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

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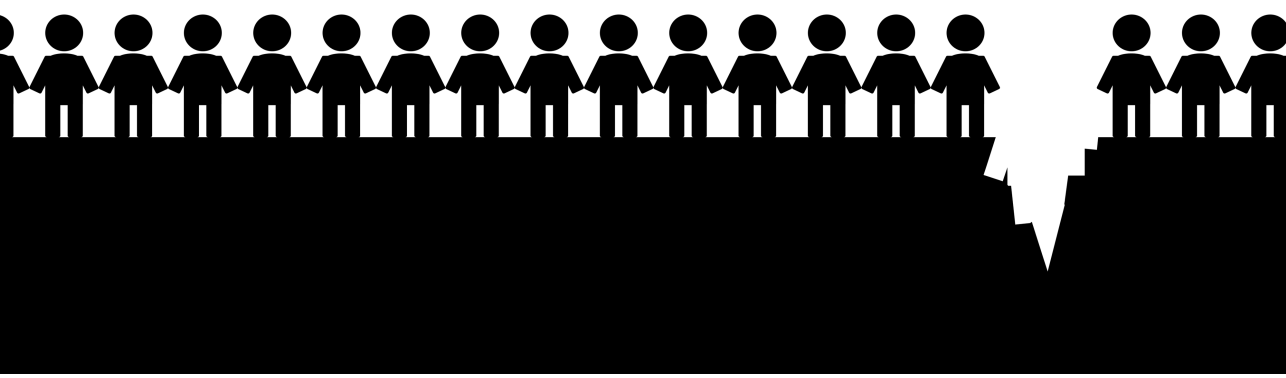
10

Summary & General Discussion



10.1 Summary

In medical care resources are scarce and choices have to be made about how these resources are distributed. To judge the optimal allocation of medical resources, cost-utility analyses can be used. In cost-utility analysis costs of a therapy are compared with the benefits in health. These benefits are estimated by health state utilities, preferences for certain health states compared to perfect health and death. Health state utilities can be elicited from patients or from members of the public. Whose' utilities are used does matter. Utilities of members of the public are found to be lower than health state utilities of patients. Several mechanisms causing this gap in health state utilities between patients and members of the public have been put forward as explanations.[17,18,203] The overall objective of this thesis is to examine some of these mechanisms, in order to gain insight in the validity of health state utilities estimated by patients or by members of the public.

Previous studies have described contrasting findings about the gap in health state utilities given by patients or members of the public.[16,44] Chapter 2 presents a meta-analytical comparison of health state utilities given by patients or members of the public. This comparison is based on 30 eligible studies including 40 estimators, which were rated by two independent judges. Overall it was found that patients gave significantly higher valuations than nonpatients (Cohen's $d = 0.20, p < 0.01$). For each elicitation method separately this resulted in an unstandardized $d = 0.05 (p < 0.05)$ for the TTO, an unstandardized $d = 0.04 (p < 0.05)$for the VAS, and an unstandardized $d = 0.01 (p = 0.70)$ for the SG. Post hoc moderator analyses showed that the difference between patients and nonpatients became smaller when an illness label was provided or when patients were asked to give valuations for a health state description instead of for their own health. We can conclude that the respondent group used does influence health state utilities elicited.

In Chapter 3 the effect of the health state description on health state utilities among patients with RA was investigated. Patients were asked to rated their own health based on three different descriptions. First, patients gave a valuation of their own experienced health of the previous week, secondly, they were asked to value a standard EQ-5D description of their own health (which was untold to them), and third, patients valued a standard EQ-5D description of their own health (identified as such) enriched with individual attributes. All valuations were given on a TTO. We found no differences in health state valuations between the three health state descriptions, but an interaction effect showed that patients with better health ap-

peared to give lower valuations to their own experienced health compared to the enriched EQ-5D health state description of their own health. Surprisingly, utilities for scenarios enriched with exclusively negative individual attributes were not lower than those for the own standard EQ-5D description. In conclusion, it remains unclear if disparities in valuations can be attributed to the EQ-5D description being too sparse.

