for non-labeled health states. Patients have their implicit labels, whereas in studies in the general public unlabelled health states from classification systems are commonly used.

This study aims for a better understanding of how TTO utilities are constructed. It is based on the increased interest in cognitive aspects of quality of life assessment (57;68;69). This study consists of two experiments. In the first experiment, the biases that influence the TTO are studied qualitatively. Qualitative data provide better insight into the construction of TTO utilities and possible themes and biases that influence it. This in turn sheds new light on discrepancies between utilities of patients and the general public. The second experiment assesses the possible effect of labeling. It further compares the derived TTO utilities with valuations from the EQ-5D tariff.

The purpose of this experiment was to test the impact of the labeling of health states on TTO utilities by healthy subjects.

Experiment 1

Methods

Procedure

Forty-five respondents were recruited through newspaper ads and pamphlets. Respondents were paid € 22.50 for participation in two interviews, one of which is the topic of this paper. Six RA health state descriptions were selected from the descriptions given by rheumatic patients in the Rheumatoid Arthritis Patients In Training study (24). Descriptions were taken from the EQ-5D system. The health states were chosen so that they would cover the utility continuum (0 – 1), using corresponding EQ-5D valuations based on the TTO (25).

We used the EQ-5D health state descriptions; 21232 (I, UK EQ-5D index = .09 (Dutch tariff = .17)), 22322 (II, EQ-5D index =.19 (.31)), 21321 (III, EQ-5D index = .36 (.52)), 21222 (IV, EQ-5D index = .62 (.65)), 21211 (V, EQ-5D index = .81(.86)), and 21111 (VI, EQ-5D index = .85 (.89)). The TTO was written using the computer program Ci3 (26). The interview took 45 minutes on average to complete. A researcher was present during all elicitations.

The experiment started with a written explanation of RA. A verbal and written explanation of the TTO followed, after which two examples were given. At any time during an elicitation, it was possible for respondents to take a break or check earlier

answers within that elicitation and change these. Elicitations ended when respondents indicated that they valued two options equally. In total, six TTO's were performed, one elicitation for each RA health state. The order of elicitations was randomized. Respondents were offered the choice between either a RA health state during the remaining life expectancy (LE) and a healthy life for period x ($x \leq LE$). Period x (offered number of years in optimal health) was varied (ping-pong) until indifference resulted. LE was based on a respondent's remaining life expectancy derived from Dutch life tables (28). Additionally, familiarity of the respondent with RA was assessed by asking whether they knew someone in the inner circle of acquaintances that suffered from RA.

All respondents were instructed to think aloud during the TTO interviews. Thinking aloud, i.e. verbalization, has been reported to affect only the time needed to complete the task (40). All qualitative data was taped and transcribed.

Coding

Initial familiarization with the qualitative data took place, this was followed by sorting, and indexing of other themes. These steps were iterative and not strictly consecutive. We focused on biases reported in the literature, and other themes relevant for TTO utilities. Two independent coders each coded the first quarter of the reports to resolve any ambiguities. Observed differences in coding were discussed and for these a consensus coding was reached. One coder coded the remaining interviews for themes based on this consensus.

In order to qualitatively determine the effect of scale compatibility, we planned to assess whether the focus lay more on life years than on the quality of life of the health state that is valued. Given the (ping-pong) task in the TTO, however, it turned

out that respondents overwhelmingly focused on life years. We therefore decided not to code this further. To assess the effect of loss aversion we coded whether outcomes were labeled as gains or losses, and explored the data for reference points (34). “Reference point" was coded if a point of view was formulated, i.e. respondents used an outcome as a starting point to indicate or calculate the difference with another outcome and, thus, indicated the perception of the outcomes as a loss or a gain.

