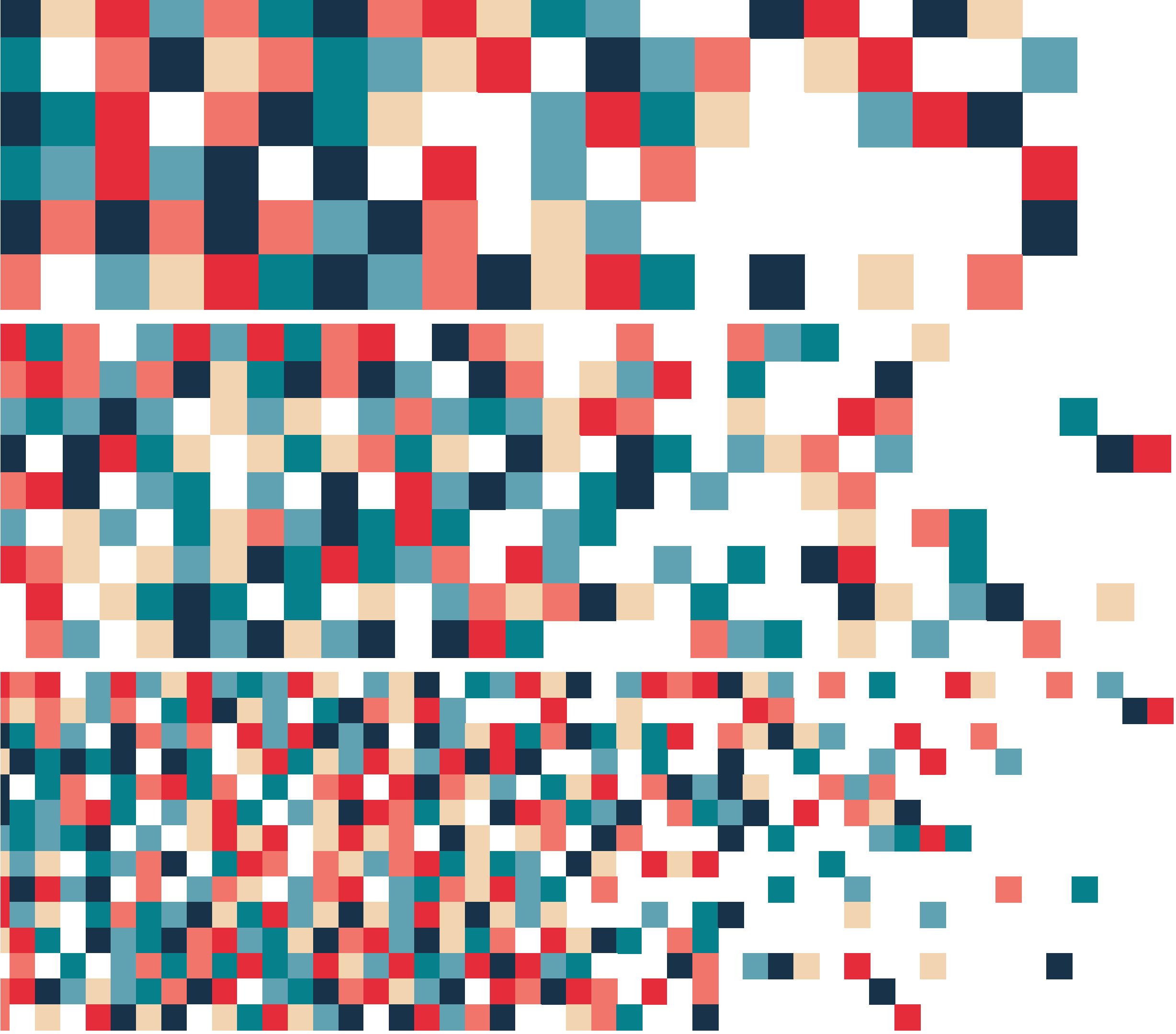
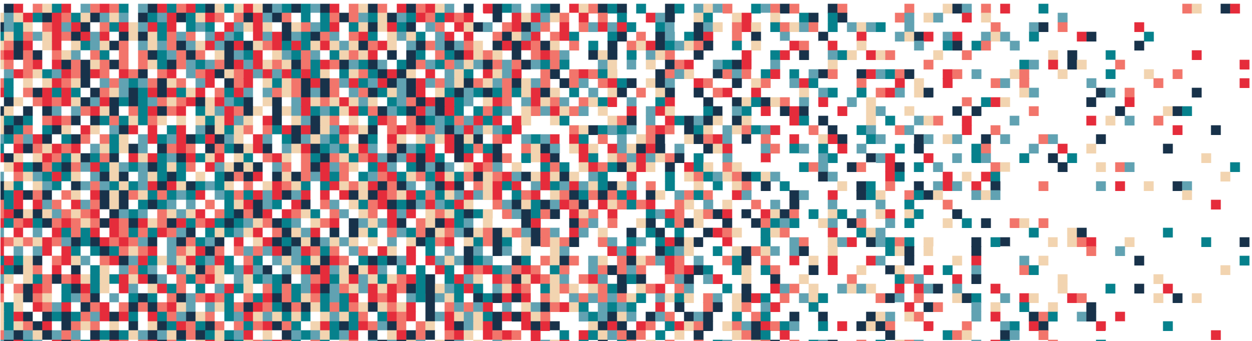


Absolutely Relative

on the value of health outcomes

Sofie Wouters



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Sofie Wouters

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Absolutely Relative
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over de waarde van gezondheidsuitkomsten

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PROMOTIECOMMISSIE:

Promotoren: Prof.dr. W.B.F. Brouwer
Prof.dr. K.I.M. Rohde

Overige leden: Prof.dr. H. Bleichrodt
Prof.dr. F.T. Schut
Prof.dr. J.J. Polder

Copromotor: Dr. N.J.A. van Exel

CONTENTS

1

Introduction

Health is a valuable asset, as an intrinsic good and as an instrument to pursue important goals in life. The United Nation's universal declaration of human rights states that "Everyone has a right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing, and medical care and necessary social services and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control" [1]. In support of this, health care systems provide and protect people's access to care. However, pressure on the available budgets due to increasing demand for health care makes it increasingly difficult to guarantee unlimited access to all available care.

Scarcity in health care resources requires difficult choices to be made regarding the amount of money invested in the health care sector and the level of care provided within the health care system. Worldwide trends of ageing populations and increasing and more expensive treatment options due to medical and technological advances are likely to boost demand for health care [2-7], which gives valid reason to invest great amounts of resources into the health care sector. In the Netherlands, for example, the health care sector's share of the gross national product was 14.3% in 2014 [8]. Regardless, demand is likely to outweigh any amount sensibly invested in the health care sector, which accentuates the need for making choices regarding the treatments that can and cannot be provided through the health care system. Indeed, there exists an obvious tension between people's a priori right to health and health care and the factual limits to health care resources.

Economic evaluations inform decision-making by assessing the costs and benefits of health interventions. The interventions that yield the largest benefits for the least amount of money may be favoured for provision or reimbursement from an economic perspective, because this allows for the most efficient use of health care resources [9]. This focus on the cost-effectiveness of interventions allows for maximization of generated health benefits within the available budget and embraces the aim to find the highest 'value for money'. Obviously, the success of finding such value for money is subject to understanding what 'value' means. This thesis aims to contribute to this by investigating one aspect of value: the relative value of health benefits.

1.1 DEFINING HEALTH BENEFITS

Health benefits are usually measured in quality-adjusted life-years (QALYs). QALYs gained from treatment are given by multiplying the duration of the health gain in years with the quality of life in those years. Duration is expressed in life years, and quality of life is expressed in a utility score between 0 (death) and 1 (perfect health), with values below 0 identifying health states worse than death. [9]

The use of QALYs in economic evaluations has implications. Traditionally, all QALY gains are treated equally, regardless of the circumstances under which they are generated and to whom they accrue. This has the advantage of straightforward comparison across interventions, as health gains from different interventions are quantified in the same manner and the total gains from intervention are calculated by merely adding-up the QALYs that accrue to different individuals. However, it has the disadvantage that the 'value' of health gains is solely measured in terms of the absolute size of QALY gains with the assumption that all QALYs have equal value and that more QALYs equals more value, whereas there may be more to it than QALY gains alone. [10, 11]

The relevance of looking beyond the QALY has been stressed in a literature that focused on 'equity concerns' [12]. Considerations other than the size of health benefits are considered to be relevant, because the interventions that yield the greatest QALY gains need not necessarily target the most needing or deserving patients. Thus, it matters to society where, how and to whom QALY gains accrue. Aspects such as the age of the patient, severity of illness and culpability have been suggested as relevant determinants for the value of a health benefits [13-19].

In addition, insights from behavioural economic research have been given relatively little attention in the health domain, while they suggest that the way people evaluate outcomes may substantially impact the value they attach to outcomes. According to prospect theory [20], the frame of reference within which outcomes are evaluated has considerable impact on the perceived value of these outcomes and therefore on preferences for such prospects [20, 21]. Prospect theory describes outcomes in relation to a neutral reference point, below which they are evaluated as losses and above which they are evaluated as gains. Loss aversion suggests that losses are perceived to be larger than similarly-sized gains [20, 21] and empirical evidence suggests that loss aversion also plays a role in the evaluation of health outcomes [22, 23].

Reference points in preference formation may have important implications for the value attached to health outcomes and taking into account both absolute *and* relative health assessments may be more in line with people's perception of health gains. However, relatively little is known about the role of reference points in the evaluation of health outcomes. Therefore, this thesis investigates the relative nature of health at the levels of individual preferences and societal decision-making.

1.2 RELATIVE VALUES IN INDIVIDUAL DECISION-MAKING

´Relative health´ may be viewed as a broad concept that defines the evaluation of health outcomes relative to some internal or external standard or reference level. It differs from and complements the evaluation of health outcomes in absolute quantities and allows for a level of subjectivity in health assessments. At the level of individual preferences, relative values may shape health perception, influence how healthy people feel, affect well-being and hence influence decision-making.

One of the reference points that will be investigated in this thesis is the health condition of others, because the health of peers (e.g. close friends and family, colleagues or other people in our social environment) may implicitly or explicitly shape our own standards or expectations. The health condition of others may therefore serve as a comparator and be used as a benchmark for the evaluation of our own condition. Such comparison effects have been extensively investigated in relation to income. 'Positional concerns' [24] refer to people's tendency to compare their own endowments with the endowments of others in order to assess how well off they are. Such positional concerns are often explained as a result of status-seeking and lagging behind as an incentive to 'keep up with the Joneses' [25, 26]. Empirical evidence suggests that social comparison provides a good explanation for stated and revealed preferences [27-32].

In the health context, the relevance of reference points at the individual level implies that people's perception of their health states may deviate from objective health measures. Taking into account such influences makes the valuation of health outcomes increasingly dynamic because changes in perceived health may originate from absolute improvements in the own health status due to treatment, relative improvements due to treatment and relative improvements due to changes in relevant intra- or interpersonal comparison standards.

1.3 RELATIVE VALUES IN SOCIETAL DECISION-MAKING

Relative values may also play a role at the societal level. Indeed, relative values may shape individual preference and influence how health outcomes are perceived by individuals, but they may also shape societal preferences and influence how health outcomes are perceived by society. For example, the average life expectancy within a country may serve as an implicit or explicit standard of longevity and shape societal perception of ‘normal’ ageing or what is considered to be a ‘fair share’ of lifetime health [19]. Consequently, allocation decisions may - intentionally or unintentionally - be influenced by ‘relative health assessments’.

Relative values at the societal level may also play a more explicit role in resource allocation. The distance of health outcomes relative to societal reference standards may serve as a measure for urgency or necessity of treatment and thereby direct allocation decisions. In this context, relative health assessments and reference points behave in a similar manner as equity concerns: they influence the societal value attached to certain health gains and therewith the priority decision-makers may attach to funding particular health benefits. In fact, priority setting in general relies on relative values in the sense that the process of choosing which interventions should be favoured for reimbursement implies that the weight attached to an intervention is relative to its comparator, i.e. the opportunity costs in terms of what other interventions are currently reimbursed or are available for reimbursement. Priority setting based on certain disease or patient characteristics, such as the severity of illness or culpability, implies that the relative social value of treatments to particular groups of patients may be larger than that of others.

Relative values at the societal level may thus play a role in decision-making via societal reference standards or via priority setting in favour of certain (groups of) patients, and incorporating such relative values seems in line with the notion that it is important to take a broad societal perspective in economic evaluations [9, 33-35], which is endorsed in the guidelines for pharmacoeconomic evaluations in the Netherlands [36]. Therefore, in addition to investigating relative values at the individual level, this thesis also focusses on relative values at the societal level.

1.4 RESEARCH OBJECTIVES

The overall aim of this thesis is to investigate the extent and nature of relative health assessments and their impact on individual well-being and societal preferences in the context of health care priority setting. Relatively little is known about such mechanisms in the assessment of health outcomes, while insights from behavioural economics suggest that relative outcome assessments and reference points play a significant role in preference formation. In the first part of this thesis, these insights are extended into the health domain by empirically investigating the role of relative outcomes on individual preferences for health. While these individual preferences are informative in the question what defines 'value' in individual decision-making, health care resource allocation takes place at the societal level. Therefore, the second part of this thesis investigates whether such relative health assessments are also relevant at the societal level. The following research questions are addressed:

1. What are the extent and nature of positional concerns in the context of health? (Chapters 2 and 3)
2. Are reference points for health relevant for subjective well-being? (Chapter 4)
3. What are the empirical and normative implications of evaluating health relative to a reference level of acceptable health? (Chapters 5 and 6)
4. Do people in the Dutch society attach more weight to health benefits in certain groups of patients? (Chapter 7)

By answering these questions, this thesis aims to contribute to the question of what defines health 'value' and thereby contribute to the ongoing debate regarding the optimal allocation of scarce health care resources.

1.5 OUTLINE OF THE THESIS

Research question 1 focuses on the measurement of positional concerns in the health domain and the comparison of positional concerns in the health domain with those measured in other life domains. This is addressed in chapters 2 and 3. **Chapter 2** presents an explorative study that investigated positional concerns for a range of health and health care related attributes. Using a hypothetical choice-task, this study investigated whether respondents attached more weight to their absolute or to their relative position. **Chapter 3** presents an extended model for positional concerns that allows for preferences to deviate from pure selfishness in two directions. Spiteful positional concerns reflect the desire to be better off than others, whereas altruistic positional concerns reflect the desire for oneself and others to be well off. Positional concerns in the health domain were compared with those in the monetary domain.

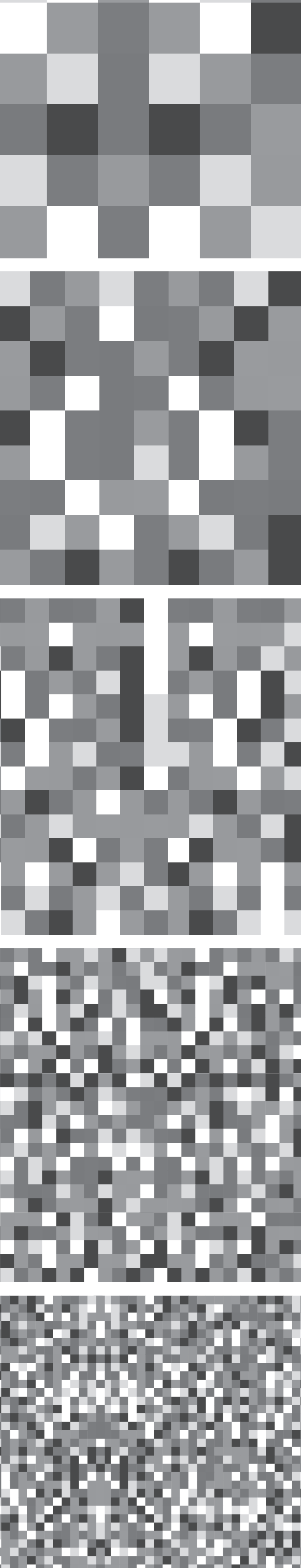
Research question 2 is addressed in chapter 4. Whereas chapters 2 and 3 focused on one specific reference point, i.e. the health of others, **chapter 4** focusses on a broader range of reference points for health. The study presented in this chapter investigated to what extent reference points influence subjective well-being by associating subjective well-being with health, using absolute and relative measurements for health.

Following these chapters on the relative value of health from an individual perspective, chapters 5, 6 and 7 present studies on relative values in the societal context. Chapters 5 and 6 address research question 3 and focus on acceptable health as a reference point in health care priority setting. In **chapter 5**, a sample of the Dutch general public identified which non-perfect health states they considered to be acceptable and which they considered to be unacceptable at different ages. These results were used to draw an 'acceptable health curve', which may serve as a reference level in the evaluation of health benefits. In **chapter 6**, the moral implications of setting a reference level of acceptable health in priority setting are discussed. This chapter draws an analogy between acceptability and sufficientarianism, a theory of distributive justice that emphasizes the relevance of having a sufficient level of well-being. Arguments in the debate surrounding sufficientarianism were used to understand the implications of valuing health benefits relative to a reference level of acceptable health.

Research question 4 is addressed in **chapter 7.** The study presented in this chapter aimed to investigate the relative value of treatments to particular groups of patients by identifying broad societal views on equity and efficiency considerations in priority setting. Particular focus was put on the relative value of health benefits from life-extending treatments.

Chapter 8 discusses the main findings and limitations of the research presented in this thesis. In addition, implications for research and policy are discussed.

Note that the chapters in this thesis are based on articles published in scientific peer-reviewed journals, or submitted for publication. Therefore, the chapters of this thesis can be read independently and some overlap between the chapters exists.



2

Do people desire to be healthier than other people? A short note on positional concerns for health

Based on: Wouters, S., van Exel, N. J. A., van de Donk, M., Rohde, K. I. M., & Brouwer, W. B. F. (2015). Do people desire to be healthier than other people? A short note on positional concerns for health. The European Journal of Health Economics, 16 (1), 47-54.

ABSTRACT

Contrary to traditional economic postulates, people do not only care about their absolute position but also about their relative position. However, empirical evidence on positional concerns in the context of health is scarce, despite its relevance for health care policy.

This chapter presents a first explorative study on positional concerns in the context of health. Using a 'two-world' survey method, a convenience sample of 143 people chose between two options (having more in absolute terms or having more in relative terms) in several health and non-health domains.

Our results for the non-health domains compare reasonably well to previous studies, with 22-47% of respondents preferring the positional option. In the health domain, these percentages were significantly lower, indicating a stronger focus on absolute positions.

The finding that positional concerns are less prominent in the health domain has important implications for health policy, for instance in balancing reduction of socio-economic inequalities and absolute health improvements.

2.1 INTRODUCTION

Traditionally, economic models assume rational, self-interested decision-makers. The'homo economicus' derives utility from his own endowment of goods and services, regardless of how others are endowed. Under this assumption, an income increase of €100 will always result in a utility increase, regardless of what happens to others' incomes simultaneously (e.g. remain stable or increase by €200). Many have argued that this assumption regarding human behaviour is descriptively flawed. Veblen [25] already observed that individuals consume certain goods with the primary goal of displaying social status to others, that is, to emphasize their relative position. Moreover, John Stuart Mill allegedly concluded: "Men do not desire merely to be rich, but to be richer than other men". Despite an absolute increase in his income of €100, an individual could thus perceive to be worse off when others' incomes increase by €200. People thus do not only care about what they have (in isolation) – i.e. their absolute position – but also how their endowment compares to that of others – i.e. their relative position [26, 37].

Acknowledging the existence of these 'positional concerns' has important practical implications for the welfare economic evaluation of policies. Traditionally, any policy that, in absolute terms, makes some or all individuals better off without making anyone worse off, would be evaluated as a Pareto improvement. However, when positional concerns matter, this need not be the case. People may perceive an absolute, yet unequal, improvement for all, as a relative worsening of their position. This may lead them to evaluate the new situation as a loss, despite the absolute improvement.

Positional concerns are also relevant in the field of health care. For example, in the Netherlands, an initiative to treat employees on a waiting list for care with priority (in evenings and weekends) was banned, even though this would have reduced waiting times for all patients [38]. The fact that the absolute waiting time would be reduced more for some than for others, so that the relative position of non-employees worsened, was crucial in this decision. The importance of relative positions in health care policy may also be illustrated by the strong focus on reducing socio-economic inequalities in health [39-41], which may, although need not necessarily, be at variance with introducing health programs yielding (unequal) absolute improvements for all.

Research directly investigating positional concerns in the context of health is scarce. Two previous studies suggest that health is among the least positional domains [42, 43], but neither investigated the health domain in depth. However, there is more indirect evidence on social comparison and relative health. For example, subjective health measurements seem to be influenced by the health in relevant comparison groups [44, 45].

In obesity research, evidence suggests that obesity spreads through social networks [46, 47]. Although similarity in environmental factors (food prices, number of fast food restaurants in the area, etc.) for members belonging to a social group may play a role [48], so may positional concerns. That is, body weight, dieting decisions and body weight perception are found to be influenced by relative body weight [49, 50].

This chapter presents an exploratory study directly and elaborately investigating positional concerns in the context of health. It does so by repeating a well-known experiment [24] and extending it elaborately into the health domain. This offers the opportunity to compare positional concerns for health to those in other domains as well as between different aspects within the health domain. To our knowledge, this is the first study doing so in this manner.

It is important to note that this chapter investigates how people value their own health in comparison to that of others, in the context of (hypothetical) trade-offs between absolute and relative positions. Our study does not investigate to which extent people care about the health of others in general (for example, as in the family effect [51, 52]).

It has been suggested that the extent of positional concerns depends on the nature of the good. That is, positional concerns are thought to be more prominent when goods satisfy a need above subsistence than when they satisfy a need below this level [53-55]. In addition, some goods may be considered basic goods, while others are labelled as luxury goods. While basic goods may satisfy needs below or above subsistence level, luxury goods always satisfy needs above subsistence level. Across domains, we may expect the extent of positional concerns to depend on the nature of goods in terms of their necessity. In the health domain, we expect to find low levels of positional concerns because in general, health care can be considered a basic good.

2.2 METHODS

In order to investigate positional concerns, a questionnaire was developed to elicit preferences for absolute versus relative positions. Positional concerns were measured using the 'two-world' survey method introduced by Solnick and Hemenway [24]. Two hypothetical states of the world were presented, the 'positional' (A) and the 'absolute' (B). For example:

A: Your current yearly income is €30,000; others earn €15,000
B: Your current yearly income is €60,000; others earn €100,000

In the positional state A, the respondent has more of an attribute than the average other in society. In the absolute state B, the respondent had less of the attribute than the average other, but more than in the positional state. Respondents were asked which state they preferred.

The questionnaire we used for this study consisted of three parts. In Part A, general demographic information was gathered. Part B was the Solnick and Hemenway [24] questionnaire, adjusted for the Dutch context (e.g. the number of weeks of vacation were adapted), to explore positional concerns for attributes related to labour (income, education and vacation time), personal characteristics (attractiveness and intelligence) and performance at work (praise and being berated) (see Appendix 2.A). Part C consisted of 14 questions on positional concerns for a variety of health and health care related attributes (see Appendix 2.B). One question was disregarded here because the printed version of the questionnaire contained a mistake.

Following Solnick and Hemenway [24], the questionnaire was distributed in a 'gain' version in which the positional state was presented first and the absolute second, and a 'loss' version in which this order was reversed. This served as a robustness check to account for the empirical findings that individuals tend to prefer the status quo [56] and value gains differently from losses [21].

Data were collected from a small convenience sample of the Dutch general public. Respondents were recruited in 2005 by one of the authors, via social networks and on the campus of the Erasmus University Rotterdam. Questionnaires were distributed on paper. A total of 143 respondents completed the questionnaire, one of whom dropped out after part B. The gain and loss versions were randomly and evenly distributed across respondents (72 for gain and 71 for loss). Females, respondents with medium or high income and respondents with a degree from higher education were over-represented; respondents in the age groups 35 to 44 and 55 and above were slightly under-represented (Table 2.1).

Table 2.1. Descriptive statistics

Characteristic	Level	N (%)
Age	<25	31 *(21.7%)*
	25-34	34 *(23.8%)*
	35-44	21 *(14.7%)*
	45-54	37 *(25.9%)*
	≥ 55	20 *(14.0%)*
Gender	Male	49 *(34.3%)*
	Female	94 *(65.7%)*
Education level	Lower education	53 *(37.1%)*
	Higher education	90 *(62.9%)*
Income	< €1,200	29 *(20.3%)*
	€1,200 – €2,750	59 *(41.3%)*
	≥ €2,750	52 *(36.4%)*
	Missing	3 *(2.1%)*
Employment	Fulltime job	59 *(42.0%)*
	Part-time job	46 *(35.0%)*
	No paid job/student/other	32 *(23.1%)*

The average proportion of positional choices in parts B and C (the non-health and the health domain) were compared using a Wilcoxon signed rank test for comparison within subjects. This test was also used to compare the proportions of positional responses between questions within parts B and C. The responses in the gain and loss versions of the questionnaire were compared using the Mann-Whitney U test for comparison between subjects.

2.3 RESULTS

Our results compare reasonably well to those obtained in the US by Solnick and Hemenway [24] and confirm that positional concerns are less prominent in the health domain.

Tables 2.2 and 2.3 report the percentages of respondents choosing the positional alternative in parts B and C. In general, positional concerns appear to be lower in part C. For the questions in part B, 22% to 47% of the respondents chose the positional alternative; this was 11% to 31% in part C. In fact, 'age child' (Q12) and 'privacy' (Q5) were the only attributes in the health domain that were more positional than the least positional attribute in part B (vacation time; Q8), as clearly shown in Figures 2.1 and 2.2. Overall, the proportion of positional choices in part C was lower than in part B ($p<0.001$).

Table 2.2. Distribution of answers in the non-health domains (part B) (n=143)

Variable		**Average**	**'Gain' version**	**'Loss' version**
Attractiveness child (Q11)	Positional	0.47	0.53	0.41
	Absolute	0.39	0.31	0.47
	Undecided	0.15	0.17	0.13
Intelligence child (Q10)	Positional	0.46	0.54	0.38*
	Absolute	0.39	0.29	0.49
	Undecided	0.15	0.17	0.13
Intelligence (Q5)	Positional	0.46	0.47	0.44
	Absolute	0.42	0.33	0.51
	Undecided	0.13	0.19	0.06
Praise (Q7)[b]	Positional	0.45	0.39	0.50
	Absolute	0.41	0.42	0.40
	Undecided	0.14	0.18	0.10
Attractiveness (Q6)	Positional	0.43	0.47	0.38
	Absolute	0.47	0.39	0.55
	Undecided	0.11	0.14	0.07
Being berated (Q4)[b]	Positional	0.36	0.38	0.34
	Absolute	0.55	0.52	0.57
	Undecided	0.09	0.10	0.09
Income (Q1)	Positional	0.30	0.42	0.18***
	Absolute	0.55	0.43	0.68
	Undecided	0.15	0.15	0.14
Education (Q2)[a]	Positional	0.30	0.37	0.24
	Absolute	0.55	0.47	0.63
	Undecided	0.15	0.17	0.13
Income (Q9)[a]	Positional	0.30	0.33	0.26
	Absolute	0.56	0.50	0.63
	Undecided	0.14	0.17	0.11
Vacation time (Q3)	Positional	0.25	0.29	0.20
	Absolute	0.65	0.58	0.72
	Undecided	0.11	0.13	0.09
Vacation time (Q8)	Positional	0.22	0.24	0.20
	Absolute	0.69	0.64	0.73
	Undecided	0.10	0.13	0.07

*** p<0.01 (p=0.002); * p<0.1 (p=0.054)

a: one missing value ; b: two missing values

Table 2.3. Distribution of answers in the health domain (part C) (n=142)

Variable		**Average**	**'gain' version**	**'loss' version**
Age child (Q12)	Positional	0.31	0.20	0.42***
	Absolute	0.60	0.69	0.51
	Undecided	0.09	0.11	0.07
Privacy (Q5)[a]	Positional	0.23	0.24	0.23
	Absolute	0.68	0.66	0.70
	Undecided	0.09	0.10	0.07
Age (Q11)	Positional	0.21	0.17	0.25
	Absolute	0.70	0.73	0.66
	Undecided	0.09	0.10	0.09
Waiting time (cateract; Q7)	Positional	0.18	0.18	0.18
	Absolute	0.73	0.70	0.76
	Undecided	0.09	0.11	0.06
Insurance coverage (Q4)[b]	Positional	0.16	0.20	0.13
	Absolute	0.76	0.71	0.80
	Undecided	0.08	0.09	0.07
Waiting time (knee; Q2)	Positional	0.16	0.17	0.16
	Absolute	0.75	0.72	0.78
	Undecided	0.09	0.11	0.07
Health child (Q13)	Positional	0.16	0.11	0.21
	Absolute	0.75	0.76	0.75
	Undecided	0.09	0.13	0.04
Waiting time (heart; Q9)	Positional	0.16	0.16	0.17
	Absolute	0.78	0.78	0.79
	Undecided	0.06	0.07	0.04
Travel to hospital (Q3)	Positional	0.13	0.11	0.14
	Absolute	0.75	0.76	0.73
	Undecided	0.13	0.13	0.13
Age (Q8)	Positional	0.12	0.07	0.17*
	Absolute	0.81	0.85	0.78
	Undecided	0.07	0.09	0.06
Health (Q1)	Positional	0.11	0.13	0.09
	Absolute	0.82	0.78	0.87
	Undecided	0.07	0.10	0.04
Health (Q6)	Positional	0.11	0.10	0.11
	Absolute	0.82	0.79	0.85
	Undecided	0.08	0.11	0.04
Co-payment (Q10)	Positional	0.11	0.14	0.07
	Absolute	0.81	0.78	0.85
	Undecided	0.09	0.09	0.09

*** $p < 0.01$ ($p = 0.004$); * $p < 0.1$ ($p = 0.071$)

a: one missing value; b: two missing values

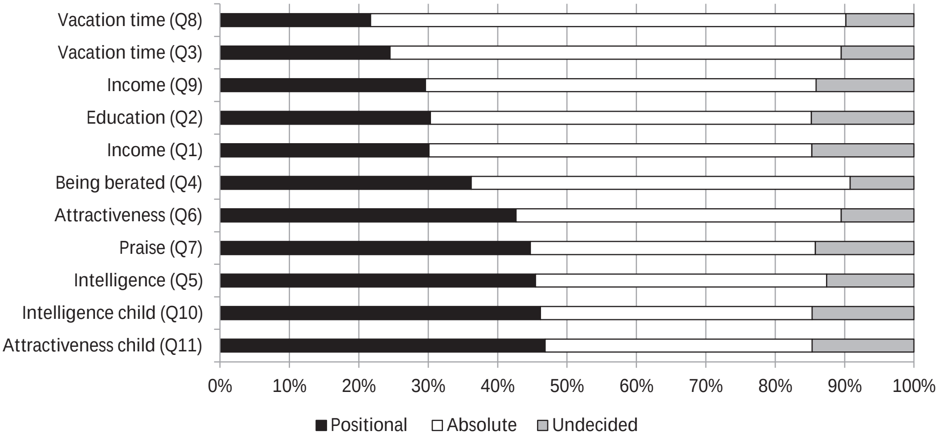


Figure 2.1. Positional concerns in the non-health domains

Figure 2.1 indicates that in the non-health domains, the attributes related to labour (income, education, and vacation time) are less positional than the attributes related to personal characteristics (attractiveness and intelligence) and performance at work (praise and being berated). Pair-wise comparisons between each of the questions confirmed that the five smallest percentages (the labour related attributes) were each significantly smaller than the five largest percentages (personal characteristics and praise from a supervisor) (all p≤0.015). The observed ranking largely resembles the results of Solnick and Hemenway [24], vacation being the least positional attribute, income and education being somewhere in the middle, and intelligence, attractiveness and praise being among the most positional. With respect to the observed strength of positional

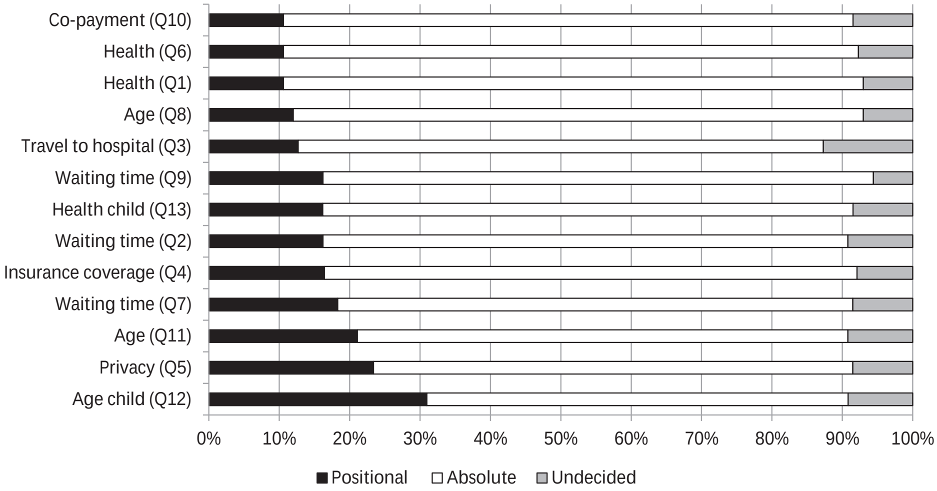


Figure 2.2. Positional concerns in the health domain

concerns, some differences were found. Notably, the proportion of positional answers in our Dutch sample ranged from 22% to 47%, versus 14% to 68% in their US sample. Also, vacation time was somewhat less positional in the US (16% in Q3 and 14% in Q11 on average) than in the Netherlands (22% in Q8 and 25% in Q3).

The results in Figure 2.2 imply that in the health domain, 'age child' was more positional than the other attributes. Pair-wise comparisons between the positional percentages in part C confirm this: age child (Q12) was more positional than each other attribute (all $p \leq 0.047$). In the questions related to longevity (age, Q8 and Q11), the attainable age in the positional state appeared to affect the degree of positional concerns. Positional concerns were more prominent when the attainable age was 80, and less when it was 70 (part C, Q11 versus Q8; $p=0.007$). Such a pattern was not observed for quality of life. In both questions, 11% of the respondents preferred the positional state (part C, Q1 versus Q6; $p=1.000$).

The gain and loss versions of the questionnaire did not yield considerably different results. Although small differences in positional concern between the versions were found, these were significant at 1% in 2 of the 24 questions only: income (Q1 in part B; $p=0.002$) and age child (Q12 in part C; $p=0.004$). Significant at 10% were intelligence child (Q10 in Part B; $p=0.054$) and age (Q8 in part C; $p=0.071$).

2.4 DISCUSSION

This study set out to explore the strength of positional concerns in the contexts of health. Our results imply that positional concerns are less prominent in the health domain than in other life domains. This confirms and expands on previous studies [42, 43].

Before addressing the implications of our findings, some limitations of our study must be noted. First, we emphasise the exploratory nature of this study. More research in the area of positional concerns in the health domain is needed to assess the robustness of our results, preferably also using different (or various) elicitation techniques such as discrete choice experiments or techniques estimating social-comparison utility functions. A natural extension of the method used here may be to disentangle status seeking motivations from egalitarian concerns, both of which have been suggested to generate positional concerns [57]. It may also be interesting to compare positional concerns in different countries, cultural groups or generations, given the existing evidence that positional concerns may be culture dependent [42, 58]. Second, our sample was a convenience sample of limited size. Hence, it was neither entirely representative for the Dutch general public nor large enough to examine preference heterogeneity within the sample thoroughly. Young people, high-educated people and females were over-represented. To our knowledge, two studies similar to ours with respect to part B investigated the effect of personal characteristics on positional concerns [59, 60]. Neither found a significant effect of age and gender, and Grolleau et al. [59] did not find a significant effect of education level on positional concerns, except for being berated by a supervisor. Therefore, given the exploratory nature of this study, we feel this sample suffices to highlight the importance of investigating positional concerns in the health domain. Even so, caution with interpreting the results remains important. Third, many people chose the positional option in the question regarding 'privacy' (sharing a room with more people in the hospital). The a priori assumption was that more privacy (sharing a room with fewer people) would be considered better in absolute terms. However, some of the respondents indicated that they preferred sharing a room with others (i.e. they like company). Hence, these results cannot be straightforwardly interpreted in terms of the absolute-relative distinction. Fourth, respondents were asked a series of 25 similarly-couched questions, which may have led to fatigue in some respondents. We thoroughly investigated this, for instance by analysing whether the number of respondents choosing 'undecided' or choosing the same answer as a default (positional or absolute) increased near the end of the questionnaire. The results indicate that fatigue did not noticeably influence our results. Finally, positional concerns may be operationalized as the cardinal ranking of a person compared to the average of a relevant comparison group, as was done in this chapter, but could also be operationalized as the ordinal ranking in a relevant comparison group [61]. That is, health perception may be influenced by the absolute difference in health as compared to what is observed in a relevant comparison group, but also by the number of better off or worse off people in the comparison group. This is an interesting area for future research.

Notwithstanding these limitations our results suggest that people may not primarily care about their relative position when it comes to health and health care. At least, in our questions they do not care enough about their relative standing to give up some of their absolute endowment. Note that the values presented do seem to matter in this context. Providing people the choice between two states of the world at higher absolute levels resulted in more positional concerns in case of longevity (Q8 and Q11 of part C). In this domain people may thus require minimum absolute attainment levels, before becoming concerned with relative positions. Our data did not support a similar reasoning for income, since both questions on income had a positional percentage of 30%. This is in line with the results of Clark and Senik [28], and reinforces our conclusion that income preferences may be different from health preferences. Further research is needed to investigate these attainment levels and to assess the robustness of our results with respect to the exact framing and values used. In addition, an interesting extension within the health domain would be to compare positional concerns across types of care, such as medically necessary care versus "luxury care" For example, is (medically unnecessary) aesthetic plastic surgery more positional than heart transplantation?

If confirmed, our findings imply that especially absolute improvements in the health domain may contribute to welfare, even when distributed unevenly. Note that an uneven distribution may be perceived as equitable if it for instance decreases pre-existing inequalities, but as inequitable if it amplifies them. Indeed, promoting a more equitable distribution is often at variance with attaining the highest health levels in absolute terms [10]. In light of our results, policies improving the absolute health of all citizens, but for some more than for others, could still be evaluated positively by members of society, even when adding to inequalities. It should be stressed, however, that our analysis relies solely on individual preferences and does not capture broader societal concerns or equity considerations which are clearly important in the context of health. In so far as relative positions do play a role, policy makers should be aware that overall subjective well-being can only be increased if zero-sum game outcomes are avoided [26, 37, 62]. The normative question of whether individual preferences based on social envy should be weighted in social decision making, needs to be addressed as well [63].

Concluding, this study has provided a first detailed investigation of positional concerns in the context of health. More investigation in this important area is needed, and strongly encouraged, to assess the robustness of our findings.

APPENDIX 2.A – NON-HEALTH QUESTIONS

In the questions below, two states of the world are presented (state A and state B). You are asked in which of the two states you would prefer to live. The questions are independent from each other. In each of the questions, please circle either A or B, or if undecided, both A and B. 'Others' can be interpreted as the average other person in society.

Which world would you prefer[1]?

1. A Your current yearly income is 30.000 euro, others earn 15,000 euro
B Your current yearly income is 60.000 euro, others earn 100,000 euro
2. A You have 12 years of education (high school), others have 8 years (elementary school)
B You have 16 years of education (college), others have 20 years (graduate)
3. A You have 4 weeks of vacation, others have 2 weeks
B You have 6 weeks of vacation, others have 10 weeks
4. A You are berated by the supervisor 4 times this year, others are berated 8 times
B You are berated by the supervisor twice, others are berated once

Assume intelligence can be described by IQ on current tests.

5. A Your IQ is 110, others average 90
B Your IQ is 130, others average 150

Assume physical attractiveness can be measured on a scale from 1 (lowest) to 10 (highest).

6. A Your physical attractiveness is 6, others average 4
B Your physical attractiveness is 8, others average 10
7. A You are praised by the supervisor 2 times this year, others are not praised
B You are praised by the supervisor 5 times this year, others are praised 12 times
8. A You have 1 week of vacation, others have none
B You have 2 weeks of vacation, others have 4 weeks
9. A Your current yearly income is 20.000 euro, others earn 10.000
B Your current yearly income is 40.000, others earn 80.000

Assume you have a child

10. A Your child's IQ is 110, other people's children average 90
B Your child's IQ is 130, other people's children average 150
11. A Your child's physical attractiveness is 6, others average 4
B Your child's physical attractiveness is 8, others average 10

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[1] This concerns the 'gain' version of the questionnaire, in which the positional state of the world was presented first and the absolute second. In the 'loss' version, states of the world A and B were presented in reversed order.