Chapter 4 describes a study in which the mechanisms of focusing illusion and adaptation are examined. Patients with RA and members of the public imagining having RA were asked to name aspects that were important to them in their previous week. Secondly, all participants rated the importance of these self-named aspects and of the EQ-5D dimensions. Overall we found that members of the public tend to name more aspects in life domains which are negatively influenced by the disease. Patients named both positive and negative aspects, reflecting life in general as well as their illness. Members of the public rated their own named aspects as less important compared to the EQ-5D dimensions, whereas patients found both groups of aspects equally important.

In Chapter 5 we compared values of patients, their partners, and members of the public to examine the effect of vicarious experience. The inconclusive findings described in Chapter 3 led us to question whether enriching a scenario would make valuations of members of the public more similar to those of patients. Therefore we also whished to assess whether the difference in health state valuations maybe due to a scenario-effect, and whether 'enriching' a scenario reduces differences between the groups. Data were collected using semi-structured interviews, similar as the one used in chapter 3, among patients with RA, partners of patients and members of the public. For all three health state descriptions ratings were significantly higher for patients than for the general public. Ratings for partners were in between. Differences between patients and the public are not likely to be due to sparseness of the scenarios, but may be due to a focusing illusion, enhanced by the negative framing of scenarios.

Chapter 6 examines the effect of adaptive abilities on health state utilities. We investigated the direct effect of adaptive abilities on health state utilities and the effect mediated by mental HRQL. Adaptive abilities were conceptualized by combining the three constructs Self-esteem, Mastery, and Optimism, as suggested by Cognitive Adaptation Theory. In an interview, patients with RA gave health state valuations for their previous week on a VAS and TTO, and filled in questionnaires measuring Self-esteem, Mastery, Optimism, and HRQL. Persons' ability to adapt

did not add considerably to the explanation of health state utilities above HRQL. In the TTO no additional variance was explained by adaptive abilities ($\Delta R^2 = .00, \beta = .02$), in the VAS a minor proportion of the variance was explained by adaptive abilities ($\Delta R^2 = .05, \beta = .33$). However, the effect of adaptation on health state utilities seemed to be mediated by the mental health domain of quality of life. Patients with stronger adaptive abilities may more easily enhance their mental health after being diagnosed with a chronic illness, which leads to higher health state utilities.

Chapter 7 further describes adaptation and examines valuation shift, in a longitudinal study among patients with Spinal Cord Injury (SCI). Health state valuations of patients with recent onset SCI were assessed at three points in time. At each time point patients gave valuations for their own health and for a hypothetical health state on a TTO and VAS. Furthermore patients rated their adjustment and filled in a questionnaire measuring their independence. Valuations given on the TTO for the own health did change over time, above improvement in independence. Furthermore we found that this change was partly related to change in self-rated adjustment. Health state valuations for the own health given on the VAS and corrected for independence did not change over time. No change was found either in valuations for the hypothetical health state description. We can conclude that the effect of psychological adaptation has an impact on the valuations of the own health based on the TTO in serious incurable disease. No support was found for the effect of valuation shift.

In Chapter 8 the effect of adaptation as well as the effect of implicit theories of stability and change were studied. Two longitudinal studies are presented: one study among patients experiencing new limb amputations, and one among patients experiencing new colostomies. In both studies patients estimated at two points in time their current well-being, functioning, and general health and predicted of their future well-being, functioning, and general health. In the second study patients not only predicted their well-being, functioning, and general health, but they also recalled previous performance on these domains. In both studies the actual change was compared to the change expected and recalled by patients. It appeared that patients expect a significant improvement and recall significant improvement on all three domains, but report little actual improvement. Apparently, patients expect stronger improvement than they actually experience: they overestimate their hedonic adaptation.

