Clinical fairness - Improving bedside rationing

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Abstract
Difficulties in medical ethics are traditionally discussed in relation to problem arising in clinical care between individuals: disagreements between patients and health care providers as to the best course of action, confidentiality, end-of-life choices, how to make ethically justifiable decisions for patients who are incapable of decision-making, and the like. Difficulties related to fairness, to sharing what resources we have equitably in caring for the sick, pose a special challenge. They are situations where thinking in terms of individuals tends to be less helpful. To address these issues, we need to think in terms of groups. In terms of weighing conflicting claims in a way that can be justified as fair overall, as well as to the individuals involved. This thesis explores the practice of clinical rationing, and the ethical issues associated with it, with a particular focus on fairness. We conducted studies showing that doctors ration care and realize that they do so, that they attempt to include various concerns for fairness in their allocation decisions, and use various strategies for doing so. Some of these [...]
Clinical fairness -
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Thèse de candidature pour l’habilitation à la fonction de privat-docent,
présentée à la Faculté de médecine de Genève

par

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Genève, 2009
Medicina non fortuna neque personis homines aestimat,  
uerum aequaliter omnibus implorantibus auxilia sua succursuram se pollicetur.

Medicine does not evaluate the fortune or identity of persons,  
but promises help equally to all who implore its rescue.

Scribonius Largus, Compositiones, 47 CE
Publications incorporated into this thesis include:


8. Hurst S.: Just Care; should doctors give priority to patients of low socioeconomic status? Journal of Medical Ethics. 2009, 35(1), pp7-1. (IF=1.345)
# Table of contents

ACKNOWLEDGMENTS .................................................................................................................. VI

INTRODUCTION .......................................................................................................................... 1

I. WHY WE NEED TO THINK ABOUT FAIRNESS IN CLINICAL PRACTICE ..... 5

  CHAPTER 1 – INESCAPABLE LIMITS: CLINICAL INDICATION AS ETHICAL APPRAISAL........ 6
  CHAPTER 2 – SETTING LIMITS IN CLINICAL PRACTICE......................................................... 13
  CHAPTER 3 - MAKING THE IMPLICIT EXPLICIT ................................................................. 30
  CHAPTER 4 - THE IMPORTANCE OF INTEGRATING FAIRNESS ........................................ 39

II. APPLYING FAIRNESS IN CLINICAL PRACTICE .............................................................. 51

  CHAPTER 5 – CLINICAL FAIRNESS? ................................................................................. 52
  CHAPTER 6 – DIFFICULTIES AND OBSTACLES ............................................................... 64
  CHAPTER 7 – LEARNING STRATEGIES FOR EQUITY FROM THE BEDSIDE ..................... 75

III. DOING BETTER? .................................................................................................................. 83

  CHAPTER 8 - AN APPROACH TO RATIONING BY CLINICAL JUDGMENT ...................... 84
  CHAPTER 9 - PRIORITY TO THE (SOCIALLY) WORSE OFF? ............................................. 98
  CHAPTER 10 - PROTECTING VULNERABILITY ................................................................. 105
  CHAPTER 11 - SHOULD ETHICS CONSULTANTS HELP? ............................................... 112

CONCLUSION .......................................................................................................................... 121

REFERENCES ............................................................................................................................ 123

APPENDICES ............................................................................................................................ 137
Tables and figures

Tables:

Table I-1: US doctors reporting ethical difficulties and allocation difficulties ............. 17
Table I-2: Resource constraints reported by US doctors .................................................. 18
Table I-3: Four Health Care Systems -WHO and OECD data ........................................ 21
Table I-4: European study respondent characteristics ..................................................... 23
Table I-5: Criteria influencing the use of expensive interventions .................................... 28
Table I-6: Beliefs regarding limited resources and the use of generics .............................. 41
Table I-7: Willingness to use a generic drug .................................................................... 42
Table I-8 Four Health Care Systems: doctors’ workload and delays .............................. 44
Table I-9: Difference in reported unavailability is parallel to health resources .............. 44
Table I-10: Four Health Care Systems: doctors’ views on fairness .................................. 46
Table II-1: Clinical equity semi-structured interview guide ............................................. 53
Table II-2: Geneva study respondent characteristics ......................................................... 55
Table II-3: Strategies reported by US doctors as responses to resource constraints ......... 76
Table III-1: Examples -triage in the ICU ................................................................. 85
Table III-2: Examples -comparison to other potential patients ........................................ 86
Table III-3: Examples -using a threshold in rationing by clinical judgment ............... 86
Table III-4: Protecting the vulnerable in health care ......................................................... 109

Figures:

Figure I-1: The indication continuum .............................................................................. 8
Figure I-2: Percentage of respondents who reported unavailability of resources ......... 24
Figure I-3: Percentage of doctors reporting rationing in the prior six months ............ 27
Figure I-4: Strategies used to limit expensive interventions ............................................ 27
Figure I-5: Agreement with bedside rationing ............................................................... 35
Figure I-6: Agreement with cost-containment policies ..................................................... 36
Figure I-7: Reported greater likelihood of being denied treatment ............................... 47
Figure I-8 Scarcity related ethical difficulties compared with end-of-life decisions .... 49
Figure II-1: Freedom and insecurity perceived by European doctors ......................... 72
Figure II-2: Gatekeeping values ................................................................................... 82
Figure III-1: A framework for rationing by clinical judgment ..................................... 87
Figure III-2: Vulnerability as a claim to special protection ............................................ 107
Acknowledgments

As this thesis brings together research conducted over several years on two continents, giving appropriate thanks to all those who deserve it is a daunting task. Fairness demands that I first thank my parents, my sister Vanessa, my nieces Cassandre and Paloma-Lou, and my god-children Marie and Django: they have seen rather less of me than they ought to have done while this manuscript was in preparation.

Professionally I must first thank Dan Wikler, who gave me the best nutshell professional advice I ever received, as well as the entire Department of Clinical Bioethics at the NIH Clinical Centre, especially Marion Danis, Zeke Emanuel, Christine Grady and Frank Miller, without all of whom I would never have embarked on this topic, known how, or enjoyed it so much. The projects started there led to many fruitful collaborations over the years, for which my special thanks go to the Values at the Bedside and Justice at the Bedside co-investigators Anne-Marie Slowther, Reidun Forde, Arnaud Perrier, Renzo Pegoraro, Stella Reiter-Theil, Claudine Burton-Jeangros, Alex Mauron, Bara Ricou, Samuele Cavalli, Noelle Junod Perron and Frédéric Gilbert. None of the studies described here would have been possible without them.

Some people will have to be thanked more than once. I am especially grateful to Arnaud Perrier for support, constructive advice, and logistical assistance in managing a part-time clinical position over the years. For this my special thanks also to the General Internal Medicine Service medical staff, many of whom remained my friends despite my aggravating habit of disappearing every three months. I also have multiple reasons to be grateful to the members of the Clinical Ethics Council of the Geneva University Hospitals, especially to Jean-Claude Chevrolet, Jacques Butel, François Loew, and Arnaud Perrier yet again. My thanks also to all those who supported and encouraged my interest in bioethics throughout my clinical training, especially Francis Waldvogel, Martine Louis Simonet, Anne-Françoise Allaz, Jean-Marie Michel, Gilbert Zulian, Karine Moynier, Pierre Chappuis, Pierre-Yves Dietrich, Catherine Châtelain, and Martynie Isabel Forest. A special thought also on this occasion to the kind and friendly memory of Charles-Henri Rapin.

The studies presented here, as well as my post-doctoral fellowship at the NIH, were funded by the Oltramare Foundation, the Geneva University Hospitals, The National Institutes of Health, the Institute for Biomedical Ethics at the University of Geneva, and the Swiss National Science Foundation grants 3233B0-107266 / 1-2 and 3200B0-107267 / 1-2. The views expressed here are of course mine and not theirs.

Many colleagues provided friendly and incredibly constructive criticism at various stages in this work. My special thanks for this to Bruce Brinkley, Dan Brock,
Alexandra Calmy, Timothy Carey, Nir Eyal, Ulrike Kostka, Nathalie Mezger, Ole Norheim, Steven Pearson, Ulrike von Pilar, Marc-André Raetzo, Dan Sulmasy, Karen Titlow, Ulrich Vischer, Rein Vos, as well as to Markus Zimmermann-Acklin, Hermann Amstad, and all the committee of the Swiss Society for Biomedical Ethics. Special thanks also to the Brocher Foundation and the participants in the 2009 symposium on ‘Fair Bedside Rationing’.

My warm thanks also to my colleagues at the Geneva Institutes for Biomedical Ethics Bernard Baertschi, Micheline Louis-Courvoisier, Bernice Elger, Nathalie Ilic, Philip Rieder, Nicolas Tavaglione, Marinette Ummel, Alexandre Wenger, whose thought-provoking, smart, and friendly presence would have been enough to convince me to remain in Switzerland even had I had no other reasons.