APPENDIX 2.B – HEALTH QUESTIONS

The previous questions concerned different aspects of life. The next part of the questionnaire will focus on health- and health care specific situations. In each question, please circle either A or B, or if undecided, both A and B. ‘Others’ can be interpreted as the average other person in society.

Which world would you prefer?

Assume health can be measured on a scale from 1 (lowest) to 10 (highest).

1. A Your health is 6, others average 4
   B Your health is 8, others average 10

Assume you need a knee-operation

2. A Your waiting time is 6 weeks, others wait 8 weeks
   B Your waiting time is 3 weeks, others wait 1 week
3. A Your travel time to the hospital is 30 minutes, others travel 60 minutes
   B Your travel time to the hospital is 15 minutes, others travel time 5 minutes
4. A Your insurance-company covers 50% of all costs of complementary care (e.g. physiotherapy), others are not covered
   B Your insurance-company covers 75% of all costs of complementary care (e.g. physiotherapy), others are fully covered
5. A You get a 4-persons room in the hospital, others get a 6-persons room
   B You get a 2-persons room in the hospital, others get a private room
6. A Your health is 4, others average 2
   B Your health is 6, others average 8

Assume you need a cataract-operation

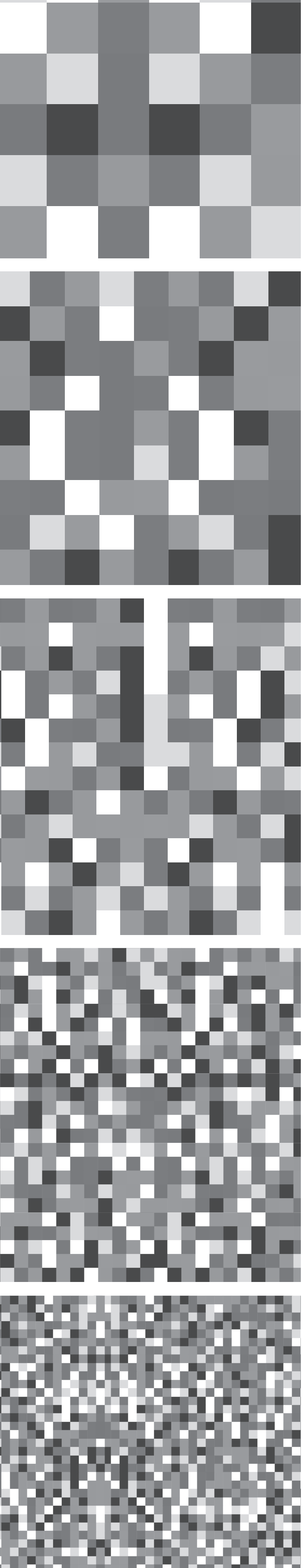
7. A Your waiting time is 6 weeks, others wait 8 weeks
   B Your waiting time is 3 weeks, others wait 1 week
8. A You will reach 70 years of age, others average 65
   B You will reach 75 years of age, others average 80

Assume you need an open-heart-operation

9. A Your waiting time is 6 weeks, others wait 8 weeks
   B Your waiting time is 3 weeks, others wait 1 week
10. A Your co-payment for consultation at the physician is 10 euro, others pay 15 euro
    B Your co-payment for a consultation at the physician is 5 euro, others pay 2.50 euro
11. A You will reach 80 years of age, others average 75
    B You will reach 85 years of age, others average 90

Assume you have a child

12. A Your child will reach 80 years, others average 75
    B Your child will reach 85 years, others average 90
13. A Your child’s health is 6, others average 4
    B Your child’s health is 8, others average 10



3

Positional concerns for health and money – revealing two sides of the coin

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ABSTRACT

Contrary to traditional economic thought, accumulating evidence suggests that people do not only care about their own endowment, but also about how it compares to the endowments of others. Such 'positional concerns' are typically explained as a concern for relative standing and have been well studied for income, assuming that improvements for others can affect own utility only negatively. Yet, the literature on subjective wellbeing and other regarding preferences suggests that improvements for others may also affect own utility positively. This chapter extends the framework for positional concerns to allow for preferences to deviate from pure selfishness in two directions, which we label altruistic and spiteful. Our framework also allows for a measurement of the degree of positional concerns and thereby allows for a precise comparison of positional concerns across different outcome domains. We measured and compared positional concerns for health and money. In a sample of the general public in the Netherlands, we found positional concerns. For health we found more altruistic than spiteful positional concerns. Moreover, altruistic positional concerns were more prevalent for health than for money.

3.1 INTRODUCTION

Traditional economic thought assumes rational, self-concerned decision-makers. However, accumulating evidence suggests that people do not only care about what they themselves have, but also about how it compares to what others have. Several stated and revealed preference methods have been used to investigate positional concerns, primarily in the context of income [24, 27-32, 43, 64-66]. These studies confirmed that both absolute and relative endowments matter.

The existence of positional concerns has important implications for the evaluation of policy outcomes. Whereas traditional approaches suggest that welfare improvements are established through absolute improvements only, positional concerns allow for welfare changes through changes in relative positions as well. In fact, an improvement in the absolute position of some people can impose negative externalities on others by worsening their relative positions [67]. Ignoring the impacts of such negative externalities may lead to sub-optimal policy decisions.

Positional concerns have been well studied in the monetary domain. Yet the majority of the studies using surveys to elicit positional concerns focus on only one type of positional concerns where an improvement for others affects own utility or wellbeing negatively. However, from the literature on other-regarding preferences we know, that improvements for others may also affect own utility positively [68-70]. Therefore, in this chapter we extend the traditional framework for positional concerns by allowing for preferences to deviate from the economic assumption of pure selfishness in two opposite directions, rather than in only one direction. In addition our extended framework allows for a precise comparison of *degrees* of positional concerns between outcome domains.

Relatively little is known about positional concerns in non-monetary domains, for instance, the health domain. A few studies found that positional concerns vary across domains and that in general, fewer people seem to be concerned with relative positions in the health domain than in many non-health domains [42, 43, 60, 71]. In these studies people showing no positional concerns may in fact have had positional concerns where improvements for others affect own wellbeing positively, or where improvements for others only weakly affect own wellbeing negatively. However, the traditional positional concerns framework does not allow preferences in this direction. Our framework distinguishes between people with these different kinds of 'positive' and 'negative' positional concerns and people without positional concerns. It thereby allows for a precise comparison of positional concerns between outcome domains.

Our framework builds on an existing survey-instrument designed to measure the degrees of positional concerns for income [30]. Positional concerns are traditionally ascribed to an underlying drive for status [25, 26] but the endowment of others need not only impact utility negatively. For example, the ‘tunnel effect’ [72] describes that advances in the social or economic position of others may give us hope, because they symbolize our own improved prospects in the economic environment. Social preference theories incorporate departures from self-interest and the existence of other-regarding preferences that need not necessarily affect own utility negatively. In order to allow for such preferences, we distinguish two types of positional concerns. On the one hand, individuals may have ‘traditional’ positional concerns in the sense that they want to be better off than others. Improvements in the endowment of others then affect own utility negatively. On the other hand, individuals may have positional concerns in the opposite direction. Improvements in the endowment of others then affect own utility positively. We will label these two types of positional concern ‘spiteful’ and ‘altruistic’, respectively.

The results of several studies on positional concerns suggest that a kind of altruistic positional concerns may exist [29, 30, 73-75]. In addition, a recent empirical study found positive spill-over effects on one’s own utility, of changes in one’s partner’s utility due to experienced life-events, such as serious illness [76].

One may expect positional concerns to differ between monetary and non-monetary outcomes like health, not only in terms of *strength* of positional concerns, but also in terms of *type* of positional concerns. In this chapter we compare positional concerns for health and money. Our framework can, however, also be applied to other outcomes domains, like education. We expect altruistic positional concerns to be stronger for health than for money, because health may be considered to be a basic good [77, 78] and health has been shown to have a positive spill-over on others [51, 52, 79, 80]. In line with traditional positional concerns, we expect status concerns to be stronger for money, because people derive a sense of achievement and/or status from having more money than others.

This chapter is organized as follows. Section 3.2 introduces the utility model we used to measure degrees of positional concerns. Section 3.3 describes the experiment that we conducted to measure the type and degree of positional concerns and Section 3.4 presents the results. Section 3.5 discusses the methods and results, and section 3.6 concludes.

3.2 THEORETICAL BACKGROUND

This chapter considers preferences $\succcurlyeq$ over distributions $(x,\bar{x})$, where x is own endowment, and $\bar{x}$ is the average endowment of others in society. Strict preference $\succ$ and indifference $\sim$ are defined as usual. Endowments can take on any real number. In line with prospect theory [21], we let endowments be deviations from a reference point $x=0$. Thus, positive endowments are gains compared to the reference point and negative endowments are losses compared to the reference point. We will only consider distributions where own endowment and endowment of others have the same sign. Thus, we consider only losses or only gains.

We consider three types of positional concerns. We say that an individual has *no positional concerns* if $(x,\bar{x}) \sim (x,\bar{y})$ for every own endowment x and all others' endowments $\bar{x}>\bar{y}$. We say that an individual has *spiteful positional concerns* if $(x,\bar{x})\prec(x,\bar{y})$ for every x and all $\bar{x}>\bar{y}$, and *altruistic positional concerns* if $(x,\bar{x})\succ(x,\bar{y})$ for every x and all $\bar{x}>\bar{y}$. A person with no positional concerns is insensitive to others' endowments. A person with spiteful (or anti-social) positional concerns strictly prefers a lower endowment for others given his own endowment. A person with altruistic (or pro-social) positional concerns strictly prefers a higher endowment for others given his own endowment. In this chapter we study the two different (opposite) types of positional concerns and label them 'spiteful' and 'altruistic'. However, we should stress that by referring to altruistic and spiteful positional concerns, we define two categories of preferences, but by no means intend to commit to particular motives underlying these types. Altruistic positional concerns, for instance, can be driven by efficiency concerns as well as by altruism.

A first step in comparing positional concerns between different domains is to compare the types of positional concerns between these domains. Yet, we would also like to compare these domains according to the exact degree of positional concerns. Consider a person with spiteful positional concerns, i.e. $(y,\bar{x}) \prec (y,\bar{y})$ for $\bar{x}>\bar{y}$. In order to determine the degree of positional concerns, we could ask this person by how much his own endowment would have to increase in the situation where others have $\bar{x}$, in order to restore indifference. In other words, we could ask for x such that $(x,\bar{x}) \sim (y,\bar{y})$. The larger the difference between x and y, the higher the degree of spiteful positional concerns. Therefore, we could take $(x-y)$ as a measure of the degree of positional concerns.

This approach, however, may not work well when comparing two different domains where amounts are expressed in different units. Consider, for instance, a comparison between positional concerns for yearly income levels and yearly days in full health. The former will concern numbers expressed in monetary units well above 1,000, while the latter will concern number of days, up to a maximum of 366. As a result, the differences $(x-y)$ concerning yearly income may always be larger than the ones concerning yearly days in full health, merely because yearly income concerns numbers on a different scale. Thus, for the comparison of the degree of positional concerns between domains with different units, we prefer a unit-invariant measure, i.e. a measure which does not change when all endowments are multiplied by a common constant factor.

The unit-invariant measure of positional concerns that we consider in this chapter is the parameter γ of the utility function used by Johansson-Stenman et al. [30]:

$$u(x,\bar{x}) = x^{1-\gamma}\left(\frac{x}{\bar{x}}\right)^{\gamma} \text{ for } x,\bar{x}>0 \qquad \text{Eq. (1)}$$

According to this model an individual derives utility from own endowment x, weighted by a factor $1-\gamma$, and from his or her relative endowment compared to others $x/\bar{x}$, weighted by a factor γ. Johansson-Stenman et al. [30] only considered situations with gains compared to the status quo, i.e. with $x>0$ and $\bar{x}>0$. In this chapter we will consider losses, i.e. with $x<0$ and $\bar{x}<0$. For losses relative to the status quo, Eq.(1) cannot be applied: the square root ($\gamma = ½$) of a negative number, for instance, does not exist. We extend Eq.(1) for losses in the following manner:

$$u(x,\bar{x}) = -(|x|)^{1-\gamma}\left(\frac{|x|}{|\bar{x}|}\right)^{\gamma} \text{ for } x,\bar{x}<0 \qquad \text{Eq. (2)}$$

Thus, the disutility incurred from two losses $x,\bar{x}<0$ equals the utility obtained from equally large gains $|x|$ and $|\bar{x}|$.

Maximizing utility function (1) is equivalent to maximizing

$$\tilde{u}(x,\bar{x})=\ln(u(x,\bar{x}))= (1-\gamma)\ln(x)+ \gamma\ln\left(\frac{|x|}{|\bar{x}|}\right) = \ln(x)- \gamma\ln(\bar{x}) \qquad \text{Eq. (3)}$$

Similarly, maximizing utility function (2) is equivalent to minimizing

$$\tilde{u}(x,\bar{x}) =\ln(-u(x,\bar{x}))= (1-\gamma)\ln(|x|)+ \gamma\ln\left(\frac{|x|}{|\bar{x}|}\right) = \ln(|x|)-\gamma\ln(|\bar{x}|) \qquad \text{Eq. (4)}$$

Thus, γ can be interpreted as the weight given to others' endowments. Altruistic positional concerns correspond to $\gamma<0$, no positional concerns correspond to $\gamma=0$, and spiteful positional concerns correspond to $\gamma>0$. If the absolute value of γ equals one, the endowments of others and own endowments get equal weight. If the absolute value of γ exceeds one, the endowments of others get a larger weight than own endowments.

From any indifference $(x,\bar{x}) \sim (y,\bar{y})$ we can compute γ as follows. The indifference $(x,\bar{x}) \sim (y,\bar{y})$ for losses $x, \bar{x}, y, \bar{y}<0$ implies

$$(|x|)^{1-\gamma}\left(\frac{|x|}{|\bar{x}|}\right)^{\gamma} = (|y|)^{1-\gamma}\left(\frac{|y|}{|\bar{y}|}\right)^{\gamma} \qquad \text{Eq. (5)}$$

which is equivalent to

$$\ln(|x|)-\gamma\ln(|\bar{x}|)=\ln(|y|)-\gamma\ln(|\bar{y}|) \qquad \text{Eq. (6)}$$

Then, it follows that

$$\gamma = \frac{\ln(|y|)-\ln(|x|)}{\ln(|\bar{y}|)-\ln(|\bar{x}|)} \qquad \text{Eq. (7)}$$

It also follows γ is unit-invariant, as multiplying x, y, $\bar{x}$, and y by a constant factor $k>0$ does not change the value of γ.

3.3 METHODS

3.3.1 Subjects

In order to investigate positional concerns for health and money, a web-based questionnaire was conducted in 2013 among 881 people representative for the adult general public in the Netherlands in terms of age, gender and education level. The questions relevant for this study were part of a larger questionnaire addressing health-related questions. Respondents were recruited by a professional survey sampling agency, which sent out invitations to people who had previously signed up for participation in (scientific) research. Email invitations were sent out to people in the survey sampling agency's panel database and by accepting the invitation to participate in this survey, respondents provided consent to the use of their response for the purposes of this study. In order to obtain a sample representative for the Dutch adult population in terms of age, gender and education level, strategic sampling was used.

The questionnaire included a time and consistency constraint and respondents were included for further analysis if they satisfied both constraints. Respondents were excluded if they completed the questions relevant for this chapter within 6 minutes. This threshold was chosen based on the results of a pilot survey among 55 respondents conducted by the sampling agency, where the mean response time was 9.2 minutes (SD = 2.7) with a median of 8.7, a minimum of 4.1 and a maximum of 18.2 minutes. Respondents were also excluded if they were inconsistent in their preferences in four or more of the seven questions relevant for this study Inconsistency was defined by choosing 'I prefer option A (B)' in the first part of the question, but then choosing 'I always prefer option B (A)' in the remainder of the question that also included this first choice. 146 respondents (16.6%) did not meet the time constraint, 70 respondents (7.9%) did not meet the consistency constraint and 5 respondents (0.6%) met neither. In total, 221 respondents (25.1%) were excluded for further analysis and 660 respondents (74.9%) remained[2].

3.3.2 Questions

Respondents were given six choice lists to elicit positional concerns and one for practice purposes. In each choice list, respondents faced 17 comparisons between situation A and situation B. In this sense our choice lists were comparable with a modified dictator game as used by Müller and Rau [81] and Blanco et al. [82]. Each situation was characterized by the distribution of own endowment and the endowment of others. The 17 comparisons within the choice lists differed in the level of own endowment in situation B, while all other endowments (i.e. own endowment in situation A and others' endowments in situations A and B) remained stable throughout the choice lists (see Table 3.1). For every choice list respondents were asked to choose the row in the list where they were indifferent between situations A and B. They were also allowed to indicate that they always preferred situation A or B, but then they were presented with a follow-up question. Respondents had two options to answer this question. They could either report the value of own endowment in situation B for which they were indifferent between both situations (but which was not presented in the choice list), or they could report their reason for always preferring one situation over the other, irrespective of the level of own endowment in situation B.

The first choice list the respondents viewed was a practice choice list regarding vacation days in order for them to get familiar with the choice lists. This choice list will be disregarded for analysis. Questions BP1 to BP3 (see Table 3.1) presented choice lists for health, concerning days with back pain (BP). Questions MT1 to MT3 presented choice lists for money, concerning municipal tax expenses. In questions BP1 and MT1, the respondent was worse off than others in both situations, except for the first two of 17 comparisons. In questions BP2 and MT2, the respondent was worse off than others in situation A and better off than others in situation B. In questions BP3 and MT3, the respondent was better off than others in both situations. Each domain consisted of three questions measuring positional concerns in order to investigate the stability of preferences when circumstances

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[2] In order to check the implications of this choice, we also conducted the analyses with the entire sample of n=881. Parameter scores (γ) for respondents with multiple inconsistencies who were for this reason removed from the main sample of n=660, were measured using their answer in the choice list and not the introductory question (the first choice). The analyses with n=881 did not yield substantial differences in the results.

Table 3.1: Choice lists

BP1				
A		B		
You	*Others*	*You*	*Others*	*γ*
14	1	6	7	-0.44
14	1	7	7	-0.36
14	1	8	7	-0.29
14	1	9	7	-0.23
14	1	10	7	-0.17
14	1	11	7	-0.12
14	1	12	7	-0.08
14	1	13	7	-0.04
14	**1**	**14**	**7**	**0.00**
14	1	15	7	0.04
14	1	16	7	0.07
14	1	17	7	0.10
14	1	18	7	0.13
14	1	19	7	0.16
14	1	20	7	0.18
14	1	21	7	0.21
14	1	22	7	0.23

BP2				
A		B		
You	*Others*	*You*	*Others*	*γ*
14	7	6	28	-0.61
14	7	7	28	-0.50
14	7	8	28	-0.40
14	7	9	28	-0.32
14	7	10	28	-0.24
14	7	11	28	-0.17
14	7	12	28	-0.11
14	7	13	28	-0.05
14	**7**	**14**	**28**	**0.00**
14	7	15	28	0.05
14	7	16	28	0.10
14	7	17	28	0.14
14	7	18	28	0.18
14	7	19	28	0.22
14	7	20	28	0.26
14	7	21	28	0.29
14	7	22	28	0.33

BP3				
A		B		
You	*Others*	*You*	*Others*	*γ*
14	21	6	28	-2.95
14	21	7	28	-2.41
14	21	8	28	-1.95
14	21	9	28	-1.54
14	21	10	28	-1.17
14	21	11	28	-0.84
14	21	12	28	-0.54
14	21	13	28	-0.26
14	**21**	**14**	**28**	**0.00**
14	21	15	28	0.24
14	21	16	28	0.46
14	21	17	28	0.67
14	21	18	28	0.87
14	21	19	28	1.06
14	21	20	28	1.24
14	21	21	28	1.41
14	21	22	28	1.57

MT1				
A		B		
You	*Others*	*You*	*Others*	*γ*
70	5	30	35	-0.44
70	5	35	35	-0.36
70	5	40	35	-0.29
70	5	45	35	-0.23
70	5	50	35	-0.17
70	5	55	35	-0.12
70	5	60	35	-0.08
70	5	65	35	-0.04
70	**5**	**70**	**35**	**0.00**
70	5	75	35	0.04
70	5	80	35	0.07
70	5	85	35	0.10
70	5	90	35	0.13
70	5	95	35	0.16
70	5	100	35	0.18
70	5	105	35	0.21
70	5	110	35	0.23

MT2				
A		B		
You	*Others*	*You*	*Others*	*γ*
70	35	30	140	-0.61
70	35	35	140	-0.50
70	35	40	140	-0.40
70	35	45	140	-0.32
70	35	50	140	-0.24
70	35	55	140	-0.17
70	35	60	140	-0.11
70	35	65	140	-0.05
70	**35**	**70**	**140**	**0.00**
70	35	75	140	0.05
70	35	80	140	0.10
70	35	85	140	0.14
70	35	90	140	0.18
70	35	95	140	0.22
70	35	100	140	0.26
70	35	105	140	0.29
70	35	110	140	0.33

MT3				
A		B		
You	*Others*	*You*	*Others*	*γ*
70	105	30	140	-2.95
70	105	35	140	-2.41
70	105	40	140	-1.95
70	105	45	140	-1.54
70	105	50	140	-1.17
70	105	55	140	-0.84
70	105	60	140	-0.54
70	105	65	140	-0.26
70	**105**	**70**	**140**	**0.00**
70	105	75	140	0.24
70	105	80	140	0.46
70	105	85	140	0.67
70	105	90	140	0.87
70	105	95	140	1.06
70	105	100	140	1.24
70	105	105	140	1.41
70	105	110	140	1.57

change. This was also done by Andersson [73], who found that individuals with consumption levels above the average tended to have lower concern for relative consumption, i.e. concern for relative position depended on the initial relative position of the respondent.

Contrary to the framework of Johansson-Stenman et al. [30], we measured the degree of positionality for bads instead of for goods. Health is often expressed in terms of bads (the amount of health problems) instead of goods (the amount of good health). Therefore, in the health domain, endowments were stated in days of illness and not days in good health. Days of illness was defined as days with back pain per year. Backpain is a health problem that is often used in experiments as it is a health state that is relatively easy for respondents to imagine[3]. All days without back pain were days in perfect health. A day with back pain was described to respondents as a day with no problems with mobility, no problems with self-care, some problems with usual activities, some pain/discomfort and no anxiety/depression (see Appendix 3.A). For this description we followed the descriptive system of the EQ-5D-3L, an instrument that measures health-related quality of life and describes health states based on the severity of health problems (i.e. no, some, or severe problems) on the abovementioned five health domains [83]. In the monetary domain, endowments were stated as municipal tax expenses per month in order to express a 'bad' in this domain as well[4]. We also used the term "region" instead of "situation" in the tax questions. The exact wordings of the questions are shown in Appendix 3.A.

The order in which the questions in the two domains were presented to the respondents was randomized, as was the order of the three questions within each domain (BP1, BP2, BP3 and MT1, MT2, MT3). Finally, within each choice list, the positions of situations A and B (right or left), the positions of oneself and others (right or left), and the order in which own endowment was varied in situation B (ascending or descending), were randomized. All these orders were randomized between and not within respondents, meaning that every respondent viewed all seven choice lists in one type of format.

3.3.3 Types of positional concerns

Responses were first broadly categorized into the three types of positional concerns. People with no positional concerns are indifferent between situations A and B in the choice lists when their own endowment is the same in these situations, which is re-

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[3] We considered relatively few days of backpain per year to make the situations as realistic as possible. In order to reduce cognitive burden for respondents, we then chose to frame the situations in terms of days of backpain rather than days of perfect health per year: 1 versus 7 days of backpain is easier to process than 364 versus 358 days in perfect health.

[4] The reference point $x = 0$ for health thereby was '0 days of backpain' and for money it was '0 municipal taxes'.

flected by indifference on the ninth row of each choice list (printed bold in Table 3.1). People with altruistic positional concerns are willing to accept a worsening of their own endowment in return for an improvement in the endowment of others, which is reflected by indifference in one of the first eight rows of the choice list (in the order as presented in Table 3.1). They could also have such strong altruistic positional concerns that they always preferred situation A. People with spiteful positional concerns are willing to accept a worsening of their own endowment in return for a worsening of the endowments of others, which is reflected by indifference in one of the last eight rows of the choice lists (in the order as presented in Table 3.1). They could also have such strong spiteful positional concerns that they always preferred situation B.

When an alternative value for own endowment in situation B was given in the follow-up question after selecting 'always A' or 'always B', respondents were assigned to a type of positional concerns based on that value and not on their response 'always A' or 'always B'. When they provided a written explanation for choosing 'always A' or 'always B', they were disregarded in further analyses on degree but not type of positional concerns, because they could be assigned to a type but not to a degree of positional concerns.

3.3.4 Degrees of positional concerns

Responses were next categorized into degrees of positional concerns. Each row in the choice list corresponds to an indifference and therefore also to a γ in Eq. (7). For people with no positional concerns, $\gamma=0$ holds, for people with altruistic positional concerns, $\gamma<0$ holds, and for people with spiteful positional concerns, $\gamma>0$ holds. Responses in the follow-up questions that included an alternative value for own endowment in situation B were also assigned a degree of positionality using Eq. (7). Because the response "0" is not allowed in an equation with a natural logarithm responses "0" were treated as "1" day or euro, i.e. the closest number in whole days or euros. This was done for between 6 and 30 responses for each question.

In order to compare degrees of positionality for health and money, the choice lists were constructed such that degrees of positional concerns in the questions on days with back pain coincided with those in the questions on tax expenses. The degrees of positional concerns in the choice lists ranged from -0.44 to 0.23 in questions BP1 and MT1 from -0.61 to 0.33 in questions BP2 and MT2, and from -2.95 to 1.57 in questions BP3 and MT3. In addition to the comparison across domains, the three questions within each domain allow us to test for stability of preferences across questions. As described by Johansson-Stenman et al. [30] and Andersson [73], the degree of positional concerns should be fairly stable across questions when the assumed ratio-comparison utility function describes a generic preference structure for positional concerns.

The values presented in the municipal tax questions were equal to the values in the back pain questions multiplied by a constant factor 5. As our measure of the degree of positionality γ is unit invariant, this ensures that the degrees of positional concerns corresponding to the back pain and tax lists coincide. We deliberately chose not to use the exact same numbers in the two domains, in order to have realistic scenarios.

3.3.5 Analysis

For the analysis of the results we used nonparametric Wilcoxon signed rank tests on median scores since our data clearly deviated from a normal distribution. We tested whether the preferences systematically deviated from no positional concerns, whether preferences differed in the comparable backpain and municipal tax questions, and whether preferences differed across questions within the two domains. We did so both for types of positional concerns and for exact degrees of positional concerns.

We conducted three regression analyses to analyse the robustness of the results of our non-parametric analyses when controlling for the respondents' characteristics. We arranged our data into 660 clusters of respondents for which we had 6 (repeated) observations so that we could combine the observations from all six choice lists. The standard errors were specified such that within, but not across clusters, the usual requirement of independency of observations was relaxed.

First, we conducted a logistic regression with a dichotomous dependent variable dividing the responses in terms of types into being non-positional or positional (either spiteful or altruistic). This model contained 3,960 observations that were clustered into 660 clusters of respondents. Second, we conducted a logistic regression with a dichotomous dependent variable dividing the subset of positional responses into being spiteful or being altruistic. This model contained 2,474 observations that were clustered into 560 clusters of respondents for which we had at least one positional response. Third, we conducted linear regression analysis with degree of positional concerns as dependent variable. This model contained 3,520 observations of γ that were grouped into 644 clusters of respondents for which we had at least one γ-value.

Socio-demographic and socio-economic variables included in all three regression analyses were age, gender, marital status (having a partner vs. being single), education level, and health status, i.e. the self-reported health status of the respondent valued according to the EQ-5D-3L utility scale, ranging from 0 (death) to 1 (perfect health). Respondents were asked to rate their level of health problems (i.e. no, some, or severe problems) on five health domains (i.e. mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). A health utility score was calculated using the validated Dutch EQ-

5D-3L tariff [84, 85]. For socio-economic status, we assessed income, employment and education variables and for family status we assessed marital status and having children. Due to high correlations between these variables, we chose to include education level as a proxy for socio-economic status and marital status as a proxy for family status. Choice list-related variables were dummy variables for answering back pain questions, for answering questions BP1 or MT1 where respondents were worse off than others, for answering questions BP3 and MT3 where respondents were better off than others, and for getting presented the absolute endowments in situation B in an improving order.

3.4 RESULTS

3.4.1 Sample characteristics

Table 3.2 shows the characteristics of our sample of 660 respondents of the adult population in the Netherlands. The average age was 46.9 with a minimum of 18 and a maximum of 82, and 48.8% of the respondents were male. 25.5% of the respondents had finished lower education, 42.7% medium education, and 31.8% higher education. In comparison

Table 3.2. Descriptive statistics

Characteristic	Level	Sample statistics	General public aged 15 and older[a]
Age (mean, min, max)		46.9 [18; 82]	40.8
EQ-5D-3L score (mean)		0.85	
Gender	Male	48.8%	49.5%
	Female	51.2%	50.5%
Education level	Low (LO, LBO, MAO)	25.5%	32.4%
	Medium (MBO, HAO)	42.7%	39.4%
	High (HBO, WO)	31.8%	26.3%
Daily activity	No paid job	44.2%	
	Paid job < 36 hrs	26.2%	
	Paid job ≥ 36 hrs	29.5%	
Household income, net per month	Low (≤ €1499)	39.1%	
	Medium (1500 – 2999)	41.4%	
	High (≥ €3000)	19.5%	
Marital status	Partner	64.7%	
	No partner	35.3%	
Children	Yes	54.7%	
	No	45.3%	

[a] Mean age and gender are based on the entire Dutch population. Education level is based on statistics for the Dutch population of 15 years and older. All population statistics are based on the year 2013. Source: CBS Statline, Centraal Bureau voor Statistiek, retrieved from http://staline.cbs.nl/Statweb/

with the general public in the Netherlands, our sample is fairly representative in terms of age and gender, but somewhat higher educated. 64.7% had a partner and on average respondents reported to have a health score of 0.85 on a scale between 0 (death) and 1 (perfect health).

3.4.2 Types of positional concerns

Figure 3.1 shows the distribution of types of positional concerns for each choice list. In all six choice lists, at least one third of the respondents showed no positional concerns. In questions BP1, BP2, BP3 and MT1, more respondents showed altruistic than spiteful positional concerns (Table 3.3) and this difference was significant (p=0.000 for BP1, BP2, BP3 and MT1). In questions MT2 and MT3 slightly more respondents showed spiteful than altruistic positional concerns, but this difference was not significant (p=0.610 for MT2 and p=0.058 for MT3).

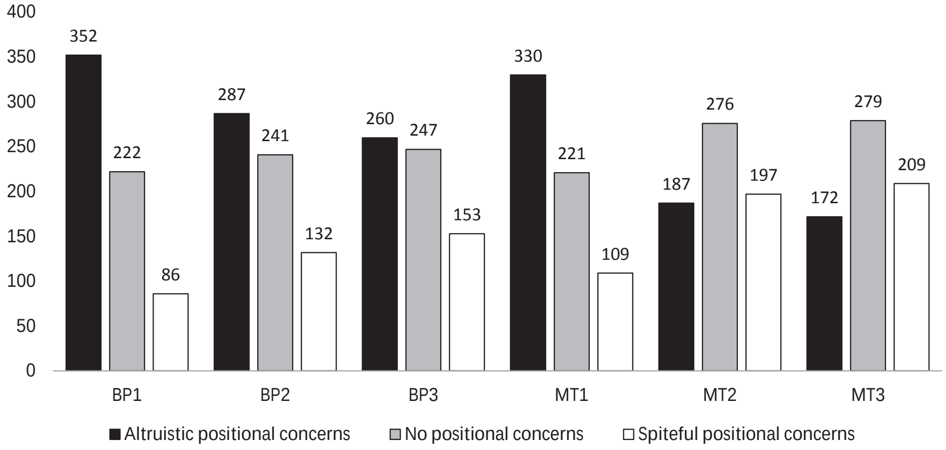


Figure 3.1: distribution of types of positional concerns (n=660)

For health the number of respondents who showed altruistic positional concerns decreased from question BP1 to BP3. The number of respondents who showed no positional concerns increased slightly from question BP1 to BP3. The number of respondents who showed spiteful positional concerns increased from question BP1 to BP3. The median and mean values of the questions (Table 3.3) suggest that positional concerns differ between BP1, BP2, and BP3. The results of the pairwise comparisons between the questions confirm that the median values differ significantly across questions (Table 3.4). The signs of the z-scores suggest that respondents exhibit more altruistic positional concerns in BP1 than in BP2 and BP3 and more altruistic positional concerns in BP2 than in BP3.

Table 3.3: summary statistics

	Health			**Money**		
	BP1	BP2	BP3	MT1	MT2	MT3
Type of positional concerns[a]						
Median	-1.00	0.00	0.00	-0.50	0.00	0.00
Mean	-0.40	-0.23	-0.16	-0.33	0.02	0.06
	n = 660	n = 660	n = 660	n = 660	n = 660	n = 660
Degree of positional concerns						
Median	-0.12	0.00	0.00	-0.04	0.00	0.00
Mean	-0.26	-0.21	-0.98	-0.20	-0.07	-0.16
	n = 594	n = 551	n = 588	n = 611	n = 581	n = 595

[a] Types coded as altruistic = -1, not positional = 0 and spiteful = 1

For money the number of respondents who showed altruistic positional concerns decreased from question MT1 to MT3. The number of respondents who showed no positional concerns increased slightly from question MT1 to MT3. The number of respondents who showed spiteful positional concerns increased from question MT1 to MT3. The median and mean values of the questions (Table 3.3) suggest that positional concerns differ between MT1, MT2, and MT3, although the difference between MT2 and MT3 seems small. The results of the pairwise comparisons between the questions confirm that the median values differ significantly across questions (Table 3.4). The signs of the z-scores suggest that respondents exhibit more altruistic positional concerns in MT1 than in MT2 and MT3 and that more respondents exhibit altruistic positional concerns in MT2 than in MT3.

Table 3.4. Wilcoxon signed rank test for pairwise comparisons within domains (two-sided p-values)

	Health			**Money**		
	BP1=BP2	BP1=BP3	BP2=BP3	MT1=MT2	MT1=MT3	MT2=MT3
Type of positional concerns	Z = -5.09	Z = -7.84	Z = -3.23	Z = -9.19	Z = -10.38	Z = -1.99
	p = 0.000	p = 0.000	p = 0.001	p = 0.000	p = 0.000	p = 0.047
	n = 660	n = 660	n = 660	n = 660	n = 660	n = 660
Degree of positional concerns[a]	Z = -2.12	Z = 3.58	Z = 5.03	Z = -7.12	Z = -4.84	Z = -2.36
	p = 0.034	p = 0.003	p = 0.000	p = 0.000	p = 0.000	p = 0.018
	n = 535	n = 564	n = 536	n = 565	n = 581	n = 562

[a] responses with missing observations in one or both questions are disregarded in this statistic

At least half of the respondents showed stable preferences within domains. 59.4% of the respondents showed stable preferences across the three back pain questions; 28.8% of the respondents were altruistic in all three questions, 23.9% were not positional in all three questions, and 6.7% were spiteful in all three questions. 52.7% of the respondents showed stable preferences across the three municipal tax questions; 17.7% of the respondents were altruistic in all three questions, 25.5% were not positional in all three questions and 9.6% were spiteful in all three questions. Throughout the entire questionnaire, 30.2% of the respondents showed stable preferences: 12.1% of the respondents were altruistic in all six questions, 15.2% of the respondents were not positional in all six questions and 2.9% of the respondents were spiteful in all six questions.

3.4.3 Degrees of positional concerns

From the classification of positional concerns into types we know that in all six questions, at least one third of the respondents exhibit a degree of positional concerns of $\gamma = 0$. These are the responses that coincide with the type 'no positional concerns'. For the remaining responses, there are some noticeable clusters of responses (see Appendix 3.B for the distributions of reported degrees of positional concerns). First, responses are clustered around the degrees of positionality corresponding to the trade-offs presented first and last in the choice lists (i.e. the trade-offs presented in row 1 or 17 of the choice list). Second, responses are clustered around the choices 'always A' and 'always B'. As a result, we were unable to assign a degree of positional concerns to respectively 66, 109 and 72 respondents in questions BP1, BP2 and BP3 and to 49, 79 and 65 respondents in questions MT1, MT2 and MT3.

The median and mean degrees of positional concerns (Table 3.3) suggest that on average, the degree of positional concerns was slightly negative. Wilcoxon signed rank tests confirm that for BP1, BP2, BP3 and MT1, the median degree of positional concerns systematically deviated from $\gamma = 0$ (all $p=0.000$) with negative z-scores implying a deviation in the negative direction. For MT3 the median degree of positional concerns systematically deviated from $\gamma = 0$ ($p=0.038$) with a positive z-score implying a deviation in the positive direction. For MT2 the median degree of positional concerns did not systematically deviate from $\gamma = 0$ ($p=0.640$).

For health the median and mean values of BP1, BP2 and BP3 (Table 3.3) suggest that the degree of positional concerns differs between the questions, which is confirmed by the results of the pairwise comparisons between the questions (Table 3.4). The mean values and signs of the z-scores suggest that respondents have a lower degree of positional concerns for BP3 than for BP1 and BP2 and that they have a lower degree of positional concerns for BP1 than for BP2. This result seems to contradict the classifications according to types, where respondents were found to have a higher degree of positional concerns in BP3 than in BP1 and BP2. This will be discussed in Section 3.5.

For money the median and mean values of MT1, MT2 and MT3 (Table 3.3) suggest that the degree of positional concerns differs between the questions, which is confirmed by the results of the pairwise comparisons between the questions (Table 3.4). The mean values suggest that respondents have a lower degree of positional concerns for MT1 than for MT2 and MT3 and that they have a lower degree of positional concerns for MT3 than for MT2. However, the signs of the z-scores suggest that respondents have a significantly lower degree of positional concerns for MT1 than for MT2 and MT3 and that they have a significantly lower degree of positional concerns for MT2 than MT3.

In the comparison of questions 1, 2, and 3 across domains, pairwise Wilcoxon signed rank tests indicated that the reported degrees of positional concerns were different for the back pain and municipal tax questions (p=0.000 for BP1=MT1, p=0.000 for BP2=MT2 and p=0.000 for BP3=MT3) and the negative signs of the z-scores suggest that degrees of positional concerns are lower in the back pain questions than in the tax questions (z=-4.26 for BP1=MT1, z=-5.77 for BP2=MT2 and z=-6.55 for BP3=MT3).

3.4.4 Regression analysis

Table 3.5 presents the results of the regression analyses. The logistic regression analysis with being non-positional as opposed to being positional as dependent variable shows that respondents were less likely to report a non-positional answer in the back pain questions than in the municipal tax questions. Moreover, they were less likely to report a non-positional answer in questions where they were worse off than others. Respondents with a high education level were more likely to be non-positional than respondents with a low education level. Respondents with a middle education level were also more likely to be non-positional than respondents with a low education level, but this effect was only marginally significant.

The logistic regression analysis with being spiteful as opposed to being altruistic as dependent variable shows that respondents were less likely to report a spiteful answer in the back-pain questions than in the municipal tax questions, and in questions where they were worse off than others. They were more likely to report a spiteful answer in questions where they were better off than others. Each additional year of age decreased the likelihood of a spiteful response and males were less likely to be spiteful than females.

The linear regression analysis with degree of positional concerns as dependent variable indicated that respondents reported lower degrees of positional concerns in the back pain questions than in the tax questions. The dummy variables 'worse off' and 'better off' had a significant negative effect, indicating that respondents reported lower degrees of positional concerns in the questions where they were worse off (BP1 and MT1) and better off (BP3 and MT3) than others as compared to the questions where they were mixed better and worse off (BP2 and MT2). The magnitudes of these effects indicate that degrees of positional concerns were lower in questions where respondents were better off than others as compared to the questions where they were worse off than others. The effect of the dummy variable 'improving' was positive and significant, indicating that respondents who received the framing of getting better off throughout each choice list reported higher degrees of positional concerns than respondents who received the framing of getting worse off throughout each choice list. On average, older and healthier respondents reported lower degrees of positional concerns.