While examining the different mechanisms suggested in the literature causing

the difference between health state valuations of patients and members of the public we were often challenged by ambiguous descriptions of the mechanisms. Chapter 9 describes such a conceptual confusions specific to the field of "response shift". To clarify the conceptual confusion around "response shift" a suggestion is made about abandoning this term and instead to use more precise language. First, response shift confounds sources of measurement error, 'scale recalibration', with true causes of change which in the language of response shift are described as 'change in values' and 'reconceptualization'. Secondly 'change in values' or 'reconceptualization' might better be changed into conceptualizations such as adaptation, which is a common term used by psychologist.

10.2 General Discussion

The main objective of this thesis was to examine mechanisms that have been suggested to explain the gap between health state utilities given by patients and by members of the public. By examining these mechanisms more insight in the validity of health state utilities of patients and members of the public is gained. In the first part of this discussion the conclusions retrieved from the previous Chapters 2 - 9 are described. The next part consists of an evaluation of the results. Finally the policy implications, implications for patient decision making and suggestions of areas for future research are discussed.

10.2.1 Mechanisms underlying the gap between members of the public and patients

Lack of Scope The results of this thesis give only limited ground for the effect of Lack of Scope. Throughout the whole thesis exploratory findings tentatively confirmed an effect of Lack of Scope. That is, in Chapter 2 the discrepancy between health state utilities of patients and members of the public was shown to be smaller in studies in which a label was provided. In Chapter 3 the EQ-5D seemed to be too sparse for patients in better health, and in chapter 4 patients valued their own named aspects as important as EQ-5D dimensions. These findings were often based on post hoc analyses, however, and were not very strong. Lack of Scope was most thoroughly examined in Chapters 3 and 5, using different health state descriptions. In both chapters the effect of using different health state descriptions was minor.

Focusing illusion Support was found for a focusing illusion. Members of the public were more focused on life domains that are negatively influenced by a health

state compared to patients (Chapter 4). Patients seemed not overly optimistic; they did not overlook the negative aspects of their health state (chapter 4).

Valuation shift Previous lack of support for valuation shift was suggested to be due to studies investigating rather mild, non-permanent health states.,[20 40] In this thesis, patients with Spinal Cord Injury, a serious condition with little or no prospect for cure, were studied, but still no support for valuation shift was found (Chapter 7).

Adaptation The results of this thesis showed that an effect of adaptation cannot be ruled out. Adaptive abilities indirectly influenced health state utilities, (Chapter 6) health state utilities measured with a TTO did change over time due to adaptation over and above improvement in independence (Chapter 7). Further, based on aspects indicated as important to patients, patients seemed to have different interests compared to members of the public (Chapter 4). Interestingly, the influence of adaptation was also seen in partners (Chapter 5) and patients early in the experience of an illness (Chapter 8). Yet, this latter group tended to overestimate their ability to adapt.

Implicit theories of stability and change Patients early in the experience of an illness seemed to base their valuations on implicit theories of stability and change. They assumed that after surgery they will get better, and that this improvement will continue over time, leading to an underestimation when recalling previous health and an overestimation when making predictions of their future health (Chapter 8).

10.2.2 Evaluating the results

Health state utilities used in cost-utility analyses to compare the costs and benefits of interventions have generally been elicited from members of the public or patients.[15] Whose preferences are used does have influence, patients tend to give higher valuations compared to members of the public (Chapter 2). Based on the results described in this thesis most of the mechanisms generally suggested do not or only marginally explain the gap between patients and public, except for the mechanisms focusing illusion and adaptation. Clearly no conclusion can be drawn about mechanisms not examined. Most of the mechanisms described in the introduction were examined, but the intensity differed.

Focusing illusion is the tendency of members of the public to focus on the difference between their current situation and a situation under consideration.[27] In previous studies in the field of medical decision making no empirical evidence for this focusing illusion has been described. Studies have aimed to defocus members of

the public through a defocusing task[24] but they were not able to reduce the focusing illusion. The study described here (chapter 4) in which evidence for focusing illusion in medical decision making was shown, was directed at describing focusing illusion. Health state valuations of members of the public seem to be biased due to focusing illusion, but reduction of this focusing illusion is challenging.

