

Linköping University Medical Dissertation No. 1215

The Art of Saying No

The Economics and Ethics of Healthcare Rationing

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Linköping University
FACULTY OF HEALTH SCIENCES

Linköping 2011

Edition 1:1

ISBN 978-91-7393-282-0

ISSN 0345-0082

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Cover artwork and design: Marit Furn

Webpage: www.maritfurn.se

Printed in Sweden by LiU-Tryck, Linköping, Sweden, 2011

To the Tinghögs

I'm gonna run to you – Bryan Adams

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ABSTRACT

It follows from resource scarcity that some form of healthcare rationing is unavoidable. This implies that potentially beneficial medical treatments must be denied to patients to avoid unacceptable sacrifices in other areas of society. By focusing on four, core, conceptual themes – individual responsibility, paternalism, incentives, and inequality – this thesis explores the matter of finding justifiable grounds for saying no in the context of health care.

By combining the perspectives of welfare economics and population-level ethics, the author explicate and discusses conflicting moral values involved in healthcare rationing. Four papers form the foundation for this thesis. Paper I articulates the potential role of individual responsibility as a welfare-promoting, rationing tool by exploring when healthcare services exhibit characteristics that facilitate individual responsibility for private financing. Paper II explores the normative relevance of individuals' time preferences in healthcare rationing and when paternalism can be justified in the context of individuals' intertemporal health choices. Paper III examines the compatibility between incentive-based organ donation and the ethical platform for setting priorities in Sweden. Paper IV empirically investigates the existence of horizontal inequalities in using waiting lists to ration care.

From the discussion it is suggested, *inter alia*, that: I) Prospective responsibility as opposed to retrospective responsibility is a more productive notion of responsibility when discussing actual policies. However, potential positive effects need to be weighed against the increased economic inequality that it is likely to invoke. II) Although cost-effectiveness analysis provides valuable input when making rationing decisions it should not be viewed as a decision rule, since it is based on utilitarian values that constantly need to be balanced against other nonutilitarian values. III) Potentially, increased health could negatively affect individuals' well-being if it creates opportunities that they are unable to take advantage of. This needs to be taken into account before embarking on paternalistic policies to improve health – policies that often target the lower socioeconomic segment.

The author concludes that decisions on rationing cannot be computed through a simple formula. Moreover, given that rationing is bound to be associated

with reasonable disagreements we are unlikely to ever fully resolve these disagreements. However, by explicitly stating conflicting moral values we are more likely to narrow the disagreements and achieve a healthcare system that is both fairer and more efficient.

LIST OF PAPERS

- I. Gustav Tinghög, Carl Hampus Lyttkens and Per Carlsson.
Individual Responsibility for What? – A Conceptual Framework for Exploring the Suitability of Private Financing in a Publicly Funded Health-Care System. *Health Economics Policy and Law* (2010) vol. 5: 201-223
- II. Gustav Tinghög.
Discounting, Preferences, and Paternalism in Cost-Effectiveness Analysis. *Submitted*
- III. Faisal Omar, Gustav Tinghög and Stellan Wellin.
Incentivizing Deceased Organ Donation: a Swedish Priority Setting Perspective. *Scandinavian Journal of Public Health (in press)*
- IV. Gustav Tinghög, David Andersson, Petter Tinghög, Carl Hampus Lyttkens.
Horizontal Inequality when Rationing by Waiting Lists. *Submitted*

ABBREVIATIONS

A4R	Accountability for Reasonableness
CEA	Cost-Effectiveness Analysis
DALY	Disability Adjusted Life Years
DU	Discounted Utility
EQ-5D	EuroQol 5-Dimension
OECD	The Organisation for Economic Co-operation and Development
PTO	Person Trade Off
QALY	Quality Adjusted Life Years
SG	Standard Gamble
SF-36	The Short Form (36) Health Survey
TTO	Time Trade Off
VAS	Visual Analogue Scale

INTRODUCTION

It is an unfortunate, but unavoidable, truth about the world that not all theoretically feasible enhancements to health and wellbeing can, or even should, be attempted. All healthcare systems must decide how to set limits, explicitly or implicitly, efficiently or inefficiently, fairly or unfairly. The idea of rationing health care might seem like cold-hearted policymaking to many. However, resources are not limitless. Moreover, health care is not the only worthy societal goal, but needs to be weighed against other important goals, such as education and personal security. Hence, from a societal perspective, healthcare rationing is both inevitable and highly desirable. As the subtitle suggests, this thesis approaches the inevitable but delicate matter of healthcare rationing from two nonmutually exclusive perspectives – that of the economist and that of the ethicist.

Rationing is not an uncommon phenomenon. Quite the opposite, it is an activity that most of us engage in on a daily basis. We might, for instance, prefer to have filet mignon instead of sausage for dinner, but choose the latter since our available financial resources are insufficient to pay for our preferred choice. When setting limits in health care this everyday activity suddenly becomes very uncomfortable and morally intricate. Denying care can result in severe consequences and even carry life and death implications. Consequently, saying no is something that goes against common moral intuitions of always trying to help identifiable individuals in need. How to make rationing decisions on justifiable grounds is therefore both an ethically and politically sensitive matter. Hence, rationing has become an area that most decision-makers prefer to shy away from, and they let rationing happen by default. However, ignoring the issue of rationing, or making decisions implicitly, will lead to decisions which are more likely to be dubious and unfair.

Traditionally it has been difficult to get decision-makers to explicitly acknowledge the inevitable need to ration health care. In the United States, attempts to discuss rationing have been met by forceful resistance. The

creation of infamous concepts like “death panels”¹ has made rationing a topic that cannot be discussed openly – arguably, contributing to the most inefficient and unequal healthcare system in the developed world. In other parts of the developed world, the idea of explicit rationing has also met resistance (although not as forcefully as in the US). In Sweden, an explicit “not-to-do list” that was introduced in 2003 was promptly labeled the “blacklist” and invoked a public outcry, which forced politicians to retreat and once again rely on implicit rationing (Bäckman, Lindroth et al. 2005; Bäckman, Karlsson et al. 2006). Thus, saying no is associated with much less praise than saying yes. Barrack Obama’s presidential campaign had good reasons to choose “yes we can!” as its slogan for the 2008 presidential election in the United States, although given the financial situation a more appropriate slogan might have been “no we can’t!” Society can’t give what it doesn’t have (at least not in the long run). This thesis explores the delicate matter of finding justifiable grounds for saying no in the context of health care, focusing on four core conceptual themes; *individual responsibility*, *paternalism*, *incentives*, and *inequality*.

From a more abstract perspective, rationing involves two general moral aims; to allocate resources in a way that yields the greatest possible contribution to health, and to distribute these resources as fairly as possible. These aims often come into conflict, calling for careful consideration of both the economic and ethical aspects at hand. Hence, rationing always involves a value judgment when balancing these core objectives. As with most value judgments, rationing is bound to be associated with reasonable disagreements concerning what solution is the best. The four conceptual themes upon which this thesis is built are intended to highlight some areas where reasonable disagreements are likely to occur.

Thesis Aim

The general aim of this thesis is to combine the perspectives of economics and ethics for exploring how to balance fairness and efficiency in healthcare rationing. More specifically, the thesis will apply these two perspectives to four conceptual themes – *individual responsibility*, *paternalism*, *incentives*, and *inequality* – in the context of healthcare rationing. Each of the conceptual

¹ Former Alaska Governor and US vice president candidate Sarah Palin used this concept in referring to healthcare legislation aimed at reducing healthcare spending.

themes corresponds to the main focus of a specific paper included in this thesis:

Paper I articulates the potential role of individual responsibility as a welfare-promoting, rationing tool by exploring when healthcare services exhibit characteristics that facilitate individual responsibility for private financing.

Paper II explores the normative relevance of individuals' time preferences in healthcare rationing and when paternalism can be justified in the context of individuals' intertemporal health choices.

Paper III examines the compatibility between incentive-based organ donation and the ethical platform for setting priorities in Sweden.

Paper IV empirically investigates the existence of horizontal inequalities in using waiting lists to ration care.

A Short Note on Disposition

It should be noted that the composition of this thesis varies somewhat from that of a traditional thesis. "Traditional" in this sense would imply supplementing the papers with a comprehensive summary (a so-called "frame story") that streamlines the findings of the consecutive papers. The present frame story is not a comprehensive summary of the consecutive papers. Instead, it should be viewed as a comprehensive summary of the contextual and theoretical landscape to which the consecutive papers relate.

In considering this thesis, a fundamental factor that needs to be recognized at the outset is my background as a trained economist. The four papers included in the thesis have been primarily written from and evaluated against the welfare-economic assumption that the most desirable rationing policy is the one that best promotes overall welfare in society. Although issues related to fairness and rationing are present in each of the papers, they are not as thoroughly explored as issues related to efficiency and rationing. Hence, the discussion of this frame story is divided into two chapters; one focusing on the main findings of the papers in relation to the conceptual themes, and another which extends this discussion by applying a broader ethical perspective focusing on fairness issues related to the conceptual themes.

This frame story proceeds as follows. Chapter 2 is devoted to a methodological discussion, which specifies the scope and point of departure of this thesis.

Chapter 3 is divided into two subsections. The first addresses some of the conceptual ambiguities that surround the central concepts of healthcare rationing and healthcare need. The second provides the contextual background by outlining two real-world cases of explicit healthcare rationing and the experiences related to health policy gained from these.

Chapter 4 sets out the theoretical context of welfare economics and population-level ethics. These nonmutually exclusive perspectives allow explicit exploration of issues related to efficiency and fairness, which will be discussed in the remaining chapters.

Chapters 5 and 6 focus on the four conceptual themes – *individual responsibility*, *paternalism*, *incentives* and *inequality* – which are likely to be associated with reasonable disagreements. Chapter 5 focuses on the main findings of the papers and discusses them primarily from a traditional perspective of welfare economics. Chapter 6 extends the discussion raised in the papers by applying a broader ethical perspective.

Chapter 7 presents some concluding remarks concerning health policy and the interdisciplinary approach applied in this thesis.

METHODOLOGICAL CONSIDERATIONS AND SPECIFICATION OF THE AIM

This thesis approaches the matter of healthcare rationing from two nonmutually exclusive perspectives – that of the economist and that of the ethicist. Before embarking on a methodological discussion of economics, ethics, and the morally perplexing issue of finding justifiable grounds for healthcare rationing, it is necessary to clarify the scope of this thesis.

A Population-Level View on Efficiency and Fairness

This thesis addresses the issues of fairness and efficiency in relation to healthcare rationing at the population level, i.e. at the institutional level. In health economics this is the natural scope since welfare economics stipulates that all effects, regardless of where and to whom in society they appear, should be taken into account when assessing the desirability of various options. In bioethics, however, it is less common to focus on the normative issues that arise at the population level. Instead, bioethics has a long tradition of focusing on issues that arise at the individual level, particularly involving the patient-doctor relationship, the boundaries of life (e.g. abortion and euthanasia), and how to apply medical knowledge and technologies in practice. Obviously, we should not diminish the importance of issues that revolve around the morality of individual conduct and character. The moral issues that arise at the population level are, however, equally vexing and often involve higher stakes. Daniels notes (2006:23) “the focus on exotic technologies may blind bioethics to the broader determinants of health and thus to factors that have more bearing on a larger good both domestically and globally.”

Bioethics at the population level deals with how to achieve a fair distribution of health and healthcare resources, thus relying on theories of justice and political philosophy. Where bioethics at the individual level focuses primarily

on the rights and responsibilities that arise in the interaction between individual patients and their doctors, bioethics at the population level focuses on the obligations of societies toward their citizens in general, and vice versa.²

Economics and Ethics

The point of departure for this thesis is founded on three fundamental observations about the world, i.e.:

- i.* **Resources are scarce in relation to human wants.** We will always want more than we can afford.
- ii.* **Resources have alternative uses.** Using resources for one thing is always done at the expense of using those resources for something else.
- iii.* **Individuals have different wants and preferences.** We value commodities and the state of affairs differently.

Based on these observations, the economic perspective applied in this thesis is concerned with how to allocate scarce resources as *efficiently* as possible to best satisfy human wants. In contrast, the ethical perspective is concerned with how to allocate scarce resources as *fairly* as possible to best satisfy human wants. To reconcile these two perspectives in a practical sense, we need to explore the normative basis for fairness and efficiency in the context of allocating scarce healthcare resources.

Normative Economics and Positive Economics

When referring to an economic perspective it is useful to distinguish between positive and normative economics. Positive economics is an observational science that focuses on logistic or technical consequences stemming from different allocations without making any claim regarding the desirability of the different consequences. Normative economics, on the other hand, is concerned with analyzing the desirability of consequences that arise from competing resource allocations. Hence, positive economics approaches the question "What is?" while normative economics approaches the question "What ought to be?" (McCloskey 1998).

² For further readings concerning the scope of population-level bioethics, see e.g. Wikler and Brock (2008)

Sen (1987) has argued that modern economics can be divided into two veins with rather different origins. One he labels the *engineering approach* and the other he labels the *ethics-related tradition*. Both, he argues, relate to politics, but in different ways. The engineering approach is, as Sen characterizes it, not always concerned with real people, since the economic models typically applied assume that individuals are motivated purely by selfish “non-ethical” concerns and are “not messed up by things as goodwill or moral sentiments” (1988:1). Sen (1987:4) continues by characterizing the engineering approach as:

...being concerned with primarily logistic issues rather than with ultimate ends and such questions as what may foster ‘the good of man’ or ‘how should one live’. The ends are taken as fairly straightforwardly given, and the object of the exercise is to find the appropriate means to serve them. Human behavior is typically seen as being based on simple and easily characterizable motives.

The much broader ethics-related tradition can be traced all the way back to Aristotle and his concerns for making judgments of social achievements and “the good for man”. Sen writes (1987:4):

This ethics-related view of social ‘achievement’ cannot stop the evaluation short at some arbitrary point like ‘efficiency’. These assessments have to be more fully ethical and take a broader view of ‘the good’.

Modern economics is often associated with positive economics, or what Sen calls the engineering approach. The fact that this thesis is called the economics *and* ethics of healthcare rationing is a typical example that ethical reasoning is something not typically associated with economics. Simply calling this thesis the economics or normative economics of healthcare (which was the initial plan) would be misleading to many of the potential readers of this work. In fact, over the years I have learned that more than a few even consider the idea of applying an economic perspective on health care rationing repugnant.

The primary ambition of this thesis is to contribute toward the ethics-related tradition of economics. However, it is important to acknowledge that the two approaches are not pure, but overlapping. Cost-effectiveness analysis (CEA)

highlights this by applying an engineering approach toward allocation decisions, based albeit (as we shall see) on a series of normative assumptions. Moreover, it is often necessary to spell out “what is” before approaching the question of “what ought to be”. The four papers included in this thesis illustrate this by applying various approaches, from strongly positive (Paper IV), to strongly normative (Paper II, Paper III), to somewhere in-between (Paper I).

Normative Ethics and Meta-Ethics

When referring to an ethical perspective on healthcare rationing it is useful to distinguish between *normative ethics* and *meta-ethics*. The ambition of normative ethics is to elaborate sound argumentation on moral questions. Moral questions are, roughly, questions that deal with the right and wrong, good and evil, associated with certain types of actions. For instance, normative ethics could be trying to deliver sound and well-articulated arguments for when, if ever, it is justifiable to withhold potentially beneficial care to patients, or what constitutes morally relevant reasons for treating individuals unequally. Meta-ethics deals with philosophical issues on a higher level of abstraction. It focuses on where ethical principles come from by trying to understand questions like: what *is* goodness? Is goodness a matter of taste or truth? Hence, meta-ethics focuses on trying to understand the nature of ethical thinking.