Table 3.5. Regression analyses of degree and type of positional concerns

	Logit on type Non-positional =1		**Logit on type Spiteful =1**		**OLS on degree**	
	OR	SE	OR	SE	Coef.	SE
Domain (Back pain=1)	.86**	.05	.51***	.05	-.34***	.05
Worse off (BP1, MT1)	.78***	.04	.39***	.04	-.09***	.02
Better off (BP3, MT3)	1.03	.05	1.22***	.09	-.43***	.07
Improving	1.21	.15	1.03	.15	.15**	.07
Age	1.00	.00	.98***	.00	-.01***	.00
Gender (male=1)	1.07	.14	.68***	.10	-.10	.07
Education middle	1.37*	.23	.90	.16	-.01	.09
Education high	2.72***	.48	.95	.19	.09	.09
Partner (y/n)	.94	.13	1.02	.16	-.03	.07
Health (EQ-5D-3L)	.67	.21	.61	.22	-.41**	.17
Constant	.54	.20	4.24***	1.78	.62***	.19
Adj R-squared		-		-		.04
Pseudo R-squared		.03		.07		-
N		3,960		2,474		3,520

Note: ***<0.01; **<0.05; *<0.1

3.5 DISCUSSION

This chapter measured positional concerns for health and money. Several studies have found that fewer respondents exhibit positional concerns for health than for money [42, 43, 60, 71]. Yet, these studies allowed for only one type of positional concerns, the type which we labelled spiteful. A person with spiteful positional concerns dislikes improvements for others, as it worsens his position relative to the others. Another person may instead favour improvements for others for reasons like altruism or efficiency. With a slight abuse of terminology we refer to such a person as someone with altruistic positional concerns. While the aforementioned studies on positional concerns could not disentangle between people without and people with altruistic positional concerns, we extended an existing framework for measuring positional concerns which allowed us to distinguish between spiteful, no, and altruistic positional concerns.

Our results indicate that many people have positional concerns and that these are not only spiteful, but also altruistic in nature. This means that some people assess the endowment of others as a competing asset for their own relative position, while others assess the endowment of others as an intrinsically valuable asset. Both types of people show positional concerns in the sense that they are not merely concerned about their own personal standing. Altruistic positional concerns were more often found for health than for money.

Overall, we found between 13% and 23% spiteful responses for health and between 16% and 32% spiteful responses for money. The percentage of positional concerns, spiteful or altruistic, were between 63% and 66% for health and between 58% and 67% for money. Compared to previous studies, we find more people exhibiting positional concerns, yet fewer exhibiting spiteful ones. This suggests that ignoring altruistic positional concerns may indeed have led to an underestimation of the prevalence of positional concerns in these previous studies. Grolleau and Said [42], for instance found that 38% of their respondents (of which 63% were students) showed spiteful positional concerns for days of illness. For money framed as goods instead of bads their percentages of spiteful responses were between 20% and 50%. Hillesheim and Mechtel [60] found 33.3% spiteful responses for income and 14.2% for fitness and physical condition, with students as respondents. Solnick and Hemenway [24] found that between 38% and 56% of their respondents (faculty, students and staff at the Harvard School of Public Health) showed spiteful positional concerns for yearly income. Solnick and Hemenway [43] found that between 33% and 48% of their respondents showed spiteful positional concerns for income and 11% for days of illness.

Our research design also allows for a precise comparison between *degrees* of positional concerns for health and money. We found that degrees of positional concerns are lower for health than for money, which implies that people are to a larger degree altruistic (when $\gamma<0$) or to a lesser degree spiteful (when $\gamma>0$) for health than for money, both framed as 'bads'. Less spitefulness is consistent with earlier studies, which in general find that fewer respondents exhibit positional concerns in the health domain than in income-related domains such as income [42, 43, 60, 71] or contribution into a pension fund [60]. However, a direct comparison of findings is difficult, because we are the first to disentangle altruistic and non-positional responses. Indeed, altruistic and non-positional responses are confounded in studies that solely allow positional concerns as status concerns (i.e. spiteful positional concerns in our study). A similar point was made by Celse [57] for egalitarian concerns, which are also confounded with 'non-positional' answers in these studies.

The results of our experiment further suggest that, even within domains, the types of positional concerns depend on the context in which they are evaluated. The pairwise comparisons across questions indicated that the proportion of respondents who showed altruistic positional concerns decreased from BP1 to BP3 and MT1 to MT3, while the proportion of respondents who showed no or spiteful positional concerns increased. This is reinforced by the findings of the logistic regressions in Table 3.5, where the non-positional and spiteful responses were least likely in the worse off (BP1 and MT1) questions and most likely in the better off questions (BP3 and MT3). This pattern implies that altruism is most prevalent when people are and remain in a worse position than others (BP1 and MT1), and least prevalent when they are and remain in a in a better position (BP3 and MT3). This suggests that people have a stronger tendency to show altruistic positional concerns when they are worse off than others and are unable to improve their relative position to such extent that they become better off (BP1 and MT1). Reducing one's comparative disadvantage may then not be worth sacrificing absolute own endowments. People may have a stronger tendency to show spiteful positional concerns when they are better off than others (BP3 and MT3) or have the ability to improve their relative position to such extent that they become better off (BP2 and MT2). They may then be more concerned with their relative position in order to make sure that they maintain their comparative advantage.

For degrees of positional concerns, the observed patterns of responses over questions 1 to 3 are similar to those found for types of positional concerns for money, but different for health. The pairwise comparisons across questions showed that for money degrees of positional concerns were lowest in MT1 and highest in MT3, whereas for health degrees of positional concerns were lowest in BP3 and highest in BP2. The latter pattern was the stronger one according to the linear regression with the responses for money and health combined.

The discrepancy between the results for types and degrees of positional concerns for health is somewhat surprising, considering that they draw from the same results and are highly related. An explanation for this finding may be that in question BP3, fewer respondents reported altruistic positional concerns than in BP1 and BP2, but those who did, reported relatively low degrees of positional concerns. These low values for degree of positional concerns in BP3 may be caused by the range of γ within the choice lists being larger for question 3 than for questions 1 and 2. Altruistic responses within the choice lists then coincide more easily with relatively low values for γ in BP3 than in BP1 and BP2. However, although we believe that this may have influenced the results to some extent, we would have seen similar results for the questions in the income domain if this were the main driver of the responses. In addition, our design allowed for degrees of positional concerns beyond the boundaries of the choice lists.

All in all, in line with previous research, our findings suggest that preferences for positional concerns may depend on the context in which they are assessed [30, 73]. Such instability of preferences suggests that positional concerns cannot be captured in one single generalized utility-function independent from context. In addition, the possibility that alternative functional forms of utility functions describing positional concerns are more appropriate, should not be overlooked [30, 61, 86].

The regression analyses yielded some noteworthy results. The effect of age on degree of positional concerns indicates that older respondents on average reported lower degrees of positional concerns and the effect of age on being spiteful indicates that for those respondents who were positional, older respondents were less likely to be spiteful than younger respondents. Being a male had a significant impact on the likelihood of being spiteful (if positional) and the odds ratio indicates that men are considerably less likely to be spiteful than women. Education level had a significant impact on the likelihood of being positional, in particular high education. Respondents with a higher education level were considerably more likely to be non-positional than respondents with a lower education level, which implies that experiments in student populations may yield significantly different results from experiments conducted in samples of the general public. Health status had a significant negative impact on degree but not on type of positional concerns. Respondents with better health had lower degrees of positional concerns, but, on average, were not more likely to belong to a specific type of positional concerns. With regard to the variations in the choice lists (i.e. domains and initial relative position), the results of the regression analyses were consistent with the earlier observed patterns in the pairwise comparisons. In addition, there is some evidence that it matters how choices are presented, since the order in which alternatives were presented significantly influenced the degree, but not the type of positional concerns.

3.5.1 Limitations

With regard to the methods, some limitations need to be addressed. First, we should note that we measured positional concerns for 'bads' and not for 'goods'. Previous research has shown that in general, more people exhibit (spiteful) positional concerns for goods than for bads [24, 42, 43]. This implies that positional concerns for health and money may be different when endowments are formulated as goods, possibly more spiteful or higher in terms of degree of positional concern. Yet, this need not influence the difference between positional concerns for health and money as long as both domains are equally affected.

It should also be noted that although endowments in both domains were formulated as bads, municipal tax is a community 'bad' while back pain is an individual 'bad'. The observed difference across domains may therefore be confounded with this difference in the type of bad at question, public or private. In addition, the use of municipal tax as a 'bad' may have led to higher levels of taxes being interpreted as inefficiency in governance, since we stressed that the level of services remained similar across regions. However, in our qualitative data from respondents who always preferred region A or B and were therefore asked to explain their preference, only 2 of the 188 explanations included an explicit remark in that direction.

Furthermore, we presented the endowment of 'others' in society, without specifying how many others there are to compare endowments with. Future research may experiment with the framing of the questions by defining different kinds of goods and/or bads and specifying (the number of) 'others'.

The use of choice lists may have resulted in measurement bias around the end-points of our lists. The results showed that there are some notable clusters of responses near the ends of the lists. Such clustering was also found in an earlier experiment that only uses positive values of γ [29]. In order to reduce this bias on degree of positional concerns, we included the options to always prefer situation A and B so that respondents could report stronger degrees of positional concerns than the choice lists allowed for. Unlike earlier studies, this prevented us from having to down-scale those responses to the fixed value ranges of γ presented in the choice lists.

Choice lists may also have made our questionnaire a difficult exercise for our respondents because many pieces of information were presented simultaneously. Indeed, 8.5% of the sample did not satisfy our consistency criterion for inclusion. This difficulty of the experiment may also have led to fatigue. For this reason, we randomized the order of the questions, in order to reduce the effect of fatigue on the overall quality of the data.

Despite the mentioned disadvantages of choice lists, we found no better alternative. The use of choice lists allowed us to present our respondents with many different comparisons of endowments without making the questionnaire extremely time-consuming. Repeated choices using a bisection method, for instance, would have been much more time-consuming. Presenting the entire choice list instead of repeated choices gave the respondents an immediate sense of what the task at hand was about. Nonetheless, future research could test the stability of preferences over various elicitation techniques.

3.5.2 Welfare implications

We found that positional concerns are more altruistic for health than for money. In addition, for both domains we found that positional concerns are certainly not only spiteful, which has important policy implications. As argued by Frank [67, 87], positional concerns may give rise to negative externalities and therefore welfare losses at the societal level. Our results suggest that positional externalities need not necessarily be negative. The existence of positive externalities suggests that social benefits may outweigh individual benefits when benefits to one person spill over to the utility of others. This is also highly relevant in the context of health, because the societal value of health interventions may be larger than the effect it has on individual health alone.

3.6 CONCLUSION

This chapter showed that positional concerns for health and money differ. For health, people tend to have positional concerns that are more altruistic in nature than for money. The traditional framework for positional concerns seems to fall short in altruistic positional concerns, which is particularly problematic in domains where spitefulness is less prominent, such as in the health domain. The existence of positional concerns suggest that externalities – negative *and* positive – may lead to discrepancies between the individual and the societal welfare gained from policies.

APPENDIX 3.A – EXPERIMENTAL INSTRUCTIONS

Below are the instructions and screenshots of our survey. The instructions are translated from Dutch.

General introduction to the health questions

In the following three questions you are asked which situation you would prefer for **the next five years**: situation A or B. The situations only differ in the average amount of days per year with back that you and others have.

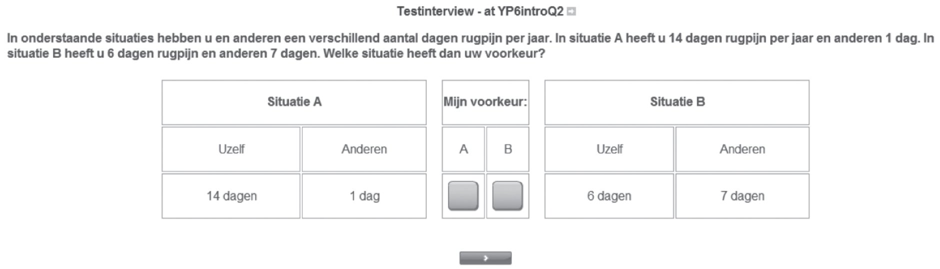
On a day **with back pain**, you have:	On a day **without back pain**, you have:
▪ No problems with walking	▪ No problems with walking
▪ No problems washing or dressing myself	▪ No problems washing or dressing myself
▪ Some problems with performing my usual activities (e.g. work, study, family-activities, hobby's)	▪ No problems with performing my usual activities (e.g. work, study, family-activities, hobby's)
▪ Moderate pain or discomfort	▪ No pain or discomfort
▪ No anxiety or depression	▪ No anxiety or depression

The same goes for others.

Health questions (BP1, BP2, BP3)

Introductory question

In the situations below, you and others have back pain a different number of days per year. In situation A you have [ ] days with back pain per year and others [ ] days. In situation B you have [ ] days with back pain per year and others [ ] days. Which situation do you prefer?



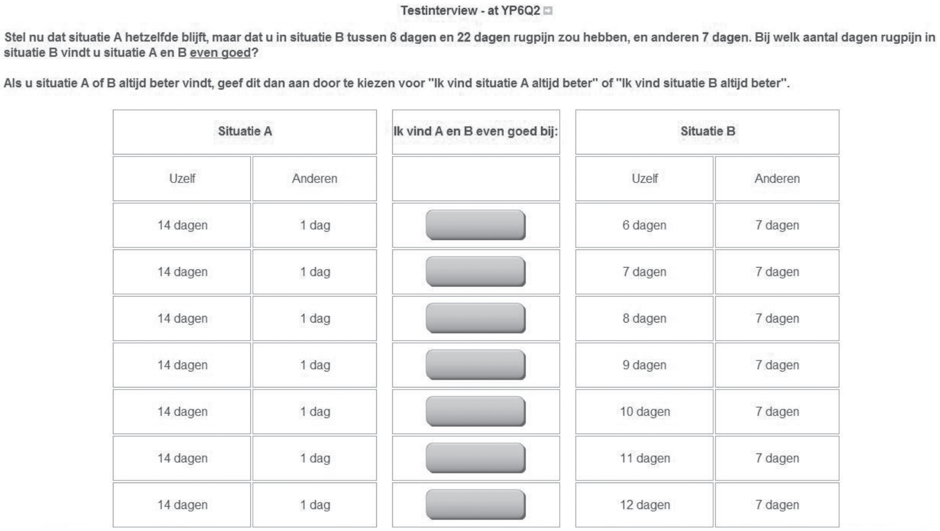
Testinterview - at YP6introQ2

In onderstaande situaties hebben u en anderen een verschillend aantal dagen rugpijn per jaar. In situatie A heeft u 14 dagen rugpijn per jaar en anderen 1 dag. In situatie B heeft u 6 dagen rugpijn en anderen 7 dagen. Welke situatie heeft dan uw voorkeur?

Situatie A		Mijn voorkeur:		Situatie B	
Uzelf	Anderen	A	B	Uzelf	Anderen
14 dagen	1 dag	☐	☐	6 dagen	7 dagen

Choice list

Now suppose that situation A remains the same, but that you have between [ ] and [ ] days with back pain in situation B, while others have [ ] days. At which number of days with back pain do you consider situations A and B equally good? In case you believe that situation A or B is always better, please indicate this by choosing "I think that situation A is always better" or "I think that situation B is always better".



Testinterview - at YP6Q2

Stel nu dat situatie A hetzelfde blijft, maar dat u in situatie B tussen 6 dagen en 22 dagen rugpijn zou hebben, en anderen 7 dagen. Bij welk aantal dagen rugpijn in situatie B vindt u situatie A en B even goed?

Als u situatie A of B altijd beter vindt, geef dit dan aan door te kiezen voor "Ik vind situatie A altijd beter" of "Ik vind situatie B altijd beter".

Situatie A		Ik vind A en B even goed bij:	Situatie B	
Uzelf	Anderen		Uzelf	Anderen
14 dagen	1 dag	☐	6 dagen	7 dagen
14 dagen	1 dag	☐	7 dagen	7 dagen
14 dagen	1 dag	☐	8 dagen	7 dagen
14 dagen	1 dag	☐	9 dagen	7 dagen
14 dagen	1 dag	☐	10 dagen	7 dagen
14 dagen	1 dag	☐	11 dagen	7 dagen
14 dagen	1 dag	☐	12 dagen	7 dagen

14 dagen	1 dag		14 dagen	7 dagen
14 dagen	1 dag		15 dagen	7 dagen
14 dagen	1 dag		16 dagen	7 dagen
14 dagen	1 dag		17 dagen	7 dagen
14 dagen	1 dag		18 dagen	7 dagen
14 dagen	1 dag		19 dagen	7 dagen
14 dagen	1 dag		20 dagen	7 dagen
14 dagen	1 dag		21 dagen	7 dagen
14 dagen	1 dag		22 dagen	7 dagen
Ik vind situatie A altijd beter			Ik vind situatie B altijd beter	

Follow-up question

In the previous question you chose "I think that situation [ ] is always better". How many days with back pain in situation B do you need to have for situations A and B to be equally good?

Testinterview - at YP6Q2b

In de vorige vraag heeft u gekozen voor 'Ik vind situatie B altijd beter'. Hoeveel dagen rugpijn zou u zelf in situatie B moeten hebben om situatie A en B even goed te vinden?

Situatie A		Situatie B	
Uzelf	Anderen	Uzelf	Anderen
14 dagen	1 dag		7 dagen

○ ________ dagen rugpijn

○ Het maakt niet uit hoeveel dagen rugpijn ik heb in situatie B, situatie B is altijd beter omdat ________

General Introduction to the municipal tax questions

In the following three questions you are asked to choose the region which you would prefer to live in **for the next five years**: region A or region B. The regions only differ in the amount of municipal tax per month that you and others pay. This difference does **not** affect the house or neighbourhood that you live in, facilities in your community, the purchasing power of you and others in your community etc.

In answering these questions, assume that you, like others in the region, have a net monthly salary of €1,825[5].

Municipal tax questions (MT1, MT2, MT3)

Introductory question

In the regions below, you and others pay a different amount of municipal tax. In region A you pay [ ] euro of municipal tax per year and others [ ] euro. In region B you pay [ ] euro and others [ ] euro. Which region do you prefer?

Testinterview - at YP6introQ6

In onderstaande regio's betalen u en anderen een verschillend bedrag aan gemeentebelasting. In regio A betaalt u 70 euro aan gemeentebelasting per jaar en anderen 35 euro. In regio B betaalt u 30 euro en anderen 140 euro. Welke regio heeft dan uw voorkeur?

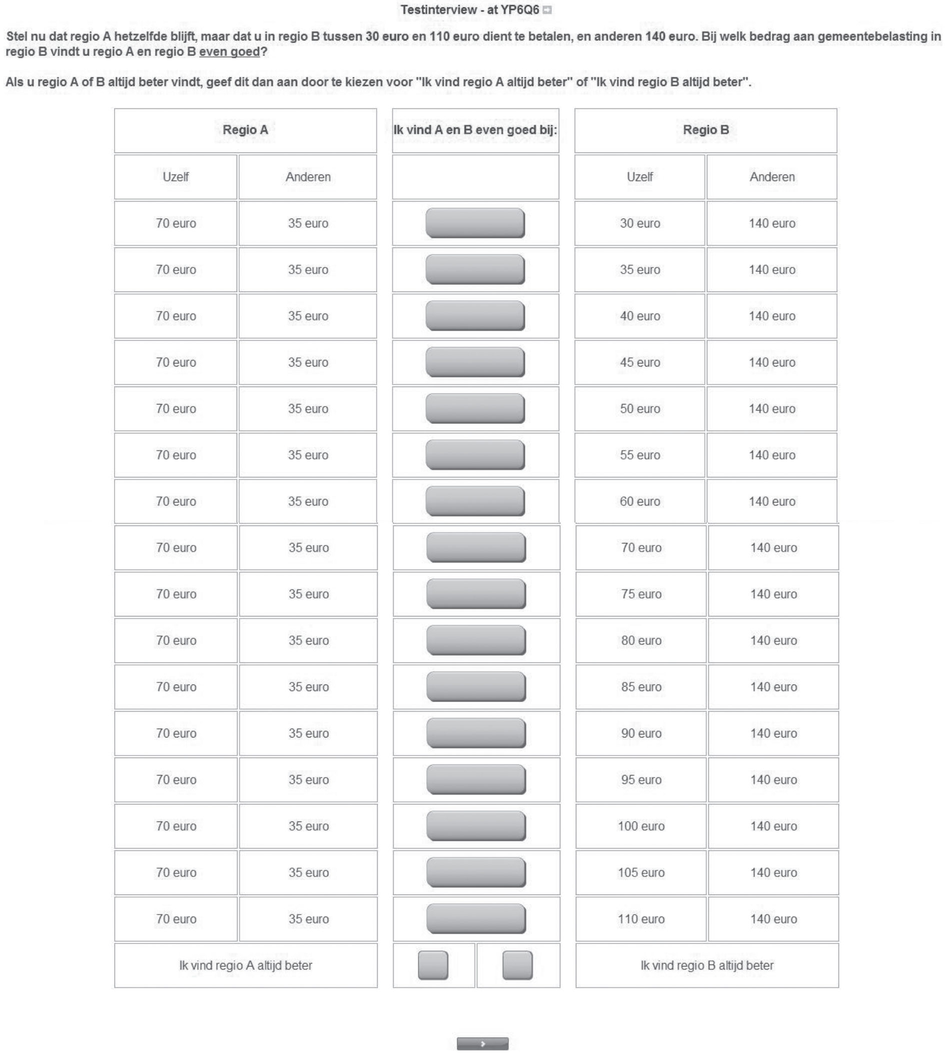
Regio A		**Mijn voorkeur:**		**Regio B**	
Uzelf	Anderen	A	B	Uzelf	Anderen
70 euro	35 euro	☐	☐	30 euro	140 euro

Choice list

Now suppose that region A remains the same, but that you need to pay between [ ] and [ ] euro, while others pay [ ] euro. At which amount of municipal tax in situation B do you consider situations A and B equally good? In case you believe that region A or B is always better, please indicate this by choosing "I think that region A is always better" or "I think that region B is always better".

---

[5] Note that in the Netherlands, municipal tax is paid on a yearly and not on a monthly basis. For this reason, municipal tax is not monthly deducted from gross or net monthly salary but paid once a year. Therefore, municipal tax is an amount that has to be paid out of net monthly salary. The monthly salary we use represents a middle income that is sufficient to live a decent life in the Netherlands.



Testinterview - at YP6Q6

Stel nu dat regio A hetzelfde blijft, maar dat u in regio B tussen 30 euro en 110 euro dient te betalen, en anderen 140 euro. Bij welk bedrag aan gemeentebelasting in regio B vindt u regio A en regio B even goed?

Als u regio A of B altijd beter vindt, geef dit dan aan door te kiezen voor "Ik vind regio A altijd beter" of "Ik vind regio B altijd beter".

Regio A		Ik vind A en B even goed bij:	Regio B	
Uzelf	Anderen		Uzelf	Anderen
70 euro	35 euro	☐	30 euro	140 euro
70 euro	35 euro	☐	35 euro	140 euro
70 euro	35 euro	☐	40 euro	140 euro
70 euro	35 euro	☐	45 euro	140 euro
70 euro	35 euro	☐	50 euro	140 euro
70 euro	35 euro	☐	55 euro	140 euro
70 euro	35 euro	☐	60 euro	140 euro
70 euro	35 euro	☐	70 euro	140 euro
70 euro	35 euro	☐	75 euro	140 euro
70 euro	35 euro	☐	80 euro	140 euro
70 euro	35 euro	☐	85 euro	140 euro
70 euro	35 euro	☐	90 euro	140 euro
70 euro	35 euro	☐	95 euro	140 euro
70 euro	35 euro	☐	100 euro	140 euro
70 euro	35 euro	☐	105 euro	140 euro
70 euro	35 euro	☐	110 euro	140 euro
Ik vind regio A altijd beter		☐ ☐	Ik vind regio B altijd beter	

Follow-up question

In the previous question you chose "I think that region [ ] is always better". Which amount of municipal tax would you need to pay region B for regions A and B to be equally good?

Testinterview - at YP6Q6b

In de vorige vraag heeft u gekozen voor 'Ik vind regio A altijd beter'. Hoeveel gemeentebelasting zou u zelf in regio B moeten betalen om regio A en B even goed te vinden?

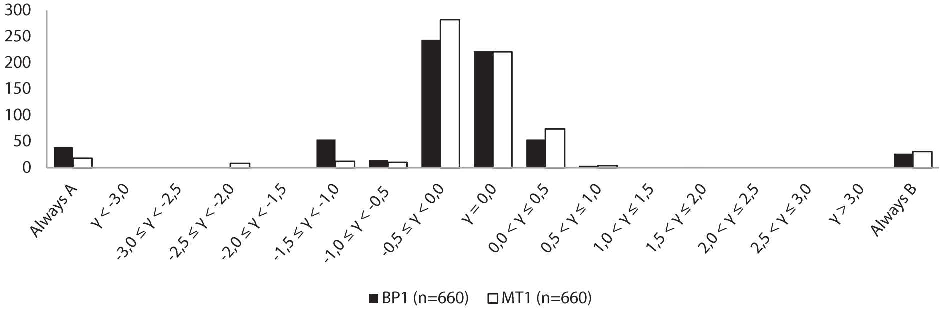
Regio A		Regio B	
Uzelf	Anderen	Uzelf	Anderen
70 euro	35 euro		140 euro

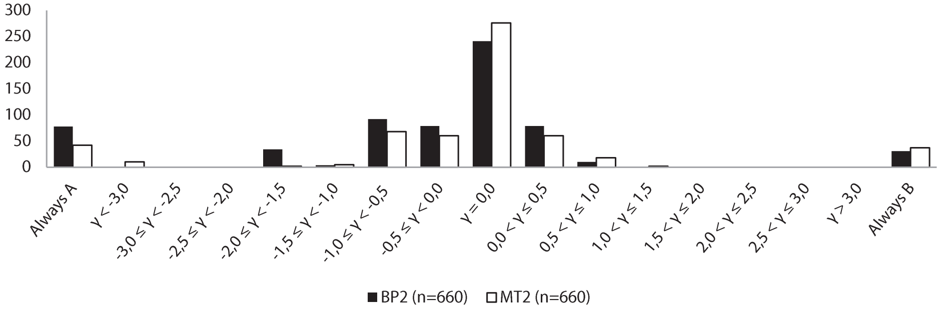
○ euro

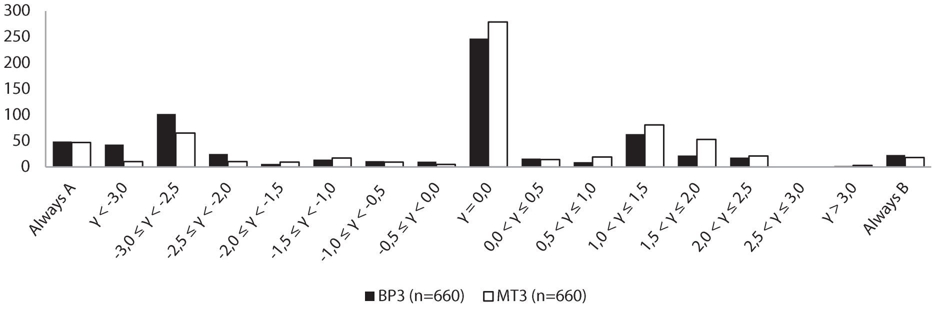
○ Het maakt niet uit hoeveel gemeentebelasting ik moet betalen in regio B, regio A is altijd beter omdat

APPENDIX 3.B – PREFERENCE DISTRIBUTIONS

Below are distribution graphs for degrees of positional concerns. We present the data of n=660 including the responses 'always A/B'.







4

Health and subjective well-being: investigating the role of relative health

Based on: Wouters, S., van Exel, N.J.A., Rohde, K.I.M. & Brouwer, W.B.F. (2015). Health and subjective well-being: investigating the role of relative health. Submitted

ABSTRACT

In this chapter we combine two streams of research on the correlates of subjective well-being (SWB), health on the one hand and attitudes and beliefs on the other hand, by investigating the relation between SWB and health, incorporating both absolute perceptions of health status and assessments of relative health. A sample of 550 adults of the general public between the ages of 18 and 75 in the Netherlands rated their SWB, their health problems and health in relation to a set of seven reference points derived from Multiple Discrepancies Theory (MDT). Linear regressions models were estimated to investigate the relationship between SWB and health in absolute and relative terms. The results of this study suggest that incorporating reference points in the measurement of self-assessed health may improve our understanding of the relationship between health and SWB. The discrepancies between what one has and what one deserves and needs seem most relevant in the context of health. Our findings imply that changes in SWB may be achieved through changes in absolute health, but also through changes in relative health.

4.1 INTRODUCTION

The increasing recognition in policy that well-being is an important dimension of life has boosted empirical research in the field of 'happiness economics' over the last decades [88, 89]. This development has intensified the crossover between psychology and economics and has resulted in an increasing number of studies using subjective well-being (SWB) as an outcome measure in economic analyses. In such studies, well-being is often measured as a subjective, self-assessed, evaluation of life, capturing how people feel and think about their lives [90, 91]. This recent trend complements the traditional economic approach of measuring utility using preference-based outcome measures [91].

A substantial portion of the literature on SWB has focused on the correlates of SWB. In an extensive review of this literature, Dolan et al. [91] identified seven broad categories of correlates: income, personal characteristics (e.g. age and personality), socially developed characteristics (e.g. education, health and unemployment), how we spend our time, attitudes and beliefs towards self, others, and life, relationships, and wider economic, social, and political environment (i.e. where we live). In this chapter, we combine two streams of research on the correlates of SWB, attitudes and beliefs on the one hand and health on the other hand, by studying the role of reference points for health in determining SWB.

A popular and growing stream of SWB literature has focused on people's perceptions of their circumstances relative to reference points [90, 91]. Discrepancy theories suggest that satisfaction judgements are based on the (perceived) gaps between current circumstances and certain standards, such as individual aspirations and goals. Similarly, comparison theories suggest that comparing oneself with relevant others may affect SWB when these others serve as a reference point in the evaluation of one's condition [90]. Such comparison effects are most extensively investigated in relation to the relative income hypothesis, which suggests that satisfaction with income depends not only on the absolute magnitude of income, but also on how it compares to the income of others [27-29, 92-94].

The relevance of reference points has also been established in the economic literature. Prospect theory [20] provides an explanation for individuals' seemingly irrational behaviour in decisions under uncertainty by suggesting that outcomes are assessed relative to a reference point. Outcomes above this reference are perceived as gains and outcomes below as losses. A second important feature of prospect theory is loss aversion, which suggests that the disutility derived from losses is larger than the utility derived from similarly sized gains [20, 21]. For the evaluation of outcomes, the presence of loss aversion suggests that the value of outcomes depends on their position relative to operant reference points. However, relatively little is known about the nature and formation of such reference points (e.g. [95]). That is, to which reference points do people compare their current situation? Obviously, such information is pivotal in understanding whether and when people consider specific attainment levels to be losses or gains as well as whether and how the underlying reference points may be influenced.

The relationship between health and SWB has also been investigated extensively. Empirical studies have found that higher levels of SWB correlate with better physical and mental health, where mental health seems stronger correlated with SWB than physical health. Interestingly, the causality in the relation between SWB and health seems to be bidirectional. On the one hand, evidence suggests that good health has a positive effect on well-being, while physical and mental illness affect well-being negatively. On the other hand, happiness and stress-free living may have a positive influence on health, while negative emotions are a predictor of worse health outcomes (e.g. through behaviour and physiological changes) [91, 96-99]. This chapter will contribute to the understanding of the complex association between health and SWB.

In this chapter, we combine these two streams of literature by investigating the relation between SWB and health, incorporating both absolute perceptions of health status and assessments of relative health. In the context of health, relatively little is known about the relevance, formation, and level of reference points, despite the fact that such reference points may play an important role in people's evaluation of their health. That is, evidence from multiple discrepancies theory [100] suggests that assessments of health relative to a set of reference points is correlated with health satisfaction, which in turn contributes to overall or global satisfaction scores [100-103]. In addition, several studies have indicated that negative life events, such as illness, have a strong negative impact on well-being in the short run, but that adaptation over time often weakens the long-term effect of such events [76, 104, 105]. Finally, 'response shift' refers to changes in patients' self-perceived quality of life over time due to processes of changing internal standards, values and conceptualizations of health-related quality of life [106]. Such mechanism also imply that (shifting) reference points may play an important role in people's health perceptions. Therefore, we will assess the role of reference points in the association between health and SWB.

4.2 METHODS

4.2.1 Participants

A professional sampling agency recruited 550 respondents from the adult population in the Netherlands. People signed up to the agency's panel and received an invitation to participate in a web-based questionnaire. By signing up to participate in surveys and by accepting the invitation to participate in this survey, respondents provided consent to the use of their response for the purposes of this study. In order to obtain a sample representative for the Dutch adult population in terms of age, gender and education level, strategic sampling was used. However, because the agency's database did not include people older than 75, our data contains a sample of the Dutch general public between the ages of 18 and 75. The data used in this chapter was collected in 2013 as part of a larger data collection on health related quality of life assessments.

4.2.2 Measures

4.2.2.1 Subjective well-being

We used two measures of self-rated well-being. A visual analogue scale (VAS happiness) was used to measure happiness and the Satisfaction With Life Scale (SWLS) [107] was used to measure life satisfaction. VAS happiness measured the response to the question "Please indicate on the scale below how happy you feel at this moment" using a scale ranging from 0 (labelled as 'completely unhappy') to 100 (labelled as 'perfectly happy'). The SWLS contains five items that describe satisfaction with life (see Table 4.1), which are each rated on a seven-point Likert-scale ranging from 'completely disagree' to 'completely agree'. SWLS scores were computed by summing the scores of the five items, therefore theoretically ranging from 5 to 35. For the ease of comparison with the VAS happiness score, the SWLS score was linearly rescaled to a range of 0 to 100.

Table 4.1. Linear regression of VAS happiness score on SWLS

Variable	**Coef.**		**S.E.**
1. In most ways my life is close to my ideal	1.38	*	0.68
2. The conditions of my life are excellent	-0.66		0.72
3. I am satisfied with my life	7.41	***	0.79
4. So far I have gotten the important things I want in life	0.31		0.62
5. If I could live my life over, I would change almost nothing	1.37	**	0.44
Constant	26.46	***	2.26
Adj. R-squared			0.50

Note: ***<.001; **<.01; *<.05

VAS happiness and SWLS measure different components of SWB. Broadly categorized, SWB consists of pleasant affect, unpleasant affect and life satisfaction [90, 107, 108]. Affect captures moods and emotions such as happiness and joy (pleasant affect) or sadness and stress (unpleasant affect). Life satisfaction refers to a cognitive judgmental process [107] and contains judgements about one's perceived circumstances relative to self-imposed standards, such as past and future life [90, 108].

In our study, VAS happiness measured an affective emotional aspect of SWB and was specific in the sense that respondents were asked about their happiness "at this moment". SWLS measured a cognitive-judgemental process of satisfaction with life and measured global satisfaction in the sense that respondents were asked about an overall judgement of their life. The correlation between VAS happiness and SWLS was 0.68 (p<0.001), which indicates that these measures of SWB are closely related, but not interchangeable. In addition, Table 4.1 shows that the first, third and fifth items of the SWLS scale were significantly correlated with VAS happiness, while the second and fourth items were not. The strongest predictor for happiness was the third item. Cronbach's alpha for SWLS was 0.91, which indicates that in our data SWLS is a reliable scale, and therefore all items were retained as part of the SWLS sum score for further analysis.

Because SWLS is a measure for satisfaction with life as a whole while VAS happiness is a measure for happiness at a particular moment in time, SWLS has been argued to be more stable over time than happiness [108]. In order to avoid a lengthy and repetitive discussion of results, we therefore present the analyses using SWLS as measure of outcome as primary result. We use the analyses with VAS happiness as outcome measure as a means to examine the sensitivity of the findings.

4.2.2.2 Health problems

Health problems were measured using the EQ-5D-5L measure [109], which describes health states using five domains, i.e. mobility, self-care, usual activities, pain/discomfort and anxiety/depression, and distinguishes five levels on each of these domains, i.e. no problems, slight problems, moderate problems, severe problems and extreme problems/unable to. We added a sixth dimension that measures problems in the domain of cognitive functioning, e.g. memory, concentration, coherence, and IQ. This extension to the EQ-5D-5L has been proposed in the literature as a way to account for the health impact of neuropsychiatric health problems, such as dementia and mental retardation, which are argued to be insufficiently captured by the conventional EQ-5D instrument [110, 111]. On each of the six domains, dummy variables were computed to distinguish between 'having no problems' and 'having slight problems' to 'having extreme problems' on that domain.

4.2.2.3 Reference points for health

For the assessment of relative health, we asked respondents to rate their current health relative to seven reference points derived from multiple discrepancies theory (MDT) [100]. MDT states that people's net reported satisfaction is a function of the perceived discrepancies between one's current conditions, i.e. what one has, and a set of seven reference points: what one wants; what relevant others have; the best one has had in the past; what one expected to have now three years ago; what one expects to have in five years; what one deserves; and what one needs. Upward comparisons, i.e. current conditions that are worse than a reference level, are thought to affect satisfaction negatively and downward comparisons, i.e. current conditions that are better than a reference level, are thought to affect satisfaction positively [90, 100].

Respondents rated their health relative to these reference points on a nine-point Likert-scale ranging from very bad to very good (see Appendix 4.A). For the analyses, dummy variables were computed to assess the effect of ranking one's health as very bad to bad (scores 1 to 4 on the 9-point Likert scale) as compared to ranking one's health as neutral to very good (scores 5 to 9) relative to each reference point. Taking 'neutral' as a status quo, we considered rankings worse than this status quo as losses in health relative to the reference levels and ranking just like or better than this status quo as gains in health relative to the reference levels. In line with prospect theory [20], we may expect losses to loom larger than gains, hence to have a particularly strong effect on well-being. Furthermore, a loss accumulation dummy was computed to test for a cumulating effect of experiencing losses relative to four or more reference points (out of the seven).

4.2.2.4 Personal characteristics

Age, gender, income, unemployment, marital status and having children were included as control variables. Age squared was added to test for non-linearity.

4.2.3 Data analysis

Linear regressions were used to investigate the relation between well-being and health and reference points for health, corrected for personal characteristics. Five models were estimated. The first model included personal characteristics and served as a basic model with control variables. The second model extended the first with health problems. The third and fourth models extended the second with variables for the seven MDT reference points for health. In the third model, MDT reference points were included as categorical variables with 9 categories corresponding to the 9-point Likert scale. In the fourth model, MDT reference points were included as dummy variables for losses on the seven reference point, replacing the categorical variables in the third model. The fifth model extended the fourth with the loss accumulation dummy. Stata 13 was used for all analyses.

4.3 RESULTS

4.3.1 Study sample

Table 4.2 presents descriptive statistics of the sample. The average age in this sample was 45.6, which is in line with the average age of 45.5 of the Dutch population between the ages of 18 and 75. The percentages of males and females were almost equal and very similar to the population statistics. All three levels of education were well represented in

Table 4.2. Descriptive statistics (n=550)

Variable	Level	Sample statistic	General public aged 18-75[a]
Age (mean, S.E. ,range)		45.6 (0.64, 18-75)	45.5
Gender	Female	49.3%	50.0%
	Male	50.7%	50.0%
Education level	Low (LO, LBO, MAO)	28.6%	30.4%
	Medium (MBO, HAO)	41.6%	40.2%
	High (HBO, WO)	29.8%	27.5%
Daily activity	Employed/ Self-employed	46.4%	
	Unemployed	10.7%	
	Other	42.9%	
Household income, net per month	Low (≤ €1499)	33.8%	
	Medium (€1500 – 2999)	46.2%	
	High (≥ €3000)	20.0%	
Marital status	Married/Living together	59.1%	
	Other	40.9%	
Children	No	42.6%	
	Yes	57.5%	
Health, EQVAS (mean, S.E., range)		76.7 (0.76, 0-100)	
Health problems, per domain	Mobility	28.0%	
	Self-care	7.5%	
	Usual activities	30.0%	
	Pain/discomfort	56.9%	
	Anxiety/depression	27.6%	
	Cognitive functioning	22.4%	
MDT reference points (SE, range)	Self needs	6.6 (0.07, 1-9)	
	Self deserves	6.4 (0.07, 1-9)	
	Self wants	6.7 (0.08, 1-9)	
	Self others	6.4 (0.07, 1-9)	
	Self best	6.5 (0.09, 1-9)	
	Self progress	6.3 (0.08, 1-9)	
	Self future	6.5 (0.08, 1-9)	

[a] Mean age and gender are based on statistics for the Dutch population between the ages of 18 and 75, education level are based on statistics for the Dutch population between the ages of 15 and 75. All population statistics are based on the year 2013. Source: CBS statline, Centraal Bureau voor Statistiek, via http://statline.cbs.nl/Statweb/

our sample, although people with a high education level were slightly overrepresented. Almost half of the respondents were employed or self-employed and 10.7% of our respondents were unemployed.