Last, but by no means least, I must take this much too infrequent opportunity to express my constant gratitude to Alex Mauron. I am fortunate and privileged to have such a mentor, and such a friend.
Introduciton

Difficulties in medical ethics are traditionally discussed in relation to problem arising in clinical care between individuals: disagreements between patients and health care providers as to the best course of action, confidentiality, end-of-life choices, how to make ethically justifiable decisions for patients who are incapable of decision-making, and the like. To the kinds of approaches we use in such circumstances, difficulties related to fairness, to sharing what resources we have equitably in caring for the sick, pose a special challenge. They are situations where thinking in terms of individuals tends to be less helpful. Here is an example of why. Imagine you need an urgent surgical intervention late at night, in a hospital where only one surgical team is on call. Fairness, you may think, could be served rather simply by making the necessary resources available to you, namely, by calling the team. But now imagine this actually happened to a different patient, who was indeed taken into the operating room. And you only arrive now, with the same need. The operating team is already occupied. Your later arrival is not due to anything you did, and certainly does not affect how much you need the intervention. Is delaying your operation fair? Is having only one on-call team the right decision in the first place? But if more than one were maintained, resources would have to be taken away in another sector. Would that be fair? To address such issues, we need to think in terms of groups. In terms of weighing conflicting claims in a way that can be justified as fair overall, as well as to the individuals involved.

In 1994, Norman Daniels outlined “four unsolved rationing problems” as a challenge to clinicians, policy makers, and bioethicists (Daniels 1994):

1. the ‘fair chances vs. best outcome’ problem,
2. the ‘priorities’ problem (how much priority should we give the worse off),
3. the ‘aggregation’ problem (when should many modest benefits outweigh fewer larger ones),
4. the ‘democracy’ problem (when must we rely on fair process as the only way to determine fairness).

All four are dilemmas which can only arise when thinking in terms of groups, and it is accurate to say that they are still unsolved.

This thesis explores the practice of clinical rationing, and the ethical issues associated with it, with a particular focus on fairness. Section I outlines why thinking about fairness specifically in the context of clinical limit-setting is important. At the root, the main reason why addressing these difficulties is increasingly important is that increasing pressure to control costs is leading to a greater awareness of resource scarcity in health care. In exploring these issues, we used a specific definition of rationing. Rationing is a concept for which there are many definitions. (Ubel and Goold 1997; Ubel and Goold 1998) We used the most general and descriptive one,
namely: “any implicit or explicit mechanisms that allow people to go without beneficial services”. (Ubel 2001) It is clear that, under this definition, at least some instances of rationing would be acceptable to reasonable persons. For example, if a large town keeps a supply of 20 ambulances rather than, say, 20'000, this means that there is some risk of significant delay in an emergency if they are all occupied elsewhere. This is unlikely to happen, but not impossible. Thus, the choice to have a manageable number of ambulances would count as rationing under this definition. It is, however, unlikely that this would be attacked as morally wrong by reasonable people. The question is not so much whether limits should be set, but which limits are acceptable and how we should choose them. This point is further developed in Chapter 1.

Limited resources must be acknowledged, but this only increases the importance of knowing how limits are set in practice, and attempting to improve their fairness. In describing resource allocation and rationing decisions, a distinction is usually made between the macro-level of general health expenditure, the meso-level of health care institutions, and the micro-level of health care providers and patients. In several studies conducted with colleagues in Switzerland, Europe, and the US, we focused on physicians’ experience with resource allocation as viewed and practiced at the micro-level of clinical care. Chapter 2 describes findings from two studies. The first is a US study physicians’ experience with resource constraints, which suggests that they do face situations where they must accept or set limits. However, in contrast to assumptions in the normative literature on rationing, they rarely make these decisions on their own, and tend not to treat these situations as dichotomous choices. Our second study showed that physicians in Switzerland, Norway, Italy, and the UK, report bedside rationing (Hurst, Slowther et al. 2006). Importantly, this is may not always be ethically problematic.

Although it may be inevitable, limit-setting remains controversial. This was strikingly illustrated recently during the 2009 US debates on health care reform. In addition to controversies regarding limit-setting per se, a separate debate has focused on the appropriate role, if any, of physicians in allocating resources within clinical care. The obligation to advocate for patients, (Hiatt 1975; Loewy 1980; Levinski 1983; Sulmasy 1992; Pellegrino 1997; Weinstein 2001; Askin 2002) and a lack of trust that doctors will make the right kind of rationing decisions, (Veatch 1997) have prompted reservations about doctor involvement in health care rationing. However, doctor involvement has also been defended on the grounds that doctors are entrusted with the stewardship of scarce resources, (Morreim 1991) could make cost control compatible with patient advocacy, (Pearson 2000; Hardee, Platt et al. 2005) and indeed may be in the best position to ration care in an appropriate and justifiable manner. (Daniels 1981; Pearson 2000; Ubel 2001). These issues are explored in Chapter 3.
Chapter 4 outlines how, in differentiating between acceptable and unacceptable limit-setting, the degree to which considerations of justice are brought to bear on such decisions is relevant. Fairness is important for several reasons: it is one of the building blocks of a fair health care system, it is necessary for public acceptance of limits, and through it for their fair application, and it is important for limit-setting’s moral legitimacy. With increasing concern for efficiency, equity is also at increased risk of being traded-off. (Ubel, Baron et al. 2000) Knowing whether, and how, physicians are able to integrate justice-based reasoning in their practice is thus important. If they are, this might reassure us on the ethical justification of their allocation decisions. It could also enable them generally to defend fairness in health care more effectively.

Section II examines some of the difficulties in applying fairness in clinical practice, and reports findings from a study showing that physicians nevertheless apply justice-based reasoning in their allocation decisions. Chapter 5 reports findings from a qualitative in-depth interview study of physicians regarding their experience with resource allocation decisions. This study found that doctors use a variety of concepts for fairness in their practice of resource allocation, but show some difficulty in articulating them. This study is also the source of the citations which open each chapter. Chapter 6 outlines difficulties inherent in applying concerns for fairness to clinical care. Chapter 7 reports findings from the same study regarding strategies used by doctors to nevertheless apply fairness to their practice.

Section III explores different ways in which we could try to improve the application of fairness in clinical decisions. An approach to rationing by clinical judgment is proposed in chapter 8. This approach, however, is based on the need to allocate resources to patients who are already at the point of needing care. Given what we know about the unlevel playing field and the socio-economic determinant of health, however, there could be a case for giving some priority to the socially worse off in clinical resource allocation decisions: a proposal examined, and tentatively rejected, in chapter 9. One aspect of this proposal, however, remains convincing: we generally agree that vulnerable persons should be afforded some form of special protection. Chapter 10 examines who vulnerable persons are, what the meaning of vulnerability could imply for their protection in clinical care, and why this concept is currently insufficient to address many clinical allocation dilemmas. Chapter 11 examines whether, and to what extent, ethics consultants could help physicians in applying fairness and facing issues of scarce resources generally.

A word about words is in order here. In the English-language philosophical literature, the terms ‘equity’, ‘fairness’, and ‘justice’ have distinct, usually non interchangeable, meanings and are often used in a precise manner. I wish to caution philosophically minded readers that these words will be much less clearly distinguished in this work, for three reasons. First, our studies report doctors’
experiences, and in this very practical context these words are not used in exactly the same manner, or indeed in a manner sufficiently clear to enable us to draw such fine distinctions between these concepts as used by doctors. I hope there will remain enough of interest in these reports to satisfy these readers nevertheless. Second, there is a translation issue. In our French-language Geneva Study, we used the word ‘équité’ to signify a concern for distributive justice. That this is not an exact equivalent of the term ‘equity’ in English is exemplified rather appropriately by the translation of John Rawls’ *Justice as Fairness* by ‘La justice comme équité’ in the French version (Rawls 2001). At bottom line, there are only two words (‘justice’ and ‘équité’) with which to translate the English ‘justice’, ‘fairness’ and ‘equity’. Attempting an exact translation from verbatim interviews conducted in French would have led to misleading distinctions. Third, what mattered to us in conducting these studies was not so much whether or not doctors are able to draw such precise distinctions, but whether they apply general concerns for distributive justice in their clinical reasoning, or not. Exploring these aspects of clinical care in more precision could not be the object of initial, often exploratory, studies, although it may be among the next steps. For all these reasons, I will often use these three terms as though they were indeed interchangeable.