From the expressed aim, it should be clear that the type of ethical approach used in this thesis is normative ethics. Moreover, since the ethical discussions in this thesis address concrete moral issues, rather than trying to construct a comprehensive moral theory, this thesis could also be described as a work of *applied ethics*.

Reasonable Disagreement

An intricate but central concept in this thesis is *reasonable disagreement*. This thesis applies four conceptual themes – *individual responsibility*, *paternalism*, *incentives*, and *inequality* – in the context of healthcare rationing. Within these conceptual themes, reasonable disagreements are likely to arise on how to balance fairness and efficiency. It is not the ambition of this thesis to resolve

what is right and wrong in these cases of moral conflict. Rather the ambition is to highlight the conflicting moral principles that surround the four conceptual themes and present my own normative reflections.

Use of the “reasonable disagreement” concept implies that not all disagreements are reasonable. The idea is most notably present in the later work of John Rawls and is what leads to his idea of “overlapping consensus for the right reasons” (e.g. Rawls 1989, 1993), which was further developed and labeled “reasonable pluralism” by Josh Cohen (1994). Also, Norman Daniels (2008) uses the idea of reasonable disagreement in aiming to identify a fair deliberative process that could narrow or (optimally) dissolve reasonable disagreement. My conception of reasonable disagreement is constituted by: moral disputes where conflicting parties base their positions on arguments that are sound and logically consistent in a way that does not violate fundamental rights. In addition, the fundamental disagreement persists regardless of how open, well informed, and free from personal stakes the deliberation process has been.

Reasonable disagreements exist in many contexts (e.g. political, artistic, and philosophical), where individuals tend to come to different conclusions even though they share the same basis of knowledge and deliberation is conducted in good faith. The disagreements focused on in this thesis stem from substantive differences concerning the value base for conducting healthcare rationing.

In practice, many disagreements are rooted in personal stakeholding and inadequate knowledge. For example, many believe that resources are not scarce and, thus, they see no need to ration care. Secondly, various stakeholders involved in the healthcare context are often driven by agendas other than trying to achieve what is best for society at large. Thirdly, individuals may have a poor understanding of the practical implications of different rationing alternatives. Ultimately, the ambition of this thesis is to move past disagreements of this sort, reach the point of reasonable disagreement, and present my personal view on the matters. But reaching this point requires achieving adequate knowledge about the practical consequences that arise from different approaches toward healthcare rationing. One of the papers included in this thesis (Paper IV) primarily contributes to the matter of reasonable disagreement by increasing knowledge about the potential consequences a certain type of rationing might have on inequality.

Here, I also wish to clarify that when referring to justifiable grounds for healthcare rationing I intend a principal argument that, if challenged on reasonable grounds, becomes a part of reasonable disagreement. Consequently, the matter of finding justifiable grounds for saying no in the context of health care implies that any conclusion will inevitably be coupled with some form of reasonable disagreement.

Moral Intuition and Moral Reasoning

Healthcare rationing is a topic that commonly triggers our moral intuitions. For instance, most individuals have a strong moral intuition that it is wrong to deny medical assistance to someone in need, and that it is more important to save the lives of children compared to elderly patients. Given that moral intuition is such a prevalent feature in rationing, it is necessary to mention the role of moral intuition in relation to moral reasoning when discussing reasonable disagreements. This is not an easily resolved issue, but I will attempt to clarify the distinction and explain how I have chosen to handle the matter.

Moral intuition typically refers to the moral judgments (or responses) that occur quickly and carry a strong automatic belief about the moral appropriateness of an act, without having gone through a conscious reasoning process that produces this judgment. Moral intuition often manifests itself in strong revulsion or disgust for certain types of actions. Kass (1997:20) calls this form of moral intuition “the wisdom of repugnance” and exemplifies:

In crucial cases /.../ repugnance is the emotional expression of deep wisdom, beyond reason’s power fully to articulate it. Can anyone really give an argument fully adequate to the horror which is father-daughter incest (even with consent), or having sex with animals, or mutilating a corpse, or eating human flesh, or even just raping and murdering another human being? Would anybody’s failure to give full rational justification for his or her revulsion at these practices make that revulsion ethically suspect? Not at all.

Advocates for this type of emotional- or disgust-based “reasoning” asserts that intuitive repulsion often provides a good starting point for making moral

judgments, or at least that it should be considered enough to put the burden of proof on those who oppose a judgment based on moral intuition.

Moral reasoning is the attempt to support moral judgments by logically consistent reasoning derived from fundamental moral principles. Eyal writes (2008:114-115):

It seeks *general principles* [emphasis added] for the regulation of behavior that are such that they can command the agreement of other, informed, rational, and free agents. The test of a proposed principle or action is that it would be found acceptable not just to the person who proposes it but to all those whom the action affects. Justification is *to* others; moral motivation, the connection of morality with our will, is supplied not by sympathy alone but by our need to act in such a fashion that our actions are both understandable to ourselves and acceptable to others.

The ethical analysis in this thesis is written in the tradition of normative ethics and hence focuses on moral reasoning as a basis for finding justifiable grounds for healthcare rationing. I do not think that we can accept moral intuition as a source for overriding moral reasons when making judgments about healthcare rationing. Judgments based on moral intuitions are likely to offer poor moral guidance if based on an emotional foundation (e.g. Singer 2005). This is not to say that moral intuitions are usually misleading, or that they are easily distinguished from moral reasoning. Quite the opposite, I believe that it is of utmost importance for policy makers to have a solid understanding of prevailing moral intuitions and avoid policies that run counter to common moral intuitions, unless these counterintuitive policies are supported by powerful moral arguments or general principles. If not, the long-term legitimacy of the decision maker is at risk of being undermined. However, as Malmqvist (2008:31) rhetorically asks:

...if intuitive, theoretically unfounded judgments are a legitimate part of ethical reasoning, what room is there for reasoned argument? Can we ever do better than articulating and advocating conclusions that we already settled for on intuitive grounds? Can we ever be rationally persuaded to give

up those judgments that might simply be reflections of cultural bias, prejudice or evolutionary heritage?

Moreover, I see it as the task of moral philosophers to continuously challenge and question prevailing moral intuitions and see if they survive extensive moral scrutiny.

BACKGROUND

This background chapter is divided into two sections. The first section addresses several basic ambiguities concerning the concepts of *healthcare rationing* and *healthcare need*. The second section describes experiences gained from two real-world cases of attempting to engage in explicit healthcare rationing. The cases chosen are the initiatives undertaken in the state of Oregon during the 1990s and the ongoing priority-setting initiative taking place in Sweden. These cases are chosen to highlight some of the difficulties that different policy approaches toward healthcare rationing may encounter.

What is Healthcare Rationing?

As indicated in the introduction, rationing is a concept that carries a bad reputation. However, in its widest sense, rationing simply means the controlled distribution of scarce resources, and as such it occurs in good as well as in bad economic times. Moreover, rationing does not only involve negative consequences since efficient and fair rationing ultimately seeks to create opportunities to meet more healthcare needs than would otherwise be possible. This thesis uses the following definition of healthcare rationing: The withholding of potentially beneficial health care to individuals under conditions of scarcity.

The above definition is in accordance with how others have used the concept of healthcare rationing (e.g. Liss 1993; Ubel and Goold 1997; Norheim 1999). Following this definition, rationing aims to bridge the gap between need and available resources by limiting the possibilities to optimally satisfy healthcare needs. An in-depth discussion of rationing requires distinguishing between the different types of healthcare rationing. Building on the typology presented by Klein (1996), I will differentiate between the following three types of healthcare rationing:

- (i) Rationing by *denial* involves the general exclusion of particular types of healthcare services, e.g. tattoo removal, hearing aids, or laser eye surgery. It could also entail exclusion through changes in indications,

- i.e. patients' healthcare needs must be associated with a more severe deterioration in health before treatment can be offered.
- (ii) Rationing by *dilution* implies that a particular healthcare need is only partially met. For example, rehabilitation to achieve full recovery after an injury may require 20 visits to a physiotherapist. However, in rationing by dilution, the patient might be granted only 10 visits to a physiotherapist, implying that the patient's health status is not fully restored. Finally, rationing by dilution could involve reductions in the quality of healthcare services, e.g. prescribing cheaper but less-effective drugs.
 - (iii) Rationing by *delay* (often referred to in the literature as time rationing) means that patients must wait longer than necessary before receiving adequate treatment.

Moreover, as rationing takes place throughout the entire healthcare system it is also useful to differentiate between what I will refer to as *bedside* and *desktop* rationing. *Bedside rationing* occurs at the patient level when medical professionals through denial, dilution, or delay withhold services that could potentially benefit the patient. Bedside rationing is often not recognized as rationing by either patients or healthcare professionals. Instead, it is often viewed as a case of malpractice in situations where it can be established that a patient had to forgo what would have been a medically beneficial treatment. However, healthcare professionals regularly make judgments, for example, concerning whether a particular diagnostic test or treatment warrants the cost associated with it – not every patient that comes in with a tummy ache gets a full body scan to rule out the presence of a tumor. *Desktop rationing* is a more abstract type of rationing that occurs outside of individual physician-patient encounters, where policy-makers withhold services that could potentially benefit patients. What further distinguishes desktop rationing from bedside rationing is that the former typically affects statistical patients temporally distant from when the actual decision was made. Bedside rationing, on the other hand, typically involves identifiable patients in a context of personal decision making.

Although rationing is more common than one might think, not all forms of limit setting can be considered acts of rationing. Ubel and Goold (1997) have established three criteria separating limit setting from rationing.³ They assert

³ Ubel and Goold (1997) use the criteria to assess bedside rationing. However, I find them equally applicable to desktop rationing.

that a rationing decision must involve: 1) withholding, withdrawing, or failing to recommend a service that, according to best clinical judgment, is in the patient's best medical interests; 2) the decision to promote primarily the interests of someone other than the patient, and 3) the decision-maker must have some extent of control over the use of the beneficial service.

Given these criteria, denial of a treatment because it is considered futile is not a case of rationing. For example, not ordinating transfusion of donkey blood to patients suffering from allergy is not rationing, since scientific evidence and clinical judgment do not show any potential medical benefits from its use. A less obvious case would be decisions resulting from concerns of overusing treatments, which could impair their future effectiveness. Denying patients potentially beneficial antibiotics is such a borderline case of rationing. At the bedside level, this decision corresponds to the three criteria. At the desktop level, however, this decision is not a case of rationing since a decision to limit the prescription of antibiotics is intended to promote a medically beneficial effect among patients in general. Prescribing antibiotic treatment in every case where it might be medically beneficial could invoke resistance against antibiotics in society, which would be a more serious consequence. Hence, conflicts between bedside and desktop rationing may arise since what is in the best interest of a specific patient might not be in the best interest of patients in general.

It is also important to acknowledge that resource scarcity related to rationing does not necessarily have to be monetary. As has already been mentioned, time is a scarce resource, which constantly forces medical staff to ration care. Moreover, resource constraints may also be physical as in the case of organ transplantations, where limited availability of organs forces healthcare professionals to engage in rationing decisions regarding who should and who should not receive an organ.

Finally, it is important to clarify the distinction between rationing and priority setting. These are two closely related concepts and are often used synonymously. Although this is understandable – since rationing cannot take place without an initial stage of priority setting – the concepts are nevertheless clearly and importantly distinct from one another. Priority setting involves ranking different services for defined groups of patients and putting some service ahead of others, i.e. choosing what *to do*, while rationing focuses on what *not to do*. This thesis centers mainly on issues surrounding healthcare

rationing, but is nonetheless highly relevant to issues concerning priority setting.

What is Healthcare Need?

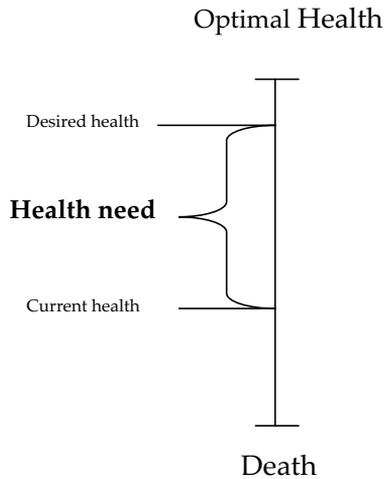
Decision-makers frequently use some notion of need to justify healthcare rationing. Despite widespread agreement that need is an essential component in conducting fair and efficient rationing, there is no consensus on what rationing *according to need* actually means; should it be interpreted to mean the severity of the health state, or the individual's capacity to benefit? To what extent should nonmedical factors such as social circumstances and individuals' past be incorporated?

The complexity inherent in questions like these gives many different meanings to the notion of rationing according to need, leading to quite different substantive rationing principles in practice. So, to avoid an incomprehensible discussion, it is important to expose some of the relevant dimensions for assessing healthcare need. I will not, however, make a fully comprehensive analysis of the concept of healthcare need. Instead I will outline only the distinction that is most relevant in the context of this thesis, namely the distinction between need for *health* and need for *health care*. Many of the thoughts presented below are heavily influenced by the work of Liss (e.g. Liss 1993 and National center for priority setting in health care 2007).

The need for health can be understood as the gap between current health and desired health (Figure 1). A person's desired health does not necessarily coincide with optimal health, since individuals typically desire less than optimal health; especially as we get older and view some deterioration in functionality as a natural course of aging. Further, the gap does not necessarily only involve one's current health; it could also involve the risk for future ill health. For example, when we take vaccine as a preventive measure we are trying to reduce the gap between the current risk and the desired risk⁴ of becoming sick.

⁴ Desired risk often corresponds to optimal risk, which would be no risk of becoming sick.

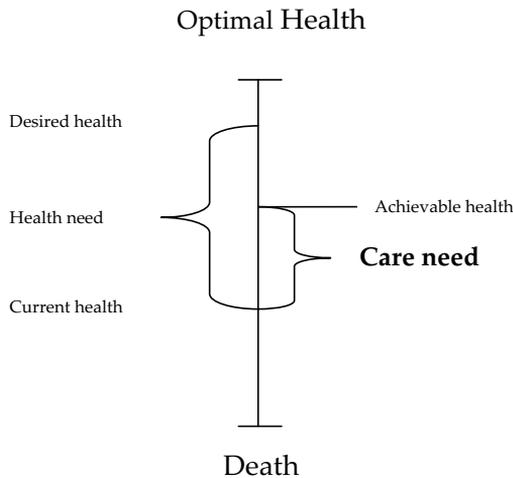
Figure 1. Graphical illustration of health need.



The defined concept of health need as a gap between current health and desired health does not, however, yield sufficient information for us to make rationing decisions on the basis of need. We must also assess what the individual has a need *for*. What kind of care is needed to reduce the gap between current health and desired health? A patient suffering from end stage renal disease has a health gap that can be reduced by kidney transplantation. Hence, two prerequisites must be present for a healthcare need to arise:

- i) A health need must exist, i.e. a gap between current health and desired health.
- ii) A care need must exist, i.e. an intervention that potentially can reduce the health gap must exist.

Figure 2. Graphical illustration of healthcare need.



Given the above definition, it is possible for an individual to have a health need without this being accompanied by a care need. If no treatments are available to reduce the gap between current health and desired health, then we cannot say that a healthcare need exists. It is important to make this distinction because the major determinant of individuals' health is not health care, but other social determinants (Marmot and Wilkinson 2005). These determinants include the economic and social conditions under which people live, and are much more influential as risk factors for many common diseases, e.g. cardiovascular disease and type II diabetes (Marmot and Wilkinson 2006). Although social determinants have an extremely important effect on health, I will touch only briefly on the issue since the main focus of this thesis is health care and how to find justifiable grounds to ration health care, not health (although this could be a consequence of rationing).