Possible outcomes that could serve as reference point were the RA health state for the remaining life expectancy, period x in optimal health, or current health state (remaining life expectancy in optimal health, i.e. status quo). The reference point RA for the remaining life expectancy was coded as reference point if respondents adopted RA as their starting point and spoke of either regaining optimal health and/or being deprived of future life years. The outcome “Living for period x in optimal health” was coded as reference point if respondents used this outcome as starting point and spoke of gaining future life years and/or giving up optimal health or wishing to stay in optimal health. “Current health state” was coded as reference point if it was used as starting point and other outcomes were viewed as losses relative to this outcome. The current health state (living for optimal health for the remaining life expectancy) was not an option in TTO.

Other themes that were coded were maximal endurable time (54), anticipated adaptation (62), explicitly not anticipating adaptation, and anticipating problems related to old age. Furthermore a "goal" was coded if a statement was made regarding the realization of a goal with respect to one or both outcomes (34).

Data Analysis

For the qualitative data, we assessed the number of remarks on a theme made by that respondent per health state that was valued. Correlations between coded themes and utilities were assessed for all health states. To give an example, assuming that loss aversion leads to higher utilities: We expected a positive correlation between the utility on the one hand, and the number of times that the RA health state was used as reference point. Using a regression analysis (enter method) with TTO utility as dependent variable, we determined themes that correlated significantly with utilities.

Results

The respondents consisted of 26 women aged 18 to 72 years (mean age = 27, s.d. = 12) and 19 men aged 19 to 61 years (mean age = 34, s.d. = 14). All respondents were educated with at least high-school level. About 50% of the respondents were university students, and 25% of the respondents had children.

The analysis reported here is based on qualitative data from the TTO. Quotes, which are used to illustrate our findings, are identified by gender, respondent age and the health state that is valued (I to VI). It was difficult for some respondents to combine verbalization and the tradeoff task, which was apparent from the reticence of some respondents to verbalize during the TTO. Respondents considered a wide array of information during the valuation task, e.g. the impact of RA on their life and/or a shorter remaining LE:

"What I can do in 52 years with rheumatism, I can do in 20 years without rheumatism." (male, 23, V)

Loss aversion

The reference point that was most often used was the RA health state that was to be valued. It was used as reference point in 201 times out of the total of 317 reference points that were deduced at group level (63%). To live in the optimal health state for x years was used as the reference point in 82 out of the 317 instances (26%). The current health state was used as reference point in 11% (34) of the cases. Use of the RA health state as reference point correlated positively with utilities ($r = .40$, $p < .01$, see Table 5.1). The use of the optimal health state for x years as reference point showed no relation with utilities ($r = .14$, $p = .35$).

Utility curvature and anticipated problems in old age

Some subjects considered potential health problems in old age in their decision. This occurred if the offered number of years in good health was close to the respondent's remaining life expectancy. Obviously, this was more frequently observed for the less severe health states. Of the 14 remarks that were made on that theme, 93% occurred during the valuation of health states IV, V, and VI. No significant relation was found between this theme and the TTO utilities ($r = -.18$, $p = .23$).

"*After nineteen years I will be fifty. After that age, your quality of life will diminish, so, that is the same as having RA."* (female, 31, V)

"In about 21 years, I will be an old man … a little bit at least. Everything will become more troublesome anyway. You will develop problems by yourself." (male, 22, V)

Anticipated adaptation

A theme that played a role in the TTO scenario was anticipated adaptation. This describes how respondents expected to adapt to the RA health state in due time. Following Ubel et al., we distinguished between psychological and physical adaptation (53). The first concerns the ability to emotionally adapt to a health state, e.g. a shift in personal interests. Respondents mentioned this consideration almost as often for health states I, II, and III (45%) as for health states IV, V, and VI (55%). Psychological anticipated adaptation correlated positively, though not significantly, with utilities ($r = 0.27$, $p = 0.08$).