The self-assessed health of our respondents was fairly good with an average score of 76.7 on VAS health, although a considerable number of respondents experienced at least slight health problems on the six health domains. The majority of respondents had at least slight pain or discomfort (at the day of participating in the questionnaire), but only few respondents encountered problems on the domain self-care. The mean MDT scores are all higher than 5 (i.e. 'neutral') and indicate that in general, respondents' health was good relative to each of the seven reference points.

4.3.2 Well-being scores

Subjective well-being scores were higher for VAS happiness than for SWLS, with scores of 74.0 and 62.8 respectively, suggesting that respondents' happiness at the moment of data collection was higher than their overall satisfaction with life as a whole. SWLS scores ranged from 0 to 100 with a median score of 70 and a standard deviation of 23.0 and, suggesting that the distribution of SWLS score is right-skewed and that there is a wide variation of SWLS scores in our data. Figure 4.1 presents the frequency distribution of responses for each of the five SWLS items and reveals some differences across items. The pattern of responses on items 2, 3, and 4 are fairly similar and more positive than scores on items 1 and 5. The overall pattern of responses over the five items suggests that the majority of respondents is reasonably positive about their satisfaction with life.

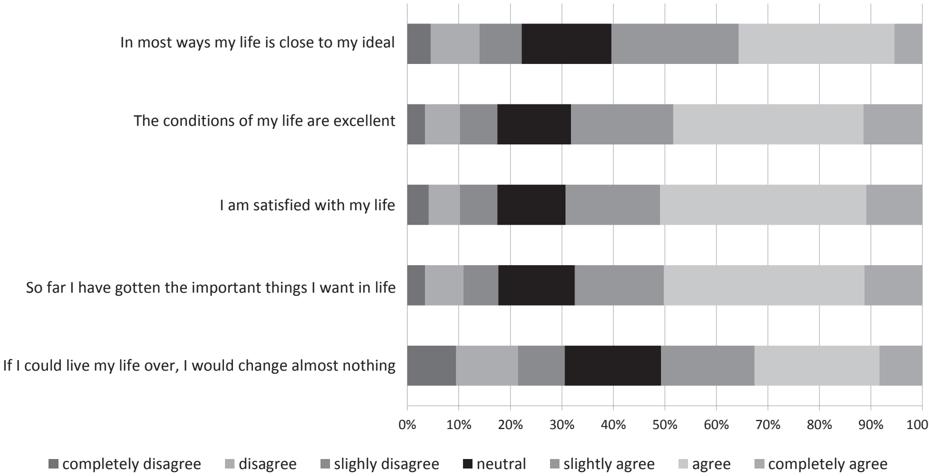


Figure 4.1. Frequency distribution of SWLS per item

On each item, at least 50% of respondents at least slightly agrees with the statement. In general, respondents seem to be reasonably satisfied with their lives and life conditions and the things they got out of life, but some may want to do things over if they could and improve their lives to get closer to their ideals.

4.3.3 SWLS regressions

Table 4.3 presents the results of the linear regressions with SWLS as measure of SWB. In the first model with control variables only, age and age squared were significant,

Table 4.3. Linear regressions of SWLS on respondent characteristics, health and reference points (n=550)

SWLS	I: Control variables		II: Health		III: MDT health reference points		IV: MDT health losses		V: MDT health loss accumulation	
	Coef.	S.E.	Coef.	S.E.	Coef.	S.E.	Coef.	S.E.	Coef.	S.E.
Age	-1.55 ***	0.39	-0.85 *	0.35	-0.84 **	0.32	-0.95 **	0.33	-0.92 **	0.33
Age sq.	0.02 ***	0.00	0.01 *	0.00	0.01 *	0.00	0.01 **	0.00	0.01 **	0.00
Gender (male=1)	-0.36	1.90	2.65	1.71	1.57	1.57	0.91	1.64	1.19	1.64
Income middle	7.92 ***	2.23	4.59 *	2.00	3.15	1.85	4.40 *	1.90	4.07 *	1.90
Income high	17.24 ***	2.83	13.62 ***	2.54	9.40 ***	2.38	12.08 ***	2.42	11.73 ***	2.42
Unemployed (y/n)	-8.95 **	3.02	-9.22 **	2.68	-8.61 ***	2.45	-8.39 **	2.54	-8.26 **	2.53
Married/ living together (y/n)	-0.84	0.75	-0.10	0.67	-0.36	0.61	-0.07	0.63	-0.11	0.63
Children (y/n)	-2.94	2.23	-2.80	1.98	-3.23	1.82	-2.98	1.88	-2.62	1.87
Health problems:										
Mobility			-5.20 *	2.30	-2.87	2.12	-3.37	2.19	-3.03	2.18
Self-care			-4.45	3.59	-1.48	3.31	-0.00	3.44	-0.59	3.43
Usual activities			-4.61 *	2.32	-1.47	2.14	-2.20	2.23	-2.12	2.22
Pain/Discomfort			-3.39	1.98	-2.06	1.81	-2.81	1.87	-2.72	1.86
Anxiety/depression			-14.18 ***	2.00	-10.94 ***	1.86	-10.89 ***	1.95	-11.22 ***	1.94
Cognitive functioning			-5.04 *	2.19	-3.84	2.01	-3.70	2.08	-3.61	2.08
MDT domain:										
Self-needs					2.23 **	0.70	-8.09 *	3.62	-9.46 *	3.65
Self-deserves					1.69 *	0.66	-11.56 ***	3.17	-12.46 ***	3.18
Self-wants					-1.01	0.67	4.63	-5.23	2.35	3.43
Self-others					1.14	0.67	-5.23	3.32	-8.12 *	3.53
Self-best					0.09	0.59	-2.87	2.97	-4.85	3.08
Self-progress					1.30	0.70	-5.42	3.24	-7.21 *	3.32
Self-future					1.01	0.68	-5.40	3.32	-7.49 *	3.43
Loss accumulation (≥4)									12.31 *	5.21
Constant	91.16 ***	9.85	82.97 ***	8.76	42.75 ***	8.85	88.91 ***	8.30	88.16 ***	8.27
Adj R-squared	0.13		0.32		0.44		0.40		0.40	

Note: ***<.001; **<.01; *<.05

indicating that the relationship between age and satisfaction with life was non-linear. The joint relationship of age and age squared with SWLS was significant (Wald test, F=8.17, $p<0.001$) and u-shaped with a minimum at 45 years. The dummy variables for income and unemployment were statistically significant. People with a middle income scored 7.9 points higher on the satisfaction with life scale and people with a high income scored 17.2 points higher compared to people with low income. On average, being unemployed decreased satisfaction with life by 9.0 points. The dummy variables for gender, married or living together, and having children were not significant.

Overall, the associations between SWLS and the control variables remained fairly stable across the models. The joint relationship of age and age squared with SWLS remained significant throughout the five models (F=3.20, p=0.042 in model II; F=3.45, p=0.033 in model III; F=4.14, p=0.016 in model IV and F= 4.00, p=0.019 in model V). The minima of the u-shaped relationship between age and satisfaction with life were between 44 and 47 years. The variables high income and unemployment also remained significant throughout the five models, with sizeable coefficients. The variable middle income lost significance when MDT reference points were added in the third model (p=0.089), but remained significant in the fourth and fifth model.

The second model, with health variables included, revealed significant associations between health and satisfaction with life on four of the six health domains. Having at least slight problems with mobility, usual activities, anxiety/depression and cognitive functioning was associated with lower SWLS scores, 5.2, 4.6, 14.2, and 5.0 points, respectively. The addition of reference points for health in the third and fourth model and accumulated losses in the fifth model resulted in a loss of significance of the health variables on the domains mobility, usual activities and cognitive functioning. Problems on the domain anxiety/depression remained significantly associated with SWLS.

The third model, with MDT reference points for health included, revealed that 2 of the 7 reference points were significantly associated with SWLS. The associations between SWLS and the discrepancy between what one has and what one needs was positive and, on average, each increment in one's position on this scale was associated with 2.2 points higher SWLS scores. This suggests that the difference between judging one's health to be very bad relative to what one needs (i.e. the lowest score on the 9-point scale) and judging one's health to be very good relative to what one needs (i.e. the highest score on the 9-point scale) is 17.8 on the SWLS scale. For the discrepancy between what one has and what one deserves, each increment was associated with 1.7 points higher SWLS scores, so that moving from the lowest to the highest position on this scale associates with a 13.5 points change in SWLS. An additional model with the seven MDT reference points as a sum score over all seven domains (not shown in Table 4.3) revealed an overall positive association between SWLS and this sum score, reinforcing the finding that improving one's position relative to reference points is generally associated with higher satisfaction with life ($\beta=0.81$, $p<0.001$).

The fourth model, with dummy variables for MDT losses included, revealed that the same 2 reference points as in the third model were significantly associated with SWLS. Health states that were judged as very bad to bad relative to the health one needs were associated with 8.1 points lower satisfaction with life than health states that were judged as neutral to very good relative to the health one needs. Health states that were judged as very bad to bad relative to the health one deserves were associated with 11.6 points lower satisfaction with life than health states that were judged as neutral to very good relative to the health one deserves. Repeating this model for gains (i.e. scores of 6 or higher on the 9-point scale) instead of losses (not shown in Table 4.3) revealed a significant correlations between SWLS and the self-needs discrepancy ($\beta=6.4$, $p=0.007$) and SWLS and the self-deserves discrepancy ($\beta=5.2$, $p=0.024$).

The fifth model, with dummy variables for MDT losses and a loss accumulation dummy included, revealed that 5 of the 7 reference points were associated with SWLS, as well as the loss accumulation dummy. For all five reference points, health states that were judged as very bad to bad relative to the reference point were associated with lower satisfaction with life scores than health states that were judged as neutral to very good relative to these reference points. The accumulation of four or more losses was associated with higher satisfaction with life scores, indicating a decreasing effect of additional losses on SWLS.

4.3.4 VAS happiness regressions

Overall, the results of the linear regressions with VAS happiness as measure of well-being (Appendix 4.B) compared reasonably well to the findings with SWLS as measure of well-being (section 4.3.3). However, there were some notable differences. First, the control variables in the basic model (I) were considerably less stable throughout models II to V for VAS happiness than for SWLS. Whereas all age and income variables reached statistical significance in the basic model, the only variable that remained significant in the second model, i.e. high income, also lost significance in the third, fourth and fifth model. Second, contrary to the findings for SWLS, problems in the domains usual activities and cognitive functioning remained statistically significant after addition of MDT reference points for health in the third model, and problems in the domain usual activities also remained significant in the fourth and fifth model. Third, there were some differences in significance of the MDT reference points for health in models III to V. Contrary to the findings for SWLS, in the third model, the discrepancy between the health one has and the health one expects to have in five years was significant. In addition, in the third and fourth models the discrepancy between the health one has and the health one needs was not significant for VAS happiness. In the fifth model, two of the MDT health losses (i.e. self-needs and self-others) and the loss accumulation dummy were not significant, while being significant in the model with SWLS.

4.4 DISCUSSION

In this chapter we have investigated the relationship between SWB and health, taking into account absolute assessments of health and assessments of health relative to a set of seven reference points. This chapter extends on two streams of previous research, i.e. studies investigating the relationship between health and SWB and studies investigating the role of reference points in the formation of preferences and perceptions. The results of our study suggest that health is associated with satisfaction with life and happiness and that this correlation works through both absolute and relative assessments of health. Incorporating reference points in the measurement of self-assessed health may therefore improve our understanding of the relationship between health and SWB.

Little is known about the formation of reference points. Here, we included seven reference points for health in our analysis in order to allow a broad assessment of which reference points matter (most). Our results indicated that the included (potential) reference points were not all equally relevant. Overall, the discrepancy between the health one has and the health one deserves seems most important for SWB, as this reference point was significant and considerable in magnitude for both SWLS and VAS happiness. More positive evaluations of own health relative to the health people feel they deserve was associated with higher levels of SWB. The nature of health as a basic or instrumental good may explain the relevance of this particular reference point. Indeed, given that a basic or minimal standard of health is generally considered to be a basic human right [1, 112], different reference points may be expected to be relevant for health than for example, for luxury goods which may be more susceptible to status consumption.

The particular relevance of the self-deserves discrepancy in our study is different from the results in earlier studies. Michalos [100, 102] found that health satisfaction was associated with the discrepancy between the health one has and the health one deserves, but that relationships between health satisfaction with the self-wants and self-others discrepancies were much stronger. Also at the level of global satisfaction (i.e. satisfaction with life as a whole), the self-deserves discrepancy has been found to be of little relevance [101, 103, 113]. Studies investigating the relationship between self-assed health and MDT evaluations for life as a whole found significant relations between health and the self-wants, self-best, self-others and self-future discrepancies [103, 113].

Model IV investigated the relationship between SWB and reference points for losses (and gains) in the health domain. This allowed us to investigate whether 'losses' in health are negatively associated with SWB and 'gains' positively, and whether these negative 'loss' associations are larger in magnitude than positive 'gain' associations, as prospect theory suggests [20]. The comparison of the coefficients for losses in model IV with those for the 9-point Likert-scales in model III indicates that such asymmetry between losses and gains indeed seems to exist, and is strongest for the association between SWLS and the self-deserves discrepancy (based on the ratio between coefficients in models III and IV). The comparison of the coefficients in Model IV for losses and for gains reinforces this: losses on the self-needs and self-deserves discrepancies were associated with 8.1 and 11.6 points lower satisfaction with life scores while gains (not shown in Table 4.3) were associates with 6.4 and 5.2 points higher satisfaction with life scores.

In model V, we included a loss accumulation dummy, which had effect on the significance of several reference points. For SWLS, the self-wants, self-progress, and self-future discrepancies turned significant and had a negative sign, suggesting that losses on these reference points were associated with lower SWB. In addition, the loss accumulation dummy was also significant and positive in sign, suggesting that the accumulation of losses somewhat lowers the negative association between losses and SWB. One explanation for these findings may be that losses have a negative impact on SWB and that this impact is marginally decreasing with the addition of more losses. For VAS happiness, the self-progress and self-future discrepancies turned significant, but the loss accumulation dummy was not significant. We should note here that we also examined loss accumulation with thresholds of 3 or more losses and 5 or more losses. The accumulation variable with 5 or more losses captured less than 10% of the data and was therefore disregarded. With 3 or more losses, we found no significant relation between SWB and loss accumulation, neither for SWLS nor for VAS happiness.

Before addressing the implications of our results, some limitations need to be addressed. First, based on our results, little can be said about the causality of the relationships between SWB, health, and reference points for health. Previous research suggests that health may affect SWB and that SWB may affect health [91, 96-99] and that these relationships may exist simultaneously [114]. In addition, health and SWB may be associated through a third variable, such as personality, that affects both health and SWB [91, 96]. These causality issues may have resulted in some endogeneity in our regression models, and therefore our estimates may be somewhat biased. Statistical analyses such as instrumental variables approach, possibly in panel data to control for unobserved time-invariant individual characteristics (such as personality) [114-116], may be used to correct for endogeneity in the relationship between health and SWB. Our data did not allow for such estimations. Therefore, a valuable contribution for future research may be to extend our analysis in this direction using adequate techniques to account for endogeneity.

Second, we should be aware that the absolute and relative health outcome measures correlate to some extent. Our results in model II suggests that problems on several health domains correlate with SWB, but these associations seemed weakened by incorporating relative health measures in models III to V. Inspection of the correlation coefficients of the variables for health problems on the six domains with the variables for the seven discrepancies (i.e. the 9-point scores) reveals moderate negative correlations between 0.20 and 0.38, all significant except the correlations of the health domain self-care with the self-others and self-best discrepancies. These correlations may be the result of using subjective, self-assessed health measures for both absolute and relative health, which may be subject to the same underlying influencers (e.g. optimism or pessimism). Future research may investigate this by using objective health measures to capture absolute health, for example health problems diagnosed by professionals.

Third, our dataset was limited in size and did not include people older than 75. Although our sample was reasonably representative for the general population in the Netherlands between the ages of 18 and 75 in terms of age, gender, and education level, our results are not generalizable to the entire adult population of the Netherlands. We may expect some differences in health status, reference points, and perceptions in the population older than 75, given that that they – and their peers – are more likely to experience or have experienced health problems than younger people. In addition, the health of people above 75 will probably be lower in objective terms, but it is unclear whether they also perceive their health as lower, how they evaluate their position vis-à-vis their reference points, and how absolute and relative health perceptions will relate to well-being in this oldest age group. This remains a topic for further research.

Despite these limitations, our results imply that relative health assessments may contribute to our understanding of the relationship between health and SWB. Reference points may shape health perceptions, i.e. how healthy people feel, and may consequently affect subjective well-being. Previous studies have shown that the correlation between SWB and objective health is generally found to be smaller than the correlation between

SWB and subjective health [91, 96]. How people feel about their health, based on their reference points, might help explain this difference.

Although the precise relationship between health and SWB remains a topic of study, it is likely that there is a causal effect of health on SWB. Our results imply that improvements in absolute and relative health may give rise to higher levels of SWB. In other words, improvements in SWB may be achieved through improvements in absolute health, but also through changes in perceived health relative to reference points (e.g. due to adaptation and coping) or by changes in reference points (e.g. due to changes in expectations or the health of peers). If these findings are confirmed in future studies, this adds another complexity to the study of the relation between health and happiness. In addition, it poses a challenge to policy making in health care. Well-being may be improved by advances in absolute and relative positions in health, but the two need not necessarily work in the same direction.

APPENDIX 4.A – MDT QUESTIONS

How would you consider your health to be relative to…

		Very bad		Bad		Neutral		Good		Very good
a.	… what you need to survive	1	2	3	4	5	6	7	8	9
b.	… what you believe you deserve	1	2	3	4	5	6	7	8	9
c.	… how healthy you want to be	1	2	3	4	5	6	7	8	9
d.	… how healthy people close to you are (e.g., friends, colleagues, neighbours)	1	2	3	4	5	6	7	8	9
e.	… how healthy you have ever been before	1	2	3	4	5	6	7	8	9
f.	… how healthy you expected now to be three years ago	1	2	3	4	5	6	7	8	9
g.	… how healthy you expect to be in five years	1	2	3	4	5	6	7	8	9

APPENDIX 4.B – LINEAR REGRESSION RESULTS FOR VAS HAPPINESS (N=550)

VAS happiness	**I: Control variables**			**II: Health**			**III: MDT health reference points**			**IV: MDT health losses**			**V: MDT health loss accumulation**		
	Coef.		S.E.	Coef.		S.E.	Coef.		S.E.	Coef.		S.E.	Coef.		S.E.
Age	-1.02	**	0.36	-0.37		0.32	-0.36		0.31	-0.41		0.31	-0.40		0.31
Age sq.	0.01	**	0.00	0.00		0.00	0.00		0.00	0.00		0.00	0.00		0.00
Gender (male=1)	-2.76		1.77	-0.12		1.55	-0.97		1.51	-1.60		1.53	-1.47		1.53
Income middle	5.65	**	2.08	2.51		1.81	1.61		1.77	2.03		1.76	1.86		1.77
Income high	9.43	***	2.64	6.03	**	2.30	3.17		2.28	4.15		2.25	3.98		2.25
Unemployed (y/n)	-2.33		2.81	-2.20		2.42	-2.16		2.35	-1.56		2.35	-1.50		2.35
Married/living together (y/n)	-0.41		0.70	0.36		0.60	0.16		0.58	0.20		0.59	0.18		0.59
Children (y/n)	-1.83		2.08	-1.66		1.79	-1.49		1.75	-1.80		1.74	-1.62		1.75
Health problems:															
Mobility				-5.30	*	2.08	-3.86		2.03	-3.82		2.03	-3.65		2.03
Self-care				-3.51		3.24	-1.39		3.17	-0.24		3.19	-0.53		3.20
Usual activities				-5.94	**	2.09	-4.19	*	2.05	-4.76	*	2.07	-4.72	*	2.07
Pain/Discomfort				0.04		1.79	0.37		1.74	0.31		1.73	0.36		1.73
Anxiety/depression				-16.29	***	1.81	-14.09	***	1.78	-13.70	***	1.81	-13.86	***	1.81
Cognitive functioning				-4.73	*	1.98	-4.22	**	1.93	-3.78		1.93	-3.74		1.93
MDT domain:															
Self-needs							-0.23		0.67	-1.05		3.36	-1.72		3.40
Self-deserves							2.40	***	0.63	-13.36	***	2.95	-13.80	***	2.97
Self-wants							-0.67		0.64	1.97		3.07	0.85		3.20
Self-others							-0.63		0.64	4.03		3.08	2.62		3.28
Self-best							-0.25		0.56	1.69		2.76	0.72		2.87
Self-progress							0.97		0.67	-5.56		3.01	-6.43	*	3.09
Self-future							1.39	*	0.66	-5.67		3.08	-6.70	*	3.19
Loss accumulation (≥4)													6.03		4.85
Constant	95.24	***	9.19	87.84	***	7.91	69.52	***	8.49	92.11		7.70	91.74	***	7.70
Adj R-squared	0.05			0.13			0.35			0.35			0.35		

Note: ***<.001; **<.01; *<.05

5

Are all health gains equally important? An exploration of acceptable health as a reference point in health care priority setting

Based on: Wouters, S., van Exel, N. J. A., Rohde, K. I. M., & Brouwer, W. B. F. (2015). Are all health gains equally important? An exploration of acceptable health as a reference point in health care priority setting. Health and Quality of Life Outcomes, 13 (1), 1.

ABSTRACT

Accumulating evidence suggests that members of society prefer some QALY gains over others. In this chapter, we explore the notion of acceptable health as a reference point in assessing the value of health gains. The value of health benefits may be assessed in terms of their position relative to this reference level, benefits above the level of acceptable health being valued differently from benefits below this level. In this chapter we focus on assessing the level of acceptable health at different ages and associations with background variables.

We recruited a sample of the adult population from the Netherlands (n=1,067) to investigate which level of health problems they consider to be acceptable for people aged 40 to 90, using 10-year intervals. We constructed acceptable health curves and associated acceptable health with background characteristics using linear regressions.

The results of this study indicated that the level of health problems considered acceptable increases with age. This level was associated with respondents' age, age of death of next of kin, health and health behaviour.

Our results suggest that people are capable of indicating acceptable levels of health at different ages, implying that a reference point of acceptable health may exist. While more investigation into the measurement of acceptable health remains necessary, future studies may also focus on how health gains may be valued relative to this reference level. Gains below the reference point may receive higher weight than those above this level since the former improve unacceptable health states while the latter improve acceptable health states.

5.1 BACKGROUND

Scarcity of health care resources makes priority setting inevitable. An increasingly used tool to inform such decision-making is cost-utility analysis, which assesses the incremental costs and health benefits of a new intervention relative to some relevant alternative (like an old intervention, doing nothing or care as usual). The results of a cost-utility analysis are typically summarized in an incremental cost-utility ratio (ICUR), expressing the incremental costs per unit of health gain [9]. Costs are expressed in monetary terms while health gains are generally expressed in terms of quality-adjusted life-years (QALYs), i.e. the amount of life time gained by the intervention corrected for the quality of life (QoL) during that time, with a QoL score of 1 representing perfect health and a QoL score of 0 representing the state of being dead [117]. An intervention may be considered to offer value for money and hence be considered for reimbursement when its costs per QALY are lower than some relevant threshold [9]. The nature and height of this threshold are a matter of ongoing discussion (e.g. [118, 119]).

In calculating the cost-utility of interventions in health care, each QALY is usually weighed equally, regardless of whom it accrues to or under which circumstances it is gained. This means that in calculating QALY gains, it does not matter whether, for example, a QALY is gained in the context of a severe or mild illness or whether the beneficiary is 10 or 80 years old. However, accumulating evidence (from the literature and policy practice) suggests that members of society do prefer some QALY gains over others. Disease and patient characteristics such as the severity of the treated illness and the age of the beneficiaries have been found to be important in the valuation of health gains [13, 17, 18]. This means that priority setting based on QALY maximization is unlikely to reflect societal preferences for the just distribution of health and health care, and that weighing QALYs according to particular equity principles may improve the societal support for health care decisions.

Two prominent equity principles that may justify and guide the process of empirically deriving such equity weights are the fair innings principle [19] and the severity of illness argument [14-16]. Fair inning aims to promote equality in lifetime health, assigning higher priority to people who have not had their 'fair share' of lifetime health than to people who have, and therefore live on 'borrowed time'. The severity argument aims to promote equality in people's prospective health, therefore assigning higher priority to those people whose health status or expectations are worse [18].

Notwithstanding the increasing focus on equity considerations, an underexplored element for QALY weighting relates to the notion of acceptability of imperfect health states. Brouwer et al. [120] suggested and empirically tested the notion of acceptable health states in relation to age. They argued that some health problems may be considered a normal part of ageing, hence making them acceptable beyond a certain age. For example, we may be inclined to view impairment in mobility (e.g. being unable to walk long distances) to be unacceptable for the average 20-year old person, while we may consider this to be quite acceptable for the average 90-year old person. In their study, Brouwer et al. [120] indeed found that people considered an increasing number and level of health problems acceptable as age progresses. Likewise, Stolk et al. [121] argue that one of the reasons for resistance against the funding of Viagra in The Netherlands was that it was considered as 'unnecessary luxury care', because erectile dysfunction was seen as a normal and acceptable consequence of ageing.

Such reasoning implies that some imperfect but still acceptable health state is used as a reference point [21] in assessing the necessity of treatment or the value of health gains. Taking such a reference point implies that health gains that accrue to people whose health is below the reference point, and thus given their age are in 'unacceptable health states', will carry more weight than equally sized gains accruing to people who are already above this reference point. This differs from the conventional way of dealing with QALY gains, in which all deviations from perfect health are seen as losses and are weighted equally.

The notion of acceptability carries elements of both the severity of illness and the fair innings arguments. The severity of illness argument suggests that health gains lower on the QoL scale carry more weight than those high on the scale. Hence, treatments for more severe diseases will get higher priority than those aimed at milder diseases. The acceptability argument refines this argument by stating that gains above a specific reference point of acceptability receive less priority than those below this reference point. Health gains may accordingly be assigned different social values. In line with the fair innings argument, the reference levels of acceptable health may be age dependent. This means that acceptable deviations from perfect health may be larger for older than for younger people. A difference with the fair innings argument is that this age-dependent reference point may be independent from health achievements in the past and solely focus on peoples' health at a specific point in time.

In allocation decisions the notion of acceptable health states can lead to a change in the value that health gains receive. A first step in operationalising the notion of acceptable health as a reference point is to investigate whether people indeed consider some imperfect health states to be acceptable and whether this depends on age. This chapter focuses on that question by investigating the acceptability of imperfect health states for people aged 40 to 90 in a representative sample of the population between the ages of 18 and 65 from the Netherlands. In addition, respondents were asked what they considered to be an acceptable age of death, which allowed us to estimate the acceptable amount of lifetime QALYs after the age of 40 years. This could be seen as a specific operationalization of 'fair innings' for lifetime health achievement. Furthermore, we investigated which socio-demographic characteristics are associated with the elicited acceptability levels, as well as respondents' own health and health behaviour and the age of death of their next of kin.

5.2 METHODS

In order to investigate whether certain imperfect health states are considered acceptable, a professional sampling agency recruited 1,067 respondents between the ages of 18 and 65. Invitations to complete a web-based questionnaire were sent out to members of the recruitment agency's panel. Members of this panel had previously signed up to participate in surveys and experiments, and by accepting the invitation to participate in this survey provided consent to the use of their response for the purposes of this study. Strategic sampling was used to obtain a sample representative for the Dutch general public between the ages of 18 and 65 in terms of age, gender and education level. The data collection was part of a larger research project exploring people's expectations of length and quality of life.

In the questionnaire, respondents were asked to indicate which level of health problems they considered to be acceptable from the ages 40, 50, 60, 70, 80 and 90 years onwards. They were also asked what they considered to be an acceptable age of death. In addition, the questionnaire included questions regarding respondents' socio-demographic characteristics, their current health status, their health lifestyle in terms of exercise, nutrition, smoking and alcohol intake, and the age of death of their next of kin (i.e., their parents, grandparents, aunts and uncles, and other family members).

Similar to Brouwer et al. [120], the health problems that respondents evaluated in terms of their acceptability were described using the EQ-5D-3L descriptive system [83]. The EQ-5D-3L describes health states using five domains (i.e. mobility, self-care, usual activities, pain/discomforts and anxiety/depression) and distinguishes three levels within each domain (i.e. no problems, some problems and severe problems). Different combinations of these three levels in the five domains allow the EQ-5D-3L to describe 243 distinct health states. These are often labeled using a 5 digit code like 11233, which refers to a health state with no problems with mobility and self-care (i.e. level 1 on domains 1 and 2), some problems with usual activities (i.e. level 2 on domain 3) and severe pain/discomfort and anxiety/depression (i.e. level 3 on domains 4 and 5). Health-related quality of life scores can be computed for each health state using validated Dutch EQ-5D-3L utility tariffs [84, 85]. The utility scores take values between 1 for perfect health and 0 for dead, while health states considered worse than dead receive a negative utility score.

In this study, respondents were asked to indicate in each of the EQ-5D-3L domains from which age onwards they considered the levels 'some problems' and 'severe problems' acceptable (see Appendix 5.A). Acceptable levels of health were computed for the ages 40 to 90 by combining the answers that respondents gave in each separate domain. These scores were then used to construct an acceptable health curve ($AHC_{AGGREGATE}$), defined by the sample average acceptable quality of life score at each age.

Combining the separate domain-specific responses in this way had the advantage that it allowed us to analyse the acceptability of each of the 243 health states described by the EQ-5D-3L, but had the disadvantage that it may have overestimated the acceptability of health states. Since respondents evaluated health problems in each domain in isolation, they may not have taken simultaneous health problems in other domains into account. For example, some problems with mobility or with self-care may be considered acceptable at the age of 60 when evaluated in isolation, but health state 22111 may nonetheless be considered unacceptable at that age. Therefore, we constructed a more conservative acceptable health curve (AHC_{WORST}), based only on the worst health problem in any 1 of the 5 domains considered to be acceptable at the different ages. For instance, in case health state 32211 was acceptable at the age of 70 based on a respondent's separate answers per health domain, $AHC_{AGGREGATE}$ was calculated based on the health state 32211 (i.e., assuming that the combination of all problems would be acceptable). However, in calculating AHC_{WORST} we assumed that combinations would not be acceptable, so that severe problems with mobility (i.e. health state 31111) would be the lowest acceptable health state (Note: the most severe problem was determined by the utility score of each level in each domain, based on Lamers et al. [84, 85], not by the level itself).

In addition to the questions described above, respondents were presented with three specific health profiles (i.e. 21211, 22221 and 33312) and were asked to indicate from which age onwards they considered each of these health states to be acceptable. Based on Lamers et al. [84, 85], the utility values of these health profiles were 0.86, 0.69 and 0.20, respectively. We constructed a (partial) acceptable health curve, $AHC_{PROFILES}$, based on the mean ages at which these QoL scores were considered acceptable, if considered acceptable at all. Respondents who indicated that complete health profiles were never acceptable were excluded from the means because these profiles were not considered to be acceptable at any age in the specified age range. Using t-tests, the mean ages at which the complete health profiles were considered acceptable were compared with an approximation of the ages at which they would be considered acceptable deduced from $AHC_{AGGREGATE}$ and AHC_{WORST}.

The area under the curve (AUC) was estimated for $AHC_{AGGREGATE}$ and AHC_{WORST} as a proxy for the acceptable total amount of lifetime QALYs after the age of 40. The AUC was approximated using a Riemann integral, dividing the area into 6 rectangular areas at the age intervals [40; 45], [45; 55], [55; 65], [65; 75], [75; 85] and [85; 90]. The surface of each area was calculated as the width of an age interval multiplied by the mean acceptable quality of life score in that interval (for example, the width of 10 years in the interval 45 to 55 multiplied by the mean acceptable QoL at age 50). For the interval [40; 45] the mean QoL score at the age of 40 was used and for the interval [85; 90] the mean QoL at the age of 90 was used. Both the $AHC_{AGGREGATE}$ and AHC_{WORST} curves started at the age of 40. The end points of $AHC_{AGGREGATE}$ and AHC_{WORST} were defined by the reported acceptable age of death, meaning that $AHC_{AGGREGATE}$ and AHC_{WORST} were cut off at the acceptable age of death when it was lower than 90 years and linearly extrapolated up to that age when it was higher than 90 years.

Linear regressions of the AUC estimation of $AHC_{AGGREGATE}$ on respondents' characteristics were conducted in order to identify characteristics that may be associated with respondents' perception of acceptable health. Variables for age, gender, income level, employment and having children were included in a basic model, which was then extended with variables for own health, health related lifestyle and age of death of next of kin. Health variables were having (had) a severe disorder or chronic illness. Health related lifestyle variables were dummy variables for regular exercise and therefore meeting the Dutch norm for healthy physical activity [122], having a healthy diet (i.e. varied, not too much, not too fat, including fruits and vegetables for at least 6 days per week) and dummies for smoking and alcohol intake (on average, drinking alcohol at least 1 day per week). In addition, the complete model was also estimated separately with mean acceptable quality of life (i.e. mean of reported acceptable quality of life scores at the ages of 40 to 90) and acceptable length of life (i.e. the reported acceptable age of death) as dependent variables. Stata12 was used for all analyses.

5.3 RESULTS

Table 5.1 presents the descriptive statistics of the study sample. Respondents were 43 years of age on average and 58% was older than 40 years. The majority had a medium or high education level, and 53% was employed or self-employed. Respondents reported to be in relatively good health with a quality of life of 0.85, but nonetheless about one third reported to have (had) either a chronic illness or a severe disorder, or both. For the majority of the respondents (53.7%), the age of death of their next of kin fell in

Table 5.1. Descriptive statistics (n=1,067)

Characteristic	Level	Sample statistic	General public aged 18-65[a]
Age (mean, S.E.)		43.2 (0.42)	42.0%
Gender	Female	49.8%	49.8%
	Male	50.2%	50.2%
Education level	Low (LO, LBO, MAO)	27.1%	31.0%
	Medium (MBO, HAO)	42.0%	40.3%
	High (HBO, WO)	30.9%	27.8%
Daily activity	Employed/ Self-employed	53.1%	
	Unemployed/student/retired/other	46.9%	
Household income, net per month	Low (≤ €1499)	30.0%	
	Medium (€1500 – €2999)	47.3%	
	High (≥ €3000)	22.7%	
Marital status	Married/Living together	64.3%	
	Other	35.7%	
Children	No	39.8%	
	Yes	60.2%	
Health	EQ-5D-3L (mean, S.E.)	0.85 (0.01)	
	Chronic illness	36.6%	
	Severe disorder	28.2%	
Lifestyle	Regular exercise	50.9%	
	Healthy diet	47.6%	
	Smoking	39.5%	
	Alcohol intake	64.0%	
Acceptable age of death (mean, S.E.)		83.3 (0.23)	
Age of death next of kin	75 years or lower	19.4%	
	From 75 to 85 years	53.7%	
	Higher than 85 years	26.9%	

[a] Mean age is based on statistics for the Dutch population between the ages of 18 and 65, gender and education level are based on statistics for the Dutch population between the ages of 15 and 65. All population statistics are based on the year 2010. Source: CBS statline, Centraal Bureau voor Statistiek, via http://statline.cbs.nl/Statweb/

the range of 75 to 85 years. Our data was sampled on representativeness for the Dutch general public between the ages of 18 and 65 in terms of age, gender and education level. Comparison with population norms for the general public in the Netherlands (see Table 5.1) indicates that our respondents are slightly older and more highly educated, but overall can be considered reasonably representative for this population.

Table 5.2 indicates that, in general, all levels of health problems were considered increasingly acceptable with progressing age. Only few respondents (≤13.8%) considered mild problems in any domain of health to be acceptable below the age of 60. However, the majority of respondents considered mild problems in the domains mobility, usual activities and pain/discomfort acceptable from the age of 70 onwards, mild problems in the domain self-care acceptable from the age of 80 onwards and mild problems in the domain anxiety/depression acceptable from the age of 90 onwards. In all domains except anxiety/depression, fewer than 10% of the respondents considered mild health problems to be never acceptable.

Only few respondents (≤6.1%) considered severe health problems to be acceptable below the age of 70. However, the majority of respondents considered severe problems in all domains except anxiety/depression to be acceptable from the age of 90 onwards. In all domains except anxiety/depression, fewer than 42% of the respondents considered severe health problems never to be acceptable.

Even fewer respondents (2.0%) considered none of the health problems acceptable at any of the ages of 40 to 90 (as presented in the last column of Table 5.2). This indicates that their reference point for acceptable health was perfect health in each domain (health profile 11111), i.e. no health problems in any of the five domains, up to the age of 90. This 2% is also the only group of respondents who reported the same level of health problems to be acceptable across all ages. The remaining 98% of respondents considered some level of health problems to be acceptable at some age, and differentiated between age categories in the level of health problems they considered acceptable.

Figure 5.1 presents $\text{AHC}_{\text{AGGREGATE}}$, $\text{AHC}_{\text{WORST}}$ and $\text{AHC}_{\text{PROFILES}}$. All curves are downward sloping, indicating that the acceptable quality of life diminishes with progressing age. $\text{AHC}_{\text{AGGREGATE}}$ and $\text{AHC}_{\text{WORST}}$ show a comparable decline up to the age of 60 years and start to diverge considerably from the age of 70 years onwards. At the age of 90, a QoL score of 0.06 is considered to be acceptable when health problems are aggregated on all 5 domains (i.e. $\text{AHC}_{\text{AGGREGATE}}$), whereas a QoL score of 0.47 is considered to be acceptable according to the more conservative approach (i.e. $\text{AHC}_{\text{WORST}}$). The areas under the curve were 31 QALYs for $\text{AHC}_{\text{AGGREGATE}}$ and 35 QALYs for $\text{AHC}_{\text{WORST}}$.

Table 5.2. Acceptability of less than perfect health states beyond a certain age in percentage of respondents (n=1,067)

Health domain	**Severity of health problems**	**Dutch EQ-5D-3L utility tariff**[a]	**Acceptability of domain-specific health problems (cum %)**						
			From age 40 onwards	**From age 50 onwards**	**From age 60 onwards**	**From age 70 onwards**	**From age 80 onwards**	**From age 90 onwards**	**Never acceptable**
Mobility	Mild problems	-0.036	2.8	5.8	22.1	65.9	92.0	96.8	3.2
	Confined to bed	-0.161	0.3	0.8	1.7	8.6	32.2	58.5	41.5
Self-care	Mild problems	-0.082	1.1	1.2	5.5	32.1	78.9	93.9	6.1
	Severe problems	-0.152	0.6	0.7	1.4	8.1	36.8	74.9	25.1
Usual activities	Mild problems	-0.032	1.8	3.1	13.7	52.0	86.7	95.4	4.6
	Severe problems	-0.057	0.8	1.3	3.4	13.2	44.2	75.5	24.6
Pain/discomfort	Moderate	-0.086	6.4	13.8	32.2	62.5	84.9	90.2	9.8
	Extreme	-0.329	1.9	2.4	6.1	17.7	44.5	63.3	36.7
Anxiety/ depression	Moderate	-0.124	6.7	9.3	14.3	27.5	45.2	56.0	44.0
	Extreme	-0.325	3.1	3.8	5.9	11.3	24.0	36.8	63.2
Total	None		89.1	80.6	56.8	18.9	4.3	2.0	2.0
	At least one mild / moderate		10.9	19.4	43.2	81.1	95.7	98.0	45.8
	At least one severe / extreme		4.3	5.2	10.5	27.8	63.3	87.5	68.9

[a] In order to attain EQ-5D-3L utility scores for health states, the standard deduction for any deviation from health state '11111' (-0.071) and the deduction for having severe problems on at least one domain (-0.234) should be taken into account in addition to the domain-specific scores presented.