Degree of urgency is another dimension commonly used to define healthcare need. For example, it can be argued that a patient who faces an immediate threat to life and/or health has a higher degree of healthcare need compared to patients who face equal, but less immediate, threats to life and/or health. This view of healthcare need, which focuses more on the temporal aspect, is sometimes labeled the *rule of rescue*. The rationale behind this rule is that society has a obligation to do everything possible to help save those individuals facing an immediate threat to life and/or health (McKie and Richardson 2003).

Explicit Healthcare Rationing in Practice

Abstract models and theoretical concepts are of little use to us in the absence of a real-world context where they can be applied. This section presents a brief description of the practical experiences gained from initiatives undertaken in the State of Oregon in United States and in Sweden. These real-world experiences also serve as practical examples of approaches that have, from the outset, emphasized two opposing views on distributive fairness; maximizing health benefit within the population versus giving priority to those with the greatest need.

The Case of Oregon

Internationally, the most well-documented initiative to engage in explicit rationing was undertaken during the early 1990s by the State of Oregon. The intent of the initiative was twofold; to expand eligibility to high-priority services among Oregon's population to cover everyone below the federal poverty level, and to use limited resources to provide the most cost-effective services as a means to maximize health benefits among the population (Ham 1998). To achieve these objectives, a ranking list of condition-treatment pairs based on cost-effectiveness ratios were developed. Depending on the state's Medicaid budget constraint, every second year the state officials would literally draw a line across the list, ensuring public coverage for all items above the line, but leaving items below the line for individuals to fund out-of-pocket (Oberlander, Marmor et al. 2001).

To achieve any substantial savings and create resources to expand coverage, Oregon was required to exclude hundreds of serious condition-treatment pairs from coverage. The initial list revealed several counterintuitive results. For example, tooth capping was ranked above appendectomies for appendicitis (see Table 1), despite the fact that the latter is typically a lifesaving intervention. While problems in some of the data led to such results, this is nevertheless an expectable result from cost-effectiveness prioritization – the problem arose because life saving treatments like appendectomies are typically much more expensive than tooth capping (Oregon estimated that it could cap a tooth in over 100 patients for the cost of a single appendectomy).

Hence, a small benefit for a large number of individuals was ranked above a great benefit for one.

Table 1. Examples from the initial priority list in Oregon based on cost-effectiveness analysis (Hadorn 1991).

Treatment	Exp. net benefit	Exp. duration of benefit	Costs (US \$)	Priority ranking
Tooth capping	.08	4	38	371
Surgery for ectopic pregnancy	.71	48	4015	372
Splints for temporomandibular joint disorder	.16	5	99	376
Appendectomy	.97	48	5744	377

The initial rankings, which were based cost-effectiveness ratios, invoked strong negative public reactions. Following massive criticism, public consultations and medical experts were used to provide input on the initial list, which was then adjusted extensively (Hadorn 1991). Individual items were moved up and down the ranking list “by hand”, informally guided by factors such as the number of affected patients, societal value placed on the item (e.g. high value was placed on palliative and child care) (Hadorn 1996).

Four years were spent revising the initial list, and the final list was made available in 1994. At that time, list included 696 items, with the cut-off point drawn at 565 (Ham 1998). In the final list, the costs associated with treatments had a negligible influence. Instead the final list was based primarily on the expected benefit associated with treatments. Hence, the final adjusted list ranked surgery for ectopic pregnancy and appendectomy among the top items, while splints for temporomandibular joint disorder and tooth capping were dropped altogether. Most of the items that ended up below the cut-off point were services where individuals generally were considered to possess the ability to be responsible for their own care, or were conditions for which no effective treatments were available (Ham 1998).

To some extent, the initiative undertaken in Oregon was a success. It succeeded in decreasing the percentage of uninsured from 19.9% of the working age population to 7.6%. This was achieved while the percentage of uninsured in the US as a whole was on the rise between 1990 and 1996 (Alakeson 2008). Further, the state’s ambition to engage in explicit rationing received strong support among the public, which created a necessary platform

for constructive dialogue (Rutledge 1997). It is important to acknowledge, however, that the Oregon initiative affected only the Medicaid system, i.e. the poor population. As Daniels (2008:152) points out, “the plan could not avoid the appearance of the *haves* setting priorities for the *have nots*”. This is a distinguishing characteristic compared to similar efforts undertaken in systems with universal health insurance coverage.

Lessons from Oregon

Perhaps the most important lesson from the Oregon experience was that it illuminated some of the implicit value judgments imbedded in cost-effectiveness analysis (CEA), which are likely to conflict with deeply held values among the public. This led to abandoning the idea of using CEA as the sole principle for rationing, since as Hadorn (1991:2219) insightfully points out:

...any plan to distribute healthcare services must take human nature into account if the plan is to be acceptable to society. In this regard there is a fact about the human psyche that will inevitably trump the utilitarian rationality that is implicit in cost-effectiveness analysis: people cannot stand idly by when an identified person's life is visibly threatened if rescue measures are available.

The moral conflicts that arose in Oregon regarding the initial CEA ranking can be characterized in what Daniels (1994) has called four unsolved rationing problems; *the aggregation problem, the priorities problem, the fair chances versus best outcome problem, and the democracy problem*. These are all practical problems in healthcare rationing, but very moral in character. Hence, people are likely to disagree on what constitutes the correct course of action.

The aggregation problem can be framed by the question: When should society allow an aggregation of modest benefits to larger numbers of people to outweigh more significant benefits to fewer people? The approach taken in Oregon was based on the economic rationale of aggregation, i.e. health maximization. This led to some non-intuitive results, e.g. that certain lifesaving treatments were ranked below some more trivial condition-treatment pairs. Aggregation clearly goes against the rule of rescue, which prescribes that rationing should be done through one-to-one comparisons,

giving priority to the patient with the most urgent need. The strong reactions that the initial list evoked showed that most people do not want society to have ‘maximize health benefits across population’ as its sole objective for distributing resources. However, this does not mean that individuals are likely find all forms of aggregation impermissible.

The priorities problem can be framed by the question: How much priority should society give to treating the sickest or most disabled individuals (i.e. those with the largest *health* need)? If two individuals are competing to receive priority for a treatment that will give them an equal amount of health benefits, most people share the moral intuition that priority should go to helping the worst-off individual. Ranking based on cost-effectiveness analysis (CEA) ignores this common intuition and is neutral between individuals in cases where the benefits are of equal size. The fact that the revised Oregon list ranked palliative and child care⁵ at the top of the list indicates that the public did not accept this neutral standpoint, but wanted to give some level of priority to the worst off.

The fair chances versus best outcome problem can be framed by the question: To what extent should society strive towards producing what is considered to be the best outcome, instead of ensuring that all individuals are given equal or proportional chances of receiving treatment? CEA focuses solely on the outcome in terms of maximizing health in the population. It could, however, be argued that it is more important that everyone has a fair chance to receive treatment. For example, imagine Larry and Jeb who are competing for the same treatment, but only one of them can get it. Larry will survive 3 additional years if he receives the treatment, while Jeb will only survive 2 additional years. The example could analogously be framed as patient groups competing for scarce resources. Following the CEA rationale, Larry should receive the treatment. However, Jeb might insist that it is unfair that he has to stand back only because Larry will live longer. Instead, he might argue that it would be more fair to have a weighted lottery where Larry has a 60% chance of getting the treatment and Jeb has a 40% chance of getting the treatment. It is unclear if this type of rationale played any significant role in abandoning the initial CEA methodology.

⁵ Child and palliative care offer an example of two different interpretations of who is the worst off. Children are worst off in the sense that they have not had their fair share of a full life, and palliative patients are worst off in the sense of severity of illness. Neither example are however the same as *health-* or *health care* need as defined in the earlier section, which further illustrate the complexity with regards to defining need in the health sector.

Finally *the democracy problem* can be framed by the question: When should society rely on a fair deliberate process as the only way to determine what constitutes a fair rationing outcome? The normative relevance of public preferences is a complicated matter. Should *public* preferences be based on the general population, or involve only the preferences of those who have experienced the specific health condition or have other forms of expert knowledge? What is evident from the Oregon experience is that one cannot ignore the views of the general public. Nevertheless, it is unclear how much weight one should give to moral reasons compared to expressed public preferences in cases when these differ. A related somewhat disturbing question about human behavior which the experience from Oregon raises is: Could it be that people are only *reasonable* or *fair minded* as long as they are not directly affected by the outcome themselves?

The Case of Sweden

Swedish experience with explicit rationing represents a different approach compared to that of Oregon. In contrast to Oregon's cost-effectiveness approach, the Swedish approach has appealed to individuals' equal value and rationing according to need. Values related to cost-effectiveness and maximizing aggregate health in society have been relegated to a secondary role. Moreover, rather than explicitly listing services that should not be publicly funded, Sweden opted for an approach based on explicit principles to which any rationing decision should adhere.

The Swedish initiative to engage in a more open and systematic approach toward healthcare rationing started in 1992. An economic downturn led to recognition, at the national level, of the unavoidable need to ration care. The idea was that openness and transparency would create legitimacy for such politically difficult decisions. This led to the formation of a parliamentary priorities commission assigned to:

“consider the responsibilities of health and medical services, their demarcation and role in the welfare state; highlight fundamental ethical principles which can furnish guidance and form a basis of open discussions and of prioritization in health and medical services.”(Ministry of health and social affairs 1993:29)

The commission's work resulted in an ethical platform for making priority-setting decisions in health care (Government bill 1996/97:60). This platform consisted of three principles intended to guide decision makers at all levels in the healthcare system when making rationing and priority-setting decisions. The principles were (and still are):

- I. *The principle of human dignity.* Meaning that all individuals have equal value and rights regardless of personal characteristics or position in society.
- II. *The principle of need and solidarity.* Meaning that resources should be used in domains (or patients) where needs are considered to be greatest.
- III. *The cost-effectiveness principle.* Meaning that resources should be used in the most effective way without neglecting fundamental duties to improve health and quality of life.

The principles are ordered lexically in the sense that the human dignity principle has superiority over the need and solidarity principle, which in turn has superiority over the cost-effectiveness principle. Following the commission's work, the legislated goals of the Swedish healthcare system were amended. Prior to the commission's report the Swedish Health and Medical Service Act (1982:763 §2) stated that: "the goal of all health care services is good health and health care on equal terms for the entire population". The amendment which was added to the formerly stated goal was: "Provision of health care services must respect the equal value of all human beings, and the dignity of the single human being. The person with the greatest need for health care services should be given priority." (Swedish Health and Medical Service Act 1997:142 2§). This means that the cost-effectiveness principle is not explicitly mentioned in the preamble of Swedish healthcare legislation, while the principles of 'human dignity' and 'need and solidarity' are. This further underlines the superiority of these two principles in comparison to the cost-effectiveness principle.

In practice, since it gives little or no real guidance on how to set priorities, the principle of 'human dignity' has played a minor role in actual rationing decisions. It gives some indication on how not to set priorities, i.e. personal characteristics such as age, gender, ethnicity, and socioeconomic status should

not influence how priorities are set, unless particular medical relevance is associated with these personal characteristics.^{6,7} Instead, the principles of ‘need and solidarity’ have to become the leading principles when making rationing decisions.

Over the years, several national initiatives have aimed at applying the priority-setting principles in explicit rationing decisions. Since 2004, the National Board of Health and Welfare has used the priority-setting principles to rank pairs of health condition-intervention in process for producing national treatment guidelines on various disease categories (Carlsson 2010). Based on the ethical principles, the Board has used a specially designed model for priority setting. This model is described as a “pragmatic” interpretation of the ethical platform, where severity of illness is balanced against cost-effectiveness considerations (Carlsson, Kärvinge et al. 2007). In similar fashion, the Dental and Pharmaceutical Benefits Agency has applied the priority-setting principles when making reimbursement decisions on public funding for pharmaceuticals. In their work, cost-effectiveness has become a key determinate when making rationing decisions with regards to pharmaceuticals (Erntoft 2010).

At the autonomous regional level, several attempts have also been made to apply the priority-setting principles in practice. The first ambitious attempt to apply such principles was undertaken by the County Council of Östergötland in 2003, which developed a set of explicitly defined limitations on providing health care. Examples of rationing were that treatments at pediatric clinics for some minor childhood conditions (e.g. head lice, obesity) and the second hearing aid would no longer be funded publicly (Bäckman, Karlsson et al. 2006). The process leading to explicit rationing in Östergötland resulted in a heated debate across the entire country and was heavily criticized from leading politicians. Most likely this discouraged other county councils from following in Östergötland’s footsteps. During the past few years, however, a new wave of initiatives to engage in explicit rationing at the regional level has arisen. A handful county councils have created lists including hundreds of services and have decided to exclude some of the services with the lowest ranking to create funding space for more important services. These more

⁶ For example, it makes little sense to screen men for breast cancer. Hence, in that case, gender becomes a medically relevant personal characteristic.

⁷ However, when allocating vaccine against swine flu, the rule of human dignity was abandoned and priority was given to individuals “important to the functioning of society as a whole”. This further illustrates that the principle of human dignity tends to be more of a symbolic gesture than anything else.

recent initiatives have met surprisingly little objection and appear to have gained public support (Carlsson 2010; Waldau, Lindholm et al. 2010).

To some extent the initiative undertaken in Sweden has been a success. The principles defined by the commission have been applied in actual rationing decisions, which prove that they are applicable at least as a framework for departure in real practice. This has spurred several national and regional initiatives to openly discuss the necessity to set limits on what the public can offer. The National Centre for Priority Setting in Health Care has emerged as a venue for interdisciplinary research that will hopefully produce further valuable insights on how priorities are set in practice. The activities described above signify a long-term commitment from the national level of the health care system to openly discuss and explore the matter of explicit rationing and to develop a systematic approach for conducting rationing.

Lessons from Sweden

In 2005, the Swedish government assigned the National Board of Health and Welfare to follow up the national guidelines for priority setting in health care and their implementation. Based on this extensive report (National center for priority setting in health care 2008) three general problems in the Swedish approach, underpinned with ethical values, can be identified. I will label these: *the vagueness problem*, *the balancing problem*, and *the leveling problem*

The vagueness problem can be framed by the question: Should ethical principles be symbolic or guiding? The inherent vagueness of the priority-setting principles has arguably rendered them of little guiding value when making distributive decisions. The Swedish 'human dignity principle' has a strong position legally, but how it should be applied in practice, when it comes to distributing scarce resources, is unclear. For example, the principle gives no indication about when age becomes a medically relevant characteristic for rationing. Moreover, the principle of human dignity may appear as less vague if it had been framed as an all-embracing procedural principle, focusing on creating equal or proportional opportunities to health care. The 'human dignity principle' does, however, have strong symbolic value that could potentially strengthen legitimacy for the healthcare system, both internally and externally. The 'need and solidarity principle' also holds strong symbolic value. However, the meaning of need has never been sufficiently specified, limiting its applicability as a guiding principle. For instance, to what extent

should individuals' capacity to benefit be taken into account when assessing need?

The balancing problem can be framed by the question: Should one ethical principle have superiority, or is it necessary to balance different principles against each other? It could be argued that the strict lexical order of Swedish principles is both inapplicable in practice and highly unlikely to be in accordance with the true preferences of the public. It seems unreasonable that rationing decisions should be based solely on individuals' level of need, thereby disregarding other aspects such as costs and capacity to benefit. For example, strict adherence to the lexical order would imply that healthcare resources would disappear into a bottomless pit⁸ when it comes to treating patients with little or no capacity to benefit. Since this is not what is happening in practice, it indicates that the lexicality of the Swedish principles should be regarded as an ambition in trying to steer the process into giving more weight to individuals' health needs compared to their capacity to benefit. However, the strict lexical order stated is, at the very least, utterly confusing when trying to understand the role of the cost-effectiveness principle.