> "*I am quite hopeful about it ... At the moment when it happens, then you will see how creative you are; how much you can stretch things. This you can see with people. At the moment you think that something is not possible, then they will get the strength from God knows where. And they deal with it, cope with it. If that is human, then also I must have something like that in me.*" (male, 39, I)

> "*It is rather annoying not being able to perform your daily activities; maybe I can become more socially active.*" (male, 45, III)

> "*I have a mother and she is over 85 years of age and she also has rheumatism. Some pain, and problems with performing her daily activities, also she is washed twice a week. So I have a role model, maybe not fair. But I have her as an example. She is happy and gets around quite well.*" (female, 46, IV)

Physical adaptation concerns the physical aspect of adaptation, e.g. getting a wheelchair. Respondents mentioned this aspect almost as often for health states I, II, and III (56%) as for health states IV, V, and VI (44%).

"*I am counting on pain medication.*" (female, 37, III)

"*It is not like you'll be immobile. There will still be aids, wheelchairs and such.*" (male, 23, VI)

"*Severe pain, the first thing that comes to mind is that, nowadays, of course, something can be done about this.*" (male, 39, I)

Only a few respondents indicated that they anticipated not to adapt to the RA health state.

"*Do you think that at a given moment you wouldn't feel that pain anymore if you have it constantly? I think you would always feel that*." (female, 20, I)

Goals

An important theme for respondents was goal aspiration. It influenced how respondents answered TTO questions. Most often, respondents mentioned not being able to achieve goals because of being in a RA health state or living fewer years in good health. A concern about whether goal aspiration was still possible was often expressed as a desire: 1) to either live life in a certain way (preferably in the same way as now), and/or 2) to achieve specific goals that have been set. Regarding the first concern, respondents considered the impact of the RA health state on their way of life, e.g. to take part in sport, to walk, or to be independent. Consequently, this concern took account of the present as well as of the future. The impossibility of achieving goals while living in that health state was mentioned more often for the more severe health states; 72% of the remarks on that theme were made during the valuation of health states I, II and III.

"If I can't do a thing all day, then I don't need to live. Being down all the time. That is not me … I am very attached to my daily activities. I do want to be able to keep on doing stuff." (male, 22, II)

"Well I don't like to be helpless, so to speak, I don't like to need help. Yes, I like being independent. I can't do my daily activities, I can't go to work then. And I have problems with washing or getting dressed, so that really bothers me ... That is not really the life I would like to have." (female, 22, II)

The second concern regarding set goals was mostly considered by respondents in comparison to the number of years in good health offered in the TTO. If the offered number of years was below the number of years needed for goal realization, respondents often preferred the RA health state in which they would still live for their remaining life expectancy. Goals were mentioned, such as raising children, knowing grandchildren, career opportunities, and enjoying a few years of pension. Consequently, this concern regarded the future. The possibility or impossibility of achieving goals in the offered number of years of good health was mentioned equally frequently for all health states. Respondents shifted their focus on different life goals, depending on the future life years involved in the task.

"*Yes, well then I will choose for option 1, because I want to live a long life. I want to become a grandmother etcetera."* (female, 41, V).

"*Still I would choose for a life with wife and children, and above that many years living in good health.*" (male, 23, III).

Maximal endurable time

The theme maximal endurable time (MET) was encountered with respect to the more severe health states. MET is the concept that when people live in a health state involving a low quality of life, at first they evaluate it positively, but after a certain period (MET) any additional time spent in that health state is viewed negatively. Consequently, death is preferable after that period (54). Of the remarks made in which respondents demonstrated MET, 72% were made during the valuation of health states I, II, and III.

> "*What is the use of 54 years of living, if you can't do a thing but sit around the house all day?*" (male, 23, III)

> *"It is that what is said here, as it concerns severe pain. That is tough to live with. At a certain point in time, enough is enough."* (male, 28, I)

Table 5.1. Univariate associations between themes and TTO utility for all health states and respondents (RP = reference point).