Limit-setting decisions made within clinical practice by doctors have been critiqued as ‘implicit rationing’, in part because of their hidden and unexamined nature. This point is well taken. In this thesis, and through the various studies described here, my colleagues and I have attempted to throw some light on the difficult, less articulated, sometimes surprisingly complex, and always necessary processes through which resource allocation decisions are made in day-to-day clinical practice.
I. Why we need to think about fairness in clinical practice
Chapter 1 – Inescapable limits: clinical indication as ethical appraisal

“(…) so, hem…there is, I think that equity, hem on paper it’s a beautiful thing but in practice hem one tries to, I think, to give the best to patients (…)” (Geneva Study, interview 25)

Is MRI imaging indicated for a persistent headache? What about CT imaging before middle ear surgery? A third occult blood stool test to screen for colon cancer? A fourth? A fifth? The difficulty of these questions has four components, which can each give rise to a separate question. First, does the available data allow us to conclude that an intervention brings any benefit whatsoever to patients? What complications and inconveniences to the patient does it ‘cost’? In other words, is there a net benefit to the patient? These are scientific questions, amenable to empirical research. But of course even where data is available, this is often insufficient to answer our initial questions. A very small benefit may be measurable but nonetheless clinically insignificant. How much benefit does it take before an intervention becomes clinically indicated? Setting limits within this indication continuum is inevitable, and represents the first reason why thinking about fairness is necessary: limits are part of routine clinical care, even outside perceptible resource constraints.

In order to show why, let us assume that the answer to this first question is yes. Whatever the selected example, the available data does allow us to conclude that this intervention brings a small benefit. Even then, we still have three additional questions to answer. The second is: is the intervention sufficiently beneficial to be clinically relevant? Is the expected benefit worth having? How large is it? How likely? Moreover, resources spent for one sort of intervention are no longer available for other interventions. Our third question is thus: is the intervention ‘reasonable’? Is the expected benefit worth having, given what we could have done instead with the same resources? Does it ‘make the cut’ in terms of net benefit to the patient as compared with its opportunity cost? This question is not readily answered. So the fourth must be: how are we to decide which interventions ‘make the cut’, and which do not? These, in a nutshell, are the main questions of fair limit setting; they are not avoidable in clinical practice.

Answers to the first question, whether or not an intervention brings any benefit, can be improved by more and better data. When grounded in sufficient research, these answers can be true. Answers to the second, third, and fourth questions, however, have strong value content requiring ethical and sometimes political exploration. Answers to these questions, strictly speaking, cannot be true or false: what they can be is right or wrong. And even that cannot always be determined once and for all.
A continuum of benefit

In practice, we use a combination of two different thresholds when asking if an intervention is indicated: clinical relevance, and opportunity cost. It is important to distinguish them: they address very different aspects of the clinical situation, and also represent very different types of decisions from an ethical standpoint.

The first threshold is based on the clinical relevance of the expected benefit. We want to use interventions that we consider to be clinically relevant, and avoid using those which bring insufficient advantages to patients to make them worth the patient’s time, efforts, and risk. Furthermore, beyond population data, it is important to assess what prospective benefits can be expected for this particular patient. Comparisons must be made between the individual patient and the study group. This is a standard necessity, and a standard difficulty, in the application of Evidence Based Medicine (Slawson and Shaughnessy 2005).

Once the benefit expected from an intervention has been assessed, however, knowing if this benefit is sufficient for the intervention to be indicated will further require that there be an agreement on the level of expected benefit sufficient to warrant treatment. If data show the intervention to have no benefit, knowing whether it is indicated is easy: it is not. Similarly, we would all agree that, where data shows a substantial benefit, an intervention is indicated. Many interventions, however, are shown to bring modest, moderate, or even small benefit to the patient. When is an intervention beneficial enough to be indicated?

Although we do not always think of it this way, this is actually a value judgment that can vary individually. As shown in Figure I-1, ‘How much benefit is enough’ is a question to which different persons can give different answers. This reflects their values and priorities: how much weight they give to the expected benefit, to the risks involved, to this intervention as opposed to other things they could be spending their time on. Although medical training does somewhat unify professional judgment around thresholds generally considered appropriate within medicine, physicians can still give different answers to this question, especially if their specialties are different or if the intervention is itself specialized.
This question is very different from that of whether or not an intervention is beneficial at all. How much benefit is enough, is a question that cannot be answered strictly by scientific means. However, neither does it require that the answer always be the same one. When opportunity costs to other patients—what we will have to sacrifice in order to use this intervention instead—are not considered, the main stakeholder is clearly the patient. In theory, the setting of a clinical discussion between physicians and patients can be legitimate and sufficient to set this first threshold on a case-by-case basis.

This is demanding in practice. For a patient to decide whether an intervention brings sufficient benefit or not, she must understand the data enough to do so. This requires clear, non-technical explanations. General understanding of probabilities is often poor (Armstrong, FitzGerald et al. 2001; Zikmund-Fisher, Fagerlin et al. 2007) and can yield contradictory decisions (Ubel, Loewenstein et al. 1996). Fortunately, it does seem that the way in which risks and benefits are presented can sometimes improve understanding (Armstrong, FitzGerald et al. 2001; Fagerlin, Wang et al. 2005; Zikmund-Fisher, Fagerlin et al. 2007; Zikmund-Fisher, Fagerlin et al. 2008). Understanding of risks and benefits can also however be affected by biases: when we are directly concerned, we more frequently tend to prefer avoiding interventions altogether, rather than accepting an intervention likely to lower our risk (such as vaccination) (Zikmund-Fisher, Sarr et al. 2006). When faced with a dangerous diagnosis, we are more likely to favour an intervention over inaction, even if its net effect is to reduce our chances of survival (Fagerlin, Zikmund-Fisher et al. 2005). The difficulties of fostering good understanding is not, however, very different from that of any other shared clinical decision: a competent patient should have the last word.

**When is an intervention “worthwhile”?**

The second threshold is the cost-effectiveness ratio required to judge that
implementing an intervention is ‘reasonable’. Again, this is a very different question. An intervention may be beneficial, even sufficiently beneficial to be indicated if it were free, and nevertheless not be worthwhile given what we would need to sacrifice in order to use it. Examples such as implantable defibrillators in low-risk patients (Neyt, Thiry et al. 2008), but also therapies such as routine combined anti-aggregation (Gaspoz, Coxson et al. 2002), and statins for primary prevention of cardio-vascular disease (Neyt, De Laet et al. 2009), are good illustrations of instances where we do currently come to this conclusion.

In a given situation, this may not be a direct question of financial cost. Although classical cost-effectiveness analysis is couched in financial terms, an opportunity cost might also be the alternative uses of a scarce MRI machine, of a transfusion when a blood bank is running low, or of vaccination for other individuals when a vaccine shortage is announced (Hurst and Danis 2007). How much opportunity cost can we accept, for how much benefit to this patient?

Distinguishing clinical relevance, and opportunity cost is important. First, clinical relevance is evaluated based on different criteria. Its components are clinical research data, medical judgment, and patient preferences. Opportunity cost brings in economic data, but also the interests not only of the individual patient but of other patients as well. Confusing them can lead to confusion on clinical elements, which can be harmful to medical reasoning. A much cited example is the prevalence of the belief by British physicians in the 70s and 80s that patients over 65 were ‘crumbly’ and unlikely to benefit from dialysis (Aaron and Schwartz 1984). Appraising an intervention as unlikely to benefit a patient is crucially different from appraising the same intervention as likely to benefit her less than the prevalent threshold for opportunity cost at a given time. Second, while clinical relevance can be appraised within the physician-patient relationship, an appropriate threshold for opportunity cost cannot. As the interests of other patients are affected, the patient can no longer legitimately have the last word. However, neither can the physician: she will be expected to advocate for her own patients, and can be biased by conflicts of interest. Moreover, how would she know what threshold her society would set if correctly asked? If affected persons must participate in legitimate decisions of an ethical nature regarding their health, participants will be very different in judging acceptable opportunity costs than in assessing clinical relevance. Despite these difficulties, however, these decisions must somehow be made. Although it is hard, limit-setting is inevitable.

The ‘R’ word

Discussions regarding limited resources in health care are often made more difficult by the confusions and misuses of the term “rationing”. As it is mostly used,
“rationing” is a thick concept: it simultaneously describes a state of affairs, and makes a value judgment about it. Since the value judgment is negative, it becomes tempting to use this term to mean “those limitations on health care which I happen to personally disagree with”. Any discussion of rationing must therefore start with a clarification of definitions. Clarifying this definition is, of course, no substitute for the normative discussion of the acceptability and justification of rationing, nor should it attempt to be such a substitute. This is of particular importance as the distinctions put forward in trying to define rationing often follow a rhetorical agenda. Since rationing is a negative term, with a heavy emotional burden, the notion that it could be justifiable even sometimes can seem unimaginable. We often have a difficult time abstaining from classifying acts as good or bad regardless of circumstances. A clear definition is necessary if we are to discuss the normative aspects of rationing without talking past each other, and since the normative aspects of rationing are what we need to discuss, requiring that a definition should pre-empt this discussion is a problem rather than a solution. A very good overview of this point was published by Peter Ubel and Susan Goold, and this section draws broadly from it (Ubel and Goold 1998).