The final stylized lesson from Sweden is *the leveling problem*. This can be framed by the question: Should ethical principles apply equally when making rationing decisions at the individual level and at the population level? The Swedish principles are formulated as if they are supposed to guide rationing decisions made by all actors in health care, i.e. the national, regional, and clinical levels. However, ambiguity exists concerning the application of cost-effectiveness, which should be applied only at the population level. One could argue that it is questionable to apply a different value basis depending on whether or not rationing decisions concern statistical or identified patients. On the contrary, adherence to the rule of rescue is a strong moral intuition among many, and one could argue that it is an important aspect when trying to foster a compassionate society.

As a concluding remark concerning the Swedish experience it seems like the ethical principles to some extent have promoted an open dialogue regarding inevitable rationing decision. Although one could argue that openness helped to increase awareness of the value base for rationing decisions, transparency and actual understanding, regarding the "true" values which underpin

⁸ If it is assumed that the needs principle does not incorporate *capacity to benefit*.

rationing decisions might have decreased as a result of the *vagueness, balancing,* and *leveling* problems.

THEORETICAL CONTEXT

This chapter outlines the theoretical context to which paper I-IV and the extended discussion included in this thesis relate. The theoretical landscape of healthcare rationing will be approached from two nonmutually exclusive perspectives; labeled the *economic* and the *ethics* perspectives. These perspectives allow explicit exploration of issues related to efficiency and fairness, which inevitably arise when discussing healthcare rationing.

Economics

The theory of economics does not furnish a body of settled conclusions immediately applicable to policy. It is a method rather than a doctrine, an apparatus of the mind, a technique of thinking which helps its possessors to draw correct conclusions.

-John Maynard Keynes

The economic perspective on rationing is concerned with how to allocate scarce resources as *efficiently* as possible to best satisfy human wants. However, a normative basis of efficiency is needed for economics to generate a satisfactory indication of how to best allocate resources. Welfare economics has traditionally provided such a normative basis.

Welfare Economics

Given that welfare economics is a normative theory, it is based on value assumptions. The first fundamental value assumption relates to the concept of economic efficiency⁹ traditionally defined through the *Pareto principle*. The Pareto principle stipulates that for a change to be efficient it must leave at least one person better off at the same time as no one else is left worse off. Or as stated by Pareto (1906:261) himself:

⁹ This should not be confused with technical efficiency, which is the ability to do more with the same resources, or alternatively to achieve the same outcome with fewer resources.

We will say that the members of a collectivity enjoy maximum ophelimity in a certain position when it is impossible to find a way of moving from that position very slightly in such a manner that the ophelimity enjoyed by each of the individuals of that collectivity increases or decreases. That is to say, any small displacement in departing from that position necessarily has the effect of increasing the ophelimity which certain individuals enjoy, and decreasing that which others enjoy, of being agreeable to some, and disagreeable to others.

The second fundamental value assumption in welfare economics is that the assessment of efficiency should be based on individuals' preferences as regards their own situation. Consequently, Pareto efficiency is coupled with the notion of *consumer sovereignty*, assuming that individuals are the best judges of their own preferences. According to the welfare economic theory a market with perfect competition, provided that certain assumptions regarding individual preferences hold,¹⁰ automatically leads to a Pareto-efficient and socially desirable distribution since all exchanges are assumed to be voluntary.¹¹ This implies that welfare economics gives little or no room for public interventions (except enforcing property rights) as long as the market is fully functioning and there is no wastage.

The healthcare market is, however, not a fully functioning market. Quite the opposite; the healthcare market is associated with extensive market failures,¹² which prevent Pareto-efficient allocations to arise. Thus, left to its own economic devices the healthcare market is likely to be highly inefficient. This creates a strong argument for public intervention to avoid inefficient and undesirable outcomes. Public interventions will, however, almost without exception, create both gainers and losers. Consequently, the Pareto principle is of little practical use when distributing scarce healthcare resources since applying it as guiding principle would block most public attempts of redistribution. In practice, economists have therefore relied on the less-strict, *potential Pareto principle*¹³ stipulates that redistribution is efficient and desirable if those made better off can hypothetically compensate those who are

¹⁰ The assumptions are *completeness, reflexivity and transitivity*. (see e.g. Shiell 2000)

¹¹ However, the market must fulfil certain demands to ensure that there is no waste: *efficient exchange, efficient allocation of production factors, and efficient choice of what to produce* (see e.g. Lipsey 2007).

¹² For example, *asymmetric information and externalities*. For more details on this topic see Paper I (Tinghög, Carlsson et al 2009) or Donaldson and Gerard (2005).

¹³ The potential Pareto principle is sometimes called the compensation principle or the Kaldor-Hicks criteria.

made worse off, while still making the “gainer” better off. Unlike the Pareto principle, there is no actual requirement on compensation from the “gainer” to the “loser”. The better off person could, if he or she wanted, compensate those who are made worse off, but this does not mean that he or she will actually do it. What efficiency means, according to the potential Pareto principle, is simply that benefits exceed burdens.

A general criticism of both Pareto principles is that they are efficiency oriented but equitably neutral, and as such give no consideration to the overall distribution of benefits and burdens among the population. Hence, welfare economics can justify policies that few people support, e.g. providing additional benefits to those already well-off. Sen (1979:22) comments:

An economy can be optimal in this sense [i.e. in the sense of both Pareto principles] even when some people are rolling in luxury and others are near starvation as long as the starving cannot be made better off without cutting into the pleasures of the rich.

Still, welfare economics requires an additional normative judgment about what it means for individuals to become “better off” for it to make practical sense. Traditional welfare economics assumes that individuals’ welfare is determined solely by the distribution of material resources. This assumption was questioned and refined during the 20th century when several economists proposed the idea that welfare involved both material and nonmaterial aspects that needed to be incorporated into the welfare concept (e.g Pigou 1912). This conception of welfare as something which incorporates both material and nonmaterial aspects was denoted utility. Welfare economics has therefore become closely allied with utilitarian ethical theory.

Utilitarianism

The classical utilitarian normative claim underpinning welfare economics is that an act is justified if, and only if, it maximizes the overall good in society. Sen (1987) dismantles the utilitarian ethical theory into a combination of three elementary requirements.

- i. *Welfarism*, which requires that goodness of a state of affairs be a function only of the utility information regarding that state.
- ii. *Maximization*, which requires that utility information regarding any state be assessed by looking only at the sum of all the utilities in that state.
- iii. *Consequentialism*, which requires that judgment regarding choices and actions be determined solely on goodness of the consequent state of affairs.

It is not uncommon to use all of these requirements interchangeably to mean *utilitarianism*. This, however, is misleading since other moral principles incorporate one or two of these requirements, but are still not equivalent to the utilitarian moral principle. For the sake of understanding, it is therefore important to distinguish these requirements from utilitarianism, which necessitates that all three requirements be fulfilled.

The first requirement, *welfarism*, deals with suitable units for valuing social welfare. According to utilitarian moral theory, social welfare can be conceived as a function of individual utilities that incorporates both material and nonmaterial aspects of welfare through preference satisfaction. The view on what part of individuals' preference satisfaction should be considered to constitute the utility that utilitarians strive to maximize is, however, open to a wide array of interpretations. Modern welfare economics identifies two main conceptions of utility that give rise to welfare. As Kahneman and Sugden (2005:162) comment:

Two different interpretations of the term 'utility' have been used in the literature of economics. In its original interpretation, which derives from Bentham, utility is interpreted in hedonistic terms, as a measure of pleasure and pain / . . . / Of course, this is not the way that most economists have used the term 'utility' over the last 100 years. During this period, utility has usually been understood as decision utility. Decision utility is a representation of preferences, and the concept of preference is understood in terms of choice: a person's preferences are the mental entities that explain his choices, and are revealed in those choices.

The original hedonistic interpretation of utility as proposed by Bentham (1789) was simply that utility is equivalent to happiness (or pleasure). Thus, the right

course of action would be the one that creates “the greatest happiness for the greatest number.” Later work by Mill (1861) introduced the idea that not all forms of happiness should be regarded as having equal value when estimating total utility. In a much-cited quote Mill states: “It is better to be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied.” The second main conception of utility rests on the idea that it is not happiness that should be singled out for maximization; instead, utility should be interpreted as representation of individuals’ preferences. The problem with utility as representation of individuals’ preferences satisfaction is that individuals do not always tend to prefer what is best for them. Individuals make mistakes and often have shortsighted preferences.¹⁴

The second requirement, *maximization*, stipulates that utilities should be aggregated across individuals according to an unweighted sum-ranking rule. This rule implies that only the sum of individual utilities is of importance when making allocation decisions. However, for a utility function to be measurable it needs to be represented by a valid cardinal utility function. Cardinal utility captures the strength of preference differences as opposed to ordinal utility, which only captures the ranking of preferences. For example, suppose a beer derives a utility of 12 utils, a cup of coffee 8 utils, and a cup of tea 4 utils. If preferences are represented by a valid cardinal utility function we could not only say that a beer is preferred compared to a cup of coffee, we could also state that it is preferred by exactly the same amount by which a cup of coffee is preferred to a cup of tea.

The third requirement, *consequentialism*, stipulates that the rightness or wrongness of an action should be assessed on the basis of the outcome, or consequence it produces. Hence, consequentialism is at times expressed through the aphorism; “The ends justify the means.” Moreover, it is usually understood as being distinct from deontology, in that deontology assesses the moral rightness of an act from the character of the act itself, rather than the consequences this act leads to. A deontologist could, for example, argue that the act of lying is always wrong regardless of the consequences that follow from telling the truth. While a consequentialist could argue that the foreseeable negative consequences from lying could make it permissible to lie. This means that no instrumental value is attached to processes that lead to consequences in utilitarianism. However, as Culyer (1998) points out, a

¹⁴ For more thorough exposition about conceptions of utility see, e.g. Hausman (2010) and Brock (1973).

process could, in principle, be conceptualized as a consequence if it affects the overall level of utility.

A general criticism often expressed against utilitarianism, which can be directed at a combination of the three requirements, is that utilitarianism ignores individual freedom (see e.g. Olsen 1997). When only consequences matter, it is easy to imagine actions that might increase total utility, but which do not correspond to a commonsense conception of justice, e.g. slavery and torture. Because of such counterintuitive implications, many utilitarians have abandoned the strict act-oriented version of utilitarianism for the rule-oriented version. Rule utilitarianism advocates the introduction of rules to guide the actions of individuals. This is because such rules are expected to maximize the total amount of utility in the longer run by creating a sense of security, reducing social tensions, and so on.

Cost-Effectiveness Analysis and Quality Adjusted Life Years

Cost-effectiveness analysis (CEA) is a standard economic tool for determining how to maximize health benefits when resources are limited. Thus CEA provides healthcare policy-makers with information about how to ration care in accordance with welfare economics and the utilitarian ethical theory. The outcome of CEA is usually expressed in terms of a cost-effectiveness ratio, where the health gain is the denominator and the corresponding cost is the numerator. Consequently, the cost-effectiveness ratio could be viewed as the "price" of the additional unit of health gain achieved by switching from current practice to the new strategy (e.g. €5000 per gained life-year or quality adjusted life year). If the decision-maker's willingness to pay is greater than the price, the new health program can be said to be cost effective. Hence, when a health program is said to be cost effective this simply indicates that it gives good value for money. CEA has nothing to do with saving money; actually a health program that saves money may very well be deemed cost ineffective. For the outcome of a CEA to result in an actual rationing decision it requires a final value judgment regarding what constitutes good value for money – an issue where CEA provides no guidance.

The quality adjusted life year (QALY) is the most widely used measure of health benefits in CEA. QALYs are often interpreted as utilities, where utility

is assumed to be dependent on health status (Q) and the number of life years. This can be described by the following formula:

$$QALYs = U(Q, T) = V(Q) \times T$$

Where $V(Q)$ is the value function of quality measured on a scale between 1 (full health) and 0 (death) corresponding to the weight, which is multiplied by life years (T). For instance, an individual with a quality level of 0.5 who will live 10 additional life years will generate 5 (0.5×10) additional QALYs.

When applying QALYs in CEA it is important to distinguish between *measuring health* and *valuing health* through QALYs. When measuring health through QALYs, generic preference-based questionnaires such as EQ-5D or SF-36 are most commonly used. These questionnaires include generic dimensions for describing health, which permit comparisons between different medical conditions. The dimensions for EQ-5D are: mobility, self-care, usual activity, pain/discomfort, and anxiety/depression. Each dimension has three levels, and patients are asked to indicate which level is most in agreement with their own situation. By combining answers from the dimensions a health profile can be assigned to the respondent. In the case of EQ-5D, 243 health profiles are possible ($3^5=243$ health profiles). (see e.g. Brazier, Ratcliffe et al. 2007)

When valuing health through QALYs, the impact that different health profiles have on welfare is estimated by so-called *preference elicitation techniques*. The two main techniques, which are founded in expected utility theory, are time trade off (TTO) and standard gamble (SG) (Johannesson 1996). Usually representatives from the public have been asked to value hypothetical health states. This implies that individuals rarely value their own health state in CEA.¹⁵ Both TTO and SG involve presenting the respondent with a choice. In TTO, the respondent can choose to give up some life years to live for a shorter period in full health. If the respondent chooses not to trade off any life years to achieve higher quality of life it is assumed the he or she has full health (1 QALY). If the individual is indifferent between living 8 years in full health and 10 years in the presented health state, a value of 0.8 QALYs is assigned to the presented health state. In SG, the valuation of QALYs is generated in a similar fashion. Respondents are asked to choose between remaining in the presented

¹⁵ This is a violation against the second fundamental value assumption in welfare economics, i.e. that individuals are the best judges of their own welfare.

health state for a period of time, or choosing a treatment that has a chance of either restoring them to perfect health, or killing them. If the respondent is unwilling to accept any risk of death to achieve full health, a value of 1 QALY is assigned to the presented health state.

For QALYs to represent a cardinal utility function they need to reflect the intensity of individuals' preferences. This implies that individuals should prefer the option that maximizes the expected amount of QALYs for the QALY to be a representation of individual utility over health. If an option that does not maximize QALYs is preferred, then QALYs cannot be taken to reflect individual utility over health. Pliskin et al. (1980) provided an axiomatic framework for identifying when QALYs represent a valid cardinal utility function, which is derived from von Neumann-Morgenstern expected utility theory.¹⁶ According to the framework, three conditions must be satisfied for QALYs to represent individual utility over health: *mutual utility independence*, *constant proportional trade off*, and *risk neutrality over life years*.

Mutual utility independence implies that life-years (T) and quality (Q) must be mutually independent. If either T or Q is held fixed at some level, utility independence imposes that preferences with respect to gambles over the other attribute do not depend on the particular value chosen. For example, if an individual is indifferent between living 10 years in a health state with moderate pain and a gamble with a 50% chance of 10 years with severe pain and a 50% chance of 10 years in full health, the individual should also be indifferent between these alternatives if the time horizon is set to 20 years instead of 10. When valuing health through SG, utility of a health state is measured as a fraction of full health, and if mutual utility independence holds the quality weight (which is equivalent to the outcome from SG) should always be the same, irrespective of time horizon.

Constant proportional trade off implies that the proportion of remaining life that an individual is willing to trade off for a specific health/quality improvement is independent of the amount of time he or she is expected to remain alive. For instance, if an individual is indifferent between 10 years with severe back pain and 5 years of full health, then he or she should also be indifferent between 10 years with severe back pain and 20 years of full health. When valuing health through TTO, utility of a health state is measured as the number of years in

¹⁶ This theory will not be described further here. The reader is referred to the original work of von Neumann and Morgenstern (1947).

full health divided by the number of years in the assessed health state. If constant proportional trade off holds, this ratio should be the same, irrespective of time horizon.