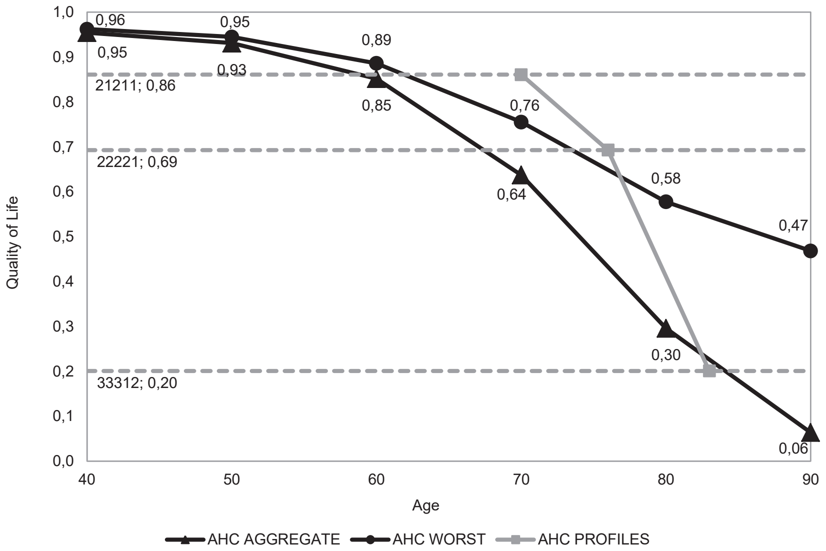


Figure 5.1. Acceptable health curves
Based on health problems on 5 domains ($\text{AHC}_{\text{AGGREGATE}}$), health problems on 1 domain ($\text{AHC}_{\text{WORST}}$), and complete health profiles ($\text{AHC}_{\text{PROFILES}}$).

$\text{AHC}_{\text{PROFILES}}$ presents the ages at which the three complete health states 21211, 22221, and 33312 (corresponding with QoL scores of 0.86, 0.69 and 0.20) were considered acceptable. Compared to this curve, $\text{AHC}_{\text{AGGREGATE}}$ and $\text{AHC}_{\text{WORST}}$ underestimated the ages at which the health states 21211 and 22221 were considered to be acceptable, but overestimated the age at which the health 33312 was considered to be acceptable. The mean age at which respondents reported health state 21211 to be acceptable was 70 years, which significantly differed from the mean ages of 59 and 62 years at which a QoL score of 0.86 appeared to be acceptable based on $\text{AHC}_{\text{AGGREGATE}}$ and $\text{AHC}_{\text{WORST}}$ ($p<0.001$ for both 59 and 62 years; n=1,037). The mean age at which respondents reported health state 22221 to be acceptable was 76, which significantly differed from the mean ages of 67 and 74 years at which a QoL score of 0.69 appeared to be acceptable based on $\text{AHC}_{\text{AGGREGATE}}$ and $\text{AHC}_{\text{WORST}}$ ($p<0.001$ for both 67 and 74 years; n=1,015). The mean age at which respondents reported health state 33312 to be acceptable was 83 years, which did not differ significantly from the mean age of 84 years at which a QoL score of 0.20 appeared to be acceptable on $\text{AHC}_{\text{AGGREGATE}}$ ($p=0.100$; n=671). The QoL score of 0.20 was not on $\text{AHC}_{\text{WORST}}$ because on this curve, the acceptable QoL did not fall below 0.47.

Table 5.3 presents the results of the linear regression analyses. The basic model contains the variables age and age squared, which were both significant, indicating that the relationship between age and the calculated area under the curve (AUC) of $AHC_{AGGREGATE}$ was nonlinear. The joint effect of age and age squared was significant (Wald test, F=13.19 p<0.001) and negative between the ages of 18 and 65. On average, the area under the curve decreased with the age of the respondents, indicating that older respondents considered more health deterioration (in quality and/or length of life) acceptable at older age than younger respondents. The dummy variables gender and having children were not significant, but both income variables and the employment variable were. The effect of having a middle or low income as compared to a high income was negative. Hence, respondents with a low or middle income considered more health deterioration acceptable at older age than respondents with a high income. The effect of being employed was positive, indicating that employed or self-employed respondents considered less health(male=1)rioration acceptable at older age.

Table 5.3. Linear regressions of the area under the curve (AUC) of AHC on respondent characteristics (n=1,067)

Variable	I: Basic model		II: Basic model & health		III: Basic model & health, lifestyle		IV: Basic model & health, lifestyle, and life expectancy		V: Mean acceptable quality of life		VI: Acceptable age of death	
	Coef.	S.E.	Coef.	S.E.	Coef.	S.E.	Coef.	S.E.	Coef.	S.E.	Coef.	S.E.
Age	-0.43 *	0.17	-0.34 *	0.17	-0.29	0.17	-0.25	0.17	-0.01	0.00	0.15	0.12
Age sq.	0.01 **	0.00	0.01 **	0.00	0.01 *	0.00	0.00 *	0.00	0.00	0.00	-0.00	0.00
Gender (male)	0.52	0.65	0.41	0.64	0.42	0.65	0.52	0.64	0.01	0.01	-0.54	0.46
Income low	-1.88 *	0.91	-1.55	0.91	-1.08	0.91	-0.93	0.90	-0.02	0.02	0.22	0.65
Income medium	-1.98 *	0.80	-1.89 *	0.80	-1.63 *	0.79	-1.42	0.78	-0.03	0.02	-0.65	0.56
Employed	2.14 **	0.72	1.51 *	0.73	1.42	0.73	1.33	0.71	0.03	0.02	-0.86	0.51
Children	1.02	0.74	0.73	0.74	0.97	0.73	1.08	0.72	0.01	0.02	0.56	0.52
Severe disorder			-2.14 **	0.81	-2.03 *	0.80	-1.78 *	0.79	-0.02	0.02	-1.14 *	0.57
Chronic illness			-1.61 *	0.77	-1.71 *	0.77	-1.59 *	0.75	-0.03	0.02	-0.67	0.54
Regular exercise					0.61	0.64	0.46	0.63	-0.00	0.01	0.35	0.45
Healthy diet					2.68 ***	0.67	2.34 ***	0.66	0.06 ***	0.01	0.38	0.47
Smoking					-0.91	0.64	-1.00	0.63	-0.01	0.01	-0.92 *	0.46
Alcohol intake					0.87	0.66	0.85	0.66	0.01	0.01	-0.13	0.47
Kin age low							-5.04 ***	0.91	-0.07 ***	0.02	-5.81 ***	0.66
Kin age medium							-3.80 ***	0.72	-0.07 ***	0.02	-2.65 ***	0.52
Constant	36.25 ***	3.17	35.42 ***	3.15	33.17 ***	3.22	35.70 ***	3.20	0.69 ***	0.07	82.78 ***	2.30
Adj R-squared	0.04		0.05		0.07		0.10		0.06		0.10	

Note: ***<0.001; **<0.01; *<0.05

The coefficients for the variables severe disorder and chronic illness in the second model were significant and negative in sign, indicating that respondents who reported to have (had) a severe disorder or chronic illness considered more health deterioration acceptable at older age. The interaction of severe disorder and chronic illness was not significant (p=0.312, not shown). Compared to the basic model, the coefficient for low income was no longer significant in the second model and the coefficient for employment decreased in significance and magnitude. From the lifestyle variables added in the third model, the coefficient for having a healthy diet was positive and significant, indicating that respondents who reported to have a healthy diet considered less health deterioration acceptable at older age than respondents who did not meet this criterion. Compared to the second model, the significant effect of employment disappeared in the third model, while the joint effect of age and age squared was still significant (F=9.22, p<0.001). The coefficients for kin age in the fourth model were negative and significant. Hence, respondents whose next of kin die at higher ages considered less health deterioration acceptable at older age. The significant joint effect of age and age squared (F=8.10, p<0.001) turned positive at the age of 61, whereas it was negative for the entire age range of 18 to 65 in the basic, second and third model. Compared to the third model, having a middle income was no longer significant as a determinant of the AUC.

The last two columns of Table 5.3 present the models with mean acceptable quality and length of life as dependent variables. In the acceptable quality of life model, as compared to model 4, having a healthy diet and age of death of next of kin remained significant. In the acceptable length of life model, as compared to model 4, severe illness and age of death of next of kin remained significant. In addition, the coefficient of smoking was negative and significant, indicating that those who smoke considered a shorter length of life acceptable.

5.4 DISCUSSION

In this chapter, we have empirically tested the notion of the acceptability of non-perfect health states, which may be relevant in the context of priority setting in health care. Our results indicate that some non-perfect health states are considered to be acceptable and that the acceptability of health problems in general increases with progressing age. At the ages of 40, 50, and 60 only few respondents considered any level of health problems to be acceptable, but the proportion that considered mild health problems acceptable increased considerably from the age of 70 years onwards. A majority of respondents considered mild problems in any health domain to be acceptable from the age of 70 onwards, except for self-care and anxiety/depression. Perhaps this age pattern is related to the common (albeit changing) pensioning age in the Netherlands of 65 years. Problems that prevent people from actively participating may be less often considered acceptable when people have yet to reach the pensioning age. Severe problems were considered acceptable by the majority of respondents from the age of 90 onwards, except in the domain anxiety/depression. As expected, at any given age severe health problems were less often considered acceptable than mild health problems. Moreover, the frequency of 'never acceptable' was considerably higher for severe problems than for mild health problems in all health domains. For example, 3% of respondents considered mild problems with mobility to be never acceptable whereas 42% considered being confined to bed to be never acceptable. Therefore, our results suggest that the distinction between unacceptable and acceptable health problems may be particularly relevant for milder health problems.

A remarkable feature of our results is the deviating pattern of responses in the domain anxiety/depression. The proportion of respondents that considered mild or severe health problems in this domain to be never acceptable was substantially higher than in the other four domains. This is in line with the earlier findings of Brouwer et al. [120] and societal preferences according to the Dutch EQ-5D-3L value set [85]. These findings suggest that people may be particularly averse to problems with anxiety/depression and that they are generally considered to be less acceptable than problems in other domains, regardless of age.

The regression analysis also yielded some noteworthy results. First, the negative effect of age on the area under the curve (AUC) of $AHC_{AGGREGATE}$ indicates that older respondents considered more health deterioration (in quality and/or length of life) acceptable than younger respondents. Perhaps older respondents considered a lower quality of life more acceptable at older ages because they better understand how to cope with a certain extent of health deterioration over time. They may also consider the health and life expectancy of their peers or next of kin as a reference, and this reference point may change as these reference groups get older (or die). Having a chronic illness lowered the AUC by 1.6 QALYs, while having (had) a severe disorder lowered it by 2.1 QALYs. This indicates that these subgroups found a considerably lower amount of lifetime QALYs after the age of 40 years acceptable. Taken together, these findings suggest that experience with health problems – through ageing, chronic illness or a severe disorder – and better understanding of their impact on normal functioning at older age possibly influenced respondents' perception of what is acceptable. Accordingly, they considered less than perfect health states acceptable more often than other respondents did.

Second, respondents with a healthy diet reported a significantly higher AUC (2.7 and 2.3 QALYs in the third and fourth model respectively) than those with an unhealthy diet. In the separate acceptable quality and length of life models, we found a significant positive effect of having a healthy diet on acceptable quality of life (0.06), but not on acceptable length of life. The higher AUC, therefore, seems primarily induced by acceptable QoL considerations. For smoking, the opposite was found: acceptable length of life was almost 1 year shorter for smokers than for non-smokers, while no effect of smoking was found on acceptable QoL or AUC. These findings indicate that people may adapt their perception of what is acceptable based on their lifestyle choices at the level of length or quality of life, but not necessarily the combination of the two, based on their understanding that some unhealthy behaviours are associated with (chronic) illness while others are associated with (earlier) death.

Third, the AUC was 5.0 and 3.8 QALYs lower for respondents whose next of kin died before the age of 75 or between the ages of 75 and 85, respectively. This effect was found for both quality and length of life, despite the fact that age of death of next of kin is a measure of length rather than quality of life. This may indicate some correlation between length and quality of life (e.g. that the quality of life of next of kin who die younger was lower).

5.4.1 Limitations

Some limitations of our study need to be addressed. First, caution is warranted in generalising our results. Although our sample was representative for the population of the Netherlands between the ages of 18 and 65 in terms of age, gender and education level, none of our respondents was older than 65. This means that we have excluded the elderly population entirely from this study, while these are the people who have most experience with ageing and coping with related health problems. Their perception of what is acceptable may be substantially different from that of our (i.e. younger) respondents. Therefore, an interesting avenue for future research may be to focus on investigating the acceptability of less than perfect health states in an elderly population. In addition, respondents were contacted by a sampling agency after voluntarily singing up to participate in scientific research, which may have resulted in selection bias.

Second, respondents assessed the acceptability of health problems in each domain separately, as already mentioned in the methods section. Evaluating a health problem in isolation does not immediately reveal how people would evaluate health profiles in which combinations of problems occur. Hence, we used two approaches (one additive and one restrictive) to calculate the AHCs. Since we also investigated the acceptability of three health profiles, we can compare the two curves to this method. The results showed that for the two milder health profiles 21211 and 22221, both $AHC_{AGGREGATE}$ and AHC_{WORST} were below $AHC_{PROFILES}$. For the worst health profile 33312, $AHC_{AGGREGATE}$ and $AHC_{PROFILES}$ were almost equal. AHC_{WORST} was constructed as a more conservative curve than $AHC_{AGGREGATE}$, and for health states 21211 and 22221, AHC_{WORST} was closer to $AHC_{PROFILES}$ than $AHC_{AGGREGATE}$ was, but for 33312 $AHC_{AGGREGATE}$ was closer to $AHC_{PROFILES}$ than AHC_{WORST} was. The exact location of an acceptable health curve using complete health states therefore remains unknown and deserves more research. However, based on the results presented here we do have some understanding of its shape. The finding that the ages at which the health states 21211, 22221 and 33312 were considered acceptable were consecutively higher is in line with the downward-sloping $AHC_{AGGREGATE}$ and AHC_{WORST} with age. A recommendation for future research may be to estimate the acceptable health curve with a larger set of complete health profiles, rather than with health problems in isolation.

Third, the concept 'acceptable health' was not further defined than the health state that may be considered 'normal' for someone at a certain age. Without further explanation of the concept of acceptable or normal health, respondents may have interpreted acceptability differently. For example, 'acceptable' or 'normal' may have been interpreted as the health needed to live a decent life, the health needed to live a minimally tolerable life, some average indication of actual health at older ages or the health needed to maintain one's standard or aspiration of life. In addition, the questions did not specify whether respondents should assess what they consider acceptable for themselves or for a random other person in society. However, the effect of respondents' lifestyle choices on their perceptions of acceptability that were found in the regression analyses suggests that respondents indicated what they considered to be acceptable for themselves. Future studies could shed more light on the relevance of these aspects, for instance, by adding follow-up questions asking respondents for their interpretation, by choosing for more specific formulations of the questions, or by experimenting with different formulations.

Finally, the results of this study are descriptive and not normative in nature. Hence, we may conclude that acceptability *can,* in theory, be used to distinguish between health problems in allocating resources, but it does not allow us to conclude that acceptability *should* be used in priority setting in health care. The normative justification of using acceptable levels of health in this context requires further attention. Future research may focus on this normative justification and the ethical implications of using acceptability as a means of differentiating treatments. Special attention may be put on the ageist implications of (this specific operationalization of) acceptable health. That is, acceptability-based rationing implies an age-bias towards the young, which may be seen as unfair. It should be noted however, that there is also a considerable body of literature on ageist preferences and support for the 'fair innings' argument [13, 17, 18].

5.4.2 Implications

If acceptable health is applied as a reference point in priority setting in health care, the societal value attached to health gains may differ based on their position relative to this reference point. Treatments directed at unacceptable health problems (or patients in unacceptable health states) may be assigned higher priority than those directed at acceptable health problems (or patients in acceptable health states). The value assigned to health gains below and above the reference level of acceptable health may then lead to differential weighting of a health gain of the same size between people of the same age (because levels of health before treatment differ) as well as between people of different ages (because the reference levels of acceptable health differ). An interesting avenue for future research is to investigate how health gains above the reference level of acceptable health are traded off against those below this reference level. In addition, it may be interesting to investigate whether, and if so, to what extent, the distance to the reference level of acceptable health within groups of acceptable or unacceptable health problems influences health state valuations. In this context, it is noteworthy that only 2% of our sample considered none of the health problems acceptable at any of the ages of 40 to 90 and therefore had a reference point of perfect health for all age groups, in line with the common QALY framework. Shifting the reference point in priority setting from perfect health to acceptable health therefore is likely to have implications for the value attached to health gains according to a very large majority of the population (i.e. 98%).

5.5 CONCLUSION

Based on the findings of this study we may conclude that there seem to be age-dependent levels of non-perfect health that are considered acceptable by the general public. Consequently, as people get older, an increasing proportion of their health problems may be expected to fall in a range that is considered to be acceptable in relation to their normal functioning, and may thus receive lower weight in priority setting from the perspective of the general public. Future research may be aimed at investigating whether assigning different weights to treatments above and below this threshold is indeed in line with social preferences. After all, given persistent scarcity in health care resources, rationing according to social preferences is essential for achieving health gains in a way that is generally considered fair.

APPENDIX 5.A – SURVEY INSTRUMENT (TRANSLATED FROM DUTCH)

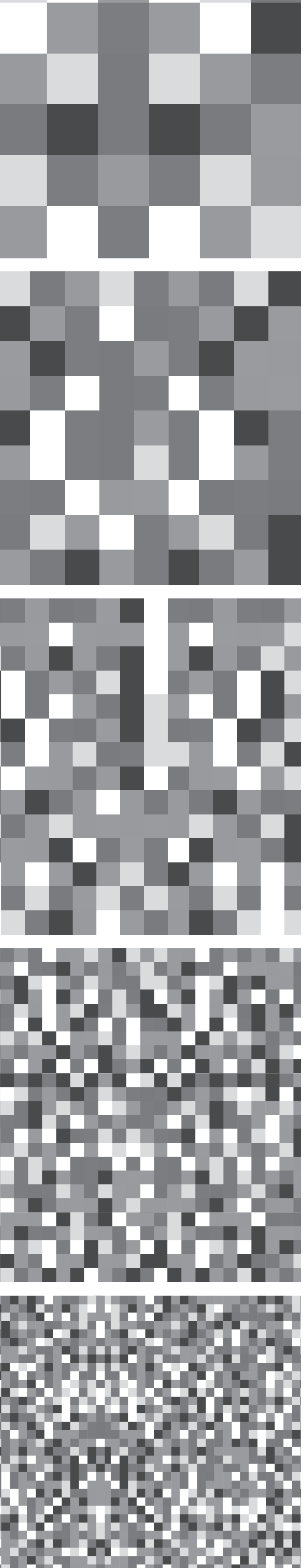
General introduction

In what follows, you receive questions regarding health at different ages. Could you please indicate which health state you consider to be acceptable at different ages. For example, consider an 80-year old person and a 20-year old person who are both unable to walk more than 1 kilometer per day. You might consider this acceptable for an 80-year old person, because it is normal for elderly not being able to walk very far. You might consider this less acceptable for a 20-year old person, because a 20-year old person should generally be able to walk 1 kilometer per day.

The following question was posed for all five EQ-5D-3L domains:

Could you please indicate from which age onwards you consider problems with mobility acceptable?

	From 40 onwards	*From 50 onwards*	*From 60 onwards*	*From 70 onwards*	*From 80 onwards*	*From 90 onwards*	*Never*
Some problems in walking about	☐	☐	☐	☐	☐	☐	☐
Confined to bed	☐	☐	☐	☐	☐	☐	☐



6

Is acceptable health sufficient? Discussing acceptable health as a sufficientarian reference level for priority setting

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ABSTRACT

Health care systems are challenged in allocating scarce health care resources, which are insufficient to fulfil all health care wants and needs. One criterion for priority setting is the 'acceptable health' approach, which suggests that society may want to assign higher priority to health benefits in people with "unacceptable" than in people with "acceptable" health. A level of acceptable health then serves as a reference point for priority setting. Empirical research has indicated that people may be able and willing to define health states as "unacceptable" or "acceptable", but little attention has been given to the normative implications of evaluating health benefits in relation to a reference level of acceptable health. The current chapter aims to address this gap by relating insights from the distributive justice literature, i.e. the sufficientarian literature, to the acceptable health approach, as these approaches are related . The focus is on investigating the implications of a sufficientarian approach for the priority weights attached to (health) benefits and discussing the normative meaning of weighting benefits accordingly. The analysis suggests that some of the sufficientarian implications may be too strong for an acceptable health approach in terms of the (lack of) priority assigned to certain health benefits. An important reason for this is that the moral validity and meaningfulness of a reference level and its usefulness in practice, need to be traded off.

6.1 INTRODUCTION

The provision and protection of people's access to health care is generally considered to be an important societal duty. However, health care systems are increasingly challenged to do so because resources available to the health care sector are typically insufficient to fulfil all health care wants and needs in the population. Therefore, sensible decisions have to be made about which treatments to fund, and which not to fund. In a number of countries, cost-effectiveness analysis is used to inform such decision-making [123-125]. In such economic evaluations, health benefits of interventions are expressed in relation to their costs, thus providing information for priority setting on the basis of efficiency and maximization of health benefits within the available budget.

Health benefits of interventions are usually expressed in quality-adjusted life years (QALYs), a measure that combines length and health-related quality of life in a health utility score. A quality of life score of 1 reflects perfect health and a score of 0 reflects dead. Scores below 0 reflect health states considered as being worse than dead [9, 117].

Recent literature [120, 126] has argued that economic evaluation studies commonly, albeit implicitly, take 'perfect health' as reference point in the valuation of health gains. Such studies consider all health states below 1 as losses in health with a potential for improvement up to perfect health, and all health gains from treatment up to perfect health as benefits. However, one may question whether perfect health is always the most relevant reference point for the valuation of health benefits, because not all deviations from perfect health may be considered equally important for treatment.

Empirical findings suggest that people may regard some non-perfect health states at older age as rather common and acceptable [120, 126, 127]. In the context of limited resources, it may then be more appropriate to adopt a more modest reference level in priority setting, for example an age-dependent non-perfect but still acceptable level of health. Consequently, evaluation studies may not give all health gains equal value, and for instance may differentiate between health gains in people with unacceptable health states and in people with acceptable (although non-perfect) health states. In this line of reasoning, people with unacceptable health states may thus receive a higher priority for treatment than those with acceptable health states. For example, if for a specific group of people (say 80-year olds) a quality of life level of 0.7 is regarded acceptable, a higher value may be assigned to health gains in 80-year olds whose health currently is below 0.7 than to health gains in 80-year olds above that acceptable level of health.

Previous research on the 'acceptability' approach was mainly empirical in nature and has focussed on investigating the reference level on the quality of life scale in relation to age. The results suggest that such reference levels of non-perfect but acceptable health are quantifiable. People are willing and able to identify levels of acceptable health, and find health problems increasingly acceptable with rising age of patients [120, 126, 127]. However, so far little attention has been given to the normative implications of evaluating health benefits in relation to a reference level of acceptable health. This chapter aims to address this gap by relating insights from the distributive justice literature to the acceptable health approach. The sufficientarian literature is of particular interest here, because it is directly relevant for an allocation framework based on a notion of acceptable health. We focus on the implications of a sufficientarian approach for the priority weights attached to (health) benefits and discuss the normative meaning of weighting benefits accordingly.

In the remainder of this chapter section 6.2 first provides brief overviews of the acceptable health and sufficientarian literature, and then discuss what the two have in common. Then, the core of this chapter section 6.3, discusses the normative implications of using an acceptable health approach for health care priority setting, using insights from the sufficientarian literature. Section 6.4 concludes.

6.2 BACKGROUND

6.2.1 Acceptable health

The notion of acceptable health is derived from the idea that some health problems may be considered as more acceptable to live with than others, and that to some extent non-perfect health may be a 'normal' part of life and ageing [120, 126]. In health state valuations, this level of acceptable health could serve as a reference point and influence the societal value attached to health benefits. Consequently, higher priority could then be given to health benefits generated in people with unacceptable health states than to health benefits in people with acceptable health states. It has been suggested that this approach could be a way to incorporate distributional preferences in the allocation of health care resources [120, 126].

Acceptable health as a reference point for priority setting stands in a line of work that stresses that other considerations than the absolute size of the health benefits alone are relevant in determining the social value of these benefits. Contrary to the traditional QALY framework, this literature suggests that it matters to whom health benefits accrue and under which circumstances they are generated (e.g. [10, 12-19, 128-130]). Acceptability underlines that the value of health benefits depends on the necessity of treatment and therefore relates to two well-known 'equity' principles in health care: severity of illness and fair innings.

The 'severity of illness' argument gives more priority to health benefits generated in people the worse health state prior to treatment [14-16]. Severity of illness and acceptability are both need-based criteria, but differ in how they define and measure need. Acceptability relates to the severity argument by also putting higher priority on treatments for the worse off, but refines it by introducing an additional reference point, i.e. the acceptable level of health, which specifies ranges of health that are seen as 'better' and 'worse' off.

The 'fair innings' approach stresses that every person is entitled to some 'normal' span of health, usually expressed in life years [19]. Fair innings aims to promote equality in lifetime health, therefore prioritizing people who have not had their fair share of lifetime health over people who have had their fair share. People who have had their 'fair share' of health, i.e. their 'fair innings', live on 'borrowed time'. People who have failed to achieve their fair share of health should then receive higher priority in allocating scarce resources. The fair innings principle thus supports priority to people who have not reached a 'normal' level of lifetime health. Likewise, the acceptability approach assigns priority to people who have not reached a 'normal' level of health in terms of quality. In combination, these approaches may provide an 'acceptable' amount of lifetime QALYs, i.e. lifetime health corrected for acceptable quality and length. For example, chapter 5 of this thesis found that the public considered 35 of the maximum of 50 attainable QALYs between the ages 40 and 90 to be an acceptable health achievement.

6.2.2 Sufficientarianism

Sufficientarians aim to promote the well-being of the worst off by strictly disentangling the moral value of benefits above a pre-determined threshold of sufficiency from those below this threshold. Generally speaking, the threshold level of sufficiency represents a standard of living without suffering and distress which allows people to live a decent life. Consequently, efforts should be made to improve the well-being of people below the threshold, i.e. those without the resources to live a minimally decent life, while improvements of the well-being above the threshold are of less moral importance. Sufficientarians claim that it is morally important to have enough, and not necessarily to have more than that. [131-134]

Sufficientarianism may be viewed as a product of dissatisfaction with egalitarianism and prioritarianism. Egalitarianism comes in many forms, but generally speaking, egalitarians generally consider it to be bad if people are worse off than others through no fault of their own, out of a concern for fairness [132, 135]. Sufficientarianism claims that it is not important that everyone has the same, but that everyone has enough. Frankfurt [133] argued that a collective aim for equality may result in a narrow focus on what people *have* and how that compares to what others have, while there may be no attention for whether people have what they actually *need*. In addition, an argumentation standardly brought up against egalitarianism is the 'levelling-down objection' [136, 137], which suggests that pure egalitarians could 'irrationally' favour equal but lower aggregate societal levels of well-being over unequal but higher aggregate societal levels of well-being. This may even come at the cost of truncating the well-being of the best-off in society without any benefits in return, if doing so contributes to equality[6] [131, 132, 136, 137].

Prioritarians put increasingly more value on improvements in well-being the worse off people are, assuming that they are in higher need, thereby focusing on absolute rather than relative levels of well-being [136, 137]. This suggests that societies should aim at improving the position of the worst off and hence prioritize benefits to the worst off over benefits to the better off [132, 136, 137]. Sufficientarianism refines this position by explicating that benefits to the worst off should only be prioritized insofar the 'worst off' are actually badly off and hence truly in need, i.e. do not have *sufficient* well-being [132]. We may argue that sufficientarianism is both broader and narrower than prioritarianism in the priority it assigns to the worse off. Sufficientarianism is broader in the sense that it puts priority on all those below the sufficiency level, and not just to the absolute worse off. At the same time, sufficientarianism is narrower in the sense of truncating priority to the worse off beyond the level of sufficient well-being.

6.2.3 Where acceptability and sufficientarianism meet

Acceptability and sufficientarianism meet in their common goal to promote the life of those in need by making a special case for people who are below a reference level. Both approaches focus on absolute outcomes in the sense that they put value on getting people's health or well-being up to this predetermined absolute level. They focus on relative outcomes in the sense that need is assessed in relation to a reference level. By doing so, they disconnect two regions on the outcome-scales of quality of life and well-being (above versus below the reference level), which is different from usual approaches

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[6] Sufficientarian reasoning assumes a consequentialistic outcome-oriented (i.e. telic) egalitarianism where inequities in outcomes and/or well-being are considered as bad *in themselves*. The levelling-down objection need not necessarily work for other types of egalitarianism, such as deontic ethics with agent-centred restrictions where injustice involves wrong*doing* rather than wrongful outcomes[136, 137]. For more on the distinction between telic and deontic views, see elsewhere [136-140].

that consider outcomes on these scales to be continuously worse (better) the lower (higher) they are positioned on the scales.

The reference level of what is acceptable or sufficient serves as a benchmark for priority setting, with lower or no priority to people whose conditions are better than the reference level and higher priority to people whose conditions are worse than the reference level. Priority weights are determined by the position of current conditions relative to the reference level. This priority setting is need-based with a reference level that reflects a standard of life with enough resources to live a 'normal' life, enabling people to function in a decent way. The contribution of the acceptability approach is that it may be seen as an operationalization of sufficient as 'acceptable', making it measurable within the health context (e.g. [120, 126, 127]).

We should note that we are not the first to see the relevance of a sufficientarian account of justice for health care priority setting. A number of papers discussed the validity of sufficientarianism within the context of health care priority setting [141-145]. However, these papers all focused on the conceptual and not the practical validity of a sufficientarian approach in the health domain. A recent paper by Mitchell et al. [146] did explore a practical application of sufficientarianism for health care priority setting. They developed a sufficient capabilities approach, including a 'threshold of sufficient capability'"… at or above which a person's level of capabilities well-being is no longer a concern for policy" (p.73). Although the authors never mentioned their concept to be an applied sufficientarian approach, it may clearly be viewed as such. We add to this literature by investigating another operationalization of sufficientarianism in the health context, while building on the conceptual groundwork from the sufficientarian literature.

6.3 UNRAVELLING SUFFICIENTARIANISM

6.3.1 A sufficientarian value function

The sufficientarian approach assumes that well-being should be treated discontinuously [147-149], because well-being levels below the reference level have inherently different societal value than well-being above the reference level. Figure 6.1a presents a sufficientarian value-function, with wb representing well-being, V(wb) representing the societal value of well-being, and the vertical dotted line representing sufficient well-being. The value function is discontinuous, as there is a sudden shock in the social value of well-being at sufficiency when well-being increases from an insufficient to a sufficient level. In addition, as implied in the sufficientarian literature, well-being levels below sufficiency are equally valued regardless of their absolute level, because they are equal in terms of insufficiency. Similarly, well-being levels above sufficiency are equal in terms of sufficiency, and therefore receive the same social value.

As a first attempt to interpret the sufficiency criterion, we may argue that the different social values attached to well-being levels above and below the sufficiency level imply that higher priority needs to be put on benefits to people with insufficient ex-ante well-being than to benefits to people with sufficient ex-ante well-being. This is in line with what Benbaji [147] calls 'The Basic Intuition' of sufficientarianism that states that "(at least some) priority should be given to helping people who are badly off" (p. 311). It seems perfectly in line with the intention to support the badly off. In terms of priority weights, this means that, for example, an improvement in the condition of a person with insufficient well-being may receive a priority weight of 1, while an improvement in the condition of a person with sufficient well-being receives a priority weight of 0. However, this basic intuition of sufficientarianism seems too simple, and there seems to be more to sufficientarianism.

The sufficientarian position comprises two components, a positive thesis and a negative thesis [131]. The positive thesis poses that it is morally important to live above the sufficiency threshold. The negative thesis denies the moral relevance of other theories of justice, particularly egalitarianism and prioritarianism. On the basis of the positive thesis, one may argue that sufficientarians put moral value on attaining the sufficient level of well-being and, correspondingly, sufficientarianism is typically referred to as a threshold concept with sufficient well-being (or here, acceptable health) as a threshold of minimum requirements. In line with this idea of a threshold, society may want to contribute to actions that help people who are below the threshold to move above the threshold, i.e. people who move from insufficient to sufficient well-being. This suggests that not only ex-ante, but also ex-post levels of well-being determine the priority attached to benefits.

Assuming that sufficientarianism has the macro-economic goal of maximizing societal well-being, the aim should be to increase the well-being of all people from below to above the sufficiency level. This well-being maximization seems to align with bringing about what is morally important according to the positive thesis, namely, sufficiency. However, this assumption rests on interpretation, since the sufficientarian approach has never formally stated a macro-economic policy goal. Here, we assume that a sufficientarian society places value on getting people up to the sufficiency level, and that this translates, in some way, into (differential) weighting of benefits. Note that other operationalisations of the sufficientarian approach can also be envisaged (see e.g.[134, 147-151], which highlights that sufficientarianism is still in development.

6.3.2 Strict sufficientarian weighting: large marginal values around the threshold

Sufficientarianism in the strictest sense may be interpreted as an approach that places value on actions that contribute to people reaching sufficiency, and that places no value on actions that do not contribute to this cause [131, 139, 149, 152]. For the weighting of benefits, such strict sufficientarianism implies that the marginal value of increments around the 'threshold' is large, even if they are small in absolute size [139, 148, 153]. In fact, gains above the threshold and those below the threshold that do not change people's position from insufficient to sufficient receive no value, and those getting people to the sufficiency level are valued maximally. This may be justified by the notion that the threshold demarcates a significant change in a person's life, from having insufficient to having sufficient, while benefits that leave a person above or below the threshold give no significant change in a person's life in terms of sufficiency.

To illustrate, consider a fixed benefit that improves well-being by Δ. The sufficientarian value function implies that this benefit receives different weights depending on its beneficiary. All people with a well-being level that is lower than the sufficiency threshold, but not lower than the threshold minus Δ, go from insufficient to sufficient well-being when they receive the benefit, and therefore will be given the highest priority. After all, only for these people the benefit Δ has a societal impact in terms of the goal to get people up to sufficiency. In addition, all people who can be lifted up to the sufficiency level, receive equal weight. Note that pure sufficiency maximization is also prone to a levelling-down objection. It may condone maximizing the number of people at sufficiency by means of reducing well-being of those above the sufficiency level, or even by reducing the well-being of the 'helpless' below the sufficiency level [131, 143]. We assume that resource allocation does not involve destroying what people already have.

Taken together, Figure 6.1b presents a strict sufficientarian weighting function for a given fixed benefit level Δ, with wb representing well-being, W(wb) representing the priority weight attached to the fixed benefit in a person with the well-being level wb, and the vertical dotted line representing the sufficiency level. In the strictest formulation, the only relevant aspect of the weighting function is the 'bump' in priority around the threshold. The weight of benefits above and below the threshold is then zero.

Figure 6.1c presents an example of a sufficientarian weighting function applied to the health domain. Here, we take ex-ante quality of life as a proxy for health care needs, but other definitions for health care needs can be envisaged [143, 145]. For the sake of argument, we assume that acceptable health is defined as a quality of life score of 0.7 on a scale from 0 (dead) to 1 (perfect health). The health benefit Δ that we consider in this example equals 0.1 points on this quality of life scale. We assume that benefits in people with unacceptable and acceptable health before treatment receive a priority weight of 0, while benefits that lift a person from below to above the threshold receive a weight of x, with x>0.

In figure 6.1c we compare three health states using the EQ-5D-3L descriptive system [83]. In the EQ-5D-3L, health states are defined on the basis of the level of health problems, i.e. no, some, or severe problems, on five health domains, i.e. mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The combination of health problems on each of the five domains is labelled using a 5 digit code, so that health state 33312, located on the left side in Figure 6.1c, represents the health of a person with extreme problems with mobility, extreme problems with self-care, extreme problems with usual activities, no pain or discomfort, and some anxiety or depression. According to validated Dutch utility tariffs that translate these health states into health-related quality of life scores [84, 85], this person has a quality of life score of 0.20, which is far below 0.7 and hence clearly "unacceptable". Health state 21211, as presented on the right side of Figure 6.1c has a quality of life score of 0.86, which is an "acceptable" health state with some problems with mobility, no problems with self-care, some problems with usual activities and no pain/discomfort of anxiety/depression. Health state 22221, presented in the middle of Figure 6.1c, has a quality of life score of 0.69 (according to the Dutch tariff) and corresponds to having some problems in the domains mobility, self-care, usual activities, some pain/discomfort, and no anxiety/depression.

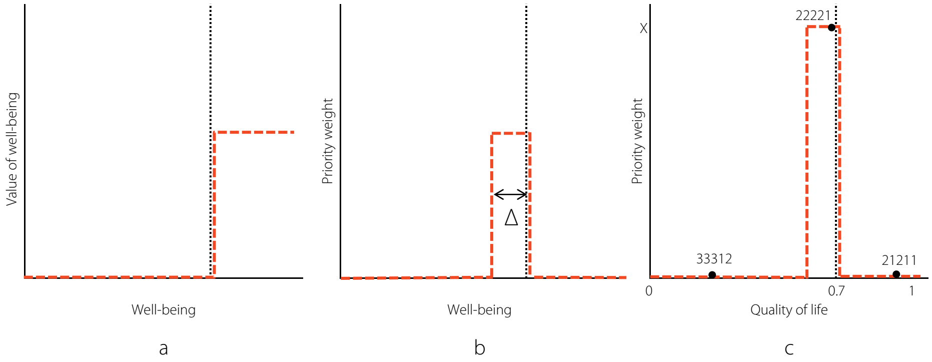


Figure 6.1. Strict sufficientarian value- and weighting functions

With the assumed ´peak´ in the weighting function around the threshold, a 0.1 points improvement reflected by Δ, in this case, receives priority when it lifts a person from unacceptable to acceptable health. This means that the benefit Δ receives a priority weight of x when it accrues to a person in health state 22221 while it receives a priority weight of 0 when it accrues to a person in health state 33312 or 21211. Obviously, the highest priority is not assigned to the person in the worst health state (i.e. 33312), but to the person who can be lifted above the acceptable health level.

6.3.3 Relaxing strict sufficientarianism

Strict sufficientarianism assumes that a shift from below to above the sufficiency level is *all* that matters, and fully demonstrates the effect of imposing a morally relevant reference level. However, it may be too strict, as it assigns no priority to benefits in people who are and remain below the threshold, while they clearly have insufficient well-being (or health). Such insensitivity to people who have insufficient, seems to contradict the sufficientarian concern for the 'badly off'. Indeed, it also contradicts our first (and intuitive) attempt to operationalize sufficientarianism in section 6.3.1, where we assumed that higher priority should be given to benefits in people below the threshold than to benefits in people above the threshold. A more modest sufficientarian approach may take into account that benefits around the sufficiency level are important, but also that higher priority should be assigned to benefits in people who are and remain below the sufficiency level than to benefits in people who are and remain above the sufficiency level.

Refining the strict sufficientarian weighting function in Figure 6.1b, Figure 6.2b presents a modest sufficientarian weighting function for a given fixed benefit level Δ, with wb representing well-being, W(wb) representing the priority weight attached to the fixed benefit in a person with the well-being level wb, and the vertical dotted line representing the sufficiency level. The priority weights assigned to benefits below the threshold are now higher than to benefits above the threshold, for example 1 for benefits below and 0 for benefits below. The priority weight attached to health benefits that lift a person up to the sufficiency level is still x, but now with $x>1$ (instead of $x>0$).

In Figure 6.2c, we again compare the three health states 33312, 22221, and 21211, but now we assume that people with unacceptable health before treatment receive a priority weight of 1 while benefits in people with acceptable health prior to treatment receive a priority weight of 0. Benefits that lift a person from below to above the threshold receive a weight of x, with $x>1$. The acceptable health level is represented by the vertical dotted line and is 0.7.