The second mechanism for which support has been found is adaptation. Adaptation is one of the most often suggested mechanisms causing the gap, especially when coping strategies and the constructs "change in values" and "reconceptualization" of response shift (Chapter 9) are taken into account. Damschroder et al.[38] found tentative support for the effect of adaptation when using an adaptation task. Members of the public who received an adaptation task gave higher health state valuations on PTO and VAS compared to members of the public who did not receive this task. However in a follow up study using the TTO and SG no such difference was found.[39]

It has been argued that the expected impact of adaptation on health state utilities is less prevalent than previously assumed. For instance, Lucas[186] described that patients do not adapt to onset of major disability. In this study, two nationally representative panel studies from Germany and from the United Kingdom were used. Based on these data it was shown that patients with onset major disability did not return to their previous levels of life satisfaction (prior to their injury). Even seven years after the injury the life satisfaction was as low as in the first year after onset of the disability. Surely this study reveals much interesting information but it is limited by the fact that the results were restricted to annual measurement points in time.

The effect of adaptation on health state utilities in this thesis is shown among patients with RA and patients with SCI. Anticipated adaptation is shown among patients who underwent amputation or colostomy surgery and partners of patients with RA. The effect of adaptation seems to generalize among different patient groups and even partners of patients. But even though the main conclusions are similar, some of the underlying results point to interesting differences. The adaptive abilities among patients with RA seemed to have more impact on the VAS (Chapter 6) whereas the change over time among patients with SCI was only prevalent in valuations elicited with the TTO (Chapter 7). These distinct findings might have been caused by the affective and cognitive nature of the measurements. The VAS can be seen as a more affective measurement whereas the TTO as a more cognitive measurement. Affective measurements have been found to be more sensitive to change,[172] leading

to a stronger effect of adaptive abilities on the VAS in Chapter 6. Yet, cognitive measurements might be more strongly related to cognitive change, such as cognitive adaptation. The TTO in chapter 7 might have triggered patients with SCI to think about future life goals which may be influenced by cognitive adaptation. A different explanation for the distinct findings in Chapters 6 and 7 might be related to the severity of the health states under consideration. Adaptation and adaptive abilities might have a different impact on health states of varying severity levels.

The mechanisms causing the gap between health state utilities of patients and members of the public have been suggested based on cross fertilization between research fields such as the fields of HRQL research, medical decision making, and social and health psychology. However, the translation of a theory from a particular research field into a mechanism explaining the gap in health state utilities is challenging. Theories from different research fields may lead to similar mechanisms with only subtle differences. Given these subtle differences and often ambiguous descriptions, similar mechanisms are difficult to examine separately.

For instance, the distinction between the failure to anticipate on adaptation on the one hand and focusing illusion on the other can be ambiguous. Some of the findings in Chapter 4 on attributes of importance could be caused by a failure to anticipate on adaptation, or by a focusing illusion, or maybe by both. Ubel et al.[24] tried to describe how to distinguish between these mechanisms. According to these authors focusing illusion is defined as a failure to appreciate that not all life domains or life events will be equally affected by a given change in circumstances. Failure to anticipate on adaptation is defined as the failure to appreciate that one's emotional response to the given change in circumstances will diminish over time. However, they do not elaborate on the distinction between focusing illusion and other aspects of adaptation, such as shifting goals and priorities, which they had described as aspects of adaptation in previous papers.[18,177]

Both in the definition of Ubel et al.[18] and according to Schkade and Kahneman,[181] focusing illusion is caused by overweighting of a subset of aspects of an entire object under consideration, for instance when only attention is drawn to a change in significant aspects of life. If we revert to this definition of focusing illusion, a failure to anticipate on a shift in priorities or goals then seem to be distinct from focusing illusion by the fact that it is not caused by an exaggerated focus on a subset of the object under consideration. Regarding the findings in Chapter 4 it seems that the distinction between focusing illusion and adaptation remains challenging due to the limited information we have. By statements as "I am not able to

play soccer" no information is provided about the underlying grounds. If a member of the public makes such statement he or she might have been thinking about the differences between his or her current situation compared to the situation when having RA (focusing illusion) or might have thought about both situations in general but failed to imagine that instead of playing soccer fulfillment can be retrieved by watching soccer instead (adaptation).