Risk neutrality over life years implies that individuals should be indifferent between living 2 years in health state x and a lottery with a 50-50 chance of living in health state x for either 1 or 3 years. This implies that individuals should have a constant marginal utility from additional years in a specific health state, i.e. every additional year in full health is of equivalent value to the individual.

If these conditions are satisfied, individuals will rank different outcomes in accordance with their desirability. The outcome that maximizes QALYs will be the most the desirable. If the conditions are not satisfied, the ranking of outcomes based on the number of QALYs it yields gives no indication of desirability.

Later work by Johannesson (1994) and Bleichrodt et al. (1997) have graphically and mathematically demonstrated that the three conditions proposed by Pliskin et al. (1980) under certain assumptions can be reduced to two: risk neutrality over life years in all health states and *zero condition*. The latter implies that for a duration of zero life years, all health states derive the same utility, which in the context of health is entirely self-evident. These conditions are, however, sufficient only if we assume a chronic health state where quality of life is constant until death. If quality of life is not constant, an additional condition of *additive separability* needs to be fulfilled. This condition implies that utility of a health state in a specific period is unaffected by the health state that precedes or follows it (Broome 1993).

The QALY Approach Toward Rationing – Critique

The so-called “QALY approach” toward healthcare rationing is to allocate available resources in a way that maximizes the number of QALYs gained. This can be achieved by giving priority to medical interventions that have a relatively low cost per QALY gained. Criticism against the QALY approach to rationing health care can be categorized into the same three main groups that form the requirements for utilitarian moral principle, i.e. *welfarism*, *maximization*, and *consequentialism*.

Welfare economics singles out welfare or utility as the object of maximization. For CEA to fit into the welfare economic framework, QALYs need to represent a valid cardinal utility function, i.e. satisfy the conditions of *mutual utility independence*, *constant proportional trade off*, and *risk neutrality over life years*. However, individual preferences used to value health states are frequently found to violate these conditions (Tsuchiya and Dolan 2005). This means that QALY maximization does not reflect desirability since it does not capture non-health benefits appropriately. According to classical hedonistic utilitarianism, utilities are typically taken to stand for happiness, but there is little evidence that healthier individuals with more QALYs are also happier individuals. This has led to the emergence of a nonwelfarist approach,¹⁷ where QALYs are interpreted to be an indication of health, but the actual utility does not necessarily have to change proportionally to the size of QALY gains. If QALYs do not represent utilities, the outcome from a CEA cannot be applied as decision rule unless the main objective is to maximize health in the sense of QALYs. However, the outcome may still be a valuable input to decision making since maximizing health is likely to be an important (but not the only) objective.

A second major criticism relates directly to the desirability of maximization, and that it ignores concerns regarding distributional fairness. Considerable empirical evidence shows that people do not think resources should be allocated simply to maximize outcomes. Studies show that people have a general preference for directing health resources toward individuals who are in very poor health states, even when doing so means generating less overall health benefit and thereby sacrificing some QALYs (see e.g. Nord 1999).

A related criticism toward the QALY approach and the desirability of maximization concerns the assumption that certain groups are discriminated against. Most notably the QALY approach has been criticized for being unfair to elderly individuals with preexisting disabilities and conditions (Harris 1987). For example, a life-prolonging treatment aimed at otherwise healthy individuals who could be saved to lives in perfect health would *ceteris paribus* generate more QALYs compared to the equivalent program aimed at individuals with preexisting disabilities who are unable to achieve perfect health. It is also easy to imagine that aged individuals, due to natural causes, can be expected to have a shorter remaining lifespan than younger individuals. Hence, at times, the QALY approach is accused of being *ageist*

¹⁷ Which is, confusingly, often referred to in the literature as extra-welfarism.

since, *ceteris paribus*, older individuals with a shorter life expectancy will always receive lower priority compared to younger individuals (e.g. Harris 1987; Evans 1997; Tsuchiya 2000).

The QALY approach evaluates allocations by their consequences on aggregated QALYs. It attaches no instrumental value to the method upon which the outcome is based. A wide range of evidence suggests that the procedure on which decisions are based upon, influence the individuals' judgment of the consequence that follows from a decision. For example, in a study by Frey and Pommerehne (1993) shows that, raising prices to ration demand was considered less fair than allocation by a "first come, first served" rule, or allocation by an authority, although the consequences were the same.

A final criticism¹⁸ directed at the standard QALY approach is that future health benefits are assigned lower value compared to more immediate health benefits. This issue has received surprisingly little consideration within the framework of CEA. However, is it really a justifiable moral view that the outcome of a CEA recommends saving one life today rather than 131 lives in 100 years?¹⁹

Ethics

Justice obliges us to pursue fairness in the promotion of health, but policy needs the guidance of ethics in determining what this mean

-Norman Daniels

The ethical perspective on healthcare rationing is concerned with how to allocate scarce resources as *fairly* as possible to best satisfy human wants. Understanding the population-level ethics perspective is, thus, closely aligned with the distribution of scarce resources and applying different theories of fairness to healthcare need. For this to make any practical sense, however, we need to establish what is meant by *fairness*. In contrast to the economic

¹⁸ For a more extensive overview of the ethical issues related to CEA and QALYs see, e.g. Brock (2003)¹⁹ If a 5% annual discount rate is applied.

¹⁹ If a 5% annual discount rate is applied.

perspective, which has a rather coherent framework for interpreting efficiency, fairness is open to a wide array of interpretations. This section will present of five theories on distributive fairness with particular relevance in the context of healthcare rationing; *maximization*, *egalitarianism*, *maximin*, *sufficientarianism*, and *prioritarianism*. In addition some ideas related to *equality of opportunity* and *procedural fairness* will be presented.

Distributive Fairness and Healthcare Rationing

Five main views on substantive fairness are commonly presented in the philosophical literature to make sense of fairness in the context of health care (Olsen 1997; Cookson and Dolan 2000). Insight into these, and how they can be applied in ranking healthcare need, provides a clearer understanding of the normative basis of different ethical approaches to healthcare rationing.

Fair distribution, according to the *maximization principle*, is that which maximizes the total sum of the entity to be distributed. As regards healthcare need, this translates into a distribution of healthcare resources that maximizes the total sum of health in society. Consequently, the maximization view on fairness places a strong emphasis on individuals' capacity to benefit from treatment, while giving no extra weight to healthcare need of those who are most severely ill or worst off. Utilitarianism is a particular type of maximizing view, which focuses on utility as the relevant entity for distribution. Utilitarians would, however, claim that their view on fairness does give extra weight to the most severely ill. The rationale for this claim is that a particular health improvement for a severely ill individual is likely to create greater utility improvement compared to a healthier individual who experiences the same health improvement. For instance, a paraplegic individual who suddenly recovers the ability to move a finger would most certainly derive a higher increase in utility compared to an otherwise healthy individual who recovers the ability to move the same finger.

Fair distribution, according to *the egalitarian view*, is that which creates the most equal outcome of the entity to be distributed. As regards health, this implies that focus should be placed on those individuals with the lowest level of current health, and even slight improvement for those individuals should receive priority. The primary concern among strict egalitarians is, therefore, the health state which an individual is in before receiving treatment, while no

consideration is devoted to individuals' capacity to benefit from treatment. In contrast to the maximization view on distributive fairness, the egalitarian view is comparative, implying that it is concerned with how people fare relative to others. Everyone should receive an identical share even if adherence to equality reduces the overall level of health or utility in society. Because of this feature, many have rejected egalitarianism due to the so-called *leveling-down objection* (e.g. Nozick 1974 and Temkin 1993). The leveling-down objection states that there is nothing desirable about equality in itself if everyone becomes worse off. For example, Temkin (2003) suggests that it is unreasonable to consider that an outcome where everyone becomes blind is more desirable than an outcome where only one person becomes blind.

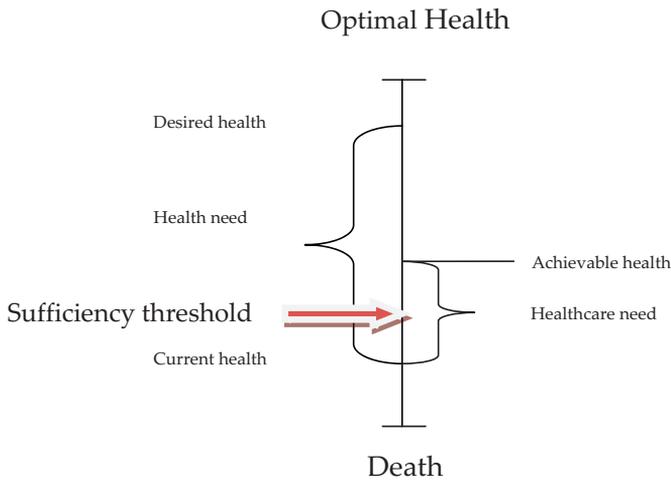
A less-strict version of the egalitarian view is the Rawls' type of egalitarianism of *maximin view* (Rawls calls it the *difference principle*). As opposed to the strict egalitarian view, the maximin view accepts inequalities, but only under the premise that it is not possible to further improve the situation for the worst off. Applied to health, this implies that the most severely ill should receive priority as long as the treatment reduces the health gap to some extent (no matter how small this reduction might be). However equality in itself is not the most important aspect for those in support of the maximin view.

The sufficientarian view on fairness is another, less-strict version of the egalitarian view. It proclaims that fairness requires that everyone gets enough of the entity that is to be distributed, but not that everyone gets the same. When individuals are "sufficiently" well off, it is no longer warranted that society should give priority to an individual merely because he or she is worse off. As Frankfurt (1987:34) suggests: "The fundamental error of egalitarianism lies in supposing that it is morally important whether one person has less than another regardless of how much either of them has". And again (1987:268): "We tend to be quite unmoved, after all, by inequalities between the well-to-do and the rich /.../ The fact that some people have much less than others is morally undisturbing when it is clear that they have plenty".

As regards health, the sufficientarian view implies that individuals below a certain level of current health should always receive priority regardless of how much a treatment reduces the existing health gap. Priority should be given until they have been elevated above this minimum, predefined, health state, which we can call the sufficiency threshold (illustrated in figure 3). Hence,

ranking on the basis of healthcare need implies that everyone gets *sufficient* health before applying any considerations regarding the capacity to benefit. The problem of inequalities in the sufficientarians' view is not that some people have a better current health state than others, but that some have an unacceptably low level of current health. Consequently, sufficientarianism – as opposed to egalitarianism – focuses on the alleviation of absolute detrition instead of relative health inequality when assessing healthcare need.

Figure 3. Graphical illustration of a health sufficiency threshold.



Many philosophers have argued about where the predefined threshold should be set. Sen (1985) and his basic capability approach represents a sufficientarian view proposing that the minimum level should be set so that everyone is equally assured of the basic capability to function in important and valuable ways.²⁰

The prioritarian view on fairness stipulates that benefiting an individual matters more the worse off that person is. This view was most prominently developed through the work of Temkin (1993) and Parfit (1995, 1997). As opposed to the egalitarian and sufficientarian views, the prioritarians allow considerations that involve individuals' capacity to benefit. As regards health, this implies that it is more important to reduce the health gap for the worse-off person than it is to achieve the equivalent reduction for a better-off person. The

²⁰ Martha Nussbaum (2000) has later attempted to define the capabilities that should be supported by all democracies.

prioritarian view is most accurately viewed as a family of views since different versions vary in terms of how much priority they give to the needs of those worst off. Prioritarians who wish to give only a little extra weight to the healthcare needs of those who are worse off are close to the utilitarian rule of ranking, which is based purely on individuals' capacity to benefit. Prioritarians who want to give substantial extra weight to the healthcare needs of those who are worst off are, on the other hand, close to the egalitarian rule of ranking, which gives no consideration to the capacity to benefit.

Fair Equality-of-Opportunity and Healthcare Rationing

In addition to the theories on distributive fairness, which focus on fairness related to the distribution of specific outcomes, the ethics perspective also encompasses theories related to the distribution of individuals' prospects or opportunities. Rawls (1971) initially introduced the concept of equality-of-opportunity in his idea of *justice as fairness*. According to this idea, social and economic inequalities are justifiable if they satisfy two conditions. The first is known as the *difference principle*, which asserts that inequalities are only justified if they are advantageous to the worst-off in society. The second condition is what has become known as the *fair-equality-of-opportunity principle*, which asserts that justice should not favor those with advantageous social contingencies.²¹ Over the years, many philosophers have elaborated on trying to further specify the meaning of fair-equality-of-opportunity. Roemer (1995) further explicates the general equality-of-opportunity view on fairness:

Equality-of-opportunity views are closely allied with a commitment to personal responsibility. Society under such views is not required to insure individuals against bad results when they are the consequence of individual choices made after opportunities have been equalized. On the equality-of-outcome view, in contrast, society's mandate is to render all lives equally

²¹ The first principle in Rawls idea of justice as fairness, which I have not mentioned, is what is known as the equal liberty principle. This principle asserts that everyone should have equal right to the most extensive basic liberties, e.g. freedom of speech and political liberty.

successful, at least in so far as this is feasible. Thus, persons are not effectively held responsible for their choices.

As regards health, the equality-of-opportunity view focuses on equalizing people's opportunity for lifetime health rather than achieved levels of health. According to this view, an unequal distribution of health and healthcare resources could be considered fair if people choose not to exercise their opportunity for achieving health. Dworkin (1981) formulated the influential distinction between *brute* and *option luck*. Brute luck refers to occurrences of luck that individuals could not have anticipated or avoided, while option luck denotes deliberate gambles or actions:

If I buy a stock on the exchange that rises, then my option luck is good. If I am hit by a falling meteorite whose course could not have been predicted, then my bad luck is brute (even though I could have moved just before it struck if I had had any reason to know where it would strike) (Dworkin 1981:73).

This distinction helps shape the general *luck egalitarian* idea that inequalities are fair as long as they follow from individuals' deliberate and fully informed choices (see e.g. Arneson 1989). However, outcomes that stem from choices or behaviors over which the individual has no control should be deemed unfair. In the context of health care this could imply that an individual who has deliberately engaged in an unhealthy lifestyle should be given lower priority compared to an individual who has acted "responsibly". However, individuals should not be held responsible for the characteristics of the group they belong to. Hence, according to the equality-of-opportunity view it may be justifiable to give a "responsible" person within a group with similar opportunities to live a healthy lifestyle priority. But since individuals rarely have similar opportunities to act responsibly, because of the social determinants of health, a less-healthy lifestyle might be just as responsible as a healthy lifestyle since individuals have different degrees of power to exercise responsibility (Roemer 1995).

Procedural Fairness and Healthcare Rationing

Procedural fairness refers to the idea that disputes concerning resource allocations should be resolved through a just process. Hence, it is the characteristics of the procedure itself that guarantee achievement of a fair

outcome. Dolan et al (2007) identify three reasons why procedural characteristics matter: first the procedure could matter simply because it promotes better outcomes (the consequentialist view); second, it might matter because the procedure has an inherent value in itself (the proceduralist view); third, procedures might be important because they promote values that are not associated with outcomes, e.g. legitimacy for the decision-maker (the instrumentalist view).

The most renowned theory of procedural fairness related to health care is Daniels and Sabin's (2008) *accountability for reasonableness* (A4R). A4R extends Rawls' theory of justice to include health care as a primary good that should be distributed fairly.²² Due to the natural lottery, the need for health care is much more varied across the population in comparison to other primary goods, e.g. food, clothing, and basic liberties such as freedom of thought. This makes it less likely for people to reach agreement on a single moral principle for resolving disputes concerning how to distribute scarce healthcare resources compared to other primary goods.²³ Given that reasonable people will inevitably disagree on what is fair distribution of healthcare resources, disputes need to be resolved through a fair process. Daniels (2000:1300) explicates:

In pluralist societies we are likely to find reasonable disagreement about principles that should govern priority setting. For example, some will want to give more priority to the worst off, some less; some will be willing to aggregate benefits in ways that others are not. In the absence of consensus on principles, a fair process allows us to agree on what is legitimate and fair.