A person with health state 33312, located on the left side of Figure 6.2c, has a quality of life score of 0.20 and has an "unacceptable" level of health. The priority weight attached to a 0.1 health benefit for this person is now 1. The weighted value of the health benefit, i.e. Δ_{33312}, consequently is $W(QoL\ 0.20) * \Delta = 1*0.1 = 0.1$. A person with health state 21211 (located on the right side in Figure 6.2c), has an “acceptable” health state with some problems with mobility, no problems with self-care, some problems with usual activities and no pain/discomfort of anxiety/depression. The corresponding quality of life score is 0.86, and consequently, the priority weight attached to a 0.1 health benefit in this person is 0 and therefore the weighted value of health benefit, i.e. Δ_{21211}, is W(QoL 0.86) * Δ = 0*0.1 = 0. A person with health state 22221, presented in the middle of Figure 6.2c, has a quality of life score of 0.69, and can be lifted above the 0.7 acceptable health level with a 0.1 health benefits reflected by Δ. The weighted value of this benefit, i.e. Δ_{22221}, is W(QoL 0.69) * Δ = x*0.1 = 0.1x with x>1, which is the largest weighted value of the three health states.

The implied preference order of the three weighted health benefits is $\Delta_{22221} \succ \Delta_{33312} \succ \Delta_{21211}$. This means that while both health state 22221 and 33312 are unacceptable health states, the improvement of the better unacceptable health state, i.e. 22221, gets priority over the improvement of the worst unacceptable health state, i.e. 33312, because the weighted health benefit Δ_{22221} changes a person’s condition from unacceptable to acceptable, while Δ_{33312} does not.

The more modest sufficientarian weighting function incorporates that the weighted value of a benefit to a person in the unacceptable (and worse) health state is now higher than that of a person in the acceptable (and better) health state. This is in line with the idea that people with unacceptable health are in higher need of treatment than people with acceptable health. Still, there is an obvious priority to lifting people up to the level of acceptable health, which has the implication that in this example, a person with health state 22221 with an ex-ante QoL of 0.69 receives priority for treatment over a person in health state 33312, with an ex-ante QoL of 0.20.

This preference of Δ_{22221} over Δ_{33312} may be problematic from a severity-of-illness perspective, which, according to empirical studies, plays a role in allocation preferences [154]. However, recent literature also suggests that people may take into account the endpoints after treatment [155-158]. This suggests that people low on the quality of life scale who remain at a low level after treatment may receive less weight than patients higher on the quality of life scale or than patients low on the quality of life scale who end up at higher levels of health. Therefore, in addition to the rationale derived from the acceptable health approach, a preference of Δ_{22221} over Δ_{33312} may also be derived from reasoning in terms of health state after treatment.

6.3.4 Size and number insensitivity

In general, the stricter one commits to the moral value of the threshold, the higher the value of x, and therefore the higher the relative value of benefits around the threshold in comparison with other benefits. If x is infinite, benefits around the threshold receive absolute priority over other benefits, regardless of their size and regardless of how many people benefit. Sufficientarians may be (too) insensitive to the number and size of benefits, assigning disproportional value to (possibly very small) benefits [131, 147, 148, 153], implying that they (implicitly) take a rather high value for x.

For large values of x, for instance x=10 in Figure 6.2c, a 0.1 benefit to a person in health state 22221 is equally valuable as a 1.0 health benefit to a person in health state 33312. Also, the value of one 0.1 gain in a person in health state 22221 is equally valuable to an 0.1 gain in 10 people in health state 33312. Moreover, a 0.1 health benefit that lifts a person in health state 22221 just up to the acceptable health level outweighs a 0.49 health benefit from 0.20 to 0.69 to a person in health state 33321 who is lifted to a level of health just below the acceptable health level. Juth [143] argued that when a person is far removed from the reference level and cannot be lifted above it, and therefore receives no priority at all (i.e. assuming x=infinite), we may take this to mean that there is no health care need. However, if people far below the reference level can benefit from treatment that improves their health without taking them all the way up to sufficiency, there is still an obvious health care need.

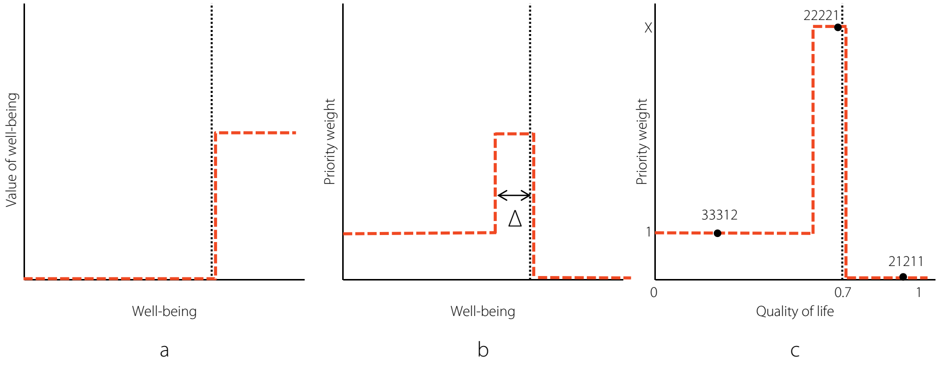


Figure 6.2. Modest sufficientarian value- and weighting functions

6.3.5 Discontinuity versus continuity

The sufficientarian approach rests on the assumption that well-being is valued in a discontinuous manner, so that the value of ex-ante well-being and the corresponding priority assigned to benefits to people in these states of well-being, is rather crudely differentiated by the threshold. Indeed, as illustrated in Figures 6.1 and 6.2, discontinuity implies a sudden shock in priority as one moves from (just) below the threshold to (just) above the threshold.

It may be informative to contrast this discontinuous weighting functions of sufficientarianism, as illustrated in Figures 6.1 and 6.2, with a continuous function for prioritarianism. Figure 6.3a presents a linear prioritarian societal value function for well-being, Figure 6.3b the corresponding prioritarian weighting function, and Figure 6.3c a quality of life weighting function that puts increasingly more priority to people the lower they are on the quality of life scale. In this approach, there are no sudden shocks in priority, but it decreases steadily instead.

We may consider the weighting function presented in Figure 6.3c to be an operationalization of the severity of illness argument, which assigns higher priority to people lower on the quality of life scale (ex-ante) than to people higher on the quality of life scale [14-16]. We should emphasize here that this is only *one* possible operationalization of the severity of illness argument, because it can also be operationalized with several other, not necessarily linear weighting functions. Regardless, the severity approach does assume a continuous weighting function, because there is no explicit restriction on priority to the worse off over the better off, as in a sufficientarian approach, implying that such priority holds for the entire quality of life scale.

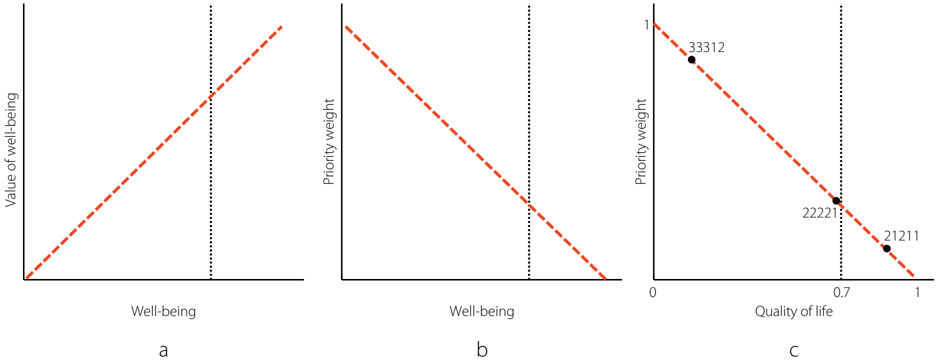


Figure 6.3. Prioritarian value- and weighting functions

For the three health states discussed above, the most compelling difference in priority weights between a continuous and a discontinuous approach is the weight attached to health state 33312 and 22221. With priority weights ranging from 1 for health states as bad as death (i.e. quality of life of 0) to 0 for perfect health (i.e. quality of life of 1), as presented in Figure 6.3c, the preference order for benefits to people in health states

33312 and 22221 reverses as compared to the modest sufficientarian acceptable health weighting in Figure 6.2c. That is, with a 0.1 health benefit, Δ_{33312} = W(QoL 0.2) * Δ = (1 - 0.20) *0.1 = 0.08 , Δ_{22221} = W(QoL 0.69) * Δ = (1-0.69) *0.1 = 0.31*0.1 = 0.031 , and Δ_{21211} = W(QoL 0.86) * Δ = (1-0.86)*0.1 = 0.14*0.1 = 0.014, and hence $\Delta_{33312} \succ \Delta_{22221} \succ \Delta_{21211}$.

6.3.6 Non-arbitrariness

In the absence of a natural or intuitive notion of the reference level, weighting on the basis of this threshold may seem constructed rather than self-evident, and may come across as arbitrary. Such arbitrariness is problematic for the moral justification of weighting benefits on the basis of their position relative to a reference level [131, 143, 152]. An arbitrarily chosen reference level gives little ground for a deliberate differentiation of the weight attached to benefits to different people on that exact level of well-being, and not on any other level [152]. Indeed, any arbitrarily pinpointed level of well-being is unlikely to support the sufficientarian implications for the priority weights attached to (health) benefits as discussed in previous sections. Non-arbitrariness of a reference level, on the contrary, may support the assumed discontinuity in value and weighting functions, the implied large marginal values around the threshold, the seemingly disproportional social value of certain benefits and the sudden shock in priority, because it gives meaning to the reference level itself. Indeed, if the reference level has the innate capacity to illustrate that something 'special' happens when reaching it, representing an all-or-nothing change in a person's life, this may warrant the implied values attached to certain (health) benefits [148, 152]. In practice, it may be difficult to find natural (non-perfect) reference points that are very clear and non-arbitrary, other than having nothing and death.

With regard to acceptable health, some efforts have been made to give meaning to the reference level. In Brouwer et al. [120] acceptable health was defined in relation to normal ageing and capabilities throughout life [159]. As argued, health capabilities commonly reduce with age. One could argue that this deterioration is only unacceptable when it extends beyond what could be expected. This level of 'normal' health deterioration may be embedded in societal norms and expectations regarding ageing. This also relates to Daniels's notion of a 'normal opportunity range', which he defined as the life plans reasonable persons within a given society would develop for themselves [160-162]. According to Daniels, relevant needs are those that achieve or maintain species-typical normal functioning. Health care has the function to maintain, restore or compensate individuals for their loss in normal species functioning caused by disease. Daniels [160] argues that "… some of our goals, perhaps those we feel are most important to us, are not necessarily undermined by failing health or disability" (p. 27).

In line with the above, acceptable health may be defined as a reference level that captures a state of affairs in which people are able to flourish as human beings with 'normal' ageing as a function of 'natural' health deterioration and (societal) norms and expectations regarding ageing. Their meaningfulness and non-arbitrariness provide such concepts moral validity, but an obvious weakness is that they fail to provide a tangible measure for everyday practice. On the contrary, acceptable health may be defined using tangible and applicable concepts that we know from everyday practice (e.g. the 0.7 score on the quality of life scale from our examples), but the validation of the reference level as a non-arbitrary threshold will then be challenging. Therefore, we may be forced to trade-off theoretical and practical validity.

Moreover, empirical research on acceptable health found that people were able to differentiate between health states in terms of them being acceptable or unacceptable [120, 126], but responses throughout the samples were heterogeneous. This implies that there is no unanimous agreement on the existence and position of *one* reference level, and endorses the intuition that there is no natural, evident and non-arbitrary definition of *the* level of health that is acceptable to live with. Therefore, we may be forced to take a middle way between moral justification and practical usefulness.

6.3.7 Weighting above and below the reference level

Sufficientarianism does not hold as a stand-alone theory of justice, because in the comparison of different benefits to people who are and remain on the same side of the threshold, i.e. above or below, sufficientarianism is uninformative (or indifferent) about how to value those benefits [143, 149]. The negative thesis of sufficiency, which denies the moral relevance of other theories of justice (i.e. egalitarianism and prioritarianism) may therefore need to be rejected. In fact, in his version of sufficiency, Crisp already allows for some prioritarian weighting below the threshold [132]. Debates around this negative thesis generally deal with how to value benefits above and below the threshold (possibly using egalitarian and prioritarian principles), and are relevant for the acceptable health approach.

First, we need to consider the relation between the height of the reference level and the priority assigned to benefits above and below this reference level. In the sufficientarian literature, Crisp's Beverly Hills case [132] illustrates this. Crisp claims that no priority should be assigned to benefits above the threshold level, because once people have enough, the need for priority ceases to exist. He substantiates this claim with a hypothetical scenario where society exists of rich and super-rich people only. Since everyone lives well above the sufficiency level, there are no obvious reasons to favour benefits to one group over the other [132]. However, Crisp' argument may be misleading, because he takes high levels of well-being, suggesting that these people are either far above the threshold level, or that they are just above an extremely high threshold. With lower levels of well-being above the threshold and/or a lower threshold, it seems unlikely that 'having enough' eliminates all morally relevant inequalities in opportunities in life [131], which implies that some kind of weighting above the threshold may be appropriate. Indeed, Casal [131] states: "Even when everyone has enough, it still seems deeply unfair that merely in virtue of being born into a wealthy family some should have at their disposal all sorts of advantages, contacts, and opportunities, while others inherit little more than a name" (p 311).

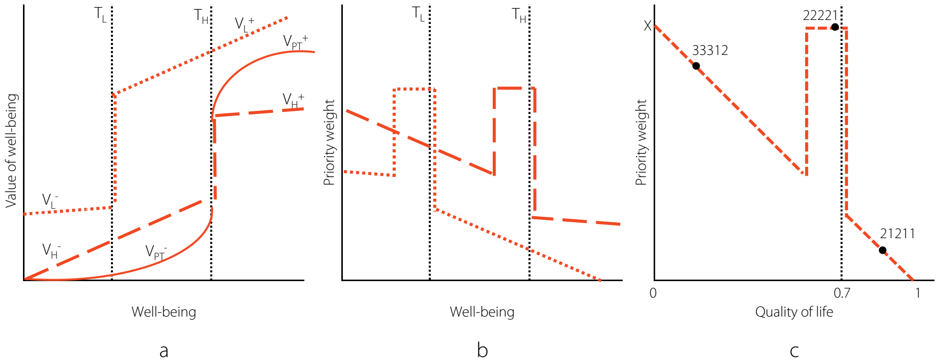
To circumvent the implied necessity of weighting above the threshold, sufficientarians may argue that the threshold is just not high enough, because morally relevant differences above the threshold should not exist under the sufficientarian assumptions [132, 148, 163]. However, the higher the threshold, the larger the discrepancies in well-being *below* the threshold and, consequently, the more likely it is that differences below the threshold are of moral relevance and should be weighted accordingly [148]. Obviously, one may argue that if such differences below the threshold exist, the threshold is simply not low enough. However, the threshold cannot be set at a lower level to avoid morally relevant differences below the threshold and *also* be set at a higher level to avoid morally relevant differences above the threshold. This implies that minimal or no weighting may be justified below the threshold when it is set relatively low and above the threshold when it is set relatively high, but it is unlikely that one threshold justifies both [131]. Moreover, it suggests that the height of the threshold level influences which weighting functions are most appropriate for weighting benefits above and below the threshold.

For the application of the acceptable health approach, the above suggests that the position of the reference level on the quality of life scale influences our intuition of which weighting functions are most appropriate for weighting different benefits above or below the acceptable health level. These weighting functions need not be similar in shape and slope. It also shows that acceptable health cannot be used as a stand-alone criterion for priority setting, although we reckon that such a claim was never made for acceptable health. A combination of different equity principles seems most appropriate.

A natural combination of principles seems to be a prioritarian-sufficientarian approach [131, 132, 134, 143, 149, 150], and in the health domain a combination of an acceptable health reference level and severity weighting for benefits above and below this reference level. Benefits may be weighted in a prioritarian sense by assigning higher weights to people who are worse off on each continuous part of the function, and in a sufficientarian sense, by assigning absolute priority to people below the reference level over people above the reference level, and by giving a 'bonus' weight to people who can go from insufficient to sufficient well-being. Considering section 6.3.6, the higher the level of arbitrariness in the reference level, the lower and more fluent the sufficientarian 'peak' in the priority function and the less discontinuous the value function may need to be.

Figure 6.4a depicts three prioritarian-sufficientarian value functions and two thresholds, a high threshold T_H and a low threshold T_L. Assuming linearity on the continuous prioritarian parts of the functions, V_H represents a value function with a high threshold and V_L represents a value function with a low threshold. Considering the above, with a high threshold, the lower part of the value function for well-being levels below the reference, V_H^-, may be steeper than the upper part of the value function for levels of well-being above the reference, V_H^+, so that increments below the reference level receive larger marginal value than similarly-sized increments above the reference level. With a low threshold, the opposite holds. The lower part of the value function for well-being levels below the threshold, V_L^-, may be less steep than the upper part of the value function for well-being levels above the threshold, V_L^+. In addition, Figure 6.4a depicts a non-linear value function. In line with prospect theory [20],the upper part of the value function for well-being levels above the threshold, V_{PT}^+, is concave, while the lower part of the value function for well-being levels below the threshold, V_{PT}^-, is convex. Increasing marginal returns below the reference level are then combined with decreasing marginal returns above it.

Figure 6.4b depicts the corresponding weighting functions for T_H and T_L. Note that in this illustration, the lower part of the weighting function with a threshold T_L and the upper part of the weighting function with a threshold T_H are almost horizontal, implying that benefits on those parts of the weighting functions are almost equally valued, regardless to whom they accrue. Figure 6.4c depicts an acceptable health weighting function, assuming equal slopes above and below the acceptable health level. In line with a prioritarian-sufficientarian weighting function, benefits to people in "unacceptable" health states, such as 33312, receive a higher weight than benefits to people in "acceptable" health states, such as 21211, and a benefit to a person in the "unacceptable" health state 22221, receives a 'bonus' weight as it lifts a person above the reference level.



Figures 6.4. Sufficientarian-prioritarian value- and weighting functions

6.4 CONCLUSION

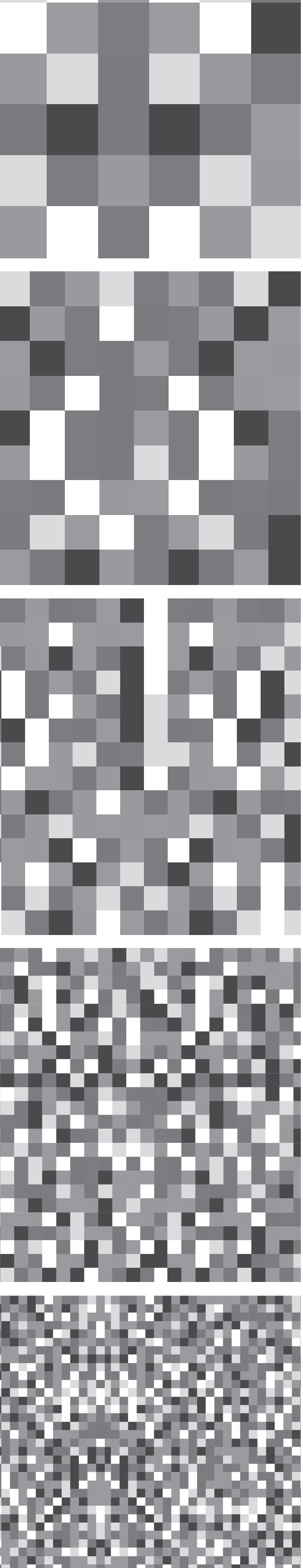
We investigated the notion of acceptable health from a sufficientarian perspective, focussing on the normative implications of a (sufficientarian) acceptable health approach for the priority attached to health benefits. Our analysis indicated that a sufficientarian value function has serious implications for priority weights and correspondingly, for priority setting. In addition to the differential weighting of health benefits above and below the reference level of acceptable health, with higher priority to benefits below than to benefits above this level, the reference level may also work as a threshold. Assigning moral relevance to reaching this threshold implies that health benefits that lift a person from below to above the acceptable health level receive priority over benefits that leave a person's position relative to the reference level unchanged. Allocating resources accordingly, may come at the cost of treating people who may attain greater health improvements in absolute size, treating more people, and/or treating people who are worse off than those that can be lifted up to a level of acceptable health.

From a moral perspective, the – perhaps far-reaching – implications of setting an explicit reference level of acceptable health may be justified when it demarcates a significant and meaningful difference between having insufficient, i.e. having an unacceptable level of health, and having sufficient, i.e. an acceptable level of health. This means that the reference level needs to be set non-arbitrarily. However, a conceptually non-arbitrary reference level seems to lack practical feasibility, while an applicable reference level in practice may be somewhat arbitrarily set. Balancing practical applicability with conceptual non-arbitrariness, implies making a trade-off between moral justification and practical usefulness, which seems key for the acceptable health approach.

Since acceptable health was never intended as a stand-alone principle, and our analysis reinforced that it needs to be considered in relation to other criteria for decision-making, future research may optimize the acceptable health approach under constraints of practical feasibility and in relation to other 'equity concerns'. Future research may investigate appropriate weighting function(s) for acceptable health, taking into account that lower moral commitments to the reference level may give a value function of health benefits with less strict sufficientarian features. This means that implied 'gap' or sudden shock in priority attached to benefits above and below the reference level may be relatively small and the implied 'peak' around the reference level may be somewhat smoother. With zero moral commitment, the discontinuous weighting function may collapse into a continuous (e.g. prioritarian) weighting function, so that both the 'gap' and the 'peak' in the weighting function disappear.

Future research may also focus on the position of the reference level, and the corresponding weights attached to benefits above and below the reference level. The implied priority weights for health states using different (combinations of) slopes and curvatures of the weighting functions may be assessed, for example, using preference elicitation exercises. Respondents may then be asked to trade-off health improvements in people below a reference of acceptable health with health improvements in people above the acceptable health level, as well as with health benefits in people who are lifted from below to above the acceptable health level.

All in all, we believe that the acceptable health approach has potential as an equity criterion in priority setting, but in applying the criterion, one should be aware that trade-offs need to be made between health benefits to different people, as well as between one's moral commitment and practical feasibility.



7

Priority to end of life treatments? Views of the public in the Netherlands

Based on: Wouters, S., van Exel, N.J.A., Baker, R.M. & Brouwer, W.F.B. (2015). Priority to end of life treatments? Views of the public in the Netherlands. Submitted.

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ABSTRACT

Recent debates in the Netherlands on health care priority setting have focused on the relative value of gains generated by life-extending medicines for people with a terminal illness, mostly new cancer drugs. These treatments are generally expensive, provide relatively small health gains, and therefore usually do not meet common cost per QALY thresholds. Nevertheless, these drugs may be provided under the assumption that there is public support for making a special case for treatments for people with a terminal illness. This study investigated the views of the public in the Netherlands on a range of equity and efficiency considerations relevant to priority setting and examines whether there is public support for making such a special case.

Using Q methodology, three viewpoints on important principles for priority setting were identified. Data were collected through ranking exercises conducted by 46 members of the general public in the Netherlands, including 11 respondents with personal experience with cancer.

Viewpoint 1 emphasized that people have equal rights to healthcare and opposed priority setting on any ground. Viewpoint 2 emphasized that the care for terminal patients should at all times respect the patients' quality of life, which sometimes means refraining from invasive treatments. Viewpoint 3 had a strong focus on effective and efficient care and had no moral objection against priority setting under certain circumstances.

Overall, we found little public support for the assumption that health gains in terminally ill patients are more valuable than those in other patients. This implies that making a special case for people who have only a short period of lifetime left, does not correspond with societal preferences in the Netherlands.

7.1 INTRODUCTION

Health care systems face an enormous challenge due to rapidly increasing demand for health care, beyond a level supported by available resources. Priority setting is essential to keep the health care system viable, which requires decision makers to make difficult choices regarding the treatments and technologies to fund within the health care system. Increasingly economic evaluations are used to inform such decisions, and in many countries, formal Health Technology Assessment (HTA) agencies have been established to inform health care decision making at the national level [164-166].

Economic evaluations inform decision makers about the costs and benefits of an intervention and help them to identify those interventions that represent the best value for money, generally expressed in terms of costs per gained quality adjusted life year (QALY). Such studies traditionally treat all costs and all effects equally [117, 167]. That is, health gains receive equal value regardless of how they are generated or who benefits, and equal costs per QALY ratios are considered to be equally 'good'. However, an increasing body of literature suggests that valuing all health gains equally may not reflect societal preferences. Different studies have shown that people care, for example, about the nature and cause of illness and characteristics of the beneficiaries of health gains [13, 14, 17, 18, 130, 154, 156, 157, 168-170]. The social value of health gains apparently varies and depends on contextual information.

Many recent debates in this area have focused on the relative value of health gains generated by life-extending medicines for people with a terminal illness, mostly new cancer drugs [164, 171-174]. These newly developed cancer drugs are generally expensive and often provide relatively small health gains, resulting in poor cost-effectiveness ratios. Because such small health gains may still be considered to be very significant to terminally ill patients and society, it may be appropriate to evaluate the cost-effectiveness of such interventions with greater flexibility. In England, for example, the National Institute for Health and Care Excellence (NICE) has made the decision to allow a higher cost-effectiveness threshold for treatments that provide short life extensions to terminally ill patients [175]. However, this has raised the question whether the implied higher social value of a QALY for end of life treatments is indeed in line with societal preferences.

The empirical evidence for the relative value of end of life treatments is limited [164] and provides mixed guidance. None of these studies are from the Netherlands. Some studies find support for a higher value for treating people with a terminal illness [176-179], but others do not [180-182]. A recent study in the UK identified three viewpoints in a sample of people with professional expertise or personal experience in end of life issues in the context of priority setting and the value of life extending treatments. Only one of the three viewpoints was found to support the decision by NICE to raise the cost-effectiveness threshold for life-extending end-of-life treatments – contingent on there being significant benefit from treatments, value for money and good quality of life [164].

In the Netherlands, cost-effectiveness is an explicit appraisal criterion in drug reimbursement decisions, and guidelines for pharmacoeconomic evaluations recommend that such evaluations take a societal perspective [36]. Still, there is lack of transparency about how the outcomes of an evaluation study are weighted against other aspects in subsequent reimbursement recommendations and decisions [18, 123]. First, although several explicit appraisal criteria are applied in reimbursement decisions, such as cost-effectiveness, added therapeutic value, medical need, severity and feasibility, 'other' (less explicit) criteria can also be considered. Second, there is no explicit guidance about the relative value of each of these criteria for reimbursement recommendations. Third, a bandwidth of acceptable cost-effectiveness ratios was recommended, from €10,000 for low severity to €80,000 for high severity [183, 184]. However, although 'proportional shortfall' [18, 185] is nowadays systematically used as criterion for severity and accommodates taking into account the severity of shortfall in both quality and length of life, low and high severity of illness have not been formally defined, and there is no formal maximum on cost-effectiveness ratios either [123, 186].

Recent policy recommendations imply that, based on severity of illness arguments, end of life treatments have a relatively high social value. Busschbach and Delwel, for instance, argued that "… if a patient for example has only few life years left (the life-threatening situation), we are prepared to pay more" [186]. Although this suggests that there is societal support for the provision of costly end of life treatments in the Netherlands, there actually is little empirical evidence for this.

Therefore, this study aimed to investigate the heterogeneity in views of the public on a range of equity and efficiency considerations that were shown to be relevant for health care decision-making, and to examine whether any of these views express support for making a special case for reimbursing costly end of life treatments.

7.2 METHODS

7.2.1 Q methodology

We used Q methodology [187-189] to explore the diversity of views on health care priority setting in the Netherlands, and our work builds on methods and findings from three recent studies with similar aims [130, 164, 170]. This study differs from two of these studies [130, 170] by its particular interest in the relative value of costly end of life treatments, and from the third study [164] by exploring end-of-life considerations within a broader context of societal preferences and by including a sample of people with personal experience with cancer. It differs from all three studies by focusing on the decision-making context in the Netherlands.

Q techniques are systematic methods designed to identify and describe the *nature* of subjective views. Respondent sampling has much in common with qualitative methods in the sense that a Q methodology study uses a purposive sample of respondents. These respondents are asked to rank a comprehensive set of statements about some topic, and to explain their ranking. The ranking is known as a "Q sort" and Q sort data are subjected to by-person factor analysis [187, 190] in order to identify patterns in the ranking of statements. These patterns are then described and interpreted with each distinct ranking representing a different shared viewpoint on the topic of study in the population that was sampled.

7.2.2 Development of the research instrument

We followed several steps in order to arrive at a comprehensive set of statements that are relevant and representative for the decision-making context in the Netherlands regarding health care priority setting in general and in the end of life context in particular. Figure 7.1 presents a flow diagram of the process.

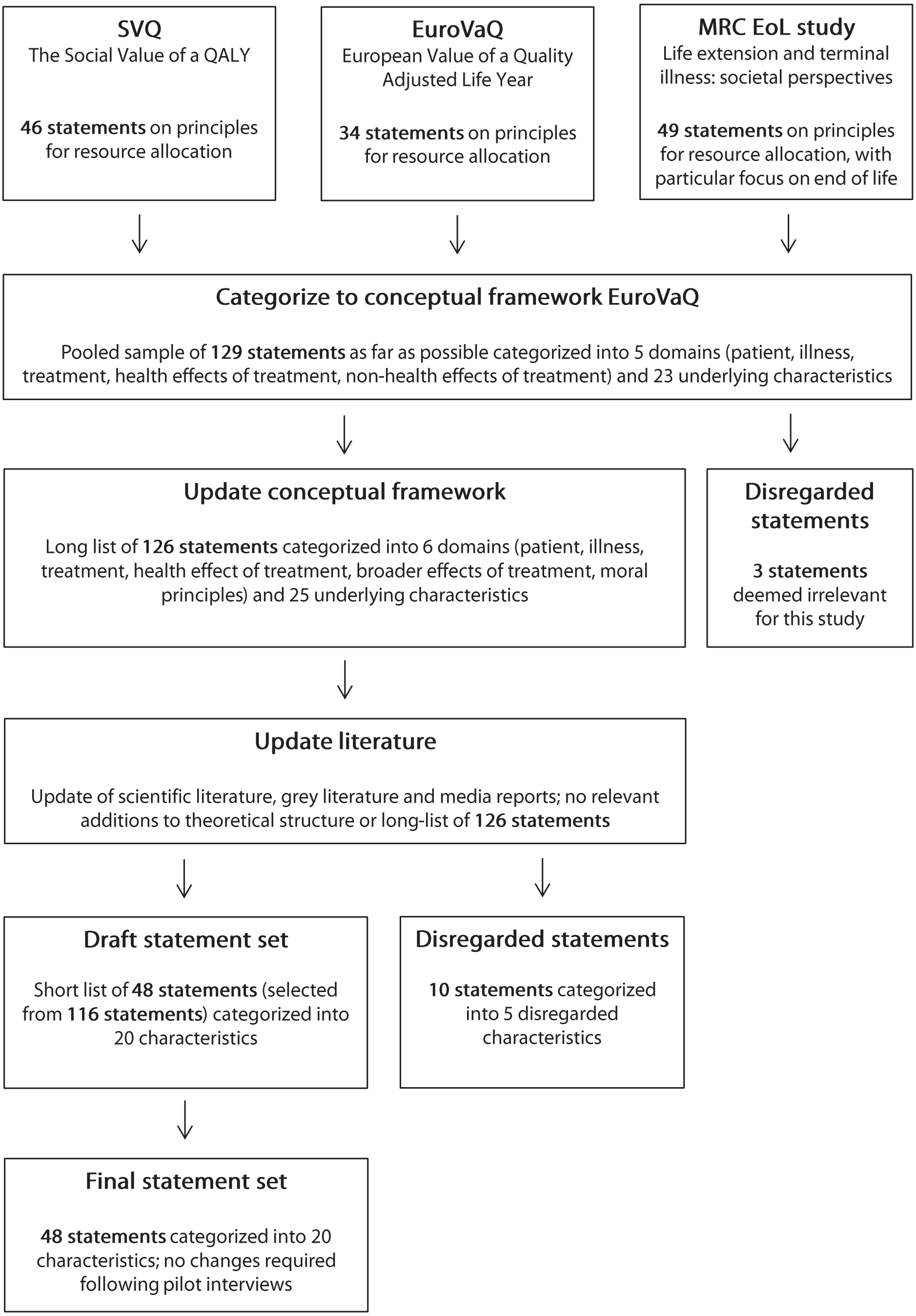

Figure 7.1 Development of the statement set

First, we gathered materials from three previous, related Q methodology studies: the Social Value of a QALY (SVQ) project from the UK [170], the European Value of a Quality Adjusted Life Year (EuroVaQ; http://research.ncl.ac.uk/eurovaq/) project which was conducted in 10 countries and an MRC Methodology Panel funded study on societal values and life extension for people with terminal illnesses (MRC EoL; http://www.gcu.ac.uk/endoflife/), also from the UK [164]. The SVQ and EuroVaQ projects focussed on principles for health care resource allocation in general and not specifically on end of life issues. The MRC EoL project was more similar to this study and aimed to examine values in relation to resource allocation, with a particular focus on the provision of end of life treatments. There were 46 statements developed for SVQ, 34 for EuroVaQ and 49 for MRC EoL.

Secondly, two researchers [SW, JE] used the conceptual framework dividing statements into different characteristics and dimension developed in the EuroVaQ project [130] to evaluate the pooled set of statements. This conceptual framework contained 23 characteristics potentially relevant for prioritisation of health care extracted from literature, in five domains: characteristics of the patient, characteristics of the illness, characteristics of the treatment, health effects of treatment and non-health effects of treatment. In an iterative process, the two researchers placed all 129 statements in the existing conceptual framework. During this process, one domain[7] was relabelled and a sixth domain added to the conceptual framework[8]. In addition, they combined[9] and added[10] some characteristics, and moved[11] several characteristics between domains. Finally, they placed one statement under a different characteristic[12] and disregarded several statements[13]. The updated conceptual framework contained 126 statements categorized into six domains and 25 underlying characteristics.

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[7] 'Non-health effects of treatment' was relabelled into a more general label 'broader effects of treatment'.

[8] The sixth domain was labelled 'moral principles'.

[9] The characteristics 'socio-economic status' and 'payment/contribution' were combined into 'income/contribution'.

[10] The following characteristics were added: 'availability' (characteristics of the treatment), 'side-effects/invasiveness' (characteristics of the treatment), 'dignified end-of-life' (broader effects of treatment), 'patient choice' (moral principles) and 'values' (moral principles).

[11] The following characteristics were placed under a different domain: the characteristic 'having dependents/family effect' was placed under the domain 'broader effects of treatment and the characteristics 'income/contribution' and 'equality' were placed under the domain 'moral principles'.

[12] The statement placed under the characteristic 'waiting lists/waiting time' was moved to the characteristic 'equality' and therefore the now empty characteristic 'waiting lists/waiting time was removed from the conceptual framework.

[13] EuroVaQ statement #12 (and therefore the corresponding characteristic 'health effects should be leading') and SVQ statements #35 and #37 were disregarded because they were deemed irrelevant for the purpose of the current study.

Thirdly, we investigated whether there were any omissions in the aspects covered by the updated conceptual framework. We updated the literature reviews underlying the theoretical framework from the EuroVaQ study [18, 129] by replicating the search strategy for recent years not covered in the reviews. In addition, we gathered material from Dutch newspaper articles, online discussion forums and current affairs programmes that discussed the increasing pressure on the health care budget, costly end of life treatments and priority setting in health care. Careful study of these materials revealed that no additional domains or characteristics of relevance for the purpose of this study.

Fourthly, the researchers reviewed the update conceptual framework and agreed to disregard five of the 25 characteristics, including the 10 corresponding statements. These five characteristics were considered either too specific or less relevant for the purpose of this study, or were observed to be less relevant in the original Q studies. The table included in Appendix 7.A lists the final 20 characteristics (second column), categorized into six domains (first column).

Fifthly, the remaining long-list of 116 potentially relevant statements was critically reviewed with the aim to develop a comprehensive and manageable short-list of statements for pilot-testing. The statements in each characteristic were grouped by the issue they addressed, and from the statements addressing the same issue a single statement was selected, or statements were combined. For example, EuroVaQ statement #4 stating that 'Patient characteristics like age, gender or income should play no role in prioritising between people' and SVQ statement #15 stating that 'Everybody, no matter what you are, whether you are young or old, should get the same access to and choice of treatment' were combined and edited into one general statement about equality : 'Patient characteristics other than their health should play no role in prioritising care' (#18). In this way, the long-list was reduced to a draft set of 48 statements.

Finally, because the statements originated from three different studies, with different backgrounds and aims, the two researchers reviewed the wording of all statements, and then separately translated them into Dutch and reached consensus about any differences.

The categorization, selection, editing and translation process was fully documented and critically reviewed by a third researcher [WB]. The translated set and other interview materials (i.e., instructions to participants and follow-up questions) were critically reviewed by two health economists and three lay persons, which led to minor changes in wording.

A sorting grid was designed to guide the ranking procedure, consisting of 9 columns, ranging from 'disagree most' on the left to 'agree most' on the right (see Figure 7.2).

7.2.3 Selection of respondents

In accordance with a previous Q study in this area [130], we anticipated that views on the relative value of health gains may be related to socio-demographic characteristics of respondents, like their age, level of education, having children and religious beliefs. In addition, because most of the scientific and popular discussion around end of life treatments concerns new and expensive cancer drugs, we were also interested in the views of people who have, or previously had, cancer.

Most participants were recruited by a professional recruitment agency. A total of 31 respondents, were sampled from the public in the Netherlands, according to age (18+), gender, education level and having children. Among these 31 was a group of 10 respondents who identified themselves as cancer patient or survivor. Sampling on the basis of religious beliefs was not possible. All respondents voluntarily signed up to participate in this study and received an incentive of €25 for participation. These respondents were interviewed in six group sessions that were held in the research studio of the recruitment agency and were moderated by two researchers [SW, JE]. Separate sessions (i.e., the third and fourth) were organized with people with personal experience with cancer (i.e., they identified themselves as cancer patient or survivor to the recruitment agency).

Because information about religious beliefs was not included in the database of the recruitment agency and some relevant subgroups (e.g., lowest education level, elderly above 70 years) failed to sign up for the study, 15 additional respondents were recruited by the research team, through their professional and social networks. For example, a number of elderly respondents were recruited through the database of a researcher that recently conducted a study in that target age group [191]. These respondents received no incentive for participation and were interviewed in their homes.

In total, we collected 46 Q-sorts: 31 in six focus group sessions and 15 in individual interviews.

7.2.4 Data collection

In the first part of the focus group sessions, respondents sat together at a large table and were briefly introduced to the topic and purpose of the study, and shown a two-minute video about the Dutch health care budget and its limits[14]. In the second part, respondents sat individually at smaller tables and were asked to perform the ranking of the statements. They were each provided with a set of statements printed on cards, a sorting grid (see Figure 7.2), step-by-step instructions for the study, and a response sheet. Respondents read the 48 statements and divided them into three piles: agree, neutral and disagree. Then, they read the statements in the agree pile once again and ranked them on the sorting grid according to agreement, working from the right side of the grid towards the middle (see Figure 7.2). Next, they repeated this step for the statements in the disagree pile, placing them on the left side of the sorting grid according to disagreement, working from the left side of the grid towards the middle. Lastly, they added the statements from their neutral pile to the grid, and checked the ranking of the statements and made adjustments until they were satisfied with the ranking as a whole. After completing the ranking exercise, they were asked to give a written explanation of the statements they most agreed and most disagreed with, to write a short statement reflecting their general view about priority setting in health care, and to complete a short questionnaire covering the sampling characteristics and a few additional questions. Finally, in the third part, respondents came back to the large table to round up the session with a group discussion on respondents' view of priority setting in health care and end of life as a special case [JE moderated the discussion; SW took notes]. We also discussed the comprehensiveness and intelligibility of the interview materials, which revealed no omissions or any other problems. This final third part of the focus group sessions was video recorded and transcripts of the discussions were provided by the recruitment agency. Because the first four focus group sessions did not result in any relevant suggestion for changes, the interview materials were confirmed as final and the discussion at the end of the session was skipped in the final two focus groups.

The 15 respondents who were interviewed individually were introduced to the topic and purpose of the study by the interviewer and then conducted the ranking exercise as described above (i.e., second part of the focus group sessions). The interviews were conducted by SW and JE.

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[14] This video - titled "Betaalbaarheid van de Zorg: welke keuzes moeten volgens u worden gemaakt?" - was released on YouTube (http://www.youtube.com/watch?v=k9IwvMhk3BM) in June 2012 by the Dutch Ministry of Health, Welfare and Sports as a part of a national campaign to increase awareness about the Dutch health care budgets and its limits; http://www.rijksoverheid.nl/onderwerpen/betaalbaarheid-van-de-zorg/de-zorg-hoeveel-extra-is-het-ons-waard.