Theme	**TTO**
RP RA for remaining life expectancy	.41 (p < .01)
RP Optimal health for period x	.14 (p = .35)
RP Current health state	.19 (p = .23)
Psychological anticipated adaptation	.27 (p = .08)
Physical anticipated adaptation	.18 (p = .24)
Impossibility to achieve goal in RA health state	-.24 (p = .12)
Impossibility to achieve goal in period x in optimal health	.13 (p = .40)
Maximal endurable time	-.24 (p = .12)

After univariate analysis (see Table 5.1), a regression analysis was performed in which themes of borderline significance ($p < .15$) were entered simultaneously. The analysis showed that the following themes were relevant to TTO utilities with an explained variance of $R^2 = 37\%$, $p < .000$, (adjusted $R^2 = 33\%$, $p < .000$): Use of the RA health state as reference point ($p < .005$), anticipated psychological adaptation ($p < .01$), and the impossibility to achieve one's goal in the RA health state ($p < .005$). The latter showed a negative relation with TTO utilities. MET did not contribute to the TTO utility anymore.

Labeling

From the qualitative results of this experiment it appeared that the labeling of the health states that we had decided to use had a strong impact, and led to higher utilities than for unlabeled health states. For the eleven people who had someone with RA in their inner circle of acquaintances the average TTO utility was .67, and for the 34 people with no one with RA in their inner circle the average TTO utility was .57 ($p = 0.17$). Many references that were made to the disease (Rheumatoid Arthritis) were related to themes such as anticipated adaptation, and use of pain killers. We therefore compared our respondents' utilities with those of the British and Dutch tariff (see Figure 5.1). Discrepancies were seen for the poor health states, (I: $p < .000$, II, and $p < .005$),[1] in which our TTO utilities were higher than Dutch EQ-5D utilities. Small discrepancies were seen in the other direction for health states V ($p < .01$), and VI ($p < .02$). We could, however, not rule out that our different utilities were due to the life expectancy we used, which was longer than the 10-year time

[1] The EQ-5D provides a 'tariff' of values for EQ-5D health states. Discrepancies were assessed per health state using the relative disutility (RD) between valuations: RD = (1 - mean TTO)/(1 - EQ-5D index). Since the EQ-5D index has a broader utility range (-0.6 to 1.0) than the TTO (0.0 to 1.0), RD between methods is more representative than the absolute difference. The RD should be 1 if respondents scored in the same way as the general population in the tariff study.

frame used in the tariff study. We therefore carried out an additional experiment to test our assumptions that labeling influenced our utilities.