Several definitions exist in the literature, and the following attempts to represent the existing spectrum, rather than to list them all. There are broadly speaking three types of definitions.

1. **Polemic definitions**, give rationing an intrinsically normative angle, explicitly or otherwise. They mix the conceptual discussion of how to define rationing with the normative discussion on its ethical justification. Here, rationing is defined for example as the inequitable distribution of necessary health care. Hadorn defines rationing as follows: “the societal toleration of inequitable access to health services acknowledged to be necessary by reference to necessary-care guidelines” (Hadorn and Brook 1991) Normative condemnation is explicitly included in this definition.

2. **Distinctive definitions**, make distinctions either between different things we could call rationing, or between different types of rationing. Their goal is either to delimit the normative debate, or to separate sub-topics within it. In contrast to polemic distinctions, they do not principally aim to defend a position, but also to introduce more clarity in discussions. The nevertheless maintain a normative dimension, and thus fail to separate the questions of definition and justification.

Some are based on distinctions which delimit the scope of what we mean by rationing. Churchill, for example, gives a definition prevalent in the US, where rationing is understood as refusing resources to those who are able to pay for them. (Churchill 1987) In contrast, another proposed definition is to understand rationing exclusively as those limits which are decided within solidarity-based insurance. (Zimmermann-Acklin 2005) Relman defines rationing as the deliberate and
systematic refusal of certain interventions, even when their benefit is demonstrated, for reasons of cost. (Relman 1990) He thus includes only conscious and systematic decisions. Norman Daniels and James Sabin also define rationing as the act of actively tracing limits. (Daniels and Sabin 2002) Rationing is sometimes defined as decreased access to health interventions, sometimes as a limit on their growth. Daniel Callahan, for example, defines rationing as a restriction on potentially unlimited demand for technological progress. (Callahan 1990) Aaron and Schwartz define rationing as any activity which determines who will receive useful resources when they are insufficient for everyone. (Aaron and Schwartz 1990) There too, there is no rationing without a conscious choice by persons. Finally, Evans defines rationing as the selection of patients who will receive a limited resource, and contrasts it with tracing the actual limit of this resource which he classifies as allocation rather than rationing. (Evans 1983)

The other type of distinctive definition traces limits between different types of rationing, so as to enable separate discussions of their normative status. In this way, some distinguish way conscious administrative decisions to limit access to certain interventions, and informal decisions made through non-explicit mechanisms. (Hall 1994; Mechanic 1997) Explicit rationing is distinguished from hidden rationing (Zimmermann-Acklin 2005), rationing based on financial limits (such as the number of intensive care beds) from that based on non-financial limits (such as transplantable organs) (Ubel and Goold 1998), limitations of necessary resources from those of useful but not strictly necessary ones (Relman 1990; Hadorn and Brook 1991; Ubel 2001).

3. Descriptive definitions aim to avoid the normative debate entirely while defining rationing. However, they can be more or less encompassing and will thus include or exclude certain elements from the scope of the normative discussion. So even here the separation is not complete.

a) Rationing as distribution is an attempted broad and descriptive definition. Here, rationing is resource allocation; and resources are necessarily limited not because they are inferior to what we would want them to be, but because they are finite (Pollock 1995). This definition keeps open the possibility that some forms of rationing may be justifiable whereas others will not be. In an abstract sense, rationing itself is, however, clearly justifiable under this definition: its opposite would be not to attempt to allocate resources fairly. However, by focusing on “the inside of the envelope”, it can leave aside critical examination of the overall limit more difficult.

b) The definition offered by Peter Ubel and Susan Goold defines rationing as “any implicit or explicit mechanism that allows persons to go without beneficial services”. (Ubel and Goold 1998) These authors explicitly reject the distinctions
made by others: they cannot be traced with sufficient precision to be of use in allocation decisions. This definition is even more normatively “abstentionist” than the previous one. It does not define rationing as necessarily negative, nor as basically positive. Rationing may, by this definition, not be necessary yet: as long as medicine is limited by its own imperfection, the questions of whether it gives us the means to do “more than is reasonable” or not remains an open one. Although it places a lot of weight on the concept of medical benefit, which is not always a clear one either, this definition does seem to be the best suited to constructive discussions of the ethical status of rationing. This is why we chose to use it as the basis of our empirical studies of rationing.

Defining rationing in this entails that it is inevitable in clinical practice. The question, then, is not whether it ought to be practiced, but to what extent it already is, how it is, and how it ought to be practiced. Even when sufficient data is available to determine that an intervention brings some benefit knowing whether this intervention is indicated still requires us to answer three additional questions: 1) is the intervention sufficiently beneficial to be clinically relevant? 2) Is the intervention ‘reasonable’ in terms of its opportunity costs? And 3) How are we to decide which interventions ‘make the cut’, and which do not? Although some of these questions integrate considerations of costs, not all do. However, all integrate value judgments, making even ‘routine’ clinical indication in part a question of ethical appraisal. Limit-setting is not only unavoidable; we already in fact accept that it is sometimes acceptable.
Chapter 2 – Setting limits in clinical practice

“So yes, for example the patient with hemorrhagic shock, ...hmmm...who well has blood pressure that is difficult to maintain, we give him a lot of blood and there now...now in these cases we have a drug called Novoseven which is extremely expensive and which we give in hemorrhagic shock to stop the bleeding, so we will...we will give a first dose and then it's a dose that can be repeated based on, on the evolution and it did happen, happen to us to not give that dose because well, it's about a thousand francs for a milligram, and you need about ten milligrams to treat a patient so it's at least ten thousand francs, then thousand francs one dose, so if we repeat that dose it's another ten thousand francs for an outcome that isn’t certain, we aren’t certain to save a patient with this drug (...) so for this drug we ask several times whether it’s in the interest of the patient, is it, but behind it, in my opinion, there is a budget constraint” (Geneva Study, interview 10)

Issues of fairness and equity in health care allocation are often brought into the discussion through concern about rising health care costs, and tend to increase along with pressure on these costs. One consequence is that the existence of limits in health care can seem to be due to these rising pressures. In fact, as outlined in the previous chapter, this is clearly not the case. Of course, the quantity of available resources, and the degree of overlap with the health care we consider to be needed, will vary. But the existence of a limit in health care is unavoidable. A further example helps to illustrate why. Suppose you collapse in the street, victim of a myocardial infarction complicated by cardiac arrest. It is in your interest that an ambulance, with a defibrillator, be available immediately. There is no question about this. No risk-free waiting, no discussion regarding whether the code team is ‘nice to have’ or ‘need to have’, this case is as clear as they come. Now, if there was only one ambulance for the entire region where you live, the risk that it will already be occupied elsewhere is quite high. So you need for there to be a second one. This decreases the risk, but does not eliminate it. A third ambulance will decrease it yet further, and so on. But the risk that you will remain unresuscitated though lack of an ambulance will never actually reach zero. If you take this example into very unlikely scenarios, you will realize that each additional paramedic (after all these ambulances need to be staffed) is also an additional hypothetical victim for a simultaneous accident using up one more ambulance. Here too, zero-level risk is unobtainable. In accepting a finite number of ambulances, we are accepting that some needed care will not be available. We are accepting unavoidable scarcity.

Scarcity

Contradictory data exist as to whether doctors are aware of facing scarcity. In The Painful Prescription: Rationing Hospital Care, Aaron and Schwartz noted that British doctors rationalized, or redefined health care standards to face scarcity more comfortably (Aaron and Schwartz 1984). Twenty years later, researchers conducting interviews with doctors regarding scarcity reported being struck with the strength
with which scarcity was denied (Alexander, Werner et al. 2004). We conducted two studies to explore this. One was a study of ethical difficulties faced by US doctors, in which many respondents gave examples related to scarcity (Hurst, Hull et al. 2005). The other was an international survey of general doctors in Italy, Norway, Switzerland, and the UK, four European countries offering universal access to health care through very different systems, with per capita expenditure on health care ranging from $3,322 in Switzerland to $1,989 in the UK (Hurst, Slowther et al. 2006; Hurst, Forde et al. 2007; WHO 2007).

Resource constraints faced by US doctors

Despite the importance and the intensity of debates within the US health care “system” – or perhaps partly because of it - strategies used by American doctors in actual situations of resource constraint had not been studied until then. Studies to date have been limited to doctors’ attitudes regarding resource allocation, (Tymstra and Andela 1993; Arnesen and Fredriksen 1995; Baines, Tolley et al. 1998; Ryynanen, Myllykangas et al. 1999; Sulmasy, Bloche et al. 2000; Cooke and Hutchinson 2001; Coast, Donovan et al. 2002) and surveys of their intended practices using hypothetical scenarios. (Ryynanen, Myllykangas et al. 1996; Ryynanen, Myllykangas et al. 1997; Ubel, Baron et al. 2000) Initially, we did not even intend to study this aspect of US health care either. We conducted a study to describe the type of ethical difficulties reported when doctors were asked for a recent example. As it turns out, an important proportion of these examples related to resource allocation; enough to conduct a secondary analysis.