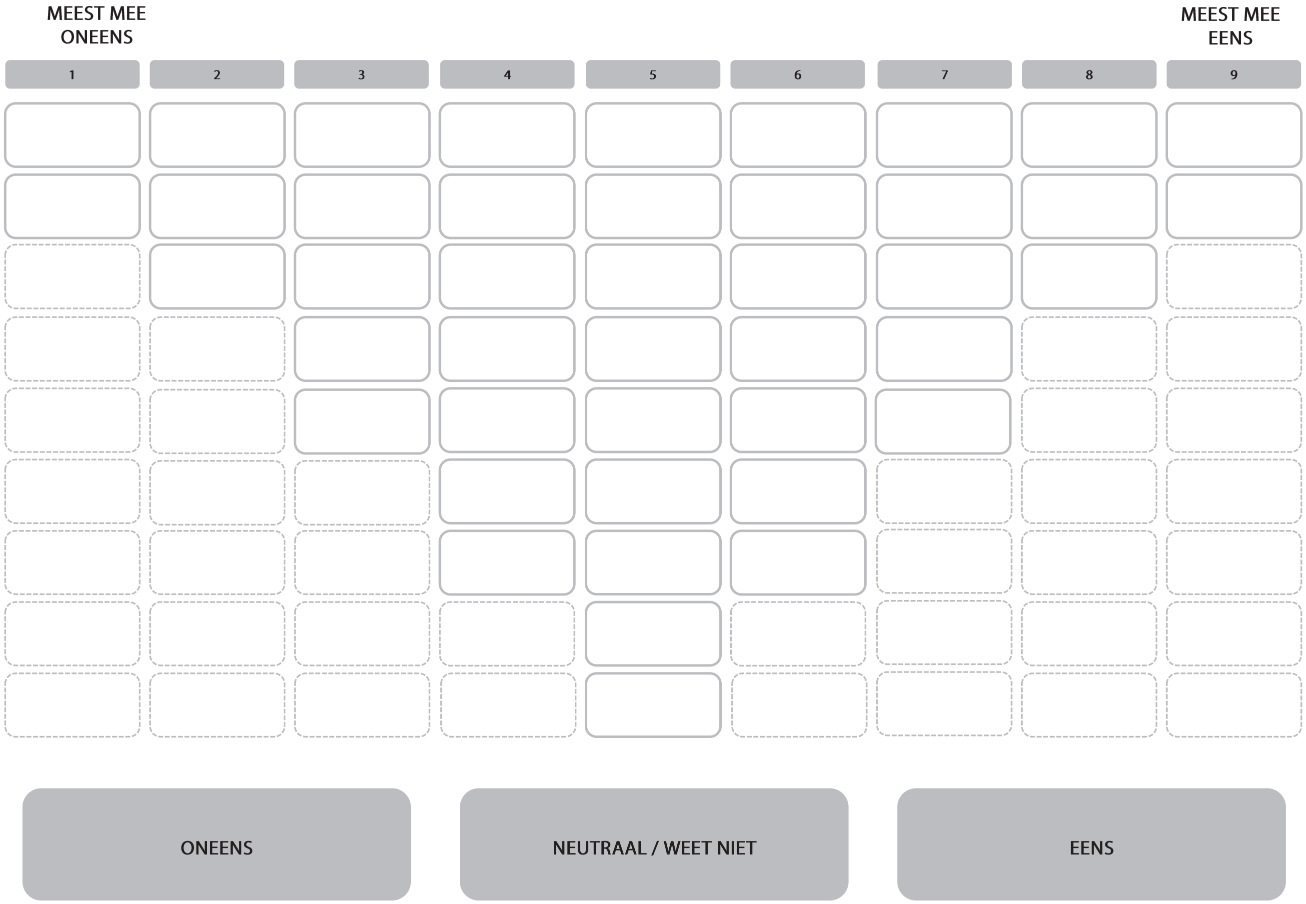


Figure 7.2 Sorting grid

7.2.5 Ethics

Respondents were given an information sheet describing the aim of the study, the task they were about to perform, the intended use of the data they would provide and how their anonymity was guaranteed. They were informed that their data would only be used if they agreed to participate in the study by signing the informed consent form at the end of the focus group session or interview. They were told they were allowed to stop at any point during the session or interview, in which case any data collected up to that point would be destroyed.

In the focus group sessions, respondents were informed about the video recording of the group discussions and all agreed to being recorded for the purpose of this study.

7.2.6 Data analysis

The ranking data collected from the 46 respondents was subject to by-person factor analysis using a dedicated software tool: PQMethod [192]. Preliminary analysis indicated that the data supported five factors, applying the following two criteria: (i) Eigenvalue > 1 and (ii) at least two defining sorts, i.e. respondents statistically significantly associated with a factor ($p<.05$) (henceforth called 'exemplars'). Based on inspection of the correlations between factors and attempts to interpret factors from different solutions, a three factor solution was chosen as the most interpretable and coherent reduction of the data.

An idealized ranking of the statements was generated for each factor by: (i) computing the weighted mean score for each statement on that factor (i.e., the score of the statement in the ranking of exemplars for that factor multiplied by the correlation coefficient of the participant with the factor); (ii) standardizing these scores with mean 0 and standard deviation 1, to make statistical comparison possible between factors with different numbers of associated participants; and (iii) ranking the statements from highest to lowest standardized score on the factor. This idealized ranking represents how a respondent with a 100% correlation with that factor would have ranked the 48 statements, and provides the statistical basis for interpretation and description of each factor. This is complemented with qualitative materials from the interviews of exemplars for that factor.

7.3 RESULTS

Table 7.1 presents the characteristics of the 46 participants and Table 7.2 presents their factor loadings. Highlighted in Table 7.2 are the results of the 11 respondents who had personal experience with cancer. Table 7.3 presents the composite sorts of the statements for the three factors. Correlations between the factor scores ranged between 0.12 and 0.59 (ρ=0.30 for 1 vs. 2; ρ=0.12 for 1 vs. 3; ρ=0.59 for 2 vs. 3). In what follows, all three shared viewpoints are described. Verbatim quotes from exemplars for each factor are used to illustrate the accounts described and noted in “” with respondent id numbers. The positioning of statements is given in parenthesis with the statement number indicated by # and the positioning on the grid, for the factor in question, following the statement number. An * beside the position on the grid indicates a statistically significantly different position (p<.01) for that statement in relation to the factor in question, relative to the other two factors.

Table 7.1 Sample characteristics (N=46)

Characteristic		**N (%)**
Age	18-35	10 (21.7%)
	35-55	24 (52.2%)
	55+	12 (26.1%)
Sex	Female	26 (56.5%)
	Male	20 (43.5%)
Education level	Low	15 (32.6%)
	Middle	11 (23.9%)
	High	20 (43.5%)
Children	No	35 (76.1%)
	Yes	11 (23.9%)
Religious[a]	No	16 (34.8%)
	Yes	9 (19.6%)
	Unknown	21 (45.7%)
Personal experience with cancer	No	35 (76.1%)
	Yes	11 (23.9%)

[a] Respondents were asked to which religious community or ideological grouping they considered themselves; those who indicated ‘none’ were categorized as not religious, all others were categorized as religious. The question about religiosity was not asked in the first four focus group sessions and therefore this information is unknown for these 21 respondents.

Table 7.2 Factor loadings

Respondent	Factor 1	Factor 2	Factor 3
Personal experience with cancer [a]			
005	0.43	0.63*	0.17
006	0.05	0.01	0.17
008	0.68*	0.31	0.08
011	0.75*	0.02	0.18
014	0.42*	-0.03	0.11
016	0.71*	0.06	0.16
018	0.77*	0.04	-0.01
019	-0.06	0.49*	0.42
021	0.76*	-0.07	0.12
022	0.74*	0.01	0.25
045	-0.13	0.14	0.00
No personal experience with cancer			
001	-0.30	0.47*	0.32
002	-0.03	0.15	0.60*
003	0.75*	0.18	0.01
004	0.29	0.53*	0.31
007	0.44*	0.26	0.25
009	0.52*	0.23	0.11
010	0.36	0.52*	0.04
012	0.76*	0.15	0.14
013	0.48*	0.08	0.30
015	0.43*	0.37	0.15
017	0.62	0.30	-0.06
020	0.12	0.02	0.49*
023	0.54*	0.36	-0.07
024	-0.20	0.13	0.48*
025	0.48	0.50*	-0.03
026	0.08	0.33	0.62*
027	-0.27	0.69*	0.48
028	0.15	0.70*	0.12
029	0.01	0.55*	0.38
030	0.25	0.56*	0.33
031	0.83*	0.09	0.05
032	0.14	0.41	0.49*
033	0.63*	0.14	-0.20
034	0.71*	-0.30	0.03
035	0.74*	0.18	-0.19
036	0.71*	0.07	0.13

Table 7.2 Factor loadings (continued)

Respondent	Factor 1	Factor 2	Factor 3
037	0.83*	-0.15	-0.05
038	0.01	0.09	0.29*
039	0.07	0.34*	0.05
040	0.78*	0.31	-0.20
041	0.61*	0.14	0.26
042	0.35*	0.22	-0.20
043	0.03	0.59*	0.39
044	0.20	0.14	0.27
046	0.30	0.26	0.38

Notes:

[a] *participants who identified themselves as cancer patient or survivor during recruitement.*

** denotes defining Q sort for factor, which means that Q sort loads statistically significantly (p<.05) on factor (i.e. correlation coefficient is larger than* $\frac{1.96}{\sqrt{48}} = 0.283$*) and is not confounded between factors (i.e. square of correlation coefficient on factor is larger than sum of squares of correlation coefficients on other two factors).*

Table 7.3 Factor scores per statement

Statement		F1	F2	F3
1	Access to health care should be based on need for care, not on other circumstances.	+4*	+2	+2
2	At the end of life it is more important to provide a death with dignity than treatments that will only extend life for a short period of time.	+2	+4*	+2
3	Children's health should be given priority over adults' health.	-1*	-3*	+4*
4	Everyone has a right to healthcare, but this does not extend beyond a certain basic level.	-1	-1	-1
5	If a special case can be made for expensive treatments for certain patient groups, an equal case could be made for other patient groups.	+1	+1	-1*
6	If a treatment is costly in relation to its health benefits, but the only treatment available, it should still be provided.	+2*	+1*	0*
7	If either 10 people could each get a large health benefit or 100 people each a small one, it is better to treat the 100 people.	0	0	-2*
8	If it is possible to save a life, every effort should be made to do so.	+3*	0	-2
9	People whose treatment has been unsuccessful should be given priority for further treatment over other people.	-1	-2	-2
10	If there is a way of helping patients, it is morally wrong to deny them this treatment.	+3*	+1	+1
11	If two groups of patients can benefit from a treatment equally, priority should be given to the patients whose quality of life before treatment is lowest.	-2	0	+1*
12	Individual responsibility should not be considered because it is never straightforward what the actual cause of illness is.	+2*	0*	-1*
13	It is more important to prevent ill health than it is to cure ill health once it occurs.	+2	+3	+2
14	It is more important to provide treatments that prolong life of people who are terminally ill than treatments that improve their quality of life.	-1*	-4	-4
15	It's not worthwhile spending money on expensive treatments for people who are not going to live very long anymore and won't benefit very much.	0*	+3	+3

Table 7.3 Factor scores per statement (continued)

Statement		F1	F2	F3
16	It's important to respect the wishes of patients who feel they should take every opportunity to extend their life.	+1*	-3	-1
17	Lifestyle should not be taken into account because people don't always have control over their way of living.	+3*	-3	-3
18	Patient characteristics other than their health should play no role in prioritising care.	+3*	0	-1
19	Patients at the end of life will grasp any slightest hope but that is not a good reason for continuing to provide treatment.	0*	+2	+1
20	Patients who provide for others should be prioritised.	-3	-2	-2
21	Patients with a family should be prioritised because their treatments will benefit others as well as the patient themselves.	-3	-1	-1
22	People should accept that if it's your time to die, it's your time.	0	+3*	0
23	People should be allowed to buy themselves priority treatment if it doesn't affect the treatment of others negatively.	-2	-2	-2
24	People who are in some way responsible for their own illness should receive lower priority than people who are ill through no fault of their own.	-2*	+2*	0*
25	People who have paid health care premiums all their lives deserve treatment when they need it.	+2*	0	0
26	People who have received a lot of health care in the past should take second place to people who have not received much health care yet.	-4	-4	-3
27	People who live a healthy life should be prioritized over people with an unhealthy lifestyle.	-3*	+1	+2
28	People with terminal conditions should be treated with priority over people with non-terminal conditions.	-2	-1	0
29	Poorer people should be given priority because they don't have the same opportunities in life.	-2	-2	-4*
30	Priority should be given to life-extending treatments to patients who have only recently found out that they are going to die soon.	0*	-3	-3
31	Priority should be given to patients who benefit most from treatment.	-1*	+1*	+4*
32	Priority should be given to those treatments that generate the most health.	+1	+1	+3*
33	Priority should be given to restoring health to a level that is sufficient for people to participate in their usual activities.	+1	+1	0
34	Priority should be given to younger people, because they may benefit from treatment for longer.	-3*	-1*	0*
35	Reimbursement of life-extending treatments should be decided on the basis of their cost and health benefits.	0*	+2	+3
36	The health system should be about getting the greatest health benefit overall for the population.	+2	+2	+2
37	The health system should be about looking after those patients in greatest need.	+1	0*	+1
38	There is no point providing treatments that will only extend life for a short time.	-1*	+2	+1
39	There is no sense in saving lives if the quality of those lives will be really bad.	0	+4*	-2
40	There's no use in providing treatment when the result is still a very poor state of health.	0*	+3	+2
41	Treating people at the end of life is important, even if it is not going to result in big health gains.	+1*	-1	-3

Table 7.3 Factor scores per statement (continued)

	Statement	**F1**	**F2**	**F3**
42	Treating terminally ill patients as more 'worthy' of receiving care undervalues the health of other patients.	0*	-1*	+1*
43	Treatment of illnesses that put a high burden on patients' families should receive priority.	-1	-1	0*
44	Treatments that are very costly in relation to their health benefits should be withheld.	-2*	0*	+1*
45	Treatments that provide a short life extension are only prolonging the pain for the patient's family and friends.	0	0	0
46	We should support patients' choice for treatment, even if it is very costly in relation to its health benefits.	+1*	-2	-1
47	You can't put a price on life.	+4*	0*	+3*
48	Younger people should be given priority over older people, because they haven't had their fair share of health yet.	-4*	-2*	0*

*Note: * p<.01*

7.3.1 Viewpoint 1

People holding this view consider the access to healthcare a basic human right: "Everyone has the right to the same level of care regardless of age or how long you can benefit from treatment" (id 3). All patients should be treated equally, because "Everyone is equal, so also in healthcare" (id 37) and "Every human being has the right to care, regardless of age, ethnicity, income etc" (id 18). Patient characteristics other than their health should play no role in prioritizing care (#18, +3), because to do so would be discriminating (id 3; id 18). In this viewpoint, 'access to care should be based on need for care, not on other circumstances' (#1, +4*). This need for care is an individual matter (id 3); every person is unique (id 11); and what constitutes "the right care" will be different for everyone (id 23). In line with this, people holding this viewpoint, more than those in the other viewpoints, believe that patients should be supported in their choices (#16, +1*; #46, +1*).

Distinctive for viewpoint 1 is the placement of almost all statements with an explicit reference to giving priority to some people over others on the left side of the grid. This holds for prioritization based on characteristics of the patient (#48, -4*; #34, -3*; #26, -4), characteristics of the illness (#28, -2; #27, -3*; #24, -2*), health effects of treatment (#11, -2; #31, -2*) and broader effects of treatment (#21, -3; #20, -3). Patients with terminal illnesses are no exception in this respect (#28, -2), but people holding this viewpoint also believe that 'if ways of helping patients exist, it is morally wrong to deny them the treatment' (#10, +3*) and 'if it is possible to save a life, every effort should be made to do so' (#8, +3*).

The placement of statements on cost-effectiveness suggest that people holding viewpoint 1 are not necessarily against providing treatments that have high costs in relation to their health benefits (#44, -2*; #6, +2*). In addition, distinguishing for this viewpoint is that there is no strong opinion about taking into account cost-effectiveness for end-of-life treatment (#35, 0*; 15, 0*), while people holding viewpoints 2 and 3 are in favour of doing so. Furthermore, in comparison with viewpoints 2 and 3, people holding viewpoint 1 are significantly more in agreement with respecting a patient's choice for treatment, even when the costs are high in relation to the health benefits (#46, +1*). A reason for this may be that they strongly agree with the statement that 'you can't put a price on life (#47, +4*). One exemplar states: "We should not think in terms of money when it concerns health, human beings and human rights" (id 23).

We call this viewpoint *'Equal right to healthcare'*.

7.3.2 Viewpoint 2

People holding this view have a strong concern for providing the right care for patients with terminal illnesses. They stress that 'the right care' is not necessarily the same as providing treatment; providing guidance towards acceptance and a dignified death may sometimes be more appropriate. This is reflected in their strong support for the statement: 'At the end of life it is more important to provide a death with dignity than treatments that will only extend life for a short period of time' (#2, +4*).

People holding viewpoint 2 believe that unnecessary treatments should be avoided: 'There is no use in providing treatment when the result is still a very poor state of health' (#40, +3). The results of treatments for terminally ill patients should be assessed in terms of quality of life (#39, +4*; #14, -4). One exemplar for this viewpoint states that treatment should only be considered "when the quality of life justifies treatment" (id 30) and another states: "Focus strictly on quality of life in the terminal phase. So no unnecessary treatments… Unnecessary treatments are life-extending treatments that decrease quality of life or at least do not increase it. Endless chemotherapy sessions instead of a nice trip to the Bahamas" (id 29).

An important aspect in viewpoint 2 is patients' acceptance of an approaching death (#22, +3*). One exemplar states: "In the end, healthcare cannot overcome death. We should not give ourselves the impression that it can" (id 28). In this context, one exemplar emphasizes the importance of a timely start of dialogue between doctors and their patients: "Doctors have the responsibility to explain what quality of life means, to guide patients towards accepting their death" (id 30). Another exemplar states that 'to treat or not to treat' is a discussion with the patient that needs to be initiated early (id 29). In line with this, people holding viewpoint 2 believe that patients' choices for treatment need not necessarily be supported (#16, -3; #46, -2). This is also reflected in their agreement with the statement: 'Patients at the end of life will grasp any slightest hope but that is not a good reason for continuing to provide treatment' (#19, +2).

People holding viewpoint 2 do not seem to place great importance on cost-efficiency as a criterion in health care decision making in general (#44, 0*), but they do acknowledge that providing treatments at the end life is not good use of money when health benefits are minimal (#15, +3; #35, +2). One exemplar states: "Money should play no role when someone can be helped", but also "A patient might want as much treatment as possible, but it is not possible to provide treatment at all costs, when health benefits are minimal" (id 4). Another exemplar states: "Spending a lot of money on treatments that only lengthen life for a short period of time, there are better ways to spend that money" (id 43).

Most of the statements that assign priority to specific groups of patients are ranked negatively, which suggests that no priority should be assigned based on those characteristics (#30, -3; #3, -3*; #48, -2*; #9, -3; #29, -2; #20, -2; #34, -2; #43, -2). One notable exception is priority setting based on people's own responsibility for their illness (#24, +2*). One exemplar explains: "If we have to choose between similar patients, both with lung cancer but one smokes and the other does not, then smoking may be taken into account" (id 27). Self-control issues are no reason to oppose against priority based on lifestyle (#17;-3). This respondent (id 27) holds the view that, in one way or the other, people always have some level of influence over their lifestyle choices.

People holding viewpoint 2 also emphasize the importance of prevention of disease (#13, +3). Three exemplars explicitly mention the importance of prevention (id 10, id 29, id 43), two of them in combination with lifestyle: "Prevention and lifestyle are important to work out" (id 29); "Spend more money on prevention. This starts early, with children. Own responsibility plays a role, but more in prevention than in treatments"(id 43).

We call this viewpoint '*Limits to healthcare'*.

7.3.3 Viewpoint 3

People holding this viewpoint are oriented towards the outcome of treatments. They believe that priority should be given to treatments that generate the most health and patients who benefit most from treatment (#31, +4*; #32, +3*). They agree with the statement that 'there's no use in providing treatments when the result is still a very poor health state' (#40, +2). Thus, patients' capacity to benefit from treatment is important in reimbursement decisions. As one exemplar states: "Treatments that generate hardly any health benefit should not be reimbursed" (id 32). In addition, health benefits should primarily be considered in terms of quality, and not length of life (#14, -4; #30; -3), which was also emphasized in viewpoint 2.

In viewpoint 3, assessing the effectiveness of treatments in relation to their costs seems more relevant than in viewpoints 1 and 2: 'Treatments that are very costly in relation to their health benefits should be withheld' (#44, +1*). This is also reflected in the attitude that people holding this viewpoint have towards treatments for terminally ill patients: 'It is not worthwhile spending money on expensive treatments for people who are not going to live very long anymore and won't benefit very much' (#15, +3). Thus, for end of life treatments, both the effectiveness and efficiency are important, which is reflected in the disagreement with the statement: 'Treating people at the end of life is important, even if it is not going to result in big health gains (#41, -3); and agreement with the statement: 'Reimbursement of life-extending treatments should be decided on the basis of their costs and health benefits' (#35, +3).

Notwithstanding the focus on cost-effectiveness, people holding viewpoint 3 agree with the statement: 'You can't put a price on life' (#47, +3*). As one exemplar explains, in this viewpoint this means: "We cannot determine *one* value for a life. It depends on many circumstances (current quality of life, and age in my opinion)" and "Balancing costs and benefits is important, but priority setting should not depend on it 100%. Other considerations could justify more expensive treatments being provided to specific patient groups" (id 2). One of these circumstances is the health of children: 'Children's health should be given priority over adults' health' (#3, +4*). Another one is lifestyle: 'People who live a healthy life should be prioritized over people with an unhealthy lifestyle' (#27, +2). One exemplar of this viewpoint explains that lifestyle may be taken into account because "People are to a large extent responsible for their own health" (id 38). People holding this viewpoint disagree with the statement that lifestyle should not be taken into account because people do not always have control over their way of living (#17, -3). In line with this, one exemplar gives priority to the health of children because they cannot be taken accountable for their lifestyle: "Children do not have the responsibility to live a healthy life (while the parents do). They should therefore be given priority over adults" (id 20).

We call this viewpoint *'Effective and efficient healthcare'*.

7.3.4 Consensus between the viewpoints

There was consensus between all three viewpoints that the ultimate aim of the health system is getting the greatest health benefit overall for the population (#36; 2, 2, 2).

In addition, there was consensus that certain criteria should not be used in priority setting. First, prior health consumption should play no role, which is reflected in disagreement with the statements: ‘People who have received a lot of health care in the past should take second place to people who have not received much health care yet’ (#26; -4, -4, -3); and ‘People whose treatment has been unsuccessful should be given priority for further treatment over other people’ (#9; -1, -2, -2). Secondly, income and contribution to the system should play no role either. There is consensus that no priority should be given to patients who provide for the family (#20; -3, -3 -2). In addition, there is shared disagreement with the statements: ‘People should be allowed to buy themselves priority treatment if it doesn’t affect the treatment of others’ (#23; -2, -2, -2); and ‘Poorer people should be given priority because they don’t have the same opportunities in life’ (#29; -2, -2, -4). This is motivated by the belief that socio-economic background should not affect people’s access to health care (“I believe that wealth should have nothing to do with health” (id 12, viewpoint 1)) and that buying priority treatment is unfair, because it differentiates people in their access to care based on ability to pay: “If people are allowed to buy themselves priority care, the rich have more opportunities for care, which is unfair in my opinion” (id 18, viewpoint 1); “It can never be the case that someone who has more money to spend gets priority in treatment” (id 4, viewpoint 2).

7.4 DISCUSSION

This study aimed to explore the views of the public in the Netherlands on a range of equity and efficiency considerations that have been argued to be relevant for health care decision-making, and whether these views express support for making a special case for treatment of people with a terminal illness. This work builds on three previous Q studies eliciting societal views in this area. The current study differs from two of the related studies [130, 170] by its particular interest in the relative value of costly end of life treatments, and from the third related study [164] by exploring end-of-life considerations within a broader context of societal preferences and by including a sample of people with experience of cancer. Furthermore, the results of the current study give insight into the heterogeneity in views in Dutch society and provide a broader understanding of the ongoing public debate on priority setting in health care in the Netherlands.

This study revealed three distinct views. Our first viewpoint, called ‘Equal right to healthcare’, is an egalitarian view in terms of emphasizing the importance of equality in opportunities and hence access to healthcare. It denies giving priority in any circumstance, because assigning priority to some patients at the cost of others conflicts with every person’s basic and equal right to healthcare. End of life situations are no exception, which translates in two directions. First, people with a terminal illness have the same right to healthcare as anyone else has, which means that they are entitled to treatment, even if this is expensive. On the other hand, no special case is made for anyone, including patients with a terminal illness. This implies that people associated with viewpoint 1 do not put higher social value on life-extending treatments for terminally ill patients. They are likely to disagree with policies that put priority on specific groups of patients and policies that restrict patient's access to the available care. Our second viewpoint, called 'Limits to healthcare', has a strong focus on setting limits on treatment for people with a terminal illness. People holding this viewpoint make a special case for these patients in the sense that they emphasize that the care that terminal patients receive should at all times respect the patients' quality of life and dignity. People holding this viewpoint would be likely to oppose provision of invasive treatments that may give only small life extensions at the cost of a dignified end of life. They would support policies aimed at improving patient awareness with respect to end of life decision-making on the one hand and prevention and lifestyle on the other hand. In addition, they may agree with policies that limit spending on costly end of life treatments when health benefits do not outweigh costs. Our third viewpoint, called 'Effective and efficient healthcare', is oriented towards the costs and effects of treatments. In addition, people holding this viewpoint have no moral objection to priority setting, which is in sharp contrast with people holding viewpoint 1. Compared to viewpoint 2, which is primarily oriented towards the costs and effects of treatments in end of life cases, viewpoint 3 makes a stronger case for cost-effectiveness as a criterion in decision-making in general. However, they also acknowledge that other circumstances, such as lifestyle and whether a child or an adult is treated, may affect the social value placed on health gains. People holding viewpoint 3 are most likely (as compared to people holding the other viewpoints) to agree with policies that prioritize treatments based on cost-effectiveness.

Overall, we found little support in the three views for the idea that health gains in terminally ill patients are more valuable than those in other patients. The statement stating that people with terminal conditions should be treated with priority over people with non-terminal conditions (#28) was ranked from -2 in viewpoint 1 to 0 in viewpoint 3, suggesting that people's opinion about this aspect is fairly neutral. In addition, people holding viewpoints 2 and 3 favoured incorporating efficiency arguments in decisions regarding the reimbursement of expensive life-extending treatments, which implies that they do not value these health gains higher than others. People holding viewpoint 1 do not wish to restrict access to care, and consequently also not to costly treatments, including those for terminally ill patients. However, they are unwilling to differentiate patients on any grounds, and therefore not more willing to pay for expensive treatments for terminally ill patients than for other groups of patients.

Our study included 11 respondents with personal experience with cancer. An interesting question therefore is whether this group of people differed in their views from the other respondents. The factor loadings of these 11 respondents (see Table 7.2) reveal that seven of them associated with viewpoint 1, two with viewpoint 2, none with viewpoint 3, and two did not associate significantly with any viewpoint. The qualitative data of our respondents (i.e. group discussions and interview materials) revealed that similar reasoning applied for choices made by exemplars throughout the sample, regardless of their personal experience with cancer, which suggests that respondents with and without experience with cancer generally did not substantially differ in their views on the topic. However, a remarkable finding from the qualitative data was that this group of cancer patients and survivors strongly emphasized the importance –and sometimes lack- of trust, dialogue and communication between medical specialists and patients. Just like exemplars for viewpoint 2, they stressed that patient involvement in treatment decisions is essential and identified a general tendency among medical specialists to focus on continuing treatment, while they (or fellow patients they talked about) did not always consider that to be in their own interest.

In this study, we built on three related Q-methodology studies [130, 164, 170], which allows for a comparison across studies. Equality in healthcare rights seems to be a central issue in health care priority setting. In line with our first viewpoint, both the EuroVaQ [130] and the SVQ [170] studies find viewpoints that stress the relevance of a basic right to healthcare. Entitlement to healthcare, the importance of access over outcome, and opposition to priority setting based on personal characteristics are central to these accounts.

A recurrent issue in all three abovementioned studies as well as the current one is the relevance of efficient and effective health care, which is reflected in our third viewpoint. Statements expressing the relevance of maximizing health benefits for the overall population, evaluating health benefits in relation to their costs and focusing on treatments that yield the largest health benefits are clustered in one viewpoint in all these studies. In addition, people holding such a viewpoint in general do not oppose priority setting (on moral grounds), but the issues that may be taken into account in such choices, for example patients' age, differ across studies.

Our second viewpoint that focused on end-of-life treatments and a concern for efficiency and not extending life just for the sake of it seems similar to one of the viewpoints in the MRC EoL study [164]. Nonetheless, people holding these viewpoints appear to differ in their perception of short life extension at the end of life. In our study, short life extensions were primarily associated with decreased quality of life and increased suffering from invasive treatments, at the cost of a dignified end of life and therefore considered as undesirable. In McHugh et al. [164], short life extensions were primarily associated with the additional time provided to patients and their families to say their goodbyes and put their affairs in order, thus contributing to a dignified end of life. This difference may be partly explained by the selection of statements in the current study. The MRC EoL study included specific statements about preparation for death, as for example: "It is important to give a dying person and their family time to prepare for their death, put their affairs in order, make peace and say goodbyes" (MRC EoL statement #11) and "It's important to provide life-extending treatments to give a dying person time to reach a significant milestone, like a family event or a personal achievement" (MRC EoL statement #47). The current study addressed this issue at a far more general level by statement #30 ("Priority should be given to life-extending treatments to patients who have only recently found out that they are going to die soon."). The broader context of our study required us to make a different selection of statements, and we judged this general statement to be more relevant in the context of health care priority setting. In addition, this difference in perception of short life extensions may also be explained by the socio-political context of the studies (i.e. the Netherlands vs. UK).

Our study, as well as the three abovementioned Q-methodology studies, reveal viewpoints that seem incommensurable. On the one hand, we find people who morally object to priority setting and restricting available care on the basis of universal rights to healthcare, thereby apparently denying the need to face issues of scarcity. On the other hand, we find people who accept priority setting as a necessary means to make decisions about allocation of a fixed health care budget, recognizing scarcity in health care resources, but differing in whether and how to weight the outcomes of healthcare. The tension between these viewpoints reflects an ethical debate between consequentialist reasoning, found in efficiency related viewpoints, and deontological reasoning, found in egalitarian viewpoints. Consequentialist ethics puts focus on the consequences of actions. It states that right acts are those that produce the best overall outcome, as judged from an impersonal standpoint that gives equal weight to the interests of everyone. Deontological (or agent-relative) ethics prohibits the performance of acts that violate our moral code of conduct, i.e. acts that are in violation of the duties and rights that we have, regardless of their outcomes [138].

Consequentialist and deontological ethics are difficult to reconcile. Indeed, people holding viewpoint 1 in our study may agree fully to the 'more health is better' principle, but believe that this does not justify a violation of people's basic rights and entitlements. Similarly, people holding viewpoint 3 may fully agree with the idea of universal rights and entitlements, but that does not justify unlimited spending on healthcare and on people whose benefit from treatment is limited. The challenge for policy makers is to find compromises that do justice to both “sides”, or to explain their choices to those people in society with opposing views.

Scarcity was a central point of departure for this study, but people whose views align with viewpoint 1 essentially seem to deny scarcity from the position that care is a basic right. The current study does not provide further insight into how people with this viewpoint reconcile a desire for unlimited access to healthcare with the reality of a limited healthcare budget, this would be an interesting topic for further study. Are these people willing to spend a larger proportion of public or personal budgets on healthcare, how much would that be, and at the cost of what else?

7.4.1 Limitations

It is important to highlight some limitations of our study. First of all, Q methodology may reveal the viewpoints society in the Netherlands holds, but it does not provide insight into the prevalence of these views among the public. Our results therefore do not provide clear policy guidance in this respect; for this purpose, additional research is needed to determine how common the viewpoints are. There are several techniques to examine factor membership in a representative sample of the public [170, 193, 194]. In such research, it may also be interesting to explore the relationship of factor membership with socio-demographic characteristics of respondents, their wider socio-political orientation, and their opinion with respect to specific choices in the context of health care priority setting, as faced by decision makers.

Secondly, we followed a careful procedure to obtain our statement set, but to arrive at our short list of 48 statements from our long list of 129 statements, choices were made. Our aim was to arrive at a comprehensive, manageable statement set reflecting the existing issues in society but given the broad scope of this topic, we acknowledge that different choices could have been made both in the detail of each individual statement and in the framework initially used to categorise statements and ensure that all domains of relevance were included. In addition, we aimed to develop a statement set that was balanced in presenting each aspect at a comparable level of abstraction and detail, to minimize the influence of our selection of statements on the possibility for respondents to reveal their viewpoint. In the pilot study participants were explicitly asked whether they missed any important topics in the statement set, and in the main study participants also had the opportunity to comment on the research materials. Based on this, we have no indication that we missed important domains or aspects in the development of the statement set. We believe that a different statement set representing the same domains and aspects (as shown in Appendix 7.A) is unlikely to expose substantially different underlying positions.

Thirdly, while we recruited respondents using a carefully designed sampling frame, it is difficult to be absolutely certain that data saturation was achieved (or is achievable) and that all different viewpoints in society are covered in this study. Additional research, alluded to above, investigating the prevalence of the three viewpoints in society identified here would be helpful. If such a study would expose sizeable groups of respondents that did not identify their views in any of the three viewpoints, this would indicate that other perspectives exist that we have failed to identify in this analysis.

7.4.2 Conclusion

This study has generated new understanding of the viewpoints in Dutch society about priority setting in health care in general, and in end-of-life situations in particular. Compared to the existing studies, this is the first to assess end-of-life considerations within a broader context of societal preferences. Three viewpoints, called '*Equal right to healthcare*', '*Limits to healthcare*', and '*Effective and efficient healthcare* ' were identified, but in none of these viewpoints we found direct support for making a special case for life-extending treatments for people with a terminal illness. This suggests that there may be little public support for the policy assumption that health gains in terminally ill patients are considered to be more valuable than those in other patients.

APPENDIX 7.A – FINAL SET OF 48 STATEMENTS ACCORDING TO DOMAINS AND CHARACTERISTICS FROM CONCEPTUAL FRAMEWORK

Domain	Characteristic	Nr	Statements
A. Characteristics of the patient	1. Age(ism) / fair innings	48	Younger people should be given priority over older people, because they haven't had their fair share of health yet.
		34	Priority should be given to younger people, because they may benefit from treatment for longer.
		3	Children's health should be given priority over adults' health.
	2. Prior health consumption / previous health profile	9	People whose treatment has been unsuccessful should be given priority for further treatment over other people.
		26	People who have received a lot of health care in the past should take second place to people who have not received much health care yet.
B. Characteristics of the illness	3. Severity	28	People with terminal conditions should be treated with priority over people with non-terminal conditions.
	4. Rule of rescue	8	If it is possible to save a life, every effort should be made to do so.
	5. Probable cause / culpability	27	People who live a healthy life should be prioritized over people with an unhealthy lifestyle.
		24	People who are in some way responsible for their own illness should receive lower priority than people who are ill through no fault of their own.
		17	Lifestyle should not be taken into account because people don't always have control over their way of living.
		12	Individual responsibility should not be considered because it is never straightforward what the actual cause of illness is.
C. Characteristics of the treatment	6. Availability	6	If a treatment is costly in relation to its health benefits, but the only treatment available, it should still be provided.
	7. Efficiency	44	Treatments that are very costly in relation to their health benefits should be withheld.
		35	Reimbursement of life-extending treatments should be decided on the basis of their cost and health benefits.
		15	It's not worthwhile spending money on expensive treatments for people who are not going to live very long anymore and won't benefit very much.

(continued)

Domain	Characteristic	Nr	Statements
D. Health effects of treatment	8. Size of the effect	32	Priority should be given to those treatments that generate the most health.
		36	The health system should be about getting the greatest health benefit overall for the population.
		37	The health system should be about looking after those patients in greatest need.
		41	Treating people at the end of life is important, even if it is not going to result in big health gains.
	9. Length vs. quality of life	39	There is no sense in saving lives if the quality of those lives will be really bad.
		14	It is more important to provide treatments that prolong life of people who are terminally ill than treatments that improve their quality of life.
	10. Distribution of fixed health gains / threshold effect	7	If either 10 people could each get a large health benefit or 100 people each a small one, it is better to treat the 100 people.
	11. Start-point before / end-point after treatment	11	If two groups of patients can benefit from a treatment equally, priority should be given to the patients whose quality of life before treatment is lowest.
		33	Priority should be given to restoring health to a level that is sufficient for people to participate in their usual activities.
		40	There's no use in providing treatment when the result is still a very poor state of health.
	12. Direction of the effect: health gain / loss avoidance	13	It is more important to prevent ill health than it is to cure ill health once it occurs.
	13. Capacity to benefit	31	Priority should be given to patients who benefit most from treatment.
		38	There is no point providing treatments that will only extend life for a short time.

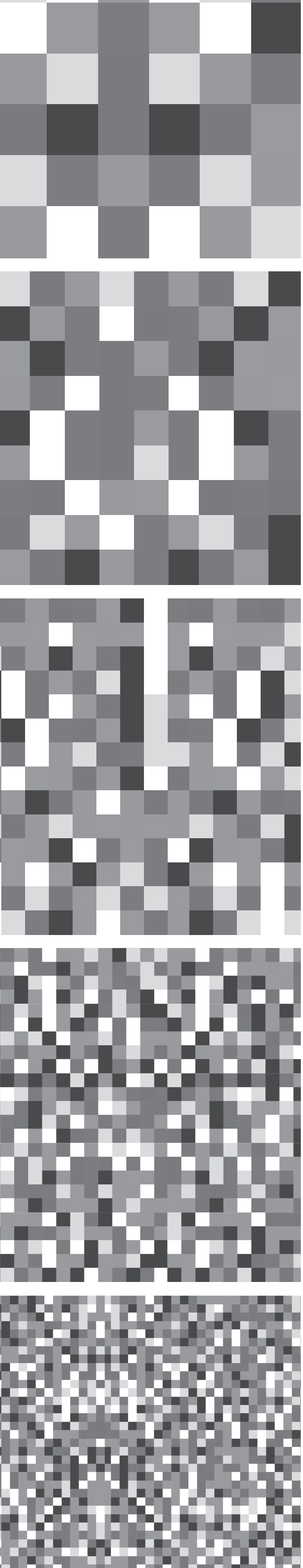
(continued)

Domain	Characteristic	Nr	Statements
E. Broader effects of treatment	14. Being dependent / caregiving effect	43	Treatment of illnesses that put a high burden on patients' families should receive priority.
	15. Having dependents / family effect / productivity	20	Patients who provide for others should be prioritized.
		21	Patients with a family should be prioritized because their treatments will benefit others as well as the patient themselves.
		45	Treatments that provide a short life extension are only prolonging the pain for the patient's family and friends.
	16. Dignified end of life	30	Priority should be given to life-extending treatments to patients who have only recently found out that they are going to die soon.
		2	At the end of life it is more important to provide a death with dignity than treatments that will only extend life for a short period of time.
F. Moral principles	17. Patient choice	46	We should support patients' choice for treatment, even if it is very costly in relation to its health benefits.
		16	It's important to respect the wishes of patients who feel they should take every opportunity to extend their life.
		19	Patients at the end of life will grasp any slightest hope but that is not a good reason for continuing to provide treatment.
	18. Values	22	People should accept that if it's your time to die, it's your time.
		47	You can't put a price on life.
		10	If there is a way of helping patients, it is morally wrong to deny them this treatment.
		4	Everyone has a right to health care, but this does not extend beyond a certain basic level.