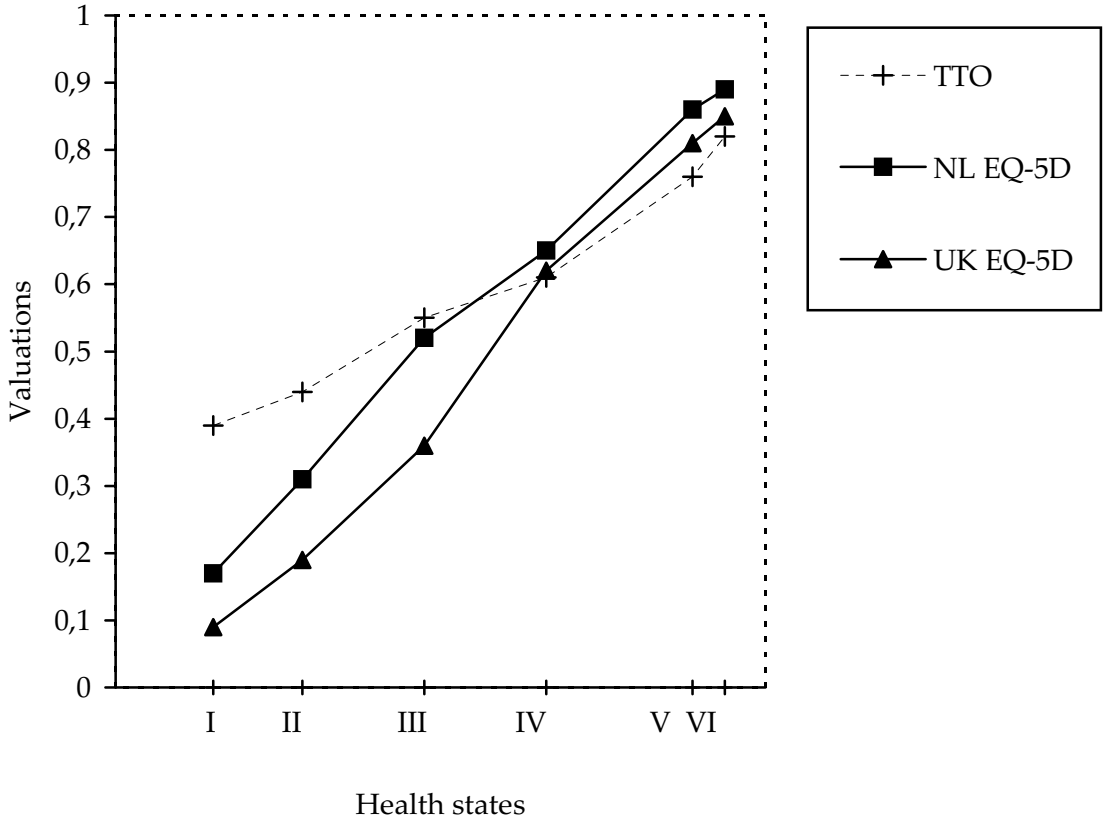

FIGURE 5.1. Mean valuation for each health state per method. The six health states are ranked on the x-axis according to the corresponding mean valuation.

Experiment 2

Methods

Eighty-four of the 112 medical students attending a Medical decision making course at the Leiden University Medical Center participated. Respondents were asked to

perform a TTO (paper version) as a matching task for the six health states used in Experiment 1. The students randomly received one of two versions: health states labeled as rheumatoid arthritis, or unlabeled health states. The remaining life expectancy was set at 10 years to equal the EQ-5D tariff studies. Using a repeated measures ANOVA, with Health states as within and Label as between factor, we assessed the overall effect of labeling. This was followed by independent t-tests to evaluate the effect of labeling for the different health states.

Results

The respondents of the No-Label group consisted of 31 women aged 21 to 46 years (mean age = 24, s.d. = 5) and 16 men aged 21 to 31 years (mean age = 24, s.d. = 3). The respondents of the group Label consisted of 26 women aged 21 to 32 years (mean age = 22, s.d. = 4) and 11 men aged 20 to 26 years (mean age = 26, s.d. = 2).

Table 5.2 shows the mean utilities (and s.d.'s) for the six health states. Remarkable are the differences in standard deviations between the two groups, with the No-label group showing significantly larger s.d.'s ($p < 0.03$) for states I to IV. Overall, the difference between the two groups reached borderline significance (MANOVA, $p = 0.055$). An interaction effect was seen between label and state ($p = 0.10$), with states V and VI not being different between the groups, state IV being significantly different ($p = 0.01$) and states I to III reaching borderline significance ($p \leq 0.10$).

Table 5.2. Mean utility (and s.d.) for labeled and unlabeled health states

	I	II	III	IV	V	VI
Label	0.56 (.20)	0.57 (.18)	0.67 (.15)	0.75 (.14)	0.85 (.13)	0.94 (.05)
No Label	0.47 (.27)	0.49 (.24)	0.59 (.25)	0.64 (.23)	0.84 (.15)	0.94 (.05)

General discussion

In the first experiment, we found evidence that the impaired health state is indeed most often used as the reference point. According to Bleichrodt, this would lead to higher TTO utilities as a result of loss aversion (6). Our data supports this finding, as the use of this reference point was associated with higher utilities. Additionally, it appeared that the main focus for the TTO in our study lay on length of life rather than on quality of life, suggesting scale compatibility. As a choice task was used, the number of years offered to live in optimal health changed according to the answer given, and it is therefore natural that this answer should receive most attention, as has been observed for the SG in other studies (51;57). We therefore decided not to further code these statements. Bleichrodt argued that scale compatibility would lead to higher utilities when the focus during the task lies more on quantity of life than on quality of life.