The survey instrument used in this study was based on cognitive interviewing with a small group of general internists, oncologists, and intensive care specialists, followed by field pre-testing of a completely revised instrument with another group of board-certified internists. (Fowler 1995) The domains of the questionnaire included: type and frequency of ethical dilemmas, type of guidance sought by responding doctors in situations of ethical difficulty, report of a specific ethically difficult situation, strategies used to resolve this specific case, type of help that would have been useful in this specific case. (DuVal, Sartorius et al. 2001; DuVal, Clarridge et al. 2004) The following open-ended questions were asked to elicit the specific example of an ethically difficult case and the strategies used to resolve it:

• Can you describe a recent ethical dilemma you experienced at your main practice site?
• What do you consider to be the primary ethical issue or dilemma raised by the situation?
• Please briefly describe the decisions that were made as the situation played itself out.
A series of closed-ended follow-up questions were asked regarding the strategies used by responding doctors in facing the situation, as well as the kind of help they would have considered useful.

Computer Assisted Telephone Interviews were used with both close-ended and open-ended questions. (Harlow, Rosenthal et al. 1985) Interviews were conducted between October 1999 and March 2000 by trained interviewers from the Centre for Survey Research at the University of Massachusetts, Boston. The interviews took an average of 26 minutes to complete. Doctors were not paid to participate. Responses to open-ended questions were entered into a database by the telephone interviewers.

As shown in Table I-1, our participants were general internists, oncologists and intensive care doctors, identified by random sampling from the American Medical Association Master List of Doctors and Medical Students for Mailing Purposes which provides a comprehensive list of doctors not limited to members of the American Medical Association. (DuVal, Clarridge et al. 2004) These specialties were chosen to capture doctors active in the primary care setting, as well as those providing highly technological care. Since our purpose was to explore an aspect of clinical experience, doctors were eligible to participate if they reported practicing medicine for at least one year prior to the survey, and spending at least 20% of their time in direct patient care. Of the 600 doctors originally identified, 537 were eligible, and 344 (response rate 64%) participated.

Transcripts of cases in which one of the central issues raised by the responding doctor was resource allocation were identified, and this list was finalized based on review of all 344 cases by consensus of the authors (SAH, SCH, MD).

Responses to closed-ended questions were entered into a statistics program (SPSS 11.0 for Windows) for analysis. Along with descriptive statistics, we used Pearson Chi-square and Mann-Whitney U as appropriate to compare allocation cases to other cases given as examples by responding doctors. Responses to open-ended questions were imported into QSR NUD*IST version N6 (QSR International, Victoria, Australia) qualitative research software to facilitate data analysis. Codes for the type of allocation cases, the strategies reported, the resource in question, the rationale offered for the strategies, the outcome and the success of the strategies were developed and refined. Cases identified as resource allocation difficulties were then coded for content by two authors (SAH and MD).

For purposes of reading ease, quotes presented in this chapter have been completed from the telegraphic style in which transcripts were taken. Additions are identified by <>. Parts of the quotes that are deleted from the text are indicated by (…).

Of our respondents, 310 (89%) could recall a recent ethical dilemma. Of these, 55 (18%) reported a recent case involving resource allocation. Responding doctors who gave a resource allocation example were significantly less likely than other
responding doctors to have access to an ethics consultation process and less confident about their knowledge of ethical standards. They were more likely to have been born in Europe, but not more likely to be trained outside the US. Internists and critical care specialists were more likely than oncologists to report a resource allocation dilemma.

In resource allocation cases, most responding doctors reported that the source of difficulty was pressure of some kind (Table I-2). In a quarter of cases, the pressure was to forgo using a resource when the doctor responding thought it should be used (24%), and in others cases the pressure was to use a resource when the responding doctor thought it should not be used (30%). Limitation in the coverage of insured individuals was the source of the difficulty in 36% of cases, while complete lack of insurance was the source of the difficulty in relatively fewer cases (20%). The problem of whether or not it was appropriate to use an expensive or scarce intervention that would yield questionable benefit – the sort of case usually discussed under the topic of clinical rationing – was mentioned in only 20% of cases. Here also, then, pressures were a predominant part of allocation as experienced by doctors.

The resource in question was most commonly a treatment modality, such as chemotherapy (64%) or access to a specific source of care, such as a nursing home (31%). Diagnostic procedures, such as MRIs, were much less frequently mentioned (7%), as was disability designation or sick leave (7%). An excessive delay, or the lack of access to a needed resource within a defined time frame, was the limitation in 17% of cases.

In 45% of cases, doctors engaged in some kind of interaction with the health care system, negotiating (33%), and on rare occasion manipulating the rules (2%).

"<I had> a patient in which he did not want to go on dialysis. He wanted to go on a transplant list. He could wait. (…) The insurance company refused to pay for the transplant because the hospital was not in the insurance program. (…) I taped <the insurance company’s> conversations (…). I threatened to go to court. Eventually the patient got the transplant and the insurance company paid for it." (US doctor study, respondent 566)

Discussions with the patient or the patient’s family were also reported frequently (22%). In one situation where the doctor “doubted <the> need of aggressive management” of a terminal patient, he reported:

“ I just explained to <the> family the current condition, gave them brief description <of> what’s going on with relative, loved one and I left decision to them to make …they came next day…he’s suffering, (…) they decided on their own to minimize the care to supportive care
from aggressive intensive care.” (US doctor study, respondent 319)

<table>
<thead>
<tr>
<th>Table I-1: US doctors reporting ethical difficulties and allocation difficulties</th>
<th>Allocation (N=55)</th>
<th>Total (N=310)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male/Female sex</td>
<td>82/18%</td>
<td>80/20%</td>
</tr>
<tr>
<td>Median Age</td>
<td>44 (28-68)</td>
<td>40 (26-79)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>78%</td>
<td>81%</td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td>p=0.001</td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>56%</td>
<td>67%</td>
</tr>
<tr>
<td>Central or South America</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Europe</td>
<td>20%</td>
<td>6%</td>
</tr>
<tr>
<td>Asia/Middle East</td>
<td>15%</td>
<td>18%</td>
</tr>
<tr>
<td>Africa</td>
<td>4%</td>
<td>1.5%</td>
</tr>
<tr>
<td><strong>Type of practice</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Solo practice</td>
<td>13%</td>
<td>11%</td>
</tr>
<tr>
<td>Single specialty group</td>
<td>38%</td>
<td>39%</td>
</tr>
<tr>
<td>Multi-specialty group</td>
<td>29%</td>
<td>24%</td>
</tr>
<tr>
<td>University hospital/practice</td>
<td>7%</td>
<td>13%</td>
</tr>
<tr>
<td>Other hospital-based</td>
<td>9%</td>
<td>13%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Median % of Managed Care reimbursement</strong></td>
<td>30% (0-100%)</td>
<td>30% (0-100)</td>
</tr>
<tr>
<td><strong>Main Admitting Hospital</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public/Private</td>
<td>40/60%</td>
<td>41/59%</td>
</tr>
<tr>
<td>For profit/Not for profit</td>
<td>17/83%</td>
<td>18/82%</td>
</tr>
<tr>
<td>Median Nb of patient beds</td>
<td>400 (36-2000)</td>
<td>400 (6-3450)</td>
</tr>
<tr>
<td><strong>No. of people in a 20 mile radius</strong></td>
<td>p=0.039</td>
<td></td>
</tr>
<tr>
<td>&lt;50,000</td>
<td>14%</td>
<td>7%</td>
</tr>
<tr>
<td>50,000-250,000</td>
<td>30%</td>
<td>31%</td>
</tr>
<tr>
<td>250,000-500,000</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>&gt;500,000</td>
<td>42%</td>
<td>48%</td>
</tr>
<tr>
<td><strong>Median total years in practice</strong></td>
<td>16 (3-44)</td>
<td>16 (2-57)</td>
</tr>
<tr>
<td><strong>Specialty</strong></td>
<td>p=0.026</td>
<td></td>
</tr>
<tr>
<td>Critical care</td>
<td>22%</td>
<td>37%</td>
</tr>
<tr>
<td>Internal Medicine</td>
<td>36%</td>
<td>26%</td>
</tr>
<tr>
<td>Oncology</td>
<td>42%</td>
<td>37%</td>
</tr>
</tbody>
</table>
The other strategies reported included financing the needed care (22%), and refusing requests (16%).

Doctors’ comments were consistent with their accepting the apparent limitations of the situation in 20% of cases, and not accepting them in 33% of cases. In the remaining cases, comments did not indicate whether or not the limitation was accepted.