The key thought behind the A4R is that although individuals are likely to disagree about first-order reasons for resource allocations, they ought to be able to reach a consensus on second-order reasons concerning how to handle disagreements on first-order reasons. A4R offers four conditions that a decision-making process for allocation of healthcare resources must meet to be legitimate and fair:

²² Rawls' theory of justice assumes that everyone has full health.

²³ Rawls states that behind a veil of ignorance individuals will unanimously choose to maximize the primary goods among the worst-off individuals.

- (i) *Publicity condition*: Decisions regarding rationing and their rationales must be publicly accessible.
- (ii) *Relevance condition*: The rationales for rationing should aim to provide a reasonable explanation of how the organization seeks to provide 'value for money' in meeting the varied health needs of a defined population under reasonable resource constraints. Specifically, a rationale will be reasonable if it appeals to evidence, reasons, and principles that are accepted as relevant by fair-minded people who are disposed to finding mutually justifiable terms of cooperation.
- (iii) *Revision and appeals condition*: Rationing decisions must have some degree of reversibility. A mechanism must exist to enable unfavorable decisions to be disputed. Further, decisions must be revised in the light of new evidence or arguments.
- (iv) *Enforcement condition*: A means must be in place to regulate the process to ensure that conditions 1 to 3 are met.

This procedural account for healthcare rationing and priority setting has been endorsed in many countries, e.g. Mexico, UK, Canada, and New Zealand. Several authors, however, have raised objections to this procedural account (e.g. Rid 2009, Friedman 2008, Sabik and Lie 2008). First, and most notably, the approach has been criticized for not making a clear distinction between legitimacy and fairness. Even though a fair process may yield legitimate outcomes, these outcomes might still be unfair. Second, it has been argued that the crucial relevance condition is too vague, and therefore it offers little guidance in practical decision-making. Third, the appeal by Daniels and Sabin for a fair process has been criticized (by people who insist that the process alone cannot tell us what is right or fair) for understating the importance of substantive principles when making rationing decisions. However, this criticism is somewhat incorrect since A4R also contains the "relevance condition", which I understand to stipulate that "fair-minded" people have reached agreement on the relevant substantive principles.

MAIN FINDINGS AND DISCUSSION – A WELFARE ECONOMIC PERSPECTIVE ON HEALTHCARE RATIONING

In this chapter I will briefly describe the four papers included in this thesis and discusses their main findings from a welfare maximizing perspective. Each of the papers corresponds to one (or more) of the conceptual themes that will also serve as a framework for the extended discussion in the following chapter, when approaching the matter of finding justifiable grounds for healthcare rationing from a broader ethical perspective. The conceptual themes are: *individual responsibility, paternalism, incentives, and inequality*.

Paper I: “Individual Responsibility for What? – A Conceptual Framework for in a Publicly Funded Healthcare System”

Although it seems likely that some notion of individual responsibility is an essential feature in rationing decisions, it is rarely explicitly articulated or evaluated in the context of health policy. Paper I presents a tentative conceptual framework for exploring when healthcare services contain characteristics that facilitate individuals’ ability to take responsibility for their own health care through private financing.

The potential role of individual responsibility in healthcare policies is not a new topic. The debate surrounding individual responsibility for health has revolved mainly around three philosophical issues: When do causal factors constitute effort or circumstance? When should choices relating to health be regarded as genuinely deliberate and free as opposed to being socially conditioned? What constitutes socially acceptable risk taking with regard to one’s own health? These interrelated issues center on a retrospective notion of individual responsibility, i.e. the moral relevance of holding people responsible for past health-related behavior. However, so far, no satisfactory

answers on how to incorporate retrospective responsibility into actual policies have emerged.

This paper applies a prospective notion of individual responsibility for health care, focusing on responsibility in terms of the healthcare services that individuals are capable of financing and managing without public involvement or subsidies – a conception of individual responsibility that has been argued to be more policy-relevant in welfare-promoting societies (Le Grand 2003).

When exploring this forward-looking conception of responsibility the characteristics of a specific healthcare service and the market failures surrounding the specific service become crucial. In some instances, the individual may be fully capable of managing the care required by certain health states. Six attributes for exploring the suitability of private financing for specific healthcare commodities are identified and discussed:

- (i) it should enable individuals to value need and quality both before and after utilization
- (ii) it should be targeted toward individuals with a reasonable level of individual autonomy
- (iii) it should be associated with low levels of positive externalities
- (iv) it should be associated with a demand sufficient to generate a private market
- (v) it should be associated with payments affordable for most individuals
- (vi) it should be associated with ‘lifestyle enhancements’ rather than ‘medical necessities’.

These attributes enable exploration of individual responsibility connected to health care as a heterogeneous group of commodities. Attributes 1 to 3 in the framework (sufficient knowledge, individual autonomy, and positive externalities) are all connected to the specific characteristics of health care that violate crucial assumptions for a well-functioning market. These attributes allow identification of services that can be allocated through the working of market mechanisms without resulting in inefficient outcomes due to market failures.

Attribute 4, sufficient demand, is further connected to specific characteristics concerning the provision of health care, which may call for public funding to ensure that individuals are able to take individual responsibility. Healthcare services that (for reasons other than market failures) are not available through private alternatives are unsuited for individual responsibility. The lack of these services would consequently make them high-priority candidates for inclusion in the publicly funded healthcare system.

In addition, policymakers also have an obligation to protect people from unbearable financial costs associated with poor health. Rationales for collective responsibility begin with some concept of fairness, usually involving the belief that no one should be denied health care due to the inability to pay, or the idea that public funds should not be spent on 'pleasure seeking' instead of pain/symptom avoidance. Such beliefs about equality and fairness constitute an important basis for including the concepts of affordability and 'lifestyle enhancements' in the framework.

Paper II: “Discounting, Preferences, and Paternalism in Cost-Effectiveness Analysis”

When making rationing decisions based on CEA, discounting enables policy-makers to compare competing health programs which entail outcomes that appear at different times. Paper II assesses the moral reasonableness of the arguments traditionally motivating public authorities to discount health outcomes when making intertemporal rationing decisions through cost-effectiveness analysis. In addition, the paper addresses the issue of when it is justifiable for policy-makers to override individuals' fully informed time preferences in making rationing decisions over time.

Frank Ramsey (1928) presented one of the earliest formulas addressing the wide range of reasons expressing why resources available in the future should be valued less than the same amount available today:

Social discount rate = $\delta + \epsilon_x g_x$

Where δ denotes individual time preference, ϵ_x denotes the elasticity of the marginal utility of the good x , and g_x is the growth rate of good x . This formula

helps to disentangle three main components why resources available in the future should be valued less than the same amount given today. First, individual time preference (δ) is motivated by the assumption that individuals are impatient and, in general, prefer to consume a given amount of resources sooner rather than later. Second, the growth rate of good x (g_x) motivates discounting because if society can transform resources available today into greater amounts in the future through investments there is an opportunity cost that a social time preference should take into account. The third part of the formula, the elasticity of the marginal utility of the good x (ϵ_x), serves as a link between these two main sources. This term implies that if we have more of a good in the future, the utility that the individual derives from the same unit of that good in the future is of less magnitude.

The paper concludes that the behavioral effects related to time preferences advanced in the literature give little or no reason for why society at large should favor the present over the future when making *intergenerational* choices regarding health. From a fairness perspective it seems impermissible that society should favor current generations over future generations purely on the basis of position in time. Moreover, there is the argument that contemporary democracy may be insufficiently sensitive to the concerns of future generations, which makes a paternalistic approach towards the social discount rate preferable. The fact that behavioral effects give little support for discounting future health does not mean that discounting in CEA should be abandoned altogether. Factors such as growth and diminishing marginal utility, which are likely to change as functions of temporal distance, still justify assigning less value to future outcomes. However, this does not mean that temporal distance in itself gives a legitimate reason for discounting, and there is no *prima facie* reason to assume that these factors should apply equally to health and money.

Regarding *intrapersonal choices*, the paper categorizes preference failures, which justify paternalistic intervention, into two distinct groups – myopic and acatic.

Myopic preference failures concern the cognitive inability to compute information adequately to make choices that maximize welfare of the individual. For example, this could include cases where logical or causal connections between choice and outcome are difficult to make, or where the quantity of information is too great for the individual to assess (Goodin 1993; New 1999). The information itself might, however, be perfectly adequate.

Judgments about probabilities and likely future outcomes of actions are particularly common myopic preference failures. The work of Tversky and Kahneman (1979) has shown empirically how people with perfect information commonly display inadequate reasoning power to interpret and calculate the implications of certain statistical or probabilistic situations.

Acratic preference failures concern the existence of reduced willpower. This could include situations where individuals act against their own better judgment and fail to do what is in their long-term best interest. For example, individuals often lack the ability to emotionally assess the force of information – knowing the facts, but not feeling the force of an outcome psychologically. Hence, even though individuals may have good judgment as to what is necessary for long-term good, they frequently choose a different course of action. This line of argument is commonly used to motivate mandatory public programs, ensure that individuals save for retirement and avoid procrastination, or to deny the preferences of addicted persons once they have checked into a rehabilitation center.

Paper II concludes that since myopic and acratia preference failures are common in the context of health choices, elicited time preferences are of little normative relevance when making decisions on the social discount rate. Some time-dependent factors of individuals' time preferences, e.g. dread and anticipation, could potentially constitute a legitimate basis for discounting in the intrapersonal context once they have been separated from myopic and acratia elements. As with intergenerational discounting, the combined argument from growth and diminishing marginal utility supply the strongest arguments for discounting in the intrapersonal context. However, there is no *prima facie* reason to assume that this argument should apply equally to health and monetary values.

Paper II is written from a traditional welfare-economic perspective focusing on solutions that aim to maximize welfare. However, it is worthwhile to consider the option of stepping outside of the traditional framework of utilitarianism when considering the issue of discounting future health. If the societal objective of making intertemporal choices is solely to maximize net welfare over time, this could easily lead to an unfair distribution of healthcare resources across generations, forcing one generation to make excessive sacrifices for the sake of future generations. Intuitively, it seems unjust to

require the current generation to commit itself to large-scale medical experiments with severe immediate consequences for the purpose of benefiting future generations, although this assumingly, would increase the net sum of welfare over time. No generation can be morally required to make more than a certain sacrifice for the sake of future generations. This is an issue that the utilitarian framework for discounting within CEA does not consider. However, CEA in general does not consider how burdens or benefits are distributed, nor does it reflect every aspect of importance in the allocation of scarce healthcare resources. This could be considered a weakness if one chooses to view CEA as a decision rule rather than decision input.

Paper III: “Incentivizing Deceased Organ Donation: A Swedish Priority-Setting Perspective”

Healthcare rationing does not necessarily have to be associated with financial shortage. It can also be associated with nonfinancial factors. Organ transplantation is a typical example of rationing driven by nonfinancial factors. The limited number of available organs forces healthcare professionals to engage in rationing decisions to determine who should and who should not receive an organ. Paper III approaches the issue of healthcare rationing indirectly by first developing a proposal for compensated deceased organ donation that could potentially address the organ shortage and increase overall welfare in society. In addition, the paper examines whether the monetary incentives in the proposal are compatible with the ethical values of Sweden’s healthcare system.

Using incentives to increase the supply of organs is often associated with a mental image of the rich buying organs from the desperately poor. In reality, however, incentives are any factors (financial or nonfinancial) that motivate individuals to take a particular course of action. In other words, incentives are the expectations that encourage people to behave in a certain way and could be tailored to achieve organizational success. Financial incentives, e.g. salaries and bonuses, are the most obvious types of incentives, but in certain settings nonfinancial incentives could be far more powerful tools when trying to influence individual behavior. When people act against economic self-interest to promote wider societal interest, various types of nonfinancial incentives can usually explain why they choose to behave prosocially.

Incentives for individuals to behave prosocially can be divided into three categories: *extrinsic motivation*, *intrinsic motivation*, and *signaling motivation*. Extrinsic motivation refers to motivation by factors external to the individual. For example, individuals may be motivated by material rewards such as money. These rewards provide satisfaction and pleasure that the behavior or task itself may not provide. Intrinsic motivation refers to motivation from factors internal to an individual; such as the pleasure one derives from the task itself, or from the sense of satisfaction in completing or even working on a task. Pure altruism, meaning selfless concern for the welfare of others without regard to reward or the benefits of recognition, could be one such intrinsic motivational factor for behaving prosocially. Finally, signaling motivation refers to motivation by an individual's concern about how he or she is perceived by others, i.e. we are more inclined to feel good about ourselves when others hold us in high esteem. These categories of motivation are mutually interdependent and may interact and possibly crowd out one another, resulting in less prosocial activity in some instances (Mellström and Johannesson 2008). Consequently, to increase an individual's willingness to engage in prosocial activities, it is important for policy makers to have a sufficient understanding of how different types of incentives interact.

According to behavioral agency theory, prosocial activity can be partially explained by differences in individuals' preferences to signal altruism in attempting to increase social esteem, or strong preferences to avoid signaling greed (Bénabou and Tirole 2006; Ellingsen and Johannesson 2007). These models incorporate all three types of incentives and give reasonable explanations for why individuals in some specific settings tend to lower their prosocial activity when material rewards are introduced (Frey and Oberholzer-Gee 1997; Gneezy and Rustichini 2000; Mellström and Johannesson 2008). It is also widely acknowledged that individuals will act more prosocially if their behavior is observable. Several field studies have shown that donations to charity increase when associated with a high degree of publicity (Harbaugh 1998; Soetevent 2005).

Building on behavioral agency theory and empirical insights concerning how to increase prosocial behavior, the paper presents a proposal for compensated deceased organ donation. This proposal incorporates intrinsic, extrinsic, and signaling motivations and can be summarized as follows:

- i. €5000 contribution to the estate or family of the deceased toward funeral expenses.
- ii. Deceased (advanced directive) or family could decline the contribution in full.
- iii. All or part of the monetary contribution could be directed as a publicized donation to a reputable charity of the deceased's (if the will is known) or family's choice.
- iv. In all circumstances, the right to self-determination of the deceased must be respected, and the decision of the family cannot be in contradiction to the explicitly stated provisions of the will of the deceased.

The proposal is carefully discussed in relation to the three ethical priority setting principles; human dignity, needs and solidarity, and cost efficiency. The discussion shows that the proposal for compensated deceased donation would be fully compatible with the priority setting principles, and therefore it merits serious consideration.

In arriving at this conclusion, the paper outlines three potential moral pitfalls associated with incentivizing individuals' health choices through monetary compensation; *coercion*, *commodification*, and *loss of public trust*. These potential pitfalls are all aspects that could make excessive use of incentives in health care ethically objectionable. Hence, the fundamental question that needs to be asked when incentivizing individual choices concerning their own health is: When do these objections become strong enough to hinder society from maximizing overall welfare? In the case of our incentive-based proposal we do not view these objections to be strong enough to allow people to die. Consequently, we suggest that the potential benefits of introducing a regulated system of compensated deceased organ donation outweigh potential disadvantages in the context of Swedish health care.

Paper IV: "Horizontal Inequality in Rationing By Waiting Lists"

Various mechanisms can be used to ration health care, the most common of which is price. Demand is restrained by monetary price, which the patient faces at the point of demand. In public systems where care is often free or priced well below market-clearing level, demand and supply must be

reconciled through other rationing mechanisms. Hence, publicly funded systems commonly rely on waiting lists as a mechanism to limit availability, while still trying to maintain that persons in equal need are treated equally. Paper IV investigates whether socioeconomic inequalities exist in waiting times for six types of elective surgeries in the Swedish healthcare system. To achieve this aim, the paper sets out to test five hypotheses that more resourceful groups receive priority when care is rationed through waiting lists:

- i. Male patients receive priority over female patients.
- ii. Younger patients receive priority over older patients.
- iii. Patients with higher incomes receive priority over patients with lower incomes.
- iv. Patients of Swedish origin receive priority over patients of foreign origin.
- v. Patients currently active in the workforce receive priority over patients currently inactive.