10.2.3 Policy implications

Organizations developing guidelines on the use of new and existing treatments (NICE, the panel of the U.S. Public Health Service, CvZ) advise the use of a societal perspective in which health state utilities elicited from members of the public are preferred.[12,14] However given the experience of patients it has incidentally been argued that patient valuations should be used instead.[12] The findings described in this thesis reveal that health state utilities of patients and public do differ (Chapter 2) which is mostly caused by adaptation (Chapter 4, 5, 6, 7) and focusing illusion (Chapters 4 and 5).

Whose utilities we should use depends on whose utilities are most valid. This validity depends on the effect that the underlying mechanisms have, that is, do they cause a true effect or do they cause an error in the health state utility elicited? Obviously utilities of members of the public that are shaped by focusing illusion are biased.[26,37] If members of the public focus too narrowly on only negative consequences of the health state under consideration they overestimate the burden of the health state leading to too low health state utilities.

The question if patients' health state utilities shaped by adaptation are biased is more difficult to answer. Ubel et al.[37] assume that failure to anticipate on adaptation leads to misjudgments of members of the public. Yet, in the field of response shift, patients' adaptation is seen as a validity threat leading to misjudgments of patients,[41] assuming that adaptation is described as change in values and reconceptualisation (Chapter 9). According to Oort et al.[204] and Sprangers and Schwartz,[41] true change in Quality of Life (QL) is only reflected when it is corrected for change in values, reconceptualization, and scale recalibration. This implies that change in patients' QL due to adaptation is regarded as untrue change. However, given that by definition (World Health Organization) QL is based on an individual's perception, change as experienced by a patient must truly reflect change. That is, QL is a subjective concept based on individual perceptions and should include subjective change if this reflects true change from the patients' point of view. A change in perception

does not have to harm the validity of QL measurement. Therefore, health state valuations shaped by adaptation do reflect true experienced health. It also seems necessary to use health state valuations shaped by adaptation when it comes to the fact that health state utilities should include all aspects of life that are affected by the health state. Patients' understanding of life in their current health state includes the influence of adaptation, especially as the influence of adaptation will differ between health states, thereby providing valid information about the perceived severity of the illness. In other words, if the ability to adapt differs between health states this does reveal important information about the severity of the illness, which should be accounted for in cost-utility analyses. Moreover, the health care system does put effort in developing physical rehabilitation and psychological interventions to help people to adjust to their illness, since this leads to an improved QL. We have to keep in mind that although patients do adapt, when given the choice they probably would not have wanted to adapt in the first place. It may even seem counterintuitive to take full adaptation into account. Gilbert et al.[26] argue that if people would take their ability to adapt into account, they would not engage in problem avoiding behavior and become "happily extinct". Although this suggestion is made for coping behavior of individual people, it can be transposed to cost-utility analyses. If people adapt to their illness anyway, we would not have to worry about health state utilities but only take the number of lives saved into account.

Further, health state utilities shaped by adaptation leave less space for a gain in benefit by treatment. The effort that patients put in adapting to their illness will cause effectiveness of treatments to decrease.[36] This creates an ethical problem; by using health state utilities shaped by adaptation the effort that patients make in adapting will lead to a decrease in availability of resources.