Based on closed-ended questions, the following strategies were used to address the situation: meetings were initiated with the clinical team in 38% of cases; the situation was discussed with the patient or family in 85% of cases, with the department head in 13% of cases, and with the hospital lawyer in 13% of cases; a
formal ethics consultation was requested in 13% of cases. Some responding doctors mentioned strategies in the closed-ended questions that they had not mentioned in the open-ended questions. Holding a discussion with the patient or family, for example, was mentioned much more frequently in the closed-ended questions. There were no significant differences between the strategies reported in the closed-ended questions by responding doctors who gave an allocation example and responding doctors who gave other kinds of examples of ethical difficulties.

Concern for the patient’s well-being was the most frequently articulated rationale for the strategies used (62%). It included concern for “our obligation to give <the> patient the best treatment” (44%), the commitment to treat the patient despite reimbursement structures (5%), or despite institutional obstacles (4%), concern for quality of life (16%), and following the patient’s wishes (9%).

Saving resources and preventing futile care was the reported rationale in 27% of cases. A concern for justice was reported as the rationale in 11% of cases. This was mostly framed as a concern for equal treatment (7%).

“The main issue I see is really <a> patient I have been treating for many years and I know his medical problems and I’m not able to help him. If I do it for him I have to do it for everyone.” (US doctor study, respondent 017)

Pragmatic rationales, which aimed to explain the strategy on the basis of some practical aspect of the case, were offered in 11% of cases.

The patients were reported to have obtained the resource in question in 45% of cases, to have partially obtained it in 22% of cases, and to have failed to obtain it in 22% of cases.

Responding doctors who gave an allocation example were significantly less likely to be satisfied with the decisions that were made than responding doctors who gave other kinds of examples of ethical difficulties (52% and 69%, p=0.021).

What does this study tell us?

This study offers a unique exploration of resource allocation at the bedside in a national sample of U.S. doctors. Results indicate that therapeutic, rather than diagnostic, interventions are the focus of concern about resource allocation. Clinicians use a variety of strategies in arriving at these decisions. While some strategies entailed decisions made by doctors on their own, most involved negotiations with patients, families, third-party payers, administrators, colleagues and other participants in the health care system. In most cases, the source of the
difficulty was external pressure. Lack of insurance was a frequent problem, but it is noteworthy that situations of underinsurance were more frequent than complete lack of insurance. Difficulties due to patients’ lack of ability to pay were not limited to the uninsured. (Bodenheimer 1992; Short and Banthin 1995; Weiner 2001)

Debates on doctor resource allocation focus on whether or not doctors ought to ration care, in the sense of allowing patients to go without the most beneficial healthcare service (Hiatt 1975; Loewy 1980; Levinski 1983; Morreim 1989; Sulmasy 1992; Ubel 2001). Two commonly held assumptions seem to be the following: first, that doctors are making these decisions on their own, and second, that the decisions to ration are simple dichotomous choices.

This (admittedly exploratory) study indicates that these assumptions are too simplistic. It would seem that two important realities about bedside rationing that have been under recognized in efforts to address the question from a normative standpoint. First, most of the cases reported to us involved some form of negotiation in their resolution. Responding doctors were, in effect, not making these decisions alone. Second, many decisions were not handled as dichotomous choices. Rather they often involved alternative solutions in the face of complexities both of the health care system and of each particular situation.

The literature on resource allocation outlines a variety of strategies that can be used to forgo treatment. One such list includes denial, selection, deflection, deterrence, delay, dilution, and termination. (Klein, Day et al. 1996) Our findings confirm the presence of some of these strategies in situations where internists allocate resources in clinical practice. Responding doctors reported refusing requests (denial), refusing or attempting to refuse requests from patients who seemed either unlikely to benefit or somehow undeserving (selection), choosing to shift authority to others (deflection), offering less expensive alternatives (dilution), and terminating care that they deemed unhelpful (termination). Deterrence and delay, intentional or not, typically exist in a system-wide fashion and would be more difficult to detect based on doctors’ accounts of what they did. It is therefore not surprising that they did not appear in our sample.

Although these data cannot conclusively show whether US doctors practice bedside rationing, they are strongly suggestive that they do.

A study of European doctors

In this study, we identified general doctors through the 2002 official list of the Norwegian Medical Association, the Swiss Medical Association, published listings of UK general practitioners and general doctors, and regional listings of Italian
general practitioners and members of the Italian Society of Internal Medicine. A random sample of 400 individuals was drawn in each country in proportions of general practitioners and general internists reflecting that of each national doctor population. This sample was chosen to capture similar doctor populations, who do the same kind of work in general internal medicine, in both in- and outpatient care.

We chose four European countries offering universal access to health care through very different systems, with per capita expenditure on health care ranging from $3,322 in Switzerland to $1,989 in the UK. As shown in Table I-3, despite differences in structure and health care expenditure, the health care systems of all four countries received similar evaluations regarding fairness of financial contribution to the health system and distribution of responsiveness in the WHO world health report of 2000 (2002 US $).

<table>
<thead>
<tr>
<th>Table I-3: Four Health Care Systems - WHO and OECD data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Per capita expenditure on health care^a</td>
</tr>
<tr>
<td>Total (US $)</td>
</tr>
<tr>
<td>Public (US $)</td>
</tr>
<tr>
<td>Out of pocket (US$)</td>
</tr>
<tr>
<td>Proportion of expenditure on health care^a</td>
</tr>
<tr>
<td>Social security</td>
</tr>
<tr>
<td>Other public</td>
</tr>
<tr>
<td>Pre-paid plan</td>
</tr>
<tr>
<td>Out of pocket</td>
</tr>
<tr>
<td>Other private</td>
</tr>
<tr>
<td>Beds, doctors, nurses^b</td>
</tr>
<tr>
<td>Acute care beds/1000 p.</td>
</tr>
<tr>
<td>Nurs. home beds/1000 p.</td>
</tr>
<tr>
<td>Nurses/1000 pop.</td>
</tr>
<tr>
<td>Doctors/1000 pop.</td>
</tr>
<tr>
<td>Elements of health policy</td>
</tr>
<tr>
<td>Universal coverage</td>
</tr>
<tr>
<td>Freedom to choose general doctor</td>
</tr>
<tr>
<td>Gatekeeping for specialist consultation</td>
</tr>
<tr>
<td>WHO assessment of equity^c</td>
</tr>
<tr>
<td>Fairness of financial contribution to health system</td>
</tr>
<tr>
<td>Distribution of responsiveness</td>
</tr>
</tbody>
</table>

^a WHO 2002 country information
^b OECD 2003 country information
^c WHO 2000 World health report
We developed a survey instrument to explore general doctors’ perception of, and attitude towards, scarcity and rationing both at the system-wide level, through resource unavailability, and in clinical practice, through bedside rationing. Whenever possible, we used validated items from other studies published in the literature. (Arnesen and Fredriksen 1995; Ryynanen, Myllykangas et al. 1999; Sulmasy, Bloche et al. 2000; DuVal, Clarridge et al. 2004) This included items relating to agreement with various cost-containment policies. (Ryynanen, Myllykangas et al. 1999) New items were independently rated by two ethicists with relevant expertise. The questionnaire was refined following their comments and piloted on 96 doctors in the US, the UK, and Switzerland. Each scale was tested for internal consistency on the pilot sample, and again on the complete sample. Survey development was further described elsewhere (Hurst, Slowther et al. 2006).

The finalized survey questionnaire explored doctors’:
1. Experience of scarcity.
2. Reported practice of bedside rationing, and agreement with clinical rationing.
3. Perception of equity in their health care system
4. Experience of ethical difficulties in general, and scarcity-related ethical difficulties in particular.
5. Views on the usefulness of ethics support.

We gathered demographic information and explored how much prior training in ethics our respondents reported.

Participation was voluntary and responses were made anonymous before analysis to ensure confidentiality. Approval was given by the IRB of the National Institute of Child Health and Development at the US National Institutes of Health, and by the Trent Multi-Centre Research Ethics Committee in the UK. This study was examined and designated exempt from ethics committee review by IRBs in Norway, Italy, and Switzerland.

Participants were contacted by mail, and told about the aims of the study in a cover letter. Questionnaires were self-administered by the respondents. To maximize response rate, cover letters were addressed by local researchers affiliated with universities in the respondents’ country. A repeat mailing was sent, including an additional copy of the questionnaire, and an incentive of €10, or the closest equivalent in local currency that could be enclosed as a single bill (Edwards, Roberts et al. 2002). We mailed questionnaires to 1600 doctors. Data collection was open from February 2003 to June 2004.

Data were analyzed using descriptive statistics, and bivariate correlations were analyzed using Spearman’s rho or Kruskall-Wallis tests as appropriate. We selected a significance level of .01 (2-tailed). We used logistic regression to identify
variables independently associated with the Agreement with rationing scale, and with individual items in the scale. The models were built using the variables that were found to be associated with agreement with rationing or with any of the items within the scale in bivariate analysis.