Paper IV was based on a retrospective approach in the sense that the lengths of the waiting times were calculated for all patients who received an elective surgery in 2007. This implied that patients who remained on the list, or exited the list for reasons other than surgery, were not included in the data set. Data on waiting time for elective procedures were obtained from the administrative healthcare register in the county of Östergötland, Sweden. The elective procedures were based on the ICD-10 codes used to classify nonacute surgical procedures. In total, 24 nonacute surgical procedures were included. These 24 elective procedures were aggregated into six surgical categories; vascular, orthopedic, gynecologic, urologic, ophthalmologic, and general surgery. The study included 4636 completed waiting-time episodes. Multiple linear regression models were used to investigate the associations between waiting times and our selected predictors; age, gender, disposable income, ethnicity, and workforce activity. Data on these independent variables were retrieved from Statistics Sweden (SCB), and by using the civic person identification number we could link waiting-time data from an administrative database to socioeconomic registers.

The results presented in paper IV provide some support for the assertion that horizontal inequality occurs when rationing elective surgeries through waiting lists. This picture, however, is not clear-cut, as inequality was not present in all

surgical specialties. No evidence of horizontal inequality was found in vascular and urologic surgery. Concerning gynecology, the results contradicted the stipulated hypothesis, i.e. that more resourceful groups receive priority when care is rationed by waiting lists. In the specialties of orthopedics, ophthalmology, and general surgery the data supported the presence of horizontal inequalities. Particularly noteworthy in this context was the finding that lower household income predicted longer waits in both orthopedics and general surgery.

In connection with the finding that low income predicted longer waiting times in orthopedics and general surgery, it is worth noting that these were also the surgical specialties where patients in general experienced the longest waiting times. A hypothesis raised by the findings of the paper is that income becomes an increasingly influential factor as waiting time becomes longer. Alternatively, the findings could suggest the existence of a threshold effect, where disutility associated with waiting is negligible as long as the waiting time does not exceed a certain length. This may be explained by the existence of an initial adjustment period allowing individuals to mentally prepare and make necessary practical arrangements. But in cases where time on the waiting list exceeds this threshold, the disutility associated with continued discomfort and anxiety take over, making individuals increasingly active in trying to gain priority, thereby favoring more resourceful groups.

The paper did not confirm the hypotheses concerning ethnicity and gender. Hence, men and patients of Swedish origin did not appear to receive priority. A possible explanation for why these hypotheses were not confirmed could be that the study focused solely on differences among patients who have already been referred for a specific elective procedure. Also, it is possible that females and patients of foreign origin could be discriminated against before being placed on the waiting list by a referring physician, but not once they have been placed on the waiting list.

This study documents that access is unequal when waiting lists are used to ration care, but only to a limited extent. Whether this is good or bad news depends on your worldview, i.e. your expectations on the functioning of public health care and your normative views on how it should function. From a policy-maker's perspective it is important to recognize that horizontal inequalities arise even when care is not rationed through ability to pay. Consequently, horizontal equality in waiting times cannot be assumed in

publicly funded healthcare systems unless this is closely monitored and openly discussed. Although our findings are to some extent context-specific, they are relevant for decision-makers in other countries that rely heavily, like Sweden, on waiting lists as a mechanism to ration care.

EXTENDED DISCUSSION – A POPULATION-LEVEL ETHICAL PERSPECTIVE ON HEALTHCARE RATIONING

In this chapter I will extend the discussion raised in the papers by applying a broader ethical perspective via the same four conceptual themes relating to healthcare rationing used in the preceding chapter, i.e. *individual responsibility*, *paternalism*, *incentives*, and *inequality*. Each of these conceptual themes represents areas where reasonable disagreements are likely to occur. My ambition with this chapter is not to resolve the reasonable disagreement associated with these conceptual themes, but rather to bring forward some of the complexities that surround them. In addition, I offer some personal reflections on what I believe to be the most appropriate way forward in dealing with these normative issues in practice.

Individual Responsibility – A Prospective Approach

Paper I, *Individual responsibility for what?*, deals primarily with the question of how individual responsibility for health care can be efficiently applied when rationing care. It focuses on the heterogeneity of healthcare commodities, the occurrence of market failure in the healthcare context, and the implications this could have for individuals' ability to take responsibility for their own health care. The question of how individual responsibility for health care can be efficiently applied when rationing care is important from both an economic and an ethical standpoint. Rationing in nonfunctioning markets will inevitably lead to excessive sacrifices in well-being – and this is not merely an economic concern. A question that the article only briefly touches on is: When is it fair to assign responsibility for past behavior? Hence, I will pursue this discussion in the context of healthcare rationing.

Poor health and the need for health care is not something that appears like a “donkey from nowhere”.²⁴ Individuals often have opportunities to minimize the risk for future healthcare consumption by refraining from unhealthy behaviors and avoiding hazardous situations. It is increasingly obvious that individuals’ choices – healthy lifestyles – are perhaps the most significant factors for being healthy. Yet, the extent to which past behavior should (or should not) influence healthcare rationing is a morally intricate matter. On one hand, we could argue that it would be excessively harsh for society to abandon individuals in need because they knowingly behaved irresponsibly. On the other hand, it seems equally impermissible to dismiss individual responsibility altogether when setting priorities. Especially since one man’s freedom to behave irresponsibly becomes another man’s financial burden in a publicly funded healthcare system. Hence, one could argue that some form of reactive measure to hinder irresponsible use of collective resources should be in place.

A common line of thought when discussing the role of individual responsibility is that an individual should be held accountable for the foreseeable consequences that are within that individual’s control. Likewise, individuals should not be held accountable for unforeseeable consequences due to circumstances outside that individual’s control. This thinking aligns with the *luck egalitarian* view on distributive fairness, which broadly asserts that fairness requires an distribution of resources that reflects individuals’ degree of responsibility (see e.g. Dworkin 1981; Arneson 1989). When discussing individual responsibility in the context of health it is difficult to ignore the fact that most unhealthy behaviors, e.g. smoking and unhealthy diets, are disproportionately common among individuals in the lower socioeconomic segments of society. Social circumstances present factors that influence certain individuals to engage in unhealthy living. Moreover, it seems unreasonable to penalize an individual for being born into a particular socioeconomic group since this circumstance is clearly beyond the individual’s control.

Even if we disregard the influence of social circumstances, other prerequisites need to be satisfied before it would seem reasonable to claim that someone is responsible for their ill health due to irresponsible past behavior. Specifically, four crucial components need to be present before any form of *retrospective responsibility* can be justified. First, the causal association between a person’s

²⁴ This is an old south Swedish expression that simply means appearing for no obvious reasons.

behavior and the state of ill health must be sufficiently clear. Second, the behavior must be conscious and voluntary. Third, the state of ill health must be the result of an unnecessary risk. Fourth, the individual needs to be fully aware of society's reactive attitudes toward certain types of conscious risk taking. Since all of these prerequisites are hard to observe in practice it seems impermissible that a retrospective notion of responsibility can be given more than a symbolic role in actual healthcare rationing.²⁵

However, while stating that I think retrospective responsibility should play a peripheral role in healthcare rationing, I still think it is important, for motivational purposes, that society to acknowledge that individuals have a responsibility for their own health. But for this to have any positive consequences it would be more appropriate to assign responsibility prospectively. This can be done through various means, e.g. taxing commodities associated with unhealthy activities or requiring compulsory insurance for certain types of risky activities. *Prospective responsibility* of this kind would be consistent with giving weight to individual responsibility when rationing care at the *desktop level*, but not at the *bedside level*. I would argue that avoiding assessment of individual responsibility at the bedside level is a desirable policy feature. If doctors were to assess not only patients' needs, but also their responsibility for ill health, it could undermine the important aspect of *trust* in the doctor-patient relationship.

A potential disadvantage of applying prospective responsibility, e.g. through taxation, is the fact that ill health is more common among the poor. Tax on cigarettes, for instance, is highly regressive in the sense that it shifts resources from the relatively poor smoker to the relatively affluent nonsmoker. Consequently, the positive effect of less unhealthy behavior needs to be weighed against the increased economic inequality that this type of prospective responsibility is likely to cause. In addition, policy-makers in public health, who design policies related to prospective responsibility, need to carefully consider other matters where reasonable disagreement is likely to arise: What constitutes justifiable grounds for overriding individuals' fully informed preferences when promoting healthy behavior? When do health policies become unjustifiable forms of paternalism?

²⁵ See the chapter by Liss in report published by National center for priority setting in health care (2008) for a more detailed discussion of the necessary prerequisites for applying retrospective responsibility for health as criteria in rationing health care.

Paternalism – Why Health is not Always Good

Paper II, *Discounting, preferences and paternalism in cost-effectiveness analysis*, deals with paternalism in the context of intertemporal rationing decisions. The article highlights two cases where it is justifiable to override individuals' fully informed time preferences relative to making rationing decisions over time. Preference failures (as opposed to market failures) that justify paternalistic intervention are categorized into two distinct groups; myopic and acratic. Myopic preference failures refer to a cognitive inability to compute information adequately in order to make choices that result in desirable outcomes. Acratic preference failures represent a weakness of will, which reduces the ability of individuals to act in accordance with their second-order preferences. Since the article focuses on paternalism related to time preferences, it touches only briefly on the crucial issue of whether improved health is always something that society should strive to achieve. I address the paternalism aspects of this discussion below.

Paternalism, in the present context, can be generally viewed as state interference with a person's liberty and is motivated by a claim that the affected person will be better off or protected from harm (Dworkin 2010). A fundamental assumption in welfare economics is that each individual is the best judge of how to maximize their own welfare. This is a questionable starting point when it comes to designing health policy, since extensive market failures are associated with the distribution of health care. To promote desirable outcomes that increase the overall good in society, at times it is necessary to override individuals' preferences by limiting or changing the array of choices available to them – paternalistic intervention.

In economics, preferences based on insufficient information or inadequate facts are generally viewed as market failures where paternalistic interventions are justified to avoid inefficient outcomes. However, it becomes more complicated to justify paternalistic interventions in cases where individuals have sufficient and adequate facts, but still make choices that negatively affect their health. Consequently, two issues have specific importance when discussing justifiable forms of paternalism in public health interventions. First, to what extent do individuals understand the potential health risk posed by unhealthy living? Second, if risks are adequately perceived, to what extent do individuals actually take them into account when making decisions?

Paternalistic interventions to promote health are motivated mostly by stating that individuals tend to have an incorrect perception about the risk associated with certain unhealthy behaviors. This motivation is dissatisfying. By now, nearly everyone in wealthy countries, e.g. Sweden and the US, should have a good understanding that it is bad for your health to smoke, drink, and follow an unhealthy diet. For example, cigarette packages carry messages in large capital letters informing the user that “SMOKING WILL KILL YOU” or “SMOKING SERIOUSLY DAMAGES YOUR HEALTH”. Further, Viscusi (1990,1992) has empirically shown that an incorrect perception of health risks is not a valid explanation for why individuals engage in more risky behavior. The health risks associated with smoking are not only well known, but are in fact generally overestimated, even among those who smoke. Thus, the motivation to incorrectly perceive health risks seems to be an (empirically) weak argument for why society should override individual preferences in its quest to promote health.

A stronger argument, I believe, for why society should act paternalistically and promote health is the claim that health is of special moral importance since it protects the range of *opportunities* open to individuals (e.g. Daniels 2008). Given that society has an obligation to protect opportunities, it also has an obligation to promote and protect individuals’ health even if this goes against individual preferences. However, I would argue that a related question has received insufficient attention in the literature on health and health care: What good are individual opportunities in the absence of corresponding *possibilities* to actually reap the benefits of having a wider range of opportunities?

Opportunities stem from individuals’ mental and physical abilities. Increased health and knowledge are two aspects that typically elevate an individual’s outset and opportunities in life. Possibilities stem from the potential to use these mental and physical abilities. Having a mentally challenging job, or the opportunity to travel and experience are typical examples of such possibilities. To exemplify, learning to float in water creates an opportunity to swim, while a lake or a swimming pool provides the possibility to swim. Or in the case of mental abilities, learning to speak Swahili creates an opportunity to communicate with people from East Africa, while meeting people from East Africa provides the possibility to speak Swahili.

Society offers a wide range of possibilities to people who are wealthy. They can ski, take a year off work, and live an active life after retirement, or they can keep on working just for fun if they like, and so on. But being able to make use of all these available *possibilities* often requires good health. Therefore, it is perfectly rational for wealthy people to promote healthy living for themselves. For the less wealthy, however, a much more limited range of possibilities is offered, since living an active life is often intensely resource consuming. Hence, for less-wealthy individuals it might very well be burdensome and irrational to increase the range of opportunities through healthy living if they have no corresponding possibilities. Instead, an increased level of health (opportunities) could possibly become a source of distress for less-wealthy individuals unable to live life to its fullest. For individuals to promote their own health when they are unable to take advantage of the opportunities that health creates could therefore decrease their general well-being.

Following this reasoning, health is of little value to individuals if it only creates opportunities they are unable to take advantage of. Both wealth and health create opportunities/possibilities for higher levels of well-being. However, I would argue that neither is sufficient for a higher level of well-being if they are isolated from each other. Instead, I believe that a steady-state relationship must exist between the two, and it needs to be maintained to increase well-being. Consequently, too much emphasis on either one could potentially have negative effects on well-being unless corresponding investments are made in the other. This needs to be taken into account before embarking on paternalistic policies to improve health – policies that often target the lower socioeconomic segment.

Incentives – Persuasion or Coercion?

Paper III, *Incentivizing deceased organ donation: A Swedish priority-setting perspective*, examines whether a diverse set of incentives (both financial and nonfinancial incentives) could combine considerations of efficiency and fairness when trying to increase the stock of organs available for transplantation. The article identifies three potential pitfalls where the use of incentives in health policy may become objectionable; *coercion*, *commodification*, and *loss of public trust*. The fundamental question that I pursue here is: When does coercion become so ethically objectionable that it hinders society from maximizing overall welfare?

Coercion occurs when individuals, due to some form of threat or external pressure, feel forced to act in a way that is not in line with their own best interests (see e.g. Anderson 2008). The common sense opposition to coercion is that it is much easier to justify, for example, extracting organs from individuals if this is done voluntarily, compared to confiscation of organs coercively (Eyal 2008). Nonetheless, few would argue to categorically forbid all forms of coercive incentives, since a certain level of coercion seems to be justifiable if the consequences are ‘good enough’.

From a utilitarian standpoint, coercive acts can be justified if overall utility in society increases. Intuitively this seems like a rather weak rule for justification – as Eyal (2008:109) points out, “It is inappropriate to calculate the likely impact on net utility before deciding not to rape someone”. Consequently, the utilitarian framework seems to yield intuitively unfair outcomes when applied as a framework for justifying coercive policies.²⁶

A common argument in deontology-inspired philosophy is that coercion harms dignity in the sense that it is intrusive to individual autonomy (e.g. Nozick 1974). Therefore, society has an obligation to protect and promote autonomy since this is usually considered an important component of a good life. However, this may come at the expense of a decreased level of overall good in society. It seems reasonable to argue that it is permissible for society to sacrifice some level of autonomy in order to increase the overall good in society, at least as long as the autonomy level does not fall below a certain minimum threshold for each individual. Autonomy is important, but it is not

²⁶ For a more detailed discussion of coercion and utilitarianism see, e.g. Eyal (2008).

the only important aspect of a good life. It needs to be balanced against other conflicting values, e.g. well-being, to achieve satisfactory outcomes.²⁷ Moreover, it could be argued that the main purpose of incentivizing desirable health behavior is to increase the net sum of autonomy in the long run, which could also help justify some short-term harm to dignity through coercion.