In summary, health state utilities shaped by adaptation are not biased, they do reflect true values, and more importantly they provide valuable information about the severity of health states. However, using utilities shaped by adaptation will lead to ethical challenges. That is, if people fully adapt, medical treatment would not be necessary anymore, or would not be cost-effective. Therefore adaptation should be taken into account in cost-utility analyses but only to a certain extent.

Concerning to what extent health state utilities shaped by adaptation should be used some suggestions from the literature may be relevant. Menzel et al.[205] suggested that disabled and chronically ill should be consulted on this topic. Another approach is that of "cost-value analysis".[10] In this approach two stages are used to construct a valuation. In stage 1, patients assign health-related utilities, and in

stage 2, based on these health state utilities, the general public assigns weights to different gains in utility. A third approach might be asking patients to recall how their health state has changed over time.[37] However, given the findings described in Chapter 8 the recalled health valuation will be significantly different from the actual health valuation. Until now it remains unclear which valuation reflects the true value. Another approach examined in this thesis might be using health state utilities of patients given to unfamiliar health states. Given the lack of evidence for valuations shift, it might be concluded that utilities of patients imagining an unfamiliar health state are similar to valuations given by members of the public. Also examined in this thesis are health state utilities given by proxies. These valuations appeared to lie between valuations given by patients and members of the public (Chapter 5). Likewise in the meta-analyses we found health state valuations of proxies to lie between valuations given by members of the public and patients (Chapter 2). Partners do seem to incorporate (vicarious) experience. The use of partners' valuations might be an interesting new approach.

For now, no conclusive advice can be given on the extent to which health state utilities should incorporate health state valuations of patients, to be used in cost-utility analyses. We do conclude that health state utilities of members of the public are biased by focusing illusion and that adaptation should be incorporated to some extent, but not fully. Therefore the use of health state utilities of patients or maybe partners of patients should be open to consideration by organizations developing guidelines on the use of new and existing treatments.

10.2.4 Implications for patient decision making

In individual treatment decisions, understanding of the mechanism causing the gap in health state utilities between patients and members of the public is also important.[206] It seems that when people imagine living in a certain health state they fail to anticipate on adaptation and focus only on those life domains that are influenced by the illness. To be able to make treatment decisions, people have to make such affective forecasts of their life in a certain health state. Based on the found biases people might make the wrong decision.

People should be made aware of these biases prior to making treatment decisions. Admittedly, given the results of Chapter 8 this suggestion has to be made with caution. Patients just recovering from surgery overpredicted their ability to adapt. Before being able to inform patients about these biases we have to understand if this overprediction occurs only in patients just having received treatment

or also in patients anticipating on their treatment. Secondly, variation exists among people's ability to adapt (Chapter 6). People who have to make treatment decisions might not only benefit from information about their failure to anticipate on adaptation and on their focusing illusion, but also from information on their personal ability to adapt. Finally and most importantly, we always have to keep in mind that patients do adapt but when given the choice they probably would not have wanted to adapt in the first place.

10.2.5 Future research

Even from the findings described in this thesis and several studies performed before[20,38,40,107] the gap in health state utilities between patients and members of the public can still not be fully explained with certainty. More research can always be performed to further investigate mechanisms underlying this gap, but it can be questioned if this will lead to more conclusive information. Based on previous finings it seems that several mechanisms are layered on top of each other, although adaptation and focusing illusion seem to have the most influence on health state valuations.

Regarding policy, future research should concentrate on how the effect of adaptation and focusing illusion on health state utilities should be handled. Concerning the ethical dilemma of using health state utilities shaped by adaptation, Menzel et al.[205] suggested that disabled and chronically ill should be consulted. In the medical context future research should concentrate on how and which information about the biases should be provided to patients. However, first the ability to anticipate on adaptation should be investigated among people who are confronted with a treatment decision.

Finally it has to be emphasized that the findings described in this thesis are based on physical health problems. From recent research we know that that the gap in health state valuations between patients and members of the public might be different for mental disorders. Given the burden of mental disorders on society, more future research should focus on mental health.