Respondents (N=656, 43% of eligible sample) ranged in age from 28-82, and had been in practice for an average of 25 years, and 38.4% were at least partly hospital-based (Table I-4). Respondents were predominantly male (85%), with the proportion of women ranging from 42.1% under the age of thirty to 7.8% from 61 to 70 years of age.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Doctors (N=656)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>28-82 (mean 51)</td>
</tr>
<tr>
<td>Years in practice</td>
<td>1-62 (mean 25)</td>
</tr>
<tr>
<td>Male</td>
<td>546 (85%)</td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
</tr>
<tr>
<td>Family medicine</td>
<td>195 (30%)</td>
</tr>
<tr>
<td>General medicine</td>
<td>188 (29%)</td>
</tr>
<tr>
<td>Internal medicine</td>
<td>179 (28%)</td>
</tr>
<tr>
<td>Country of practice</td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td>139 (21%)</td>
</tr>
<tr>
<td>Norway</td>
<td>222 (34%)</td>
</tr>
<tr>
<td>Switzerland</td>
<td>183 (28%)</td>
</tr>
<tr>
<td>UK</td>
<td>112 (17%)</td>
</tr>
<tr>
<td>Primary practice site</td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>258 (38%)</td>
</tr>
<tr>
<td>Solo practice</td>
<td>182 (28%)</td>
</tr>
<tr>
<td>Primary care group</td>
<td>164 (25%)</td>
</tr>
<tr>
<td>practice</td>
<td>23 (4%)</td>
</tr>
<tr>
<td>Multi-specialty group</td>
<td>28 (4%)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Admitting hospital</td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>572 (94%)</td>
</tr>
<tr>
<td>Private</td>
<td>21 (3%)</td>
</tr>
<tr>
<td>For-profit</td>
<td>81 (17%)</td>
</tr>
<tr>
<td>Not-for-profit</td>
<td>406 (82%)</td>
</tr>
<tr>
<td>Teaching hospital</td>
<td>264 (46%)</td>
</tr>
</tbody>
</table>

Percentages shown exclusive of missing data, and rounded to the nearest whole number

What did this four-country study find regarding doctors’ perception of scarcity?
The vast majority of respondents (87.7%) perceived some resources as sometimes unavailable. The most prominent were: access to nursing home, mental health services, referral to a specialist, referral to surgery, and rehabilitation for stroke (Figure I-2) (Hurst, Forde et al. 2007). Mean score on the Perceived scarcity scale (range 0-44) was highest in the UK (9.4), followed by Italy (7.7), Norway (7.4), and Switzerland (4.2) (p<0.001). Although all surveyed countries offer universal coverage, 45.6% of respondents reported instances where a medical problem could not be treated because patients could not afford their share of the cost. This was highest in Norway (58.9%), followed by Italy (50.4%), Switzerland (48%) and the UK (24.7%) (p<0.001).

Figure I-2: Percentage of respondents who reported unavailability of resources

Thus, doctors in the four countries we studied seem to be aware of scarcity in their practice. Reports of scarcity in all the surveyed health care systems is not surprising. Every system in the world rations health care, some by wait times, some by availability of services, coverage decisions, or by ability to pay. There are thus good reasons for some resources to be unavailable, as choices will have to be made whenever demands exceed resources. Doctors are in a unique position to observe the impact of these choices, including when they may be unexpected.

For example, despite universal coverage, doctors reported underinsurance. This is not incompatible. Universal health insurance means that coverage extends to all persons who legally reside in the country, as well as to foreigners in situations of

1 Cronbach’s alpha 0.84
emergency. It does not, however, necessarily mean that access to all interventions will be covered financially. For example, Switzerland and Norway mostly do not include coverage for dental care in health insurance. Neither does it mean that all included interventions will be covered without cost-sharing. This factor can vary extensively between the four systems. The extent of reported underinsurance was not related to the amount of national health care expenditure, suggesting that organizational factors and coverage decisions also contribute to apparent underinsurance.

Our respondents’ aggregate assessment of how various interventions were more or less sufficiently available differed across interventions, and between countries. Health care systems do not allocate their resources in identical ways; asessment of how existing services fit with perceived need, however, can be difficult. Despite growing research on variations in the distribution of resources in health care systems, and in utilization (Wennberg and MacAndrew Cooper 1999), there is no gold standard on the proper availability of resources. Utilization is often used as a proxy outcome for availability, but making the distinction between utilization, need, and availability can be challenging (Andersen and Aday 1978). Availability is thus difficult to evaluate (Penchansky and Thomas 1981). In our study, we assessed unavailability of services based on doctors’ assessment of need rather than on a measure derived from utilization.

**Doctor bedside rationing**

When we started the international four-country study described above, data suggested that doctors accept prioritization decisions, both when faced with hypothetical scenarios (Ryynanen, Myllykangas et al. 1997; Wouters, Timmermans et al. 1997; Baines, Tolley et al. 1998; Ryynanen, Myllykangas et al. 2000; Ubel, Baron et al. 2000; Cooke and Hutchinson 2001; Perneger, Martin et al. 2002; Rosen and Karlberg 2002; Escher, Perneger et al. 2004; van Delden, Vrakking et al. 2004), and when reporting on their practice (Arnesen and Fredriksen 1995; Ryynanen, Myllykangas et al. 1999; Hurst, Hull et al. 2005). In one study, Ayres had reported attitudes of general practitioners in the UK regarding the relevance and impact of rationing, and the strategies they would advocate for resolving rationing dilemmas, both at the individual and population level. (Ayres 1996) The attitudinal data, however, and the focus on acceptable policies for resource allocation at the macro-level, meant that their experience of day to day clinical strategies used in dealing with scarce resources were incompletely addressed. Three key aspects had not been explored: 1) the frequency of rationing decisions made by doctors in clinical practice, 2) the type of interventions to which these decisions are applied, and 3) the criteria used in making these decisions. Therefore, these three questions constituted the main focus of our own study.
There are two reasons to look at doctor bedside rationing. If we find that it happens, it will again point to situations where scarcity is identified. In addition, however, if we wonder whether or not doctors should take part in resource allocation, then we may need to know whether, and especially how, rationing takes place in clinical practice (Asch and Ubel 1997; Ubel 2001). Descriptive data about what doctors withhold, from whom, and how they make these decisions, can be crucial to make normative judgments about the ethical acceptability of bedside rationing. If one takes the normative perspective, as we do, that rationing ought to maximize fairness, data can eventually be used to examine whether doctors withhold in a discriminatory or even-handed manner and hence whether or not bedside rationing is morally problematic. If doctor reasoning is consistent with practice guidelines, and cognizant of issues of fairness, then bedside rationing might be an ethically acceptable component of the processes dictating the distribution of medical resources.

**A difficult research topic**

This four-country study thus addressed a not-so-straightforward question (Ubel 2006): do doctors, in fact, ration care (Hurst, Slowther et al. 2006)? Because of the controversial nature of rationing and the lack of clarity about its definition, we did not use the word ‘rationing’ in the questionnaire. As outlined earlier, we based our definition of rationing on the more comprehensive definition proposed by Ubel & Goold, who define rationing as “any implicit or explicit mechanisms that allow people to go without beneficial services” (Ubel and Goold 1998). Based on this definition, we asked respondents exclusively about those decisions they had made that led to patients going “without beneficial services”. We specified that we meant decisions based on costs, in order to avoid confusion with situations where beneficial services were withheld because patients did not want them.

**Reported rationing**

Rationing of interventions was reported by 56.3% of respondents for the prior six months (Figure I-3). The most frequently rationed interventions were MRI (40.9%) and screening tests (28.6%), and the least frequently rationed were referral to ICU (13.7%) and dialysis (15.4%). The mean score on the Rationing scale was 3.4 out of a maximum of 40 for the total sample, with a mean score of 6.4 for those doctors who reported rationing. A score of 6 could signify rationing each of 6 interventions less than once a month, or rationing one intervention daily and one intervention.

\[2^2\text{ Cronbach’s alpha}= .90\]
Figure I-3: Percentage of doctors reporting rationing in the prior six months

Percentages shown exclusive of missing data

Figure I-4: Strategies used to limit expensive interventions

Percentages shown exclusive of missing data
Among doctors who reported rationing, the median was once a month for lab tests and less than once a month for all other interventions. However, rationing was reported as often as daily for all interventions. Rationing of time was reported by 61.3% of respondents.

When asked about strategies for rationing, a majority of respondents (82.4%) reported that they explained their reasoning to their patients at least sometimes when avoiding an expensive intervention. However, 36.5% also reported that they sometimes did not let their patient know about the expensive alternative (Figure I-4).