We found little evidence for the bias of utility curvature (34). Linearity of the utility for life years is questionable if living for your remaining life expectancy, or a period close to it, is viewed as an unattractive prospect (theme: anticipating problems in old age). This was mentioned sometimes, mostly for the less severe health states, and despite the statement that these years will be spent in optimal health. This theme was

observed in another study as well (70). However, we observed no significant relation with TTO utilities.

The qualitative data showed that respondents incorporated several themes into their decisions. Themes that have been argued in the literature to attribute to the TTO utilities are: maximal endurable time (54), subjective expectations about length of life and quality of life (70;71), family circumstances, and religious beliefs (72). We will discuss themes considered by respondents, and evaluate the possible effects on TTO utilities, and the possible effect of labeling on TTO utilities.

Each person aspires to live to a certain age: the aspiration level (42). Life goals could be a factor strongly involved in the personal setting of the aspiration level. The role of the aspiration level in medical decision making has become more and more acknowledged (29;43;44;47;73). We used the remaining LE as time frame and, therefore, allowed the aspiration level to have a role in TTO valuation, as is the case in genuine situations. Our findings and analysis lead us to argue that respondents considered the aspiration of goals an important theme. The impossibility to realize one's goals while living with RA led to significantly lower utilities.

Maximal endurable time was considered by respondents, especially for the severe health states. The presence of this theme should lead to lower TTO utilities, although the effect did not reach significance in our study. In a regression analysis, the relation with TTO utility was still negative, but the effect was less significant.

In the first experiment, discrepancies between EQ-5D index and TTO existed. For the health states involving a low quality of life, the EQ-5D index provided much lower valuations than the TTO in our study. We hypothesized that labeling of our health

states resulted in this difference, given the importance of anticipated adaptation, and the association with familiarity with RA. A study by Gerard et al. (65) showed a shift in valuation that was partly due to labeling as well. Anticipated adaptation is more likely if a person knows more clearly to what one will be adapting. Psychological anticipated adaptation indeed showed a significant and positive relation with TTO utilities in the first experiment of our study.

However, further evidence was required as the EQ-5D tariff was based on a TTO with a ten year time frame, in contrast to the remaining life expectancy frame that was used in our experiment. In the second experiment that used a more similar TTO method, differences were observed between unlabeled and labeled utilities, although not all reached statistical significance. For two of the six states this absence of significance could be due to a ceiling effect. Remarkable was that for the states in which no ceiling effect was seen, the standard deviations were much larger in the unlabelled condition. As may be expected, labeling makes people think of the same condition. A label provides a more elaborate description, and factors such as experience and familiarity may then be significantly associated with the valuation of the health state (53). Imagination can flow freely without a label, resulting in more variation. Respondents used a broader range of the utility continuum, and, as a result, utilities became more scattered.

Conclusions

We found evidence that the bias loss aversion led to higher TTO utilities. Scale compatibility leads to higher TTO utilities, and we found evidence that this occurs for the TTO. In our experiment, the bias of utility curvature appeared to have no significant effect on TTO utilities. The impossibility to realize goals in the RA health state led to lower utilities, whereas the RA health state as reference point, and psychological anticipated adaptation led to higher utilities. As the reference point most often used by our respondents was the health state to be valued, the bias loss aversion will also most likely operate similarly for patients as well as the general public. It has been argued that patients use less of the utility continuum than the general public when valuing similar health states. Labeling may have a similar effect, but to a lesser extent (74). Patients valuing their own health implicitly include labeling. Consequently, labeling a health state could potentially lower the discrepancies between patient and public estimates of quality of life.