When discussing the use of incentives in health policy it is useful to distinguish between *positive incentives* (carrots) and *negative incentives* (sticks). Positive incentives focus on rewarding desirable behavior, while negative incentives focus on penalizing undesirable behaviors. In the preceding discussion on the role of individual responsibility in healthcare rationing I have already indirectly addressed the role of negative incentives in health policy. In addressing incentives, I will focus on the point where positive incentives in health policy shift from being persuasive to being coercive.

When offering positive incentives to individuals, e.g. monetary compensation for organ donation, the individual is faced with a persuasive or coercive offer. The general idea is that when individuals find themselves in a situation where even a very unfair and unattractive offer is the best available for the individual, it could be argued that the created incentive is coercive and hence morally impermissible (e.g. Feinberg 1986 and Van De Veer 1979). Moreover, positive incentives could also be regarded as a form of bribe conflicting with pro-social behavior and altruistic motivation. Monetary compensation for organs or blood is an example of the incentives that are typically viewed as being in conflict with altruistic motivation. Hence, this type of material incentive has a tendency to crowd out altruistic motives. Even if the compensation is high enough to compensate for this crowding-out of pro-social behavior we might end up with a less compassionate society. This could be considered an undesirable outcome associated with excessive use of positive incentives in health policy.

An ongoing trend in many healthcare systems is the use of positive incentives to encourage individuals to adopt desirable health behaviors, e.g. physical exercise and participation in screening programs. As Voigt (2010) points out, the various strategies to implement positive incentives in health promotion may also have a substantial impact on inequalities within the healthcare system. They may indeed have the potential to efficiently contribute to better

²⁷ For a more extensive discussion about how to balance autonomy and well-being when they are in conflict see, e.g. Brock (1988).

health among the population. Wrongly implemented, however, they could increase inequality if the individuals likely to benefit from the incentives are those who are most well off. A way to avoid this might be to focus on participation-incentive schemes tailored to the abilities and needs of the disproportionately unhealthy groups – avoiding positive incentives associated with attainment of specific health goals – since these are likely to primarily benefit healthy individuals (Voigt 2010).

When discussing the positive incentives of monetary compensation associated with health, I think that an unmentioned psychological aspect should also be addressed in this context, namely *repugnance*. This is an emotional state of extreme dislike, manifesting itself in feelings of disgust that cannot be easily explained through reasons. Roth (2007) notes that transactions that are not considered repugnant, such as in-kind exchanges, frequently become repugnant when money is added. Roth (2007:44) exemplifies: “...loans themselves and adoption and love are widely regarded as good things when given freely, even when their commercial counterparts are regarded in a negative way”. Some argue that morality is not a matter of reasoning, but rather having a gut feeling about what is right and wrong.²⁸ Whether or not this type of “disgust-based” morality has any real philosophical merits is a very complex question. On one side it seems questionable since repugnance has been used throughout history by individuals in governing roles to justify various forms of persecution, e.g. anti-Semitism and homophobia (see e.g. Nussbaum 2004). Nevertheless, for policy-makers who want to design efficient incentive schemes the existence of repugnance could be a very important aspect to consider. Public policies that run counter to prevailing moral intuitions are likely to undermine the legitimacy of the policymaker unless they are supported by powerful moral arguments or general principles.

Inequality – When are Inequalities Unfair?

Paper IV, *Horizontal inequality in rationing by waiting lists*, investigates whether the publicly funded Swedish healthcare system has horizontal inequalities in access to care. The article documents that access is unequal (but only to a limited extent) when waiting lists are used to ration care. However, the article says little about the normative question related to inequality and healthcare

²⁸ See, e.g. Burke (1894).

rationing: When are inequalities unjust, and when does inequality become inequity?

To avoid an incomprehensible discussion about inequality, it is important to distinguish between inequality as regards *health* and inequality as regards *health care*. The main focus of this thesis has been to discuss some of the reasonable disagreements concerning the rationing of health care. Although I will refrain from an in-depth discussion concerning the point at which health inequalities become unjust, it is impossible to fully avoid the issue. Inequality/inequity in health care is most often framed in terms of equal access for equal need. Consequently, *need* is often used in specifying unjust inequalities. As illustrated in previous sections, interpreting and applying the concept of need is perhaps the most recognized area of reasonable disagreement in healthcare rationing.

Somewhat less complicated, but equally important for understanding when healthcare inequalities become inequities, is the concept of equal access. Goddard et al (2001) present a valuable framework comprised of four key factors for assessing equal access to health care:

- i. Availability: differences may exist in the sense that certain healthcare services might not be available to some population groups, or that clinicians may have different propensities to offer treatment to patients with “identical” needs from different population groups;
- ii. Quality: differences in the level of quality of certain health services offered to “identical” patients may vary between population groups;
- iii. Costs: differences in costs that a health service imposes on identical patients may vary between population groups;
- iv. Information: differences in health services may fail to ensure that all population groups are informed with equal clarity about the availability of certain services.

In offering a broad – but in the field of public health, influential (see e.g. Braveman et al. 2001) answer to the question of when inequalities become inequities, Whitehead (1992) asserts that inequalities count as inequities if they are *avoidable*, *unnecessary*,²⁹ and *unfair*. Following this definition, not all avoidable inequalities are unfair, nor are all unfair inequalities avoidable. Applied to health care this could imply, e.g. that unequal availability to care

²⁹ I will however refrain from using this concept since I interpret it to be fully incorporated within the other two concepts when applied to inequalities.

between population groups, which is avoidable in practice, is not automatically unfair *per se*. Likewise, unfair inequalities in access to care are not always avoidable. For example, an unavoidable fact is that not everyone can live equally close to a university hospital with full medical facilities. According to Whitehead's account of inequity, neither of these types of inequality constitutes inequity. Consequently, it is not sufficient for inequalities to be deemed unfair or avoidable on their own; for inequities to arise both prerequisites need to be fulfilled.

If we assume that all existing inequalities are unavoidable, we still need to apply a notion of fairness to make sense of when inequality becomes inequity. Rawls' *Theory of Justice* (1971), which includes the *difference principle*, has been the most widely discussed theory for deciding which of the last 40 years' inequalities are unjust. The difference principle allows inequalities in the distribution of goods, but only in so far as these inequalities benefit the worst-off individuals in society. According to the difference principle, inequalities are permitted only as long as they do not compromise basic rights and liberties. Rawls' theory of justice is an example of the currently dominating approach toward fairness that Sen (2009) calls the *arrangement-focused approach*. This approach strives toward a perfectly just or fair society by identifying institutions and social arrangements that can achieve this. The idea of finding a flawless theory of fairness that can actually be implemented in practice is perhaps unrealistic. For instance, the concept of *reasonable people* plays a central role in most arrangement-focused approaches,³⁰ but who are these reasonable people? Where do they hide? Moreover, as Williams comments (1997:128):

There is a regrettable tendency for equity arguments to be conducted within a rhetorical framework in which it appears to be possible to "do good" at no opportunity cost whatever. It generates a great deal of righteous self-satisfaction for the romantic escapist, and it puts economists back in the role of the dismal scientists always stressing the sacrifices, but it does not help the hard-pressed decision-makers who grapple with the issues in real life every day.

From a health policy perspective it seems farfetched that decision-makers should turn to Rawls or other arrangement-focused theories of justice when assessing inequalities relating to health care. Moreover, it does not seem like a

³⁰ A concept that both Rawls (1971) and later Daniels (2008) frequently use in their theories.

reasonable objective for policy-makers to strive toward finding arrangements that will secure a perfectly fair healthcare system. A more reasonable objective would be to focus on what Sen (2009) calls the *realization-focused approach* toward justice. This approach implies that instead of trying to achieve a perfectly just system, decision-makers should concentrate on removing clear cases of injustice. Clear cases of injustice are unfortunately common in the real world, and new cases of injustice continuously arise. Although a perfectly just healthcare system is an admirable ambition, starting out by making things better is probably a more realistic way forward.

FINAL REMARKS

The interdisciplinary approach

Combining economics and ethics at the population level is not a new invention. Some level of cross-disciplinary discussion has always accompanied issues such as discounting, equity, and paternalism. Unfortunately, economics and ethics are commonly viewed as mutually exclusive disciplines, and only rarely are the two explicitly merged. This is remarkable since the defining task of both disciplines is to find satisfactory indications for the optimal distribution of scarce resources.

A crucial strength of economics as a normative science is that it recognizes that, ultimately, the conclusions it produces must be possible to implement in the “real world”. Consequently, economics tries to take the step from abstract theory to practical action, which is something that ethics at the population level seldom tries to accomplish. However, economics could become more useful in making policy decisions if greater attention was paid to the moral assumptions upon which it is based. A comparative strength of ethics at the population level is that it provides a more nuanced approach for making judgments on the distribution of scarce resources. Ethics could, on the other hand, become an even more useful tool for policy-makers if its conclusions were designed to be more in touch with the “real world”. Both disciplines have much to gain through greater cross-disciplinary dialogue, but for this to be productive, economists need to acknowledge the flaws in the normative basis of economics, and ethicists need to acknowledge that any conclusions that follow from their reasoning should be less detached from real-life situations.

In healthcare rationing it seems as if economists and ethicists alike lack the ability to strike a chord with public opinion. Arguably, this is because economists have traditionally targeted the rational, utility-maximizing individual, while ethicists typically target the reasonable, morally-thinking individual. Quite frankly, however, individuals tend to be neither rational nor reasonable when it comes to healthcare rationing. The emerging trend toward greater interest in behavioral economics is positive in this respect. A better understanding of norms and actual behavior will hopefully serve as a natural

link between ethics and economics and will help both disciplines stay in touch with reality. Another emerging, albeit troubling, trend is that health economics is rapidly becoming a discipline that mostly incorporates technically skilled statisticians and mathematicians with little background or interest in normative science.

The art of saying no

Healthcare rationing is not for the weak-minded. For most people, telling someone that they cannot have what they want is stressful even in the “ordinary” world. In the healthcare context, where wants become needs, this becomes even more stressful. Moreover, saying no in the context of health care is often frowned upon by the general public, adding to the emotional burden of saying no. The public’s dislike is often fueled by scare tactics employed by the media, stakeholders, and politicians competing for office. As a result, politicians who say no tend not to get reelected, and medical personnel usually gain nothing but trouble by saying no. So, who in their right mind would ever say no in the context of health care?

I have no answer to this question, but I desperately would like one. Neither economics nor ethics provide any satisfactory answers. Future research within the field of behavioral economics and neuroeconomics will hopefully shed further light on the matter. Even if this future research is promising, it does not mean that we can simply answer moral questions by appealing to what people generally think or do. We must continually pursue answers to understand why we regard certain actions to be right or wrong, and expose these reasons to public scrutiny.

The case of explicit rationing undertaken in Sweden and in the State of Oregon elucidates two different approaches toward explicit healthcare rationing. They highlight some of the available policy options for explicitly dealing with healthcare rationing. More importantly they reveal valuable lessons on how the public might perceive these policy options. What the Oregon experience shows is that simple decision rules are unlikely to be a viable way forward in rationing health services. The so-called QALY approach has merits, but it should not be portrayed as “the truth”. It is the outcome of a particular normative standpoint that needs to be balanced against non-utilitarian moral values. What the Swedish example shows is that an ambition to increase openness toward core ethical values might very well result in reduced

transparency. This is arguably what has happened in Sweden, where the ethical principles have a strong legal status, although their meaning and application has remained unclear and insufficiently specified. What the Swedish experience also shows is that it is possible to foster greater acceptance for the fact that rationing is an inevitable feature of any healthcare system. Decision-makers should look beyond the immediate reactions of stakeholders and the media when assessing the public's reaction to rationing decisions.

I see one simple solution to the reasonable disagreements brought forward in this thesis, and that is to acknowledge that there are no simple solutions. Given the complexity of the issues, it would be self-defeating and unrealistic to strive toward consensus agreements on all issues at hand. Instead, the most promising way forward is to be explicit about reasonable disagreements. The second step would be to create institutions and procedures where these reasonable disagreements could be meaningfully addressed. For such institutions and procedures to be productive it will be necessary to foster public willingness to look beyond conflict and accept reasonable disagreement.

ACKNOWLEDGEMENTS

I am thankful to many people who have supported and encouraged me over the years. I especially like to express my sincere gratitude to the following:

Per Carlsson, my supervisor, for always supporting me and being a genuinely nice person. I know that I have not always been easily managed but you have allowed me to continuously grow as a researcher and pursue new ideas.

Carl Hampus Lyttkens, my co-supervisor, for invaluable guidance and support. I have always felt secure having you on my "team".

Petter Tinghög, my brother and secret supervisor, for writing my job application to become a PhD student in Linköping. I wish everyone could have a big brother like you. Your input and support during the final hectic stages of writing this thesis have been invaluable.

Magnus Johannesson, my academic role model, for introducing me to neuroeconomics and providing me with the opportunity to conduct exciting research in the future.

Thor-Henry Brodtkorb, my dear friend and collaborator, for endless discussions which are always both fruitful and fun. We still have a lot of exciting project to pursue in the future. Your friendship and input during the years have been greatly appreciated.

Emelie Heintz, my dear friend and colleague, for introducing me to the word diabetic rephropathy but perhaps more importantly for being a truly awesome friend.

Almina Kalkan and **David Andersson**, my dear younger colleagues, for being the next generation.

Lena Hector, for being the nicest of all nice persons and for always being helpful and looking after the weird administrative rules of academia which I tend to neglect.

Faisal Omar, my collaborator and flatmate, for always helping out and making Linköping feel more like home. It is my intention to be equally supportive when you soon are to wrap up your thesis.

All my friends and colleagues at the **Division of Health Care Analysis** and the **National Center for Priority Setting in Health Care** for making my time as a PhD student pleasant and fun. A special thank you to: **Lars Bernfort**, **Thomas Davidson**, **Nathalie Eckard** and **Ann-Charlotte Nedlund** for giving me valuable input on earlier drafts of this thesis. Special thanks are owed to **Jenny Alwin** for giving me valuable pointers on how to obey the administrative rules of Linköping University

My one year stay at the **Program in Ethics and Health** at **Harvard University** was a truly enlightening experience. Therefore I wish to thank all of those who made my stay there such an eye opening experience and crucially influenced the scope of this thesis. I especially like to thank **Greg Bognar**, **Dan Brock**, **Alena Buyx**, **Norman Daniels**, **Nir Eyal**, **Elisabeth Fenton**, **Adriane Gelpi**, **Paul Kelleher**, **Keren Ladin**, **Andras Miklos**, **Kristin Voigt**, and **Dan Wikler**.

The county council of Östergötland, for making this thesis possible by their financial support.

The Brocher Foundation, for supplying me with superb research facilities and a creative surrounding when writing parts of this thesis.

IFK SPADEN, my floorhockey team, for being such an inspiring bunch of people. I especially like to thank **Johan Fehrman** and **Ingemar Lundin** for always remaining my friends.

Marit Furn who put much talent, creativity and energy into designing the cover of this book.

Gabriella Tinghög Olofsson, for always looking after her little brother.

Bryan Adams, **Veronica Kloo**, **Nisse Hellberg**, **Old 97's** and **Kula Shaker** for bringing the music that inspired me to write this thesis.

Academic input aside the most profound thank you goes out to my parents **Mats** and **Boel Tinghög**, for making me such an unjustifiably privileged person. You have always supported me in all sorts of things, large and small, and I am deeply grateful for this.

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