(continued)

Domain	Characteristic	Nr	Statements
	19. Income / contribution	23	People should be allowed to buy themselves priority treatment if it doesn't affect the treatment of others negatively.
		29	Poorer people should be given priority because they don't have the same opportunities in life.
		25	People who have paid health care premiums all their lives deserve treatment when they need it.
	20. Equality	1	Access to health care should be based on need for care, not on other circumstances.
		18	Patient characteristics other than their health should play no role in prioritising care.
		5	If a special case can be made for expensive treatments for certain patient groups, an equal case could be made for other patient groups.
		42	Treating terminally ill patients as more 'worthy' of receiving care undervalues the health of other patients.

Note: five characteristics from the theoretical structure of the EuroVaQ project were disregarded: rarity, side-effects / invasiveness, certainty of the effect occurring, prospective health / prognostic difference, and productivity/work.



8

Discussion

8.1 INTRODUCTION

Health care systems are increasingly challenged in finding appropriate ways to allocate scarce health care resources. The demand for health care shows a rapid increase due to ageing of populations and advances in medical technology, while the available budget to supply health care remains limited. This scarcity in health care resources requires sensible choices to be made about the amount of resources to be invested in the health care sector as well as about to the allocation of those resources within the health care sector. The tension between people's (perceived) right to health care on the one hand and the necessity of priority setting on the other hand calls for prudent decision-making.

Economic evaluations may be used to support difficult choices about which treatments to fund and which not to fund within publicly financed health care systems. Economic evaluations compare the costs and health benefits of alternative interventions, allowing for choices based on efficiency in the use of scarce resources, while potentially being sensitive to equity concerns as well [9]. Their use supports the optimization of health benefits within an available budget and supports the aim to find the highest 'value for money'. This thesis aimed to contribute to the understanding of what 'value' means by investigating the importance of relative health values for decision-making in health care.

When people compare (absolute) health states with (implicit or explicit) reference points or reference standards, such comparisons may influence how they perceive these health states. Correspondingly, 'relative health' assessments may affect the value that people attach to health outcomes. Little is known about the role of such 'relative health assessments' for the evaluation of outcomes in health care, while they may have a significant role in preference formation. Therefore, the overall aim of this thesis was to investigate the extent and nature of relative health assessments and their impact on individual well-being and societal preferences in the context of health care priority setting.

The following research questions were addressed:

1. What are the extent and nature of positional concerns in the context of health? (Chapters 2 and 3)
2. Are reference points for health relevant for subjective well-being? (Chapter 4)
3. What are the empirical and normative implications of evaluating health relative to a reference level of acceptable health? (Chapters 5 and 6)
4. Do people in the Dutch society attach more weight to health benefits in certain groups of patients? (Chapter 7)

This final chapter discusses the main findings and limitations of this thesis and the research and policy implications, followed by the overall conclusions.

8.2 RELATIVE VALUES IN INDIVIDUAL DECISION-MAKING

In chapters 2 and 3, relative values for health at the individual level were investigated using different methods to examine 'positional concerns', i.e. people's tendency to evaluate how well-off they are by comparing themselves with other people. These chapters were complementary in the sense that chapter 2 presented a broad explorative study to investigate the existence of positional concerns for a range of health and health-care related attributes, whereas chapter 3 provided an in-depth analysis of the extent and nature of positional concerns for one particular health state, i.e. having back pain.

The results of chapter 2 showed that the prevalence of positional concerns was generally smaller for attributes in the health domain than for those in non-health domains. People could choose between a situation A or B. In situation A they had less in absolute terms than in situation B, but they were better off than other people. In situation B, they had more in absolute terms than in situation A, but they were worse off than others. For example, in situation A respondents would have a health of 6, graded on a scale from 1 to 10, while others had a health of 4, while in situation B they would have a health of 8 but others would have a health of 10. People showed positional concerns if they preferred situation A and no positional concerns when they preferred situation B. For the health attributes, 11 to 31% of the respondents had positional concerns, with own or one's children's life expectancy being among the attributes with the most positional concerns. Health grade (on a scale from 1 to 10) was among the attributes with the least positional concerns. For the non-health attributes, 22 to 47% of the respondents preferred the positional option, with attractiveness and intelligence of one's child being domains with the most positional concerns. Vacation time was among the domains with the least positional concerns.

The extended framework for positional concerns developed in chapter 3 relied on the idea that defining positional concerns in terms of status-seeking alone is only half the story to tell. The results of this study revealed that people do not only want to be better off than others (defined as spiteful positional concerns), they also want others to do well (defined as altruistic positional concerns). For both the health and the income domains, a considerable proportion of respondents showed no positional concerns (i.e. between 33 and 42%), but the majority did. In the health domain, more than in the income domain, altruistic positional concerns prevailed over spiteful positional concerns.

Chapters 2 and 3 addressed research question 1, aimed at investigating the extent and nature of positional concerns in the context of health. The results of these two studies revealed that the status people derive from being better off than others seems substantially smaller in the health domain than in several non-health domains, especially the income domain. This suggests that the relevance of conventional positional concerns is relatively small for health and health-related attributes. However, the extended framework of positional concerns showed that altruistic positional concerns were more relevant for the health domain than spiteful positional concerns. This suggest that both the extent of positional concerns, i.e. how strong they are, and their nature, i.e. whether they are spiteful or altruistic, affect how people value their own health position.

Chapter 4 adds to the previous two chapters by investigating a broader set of reference points for health and their relationship with subjective well-being (SWB). The results of this study suggest that health is associated with SWB and that this correlation works through both absolute and relative health. Assuming causality from health to SWB, this implies that changes in absolute *and* relative health may give rise to changes in SWB. With regard to the research question whether reference points for health are relevant for SWB, this study thus provided some evidence confirming this. However, some of the reference points were more strongly correlated with SWB than others. For the seven reference points included in the analysis, the discrepancy between the health one currently has and the health one feels to deserve was the strongest correlate with SWB.

8.3 RELATIVE VALUES IN SOCIETAL DECISION-MAKING

Chapters 5 and 6 centred around the idea that the social value of health benefits may be higher if they accrue to people in unacceptable health states than if they accrue to people in acceptable health states. A reference level of acceptable health may then be used as a criterion for health care priority setting. Chapter 5 was empirical in nature and explored the acceptability of non-perfect health states at different ages. Chapter 6 discussed the implications of setting an explicit reference level of acceptable health for the weights attached to health benefits to people in acceptable and unacceptable health states, and consequently for priority setting in health care.

The results of chapter 5 revealed that to some extent, health states worse than perfect health were considered to be acceptable by a sample of respondents from the adult population in the Netherlands. As viewed by respondents, the acceptability of health problems of people between the ages of 40 to 90 increased with progressing age. Only a small proportion of respondents (i.e. 2%) considered any level of health problems at any age unacceptable, reinforcing the idea that, to a certain extent, health deterioration becomes acceptable at some point in life. The results also revealed that older respondents considered more health deterioration acceptable for people between the ages of 40 to 90 than younger respondents. The implication of this finding is that based on the acceptability of health problems, priority for treatment may decline with age for a number of problems. From the total number of 50 attainable QALYs between the ages of 40 to 90, the average estimated acceptable QALY loss was between 15 and 20 QALYs. Chapter 6 revealed that setting an explicit reference level for acceptable health in priority setting has normative implications that need to be considered, and in some cases, may be too strong for an acceptable health approach. The analysis in this chapter also suggested that the moral validity and meaningfulness of a reference level and its usefulness in practice, may need to be traded off.

Chapters 5 and 6 addressed research question 3, aimed at investigating the empirical and normative implications of evaluating health relative to a reference level of acceptable health. Overall, these chapters indicated that the 'acceptability' criterion has potential as a basis for priority setting in favour of those in highest need, but the question of how to apply an acceptable health approach in practice, needs further attention. The implications of an acceptable health approach for the weights attached to health benefits in different people, as well as the required trade-off between feasibility and moral validity, requires further deliberation.

Chapter 7 took a broader societal perspective by investigating societal views on health care priority setting and their implications for the relative values attached to health benefits in certain groups of patients. A particular focus of this study was the relative value attached to health benefits generated by life-extending treatments for terminally ill patients. Three distinct viewpoints were distinguished. The first viewpoint was egalitarian in nature and stressed the importance of treating people equally and assigning no priority to any group of patients in particular. The second viewpoint emphasized that quality of life should be leading in decisions regarding end-of-life treatments and the third viewpoint focussed on effective and efficient care.

Chapter 7 addressed research question 4, investigating whether people in the Dutch society attach more weight to particular groups of patients, and the results for this were somewhat mixed. In viewpoint 1, the opposition against assigning priority to any group of patients implied equal values across patient groups, including the terminally ill. Contrary to viewpoint 1, in viewpoints 2 and 3 there were no moral objections against priority setting per se. There was little support for giving higher priority to terminally ill patients, but there was support for giving higher priority to other groups of patients.

Viewpoints 2 and 3 provided support for giving priority on the basis of individual responsibility and lifestyle and viewpoint 3 for giving higher priority to children.

8.4 LIMITATIONS

The studies presented in this thesis provide insight into the importance of relative values in the health domain, but some limitations need to be addressed.

The empirical results presented in this thesis are largely based on (online) questionnaires conducted in samples from the public in the Netherlands. The use of online questionnaires has the advantage that it allows for the efficient collection of larger sets of quantitative data in a relatively short period of time, and puts less strain on respondents than data collection in person. However, the use of online questionnaires has the disadvantage that it is more difficult to guide and monitor respondents through the exercises than in other methods of data collection, such as in-person interviews or laboratory experiments. This may lower the quality of the data, particularly when choice-tasks are complex and respondents have difficulty comprehending the exercises at hand. In addition, the use of online questionnaires gives little opportunity for the collection of qualitative data, while that may strengthen the interpretation of results. Indeed, in chapter 7, the qualitative data regarding respondents' motivation for their attitude towards statements proved to be of added value in the interpretation of the viewpoints.

The sole use of data of samples from the public in the Netherlands has implications for the generalizability of the results to other countries. Socio-economic, cultural and institutional differences between countries may influence attitudes towards outcomes and preferences at the individual and societal level, as well as response-styles [195, 196]. Therefore, caution is warranted with extrapolating the results to other countries and further research remains necessary. Nonetheless, preferences elicited in members of the Dutch public are relevant for policy-making in the Netherlands and data from representative samples of the population allow decision-makers to take a societal perspective.

The results of the studies on positional concerns (chapters 2 and 3) were obtained using stated preferences in hypothetical choice-scenarios, and not revealed preferences in real-life situations. Obviously, revealed preferences are more in line with real-life decision-contexts and may therefore be more directly translated into policy recommendations than results based on stated preference methods. In addition, stated preference methods may be more prone to reporting biases and biases in the interpretation of choice-options [197]. Nonetheless, the stated preference methods used in this thesis provided insights into health preferences in a broad range of hypothetical scenarios. For example, in chapter 3, the use of stated preference methods had the advantage that it allowed for a broad examination of potential states of the world and comprehensive variation in the endowments used. Moreover, distributing endowments over people in society may be done in a real-life setting in domains such as income, where experiments with real incentives are indeed conducted, but this is obviously more difficult if not impossible in the context of health.

The second part of this thesis focused on relative values in the societal context, but the current research does not – yet – justify conclusions about the extent of societal support for applying certain criteria in priority setting. Chapter 5 was descriptive in nature and refrained from the normative question whether acceptability should be used as a decision criterion. Chapter 6 discussed how an acceptable health approach may translate into explicit priority weights assigned to health benefits. Although this chapter discussed the underlying normative assumptions of such weighting, still little is known about society's view on these assumptions. Further research is needed to address this. Chapter 7 does not allow for conclusions about the prevalence of each of three observed viewpoints in society. Several techniques have been developed in the past few years to address this [170, 193], and a follow-up study may therefore focus on applying these in this context.

A general limitation of this thesis is its strong focus on the empirical investigation of reference points and relative values in the health context. This therefore leaves open relevant questions of whether and how to deal with these empirical findings in policy. The results of the first part of this thesis suggest that reference points and relative values influence how individuals evaluate outcomes, implying that outcomes in health policy may be valued differently from how policy-makers had anticipated based on absolute values. The results of the second part of this thesis suggest that the social value of health benefits may deviate from their absolute value, implying that policies may ignore important societal preferences when they fail to take into account relative values. Thus, an important, yet underexplored element of this thesis is how relative values may, or perhaps, should, be incorporated into policy-making.

8.5 RESEARCH IMPLICATIONS

This thesis aimed to contribute to the understanding of what 'value' means in the context of health and health care, by focusing on the importance of relative health values for decision-making in health care. Relative health was studied in the individual and societal context, but the novelty and explorative nature of this research in the health domain warrants future research. Such research may, for instance, assess the validity and reliability of the results presented in this thesis by replicating the studies in different settings and using other methods and instructions to respondents. Methodological extensions on this research are possible in several ways.

First, different methods can be used to assess the nature and extent of relative health assessments, as illustrated by the variety of techniques used in this thesis. An interesting avenue for future research is using discrete choice experiments (DCEs), which are increasingly used to elicit health and health care related preferences [157]. DCE's may be used to examine the relative weights attached to the absolute and the relative components of outcomes, in order to assess their relevance in relation to each other. For instance, in the context of positional concerns (chapters 2 and 3), DCE's may provide insight into the relative weights of positional and non-positional preferences. That is, while the methods used in these chapters assumed that people had either non-positional or positional preferences, and if positional, either altruistic or spiteful, people may also have a mix of preferences. DCE's may also provide more insight into the relative importance of different reference points, for example those investigated in chapter 4.

Second, different types of data may be used. Panel data may provide further insight into how absolute and relative health assessments behave over time and how they correlate with each other, corrected for coping and adaptation as well as for time-invariant factors such as personality. Multi-country data may be used to assess the influence of the socio-economic, cultural and institutional context, and hence the generalizability of the findings presented here to other societies.

Third, the preferences of the elderly population should receive more attention. The elderly population was underrepresented in the research presented here, while responses from this group may be highly relevant for the research questions addressed. The elderly constitute a large subgroup of health care 'consumers' in the Netherlands [198], and their perceptions and preferences may substantially differ from those of other groups in society. Their age, reference group, expectations, and (likely) experience with health problems may considerably influence their point of reference, and, correspondingly, the value attached to health outcomes. Mechanisms such as coping and adaptation to ill-health [106, 199] may play an important role in this responder group.

In addition to the abovementioned methodological suggestions for future research, this thesis provided several other avenues for future research. In line with chapters 2 and 3, investigating positional concerns for health, future research may use the extended framework of positional concern within different contexts and using various health variables. Indeed, while chapter 2 revealed that the prevalence of positional concerns was different across health variables, chapter 3 focussed on defining and measuring positional concerns for one health state (i.e. having back pain). Also, little attention was paid to investigating to whom people compare their own situation. Future research may investigate the size and composition of people's reference groups in the context of health. In line with chapter 4, investigating the correlation between reference points for health and subjective well-being (SWB), future research may investigate different types and conceptualizations of reference points for health, as well as the causality of their relation with SWB. Such research may increase the understanding of how improvements in absolute *and* relative health influence SWB, and thereby contribute to understanding how policies aimed at health improvements, affect individuals' well-being.

In line with chapters 5 to 7, investigating relative values in the societal context, future research may investigate whether, and if so, how, people trade-off health gains in different groups of people. With regard to the acceptable health approach (chapters 5 and 6), future studies may ask respondents to make explicit trade-offs between health benefits in people with unacceptable and acceptable health states. This may be informative for the question whether acceptable health may be used as a criterion for priority setting. If so, such research is also informative for the (implicit) value assigned to benefits above and below the acceptable health level and may provide input for an estimation of the shape, slope and curvature of an acceptable health weighting function. For the societal viewpoints expressed in chapter 7, future research may investigate whether these stated preferences are in line with revealed preferences in actual case-studies or real-life choices. The findings of chapter 7 suggest that one group of people in the Dutch population is fundamentally unwilling to make any trade-offs, while other groups may make trade-offs on various criteria. It would be interesting to assess how these viewpoints are reflected in choice-behaviour and policy preferences. In addition, it would be interesting to assess what happens with people's choice-behaviour if they are forced to make a choice (i.e. if there is no opt-out), even if they don't initially prefer to do so.

8.6 POLICY IMPLICATIONS

The overall finding of this thesis is that reference points and relative values may play an important role in the evaluation of health outcomes, at the individual and the societal level. These findings give rise to questions whether, how, and to what extent such relative values may, or should, be taken into account in societal decision-making. An important implication for health policy is that anticipated outcomes may be biased when relative values are not taken into consideration, while they in fact – implicitly or explicitly – do play a role in the value that is attached to health outcomes.

In economic evaluations, for example, welfare effects due to treatment may be misrepresented in the estimated 'health benefits' when these are measured on the basis of absolute, but not on relative values. At the individual level, treatment may affect subjective well-being through absolute and relative changes in health. The overall effect of treatment on well-being measured on the basis of absolute and relative effects may therefore deviate from measures only incorporating conventional (non-relative) health changes. At the societal level, absolute health improvements in some groups of patients may be valued higher by society than (similarly-sized) health improvements in other groups of patients, leaving a discrepancy between absolute health gains in patients (i.e. the conventional QALY gains) and their social value.

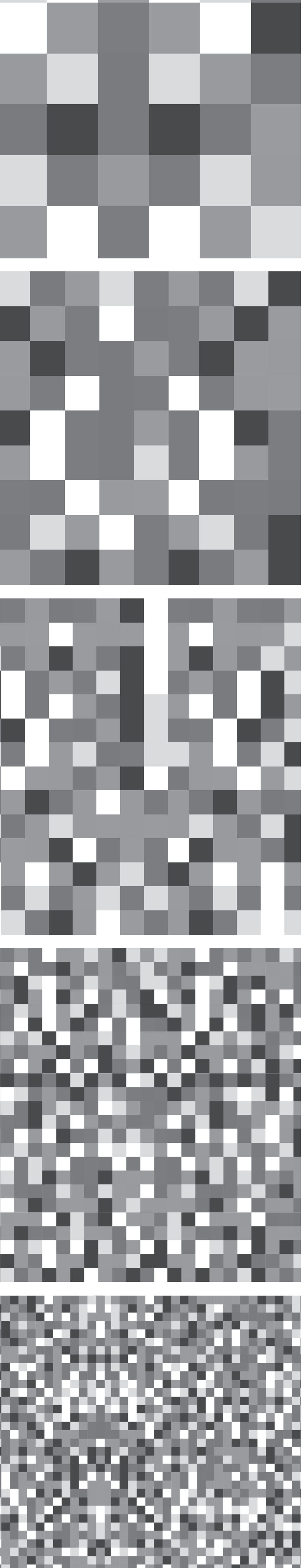
For more accurate estimates of the welfare effects of policy outcomes, policy-makers may want to put relative values, in some way, into the equation. In the context of economic evaluations, for instance, QALYs may in some way be weighted to incorporate relative values into decision-making. Conventional QALYs may then be adjusted on the basis of their broader welfare effects on individuals and society. However, such explicit incorporation of relative values into outcome measures also adds a level of complexity. At the individual level, reference points and relative values may introduce a great level of subjectivity to the valuation of health outcomes. This makes it increasingly difficult to compare outcomes across individuals, and thereby the overall welfare effects generated by health policies. At the societal level, the heterogeneity in preferences across society implies that there is not *one* definite and exhaustive relative value (or weight) that determines the social value attached to health benefits. This challenges policy-makers in incorporating social values in a practical manner, while also doing justice to societal preferences. A further difficulty for policy-makers is that little is known about the stability of relative health preferences over time and contexts, which may be susceptible to mechanisms such as coping and adaptation, as well as changing societal health standards and expectations.

At this point, there seems no self-evident answer to the question of how to deal with relative values in policy-making. Nonetheless, policy-makers are encouraged to recognize the role that relative values may play in the evaluation of health outcomes, and thereby their relevance for policy. Simultaneously, researchers are encouraged to increase the understanding of relative values, their role on outcome assessments and their potential to refine health valuation.

A further recommendation for policy-makers is related to the finding in chapter 7 specifically. This chapter identified a fundamental difference in the societal viewpoints on priority setting, which are difficult to reconcile. People who strongly focus on the right to health care consider priority setting to be ethically unacceptable and implicitly negate the idea that scarcity in health care resources is an innate problem. People who have no fundamental difficulty with priority setting and on the contrary endorse that scarcity may be a problem. This contradiction poses an obvious challenge for policy-makers. While decisions, and probably compromises that need to be made, are likely to benefit from broad support in society, such support may not be easily found throughout society given the different (incommensurable) viewpoints in its members. For this reason, policy-makers are encouraged to take an active lead in stimulating and shaping public debates that do not only focus on specific arguments in favour or against priority setting, but also on the underlying rationales. Such debates may result in some convergence of public views, or at least in an increased understanding of the consensus and discrepancies between the different viewpoints and their implications for (the support for) policies.

8.7 GENERAL CONCLUSION

Scarcity in health care resources requires sensible and well-founded choices to be made regarding the treatments that are provided through publicly funded health care systems. Comparisons between interventions may be made on the basis of their costs and health benefits, but this requires understanding of the value attached to such health benefits by individuals and society. This thesis aimed to contribute to this by providing more insight into the nature and extent of relative health values and their impact on individual well-being and societal preferences. Overall, the results presented in this thesis suggest that health value may consist of absolute *and* relative components, both at the individual and societal level. For determining the welfare effects of policies that aim to contribute to people's health, these findings imply that measurements on the basis of only absolute health assessments may be biased. However, more research into relative health values is warranted, as the research presented in this thesis was novel and explorative, and left many relevant questions unanswered. Therefore, more investigation into the role and implications of relative values and reference points in the health context is strongly encouraged.



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Summary

Health care systems face the challenge of how to allocate available resources in the best way. While the demand for health care increases for instance due to ageing of the population and increasing treatment options, the budget to supply health care remains limited. This means that there is scarcity in the available resources and that difficult choices need to be made about how to spend these. Economic evaluations can be used to support these choices. Economic evaluations compare the costs and benefits of alternative health interventions and can be used to identify the interventions with the lowest costs per unit of health gain generated. Therefore, economic evaluations can be used to optimize the amount of health generated within the available budget, providing the highest 'value for money'. In order to find such value for money, it is important to know what 'value' means. This thesis aimed to contribute to this by investigating relative health values.

'Relative health' assessments are comparisons that people make between absolute health states and implicit or explicit reference points. These relative health assessments may affect how people perceive health outcomes and the value they attach to these outcomes. This thesis investigated which reference points may play a role, and to what extent they play role in the evaluation of health outcomes. This was done both at the individual level (chapters 2 to 4) and at the societal level (chapters 5 to 7).

Chapters 2 and 3 investigated the extent and nature of positional concerns in the context of health. 'Positional concerns' describe people's tendency to evaluate how well-off they are by comparing themselves with other people. Two types of positional concerns were investigated. Spiteful positional concerns capture that people want to be better off than other people. Altruistic positional concerns capture that people want others to do well. Chapter 2 revealed that in the health domain, spiteful positional concerns were less prevalent than in several non-health domains. Chapter 3 revealed that in the health domain, altruistic positional concerns were more prevalent than spiteful positional concerns, and that they were more prevalent than in the income domain.

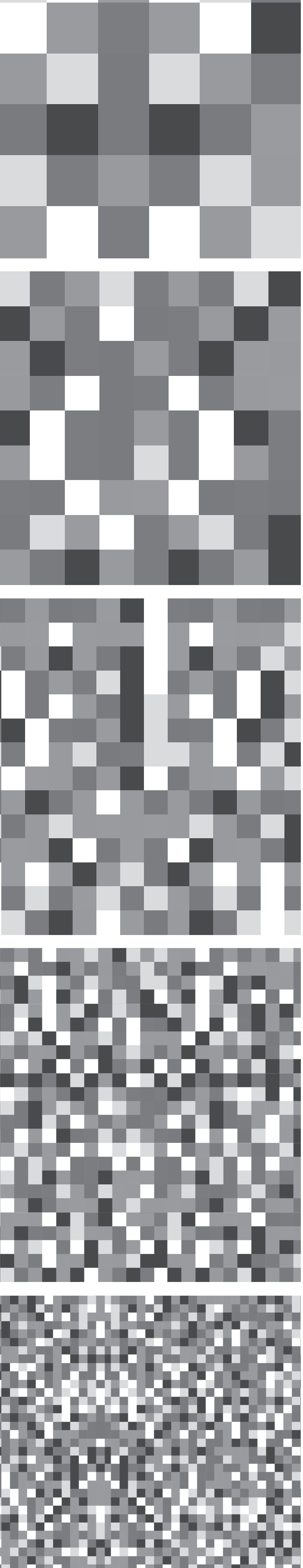
Chapter 4 investigated a broader set of reference points for health and their correlation with subjective well-being (SWB). The results revealed that both absolute health and health assessed in relation to reference points correlate with SWB. Assuming that health influences SWB, these results imply that changes in absolute *and* relative health may give rise to changes in SWB.

Chapters 5 and 6 focused on the empirical and normative implications of evaluating health relative to a reference level of acceptable health. The central assumption in these chapters was that the social value of health benefits gained in people in unacceptable health states is higher than the social value of health benefits to people in acceptable health states. Chapter 5 revealed that a distinction between acceptable and unacceptable health states can, empirically, be made. Chapter 6 revealed that it is important to be aware that making such a distinction has important implications for priority setting in health care. Furthermore, this chapter revealed that for the use of a reference level in practice, sacrifices need to be made in terms of moral depth. Overall, chapters 5 and 6indicated that the 'acceptability' criterion has potential for use in priority setting, but needs further attention.

Chapter 7 studied whether people in the Dutch society attach more weight to health gains in particular groups of patients. Little support was found for assigning higher priority to health benefits in terminally ill patients. There was some support for taking into account lifestyle, own responsibility for disease, and age (i.e. priority for children over adults), but there was one group in society who objected against any kind of priority setting. The latter group appeared to adhere to the notion that everyone has equal rights to health and health care.

The overall finding of this thesis is that reference points and relative values may play an important role in the evaluation of health outcomes, both at the individual and the societal level. The novelty and explorative nature of research on relative values in the health domain warrant future research. Such research may assess the validity and reliability of the results presented here by replicating these studies in different settings and using different methods. Future research may also address follow-up questions derived from the research presented in this thesis.

An important implication for health policy is that anticipated policy outcomes may be biased when relative values are not taken into consideration, while they in fact – implicitly or explicitly – do play a role in the value that is attached to health outcomes. For more accurate estimates of the welfare effects of policy outcomes, policy-makers may therefore wish to explicitly include relative values in the decision making process. However, at this point, how to do so remains unclear. Nonetheless, policy-makers are encouraged to recognize the role that relative values may play in the evaluation of health outcomes. Moreover, researchers are encouraged further investigate relative values, their role on outcome assessments, and their potential to refine health valuations.



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Samenvatting

De gezondheidszorg heeft te maken met de moeilijke vraag hoe we schaarse middelen op de beste manier kunnen besteden. Door onder andere vergrijzing van de samenleving en het beschikbaar komen van steeds meer behandelmogelijkheden, groeit de vraag naar behandelingen, terwijl het budget dat beschikbaar is voor gezondheidszorg beperkt blijft. Dit betekent dat moeilijke keuzen gemaakt moeten worden over hoe deze middelen besteed dienen te worden. Economische evaluaties kunnen hierbij helpen. Economische evaluaties vergelijken de kosten en baten van verschillende (alternatieve) behandelingen en kunnen gebruikt worden om er achter te komen welke behandelingen de laagste kosten hebben per eenheid gezondheidswinst. Door die behandelingen te vergoeden met de laagste kosten per eenheid gezondheidswinst, kunnen we de hoeveelheid gewonnen gezondheid met het beschikbare budget maximaliseren, waardoor we het meeste ´waar voor ons geld´ kunnen krijgen. Het is echter belangrijk in zulke berekeningen om te weten wat we verstaan onder gezondheidswinst. In dit proefschrift wordt een bijdrage geleverd aan deze vraag door onderzoek te doen naar relatieve gezondheidswaarderingen.

Als mensen gezondheidstoestanden vergelijken met referentiepunten die ze, al dan niet bewust, hanteren, krijgen absolute gezondheidstoestanden een relatief karakter. Ze worden dan gerelateerd aan impliciete of expliciete referentiepunten. Zulke 'relatieve gezondheidsbeoordelingen' kunnen beïnvloeden hoe mensen gezondheidsuitkomsten beoordelen en welke waarde ze aan de uitkomsten toekennen. In dit proefschrift is onderzocht welke referentiepunten een rol zouden kunnen spelen in de evaluatie van gezondheidsuitkomsten en hoe groot deze rol is. Dit is gedaan op het niveau van individuele besluitvorming (hoofdstuk 2 t/m 4) en op het niveau van maatschappelijke besluitvorming (hoofdstuk 5 t/m 7).

Hoofdstuk 2 en 3 onderzochten de mate en aard van 'positional concerns' in de context van gezondheid. 'Positional concerns' beschrijft het idee dat mensen geneigd zijn om zichzelf te vergelijken met anderen, en op basis daarvan hun eigen welzijn te evalueren. Twee typen positionele gevoelens zijn onderzocht. Het concept 'spiteful positional concerns' beschrijft dat mensen beter af willen zijn dan andere mensen. Het concept 'altruistic positonal concerns' beschrijft dat mensen graag zien dat anderen ook goed af zijn. De resultaten van hoofdstuk 2 lieten zien mensen minder geneigd zijn om beter af te willen zijn dan anderen in het gezondheidsdomein dan in een aantal andere domeinen. De resultaten van hoofdstuk 3 lieten zien dat in het gezondheidsdomein, altruistische gevoelens meer voorkomen dan competitieve gevoelens. Ook lieten de resultaten zien dat altruistische gevoelens sterker waren in het gezondheidsdomein dan in het inkomensdomein.

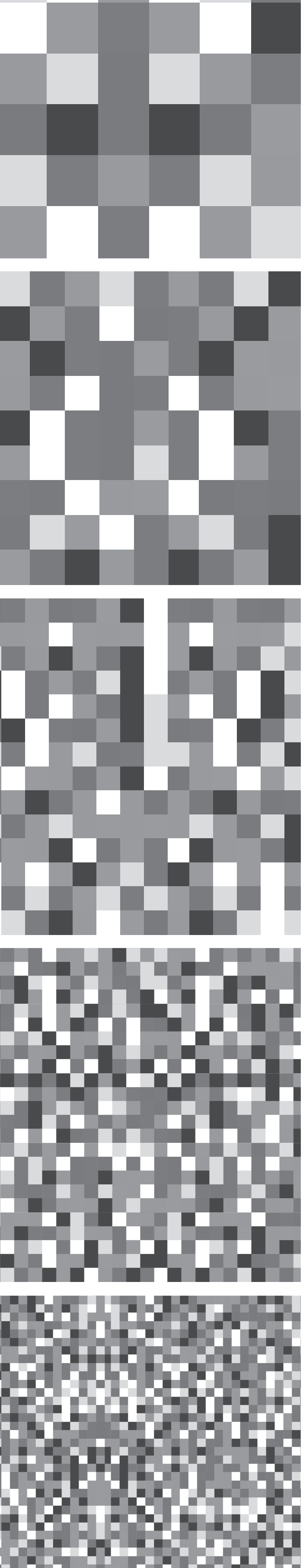
Hoofdstuk 4 onderzocht een bredere set van referentiepunten voor gezondheid dan de gezondheid van anderen alleen, en onderzocht ook hun correlatie met het subjectief welzijn (subjective well-being). De resultaten lieten zien dat zowel absolute als relatieve gezondheidsbeoordelingen correleren met subjectief welzijn. Wanneer aangenomen wordt dat gezondheid van invloed is op subjectief welzijn, wijzen deze resultaten er op dat veranderingen in absolute én in relatieve gezondheid kunnen leiden tot een toename in subjectief welzijn.

Hoofdstuk 5 en 6 gaan over het evalueren van gezondheid relatief aan een referentiepunt van acceptabele gezondheid. In deze hoofdstukken is ingegaan op de empirische en normatieve implicaties van het relateren van gezondheid aan dit referentiepunt. De aanname in deze hoofdstukken was dat we als maatschappij meer waarde zouden kunnen hechten aan behandeling van iemand in een onacceptabele gezondheidstoestand dan aan behandeling van iemand in een acceptabele gezondheidstoestand. De maatschappelijke waarde van gezondheidswinst voor iemand in een onacceptabele toestand zou dan hoger zijn dan de maatschappelijke waarde van eenzelfde gezondheidswinst voor iemand in een acceptabele toestand. Hoofdstuk 5 liet zien dat mensen een onderscheid kunnen maken tussen onacceptabele gezondheid en acceptabele gezondheid. Hoofdstuk 6 liet zien dat daadwerkelijk keuzes maken op basis van dit onderscheid grote (ethische) gevolgen kan hebben voor de prioriteit die wordt gegeven aan bepaalde behandelingen. Ook liet dit hoofdstuk zien dat er een wisselwerking is tussen de praktische toepasbaarheid van acceptabele gezondheid als criterium voor besluitvorming, en de morele onderbouwing van het criterium. In zijn algemeenheid lieten deze twee hoofdstukken zien dat acceptabele gezondheid mogelijkheden biedt voor de prioritering binnen de gezondheidszorg, maar dat vervolgonderzoek noodzakelijk blijft.

Hoofdstuk 7 onderzocht of mensen in de Nederlandse maatschappij meer waarde toekennen aan gezondheidswinst in bepaalde groepen patiënten dan aan gezondheidswinst in andere groepen patiënten. Deze studie vond weinig steun voor het toekennen van hogere prioriteit aan patiënten die terminaal ziek zijn en nog maar kort hebben te leven. Er was enige steun voor het in besluitvorming meenemen van leeftijd, leefstijl en eigen verantwoordelijkheid voor ziekte. Echter, er bleken ook mensen in de maatschappij te zijn die geen enkele patiëntengroep voorkeur wil geven boven anderen. Deze groep in de maatschappij vindt dat iedereen gelijke rechten op gezondheid en gezondheidszorg heeft.

De resultaten in dit proefschrift wijzen erop dat referentiepunten en relatieve waarden een belangrijke rol kunnen spelen in de beoordeling van gezondheidsuitkomsten, op het niveau van individuele en maatschappelijke besluitvorming. Omdat onderzoek naar referentiepunten en relatieve waarden nieuw is in het domein van gezondheid en gezondheidszorg, is vervolgonderzoek noodzakelijk. Onderzoek kan gedaan worden naar de validiteit en betrouwbaarheid van de resultaten die gepresenteerd zijn in dit proefschrift. Dit kan worden gedaan door de gepresenteerde studies te herhalen in verschillende en andere contexten, en met gebruik van verschillende methoden.

Een belangrijke implicatie van het onderzoek in dit proefschrift is dat vooraf geschatte uitkomsten van gezondheidszorgbeleid op het welzijn van mensen onjuist kunnen zijn. Dit kan het geval zijn wanneer beleidsmakers in hun verwachtingen geen rekening houden met relatieve uitkomsten, terwijl relatieve waarden in feite– impliciet of expliciet – wel een rol spelen. Voor betere en preciezere schattingen van welzijnseffecten van beleidsuitkomsten zouden beleidsmakers daarom ook relatieve waarden expliciet mee kunnen nemen in het besluitvormingsproces. Echter, op dit moment is er onvoldoende kennis om te weten hoe dit gedaan kan worden. Toch worden beleidsmakers naar aanleiding van dit proefschrift aangemoedigd om de rol die relatieve waarden kunnen spelen, te onderkennen. Onderzoekers worden aangemoedigd om verder onderzoek te doen naar relatieve waarden in het gezondheidsdomein, de rol die relatieve waarden spelen in de beoordeling en evaluatie van uitkomsten, en de mogelijkheden om gezondheidswaarderingen op basis van relatieve waarden te verbeteren.



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PhD portfolio

PhD Training

2014	Wetenschapsfilosofie, Faculty of Philosophy, Erasmus University Rotterdam
2013	Ethische kwesties, Faculty of Philosophy, Erasmus University Rotterdam
2013	Archeologie van het Economische denken, Faculty of Philosophy, Erasmus University Rotterdam
2013	Training scriptiebegeleiding en -beoordeling, De Loef Training, institute of Health, Policy and Management, Erasmus University Rotterdam,
2013	Inleidende module docentprofessionalisering, De Loef Training, institute of Health, Policy and Management, Erasmus University Rotterdam,
2013	Workshop Q Methodology, 29th Annual Q-conference, Amsterdam
2012	Inleiding Epistemologie, Faculty of Philosophy, Erasmus University Rotterdam
2012	Cognitie en bewustzijnsfilosofie, Faculty of Philosophy, Erasmus University Rotterdam
2012	Inleiding metafysica, Faculty of Philosophy, Erasmus University Rotterdam
2012	Dialectische filosofie en differentiedenken, Faculty of Philosophy, Erasmus University Rotterdam
2012	Workshop groepsdynamiek, Risbo Research-Training-Consultancy, Erasmus University Rotterdam
2011	Ethical aspects of Economics, Faculty of Philosophy, Erasmus University Rotterdam
2011	Risk & Rationality, Tinbergen Institute, Amsterdam
2011	Academic Writing in English, institute of Health, Policy and Management, Erasmus University Rotterdam

Teaching

2014	Workgroups Methoden en Technieken 2, bachelor Gezondheidswetenschappen, institute of Health, Policy and Management, Erasmus University Rotterdam
2014	Workgroups and supervision Writing and research skills for premaster students, premaster program institute of Health, Policy and Management, Erasmus University Rotterdam
2012 - 2013	Workgroups Inleiding gedragseconomie, bachelor Economie en Bedrijfseconomie, Erasmus School of Economics, Erasmus University Rotterdam
2012	Workgroups Methoden en Technieken 1, bachelor Gezondheidswetenschappen, institute of Health, Policy and Management, Erasmus University Rotterdam

Presentations at conferences

2014	Podium presentation at the 10th World Conference in Health Economics (joint IHEA & ECHE conference), Dublin
2014	Podium presentation at the 16th Conference on the Foundations of Utility and Risk (FUR), Rotterdam
2014	Podium presentation at the Nederlands Congres Volksgezondheid 2014 (NCVGZ), Rotterdam
2013	Podium presentation at the 9th International Meeting on Experimental and Behavioural Economics (IMEBE), Madrid
2012	Poster presentation at the 11th TIBER Symposium on Psychology and Economics, Tilburg

Presentations at other meetings

2013	EIPE PhD student seminar, Erasmus Institute of Philosophy and Economics, Erasmus University Rotterdam
2012	iBMG research seminar, Institute of Health Policy and Management, Erasmus University Rotterdam

Other meetings and conferences

2013	29th Annual Q Methodology Conference, Amsterdam
2012	5th Maastricht Behavioural and Experimental Economics Symposium (M-Bees), Maastricht
2012	4th Lowlands Health Economics Study Group (LoLa HESG), Almen

Scientific publications

Wouters, S., van Exel, N. J. A., van de Donk, M., Rohde, K. I. M., & Brouwer, W. B. F. (2015). Do people desire to be healthier than other people? A short note on positional concerns for health. The European Journal of Health Economics, 16 (1), 47-54

Wouters, S., van Exel, N. J. A., Rohde, K. I. M., & Brouwer, W. B. F. (2015). Are all health gains equally important? An exploration of acceptable health as a reference point in health care priority setting. Health and Quality of Life Outcomes, 13 (1), 1.

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About the author

Sofie Wouters was born on June 21th 1989 in Zoetermeer. In 2011 she obtained her Master's degree in Economics and Business, with specialization Health Economics, at the Erasmus University Rotterdam. After finishing her Master's, she started working as a PhD student at the Institute of Health Care Policy and Management at the Erasmus University in Rotterdam on a joint research position with the Behavioural Economics Group at the Erasmus School of Economics. During her studies, she also started in a Bachelor program Philosophy of Economics at the Erasmus University Rotterdam, which she continued during her PhD until and resulted in obtaining a Ba degree in 2014.

Her research focused on priority setting, defining health outcomes, relative health assessments and health perceptions, and social decision-making. She has a broad research interest in the areas of Health Economics, Behavioural Economics and Philosophy and combined insights from these field in her research.

Since March 2016, Sofie works as a financial advisor at the Ministry of Health, Welfare and Sports.

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Absolutely Relative

on the value of health outcomes

The resources available for health care are scarce. While the demand for health care increases, for instance due to ageing of the population and increasing treatment options, the available budget is limited. This means that difficult choices need to be made about how to spend these resources optimally. Economic evaluations may guide such choices. They compare the costs and health benefits of alternative interventions and identify which interventions provide most 'value for money'. Understanding what health 'value' means, is essential for making such comparisons. This thesis contributes to this by investigating one component of health 'value': relative health value.

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