### Table I-5: Criteria influencing the use of expensive interventions

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Percentage of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>The aim is to prolong the life of a patient whose quality of life you judge to be low</td>
<td>71</td>
</tr>
<tr>
<td>The aim is to improve quality of life in a patient whose life expectancy is short</td>
<td>35</td>
</tr>
<tr>
<td>The benefit to the patient is small</td>
<td>82</td>
</tr>
<tr>
<td>Chances of success for the intervention are low</td>
<td>80</td>
</tr>
<tr>
<td>While you think the patient would benefit, the evidence base for the intervention is lacking</td>
<td>58</td>
</tr>
<tr>
<td>The intervention is primary prevention</td>
<td>26</td>
</tr>
<tr>
<td>The condition is attributable to smoking</td>
<td>18</td>
</tr>
<tr>
<td>The condition is attributable to a dangerous sport</td>
<td>15</td>
</tr>
<tr>
<td>The condition is attributable to pregnancy</td>
<td>7</td>
</tr>
<tr>
<td>The condition requires chronic care</td>
<td>30</td>
</tr>
<tr>
<td>The patient is over 85</td>
<td>70</td>
</tr>
<tr>
<td>The patient is frail</td>
<td>63</td>
</tr>
<tr>
<td>The patient is cognitively impaired</td>
<td>50</td>
</tr>
<tr>
<td>The patient holds an important position in society</td>
<td>7</td>
</tr>
<tr>
<td>The patient asks for the intervention</td>
<td>12</td>
</tr>
<tr>
<td>The patient is poor</td>
<td>8</td>
</tr>
<tr>
<td>The patient will not work again</td>
<td>15</td>
</tr>
</tbody>
</table>

Percentages shown exclusive of missing data, and rounded to the nearest whole number.

*A patient you are treating would benefit from an intervention. This intervention is very expensive. It is paid for by public money, or by a private insurer, or both. Under these circumstances, do the following factors make you more or less likely to use this intervention?
When respondents were asked whether the presence of different kinds of criteria would make them more or less likely to use an expensive intervention, their responses showed important variations. The most frequently reported criteria for rationing decisions were a small expected benefit (82.3%), low chances of success (79.8%), an intervention intended to prolong life when quality of life is low (70.6%), and a patient over 85 years of age (70%). Some criteria, however, were reported by some doctors as reasons to use an intervention less and by some doctors to use it more (Table I-5). This may reflect diversity in the types of cases they had in mind when replying, differences in their considerations and priorities in making allocation decisions, or both. Both can be understood as reflecting difficulty in making allocation decisions in clinical practice.

These studies are important in documenting what has often been termed ‘implicit rationing’. Rationing which is not determined ahead of time by rules. Although such limit-setting has been criticized as inherently ethically problematic, I would contend that this is not necessarily the case. The reasons why critiques of clinical rationing are initially convincing are based on presumptions that it is opaque, often arbitrary, susceptible to inappropriate variations, and an illegitimate use of clinical power. While all this may sometimes be true, each of these issues can theoretically be addressed. Indeed, it is important to do so, since it is arguably impossible to remove limit-setting from clinical practice altogether. The questions then become: how can bedside rationing be practiced a fair, consistent, and legitimate manner. And indeed the first step is making it less opaque.
Chapter 3 - Making the implicit explicit

“I associate patients but I think we can’t do it just any old way, you can’t tell the patient: this is too expensive for you, because that won’t make him happy [laughs], because you must say it a little differently and you should tell him hmm…and him and me we pay every day, every month for our insurance premium and that hmm if we want hmmmm…if we don’t want it to go up too fast we have a duty to do as best we can, to work with efficiency at least, to not throw money out the window doing just anything and that is, is our duty for both of us well I present things a little like that, yes.” (Geneva Study, interview 22)

Discussions regarding how clinical rationing should take place have been difficult for several reasons. As long as clinical rationing is viewed as intrinsically wrong, the question may even seem irrelevant. As defined by Ubel and Goold, however, this is not the case. Clinical rationing has also been viewed as opposed to the ethos of clinicians, and wrong for this other, more specific reason. Finally, discussions of how it ought to happen are difficult because analysing any sort of clinical reasoning is difficult. Before we can begin to explore the ethical status of clinical rationing, then, we need to make the implicit explicit. This was one of the goals of our four-country study, and of the Geneva study presented in Chapter 5-7. We are thus in a position to rethink these open questions: should doctors participate in limit-setting, is clinical rationing opposed to the ethos of doctors, and does it happen in a justifiable way?

Bedside rationing is a reality

Bedside rationing is reported by doctors in all four of the European countries we studied. Doctors who personally agree with rationing, perceive more pressure to ration, and perceive more scarcity, are more likely to report rationing. The interventions reported as being rationed the most frequently are personal time spent with patients, MRI, screening tests, lab tests, and prescription drugs. Although the most frequently mentioned criteria were a small expected benefit, and low chances of success, a majority of respondents also reported being more likely to refrain from using an intervention if the patient was over age 85.

Our results complement studies that have examined clinical rationing such as non-referral to dialysis (Mendelsohn, Kua et al. 1995; Wilson, Godwin et al. 2001). While it has been suggested that doctors often deny scarcity (Alexander, Werner et al. 2004), our findings indicate that doctors are aware of personally denying some modicum of benefit to their patients. These findings will need to be supplemented with additional data gathered from sources such as medical records and administrative datasets. However, despite the exploratory nature of this study, our
results raise a number of intriguing points.

We found significant differences between countries regarding the frequency of reported rationing. While one might expect that doctors in countries that spend more money per capita would report rationing less, this does not appear to be the case. Doctors in Switzerland, where the most is spent, report the most rationing. One plausible explanation is that, when more leeway is left to doctors by the structure of their health care system, a larger share of the responsibility for rationing falls to them. Thus, they may indeed more often “personally refrain from using interventions” which a more rule-bound system would simply not have given them the discretion to use. Whether more leeway for clinical decisions regarding rationing is a favourable arrangement, depends upon judgements about where rationing decisions ought to take place and upon clinical outcomes that we did not measure here. Moreover, we cannot know precisely all the factors that dictate the reported frequency of rationing. In addition to scarcity, or to agreement with rationing, it could also be a function of how often the clinical need arises.

This study has several implications. First, our results suggest an interaction between resource allocation at the levels of health care systems and individual providers. This interaction, may occur at various levels of health care organization including national and more local levels. The literature on practice variation shows that the availability of resources such as hospital and ICU beds vary geographically within a country and that utilization rates parallel this availability (Wennberg and MacAndrew Cooper 1999). Our finding that doctors’ self reports of rationing correlate with their perception of scarcity helps to provide an insight into this relationship. At a national level we found that Italy, the country with the highest number of doctors per 1000 population (OECD 2005), is also where our respondents reported the least rationing of time. This suggests that manpower allocation decisions at the system level, whether intentionally or otherwise, impact reported bedside rationing. A similar finding was reported in the RICH Nursing study as regards nurse staffing levels in Switzerland (Schubert, Glass et al. 2008).

Second, it seems that both health care systems that are more centralized, as exemplified by the UK, and those that are more market-based, as exemplified by Switzerland (Herzlinger and Parsa-Parsi 2004), include clinical rationing behaviour, as judged by doctor self-reports. This of course could also be of interest to countries such as the US, where rationing is often thought to be driven by inability to pay due to uninsurance (Committee on Consequences of Uninsurance 2002) or by insurance coverage rules (Wynia, VanGeest et al. 2003): while expansion of insurance may reduce inequities in access to care, it will not eliminate rationing. One can, however, hope that the pattern of rationing might be fairer. In that regard this study is aimed at providing initial insights that may yield fair rationing strategies.
Overall, our study indicates that bedside rationing is ubiquitous but its extent and patterns vary with system-wide factors. Those who consider bedside rationing by doctors to be ethically unacceptable can glean from our findings that it would be prudent to promote aspects of any health care delivery systems that reduce pressure for doctors to personally take responsibility for the cost of care. But they might also be reassured by the finding that those interventions that are reportedly rationed involve non-vital benefits and interventions for which there are clinical alternatives. Moreover, given the prevalence of rationing, the public may be well served by more explicit discussion of how best to ration care at the bedside in an ethically justifiable manner. The concepts and skills required for fair rationing would also need to be included in medical curricula, which typically do not currently include such training. Indeed, some of this content currently does not exist and will need to be developed first. This, however, can only happen once the discussion shifts from whether rationing does and should happen, to how it ought to happen to be ethically justified.

**Determinants of reported rationing**

In bivariate analysis, doctors’ age, gender, specialty, site of practice (in- or outpatient, public or private admitting hospital, teaching admitting hospital), appointment with a university department, and years in practice since graduation were not associated with the degree of reported rationing, based on the Rationing scale. Degree of rationing was positively associated with number of hours a week in patient care, perceived scarcity, perceived pressure to ration and agreement with rationing. There was a negative association between the degree of rationing and length of waiting time for an appointment, perceived freedom, and working in Norway or the UK.

A logistic regression model of factors associated with reported rationing included both personal attitudes toward rationing as well as perceptions of rationing at the system-wide level. Doctors were more likely to report rationing if they perceived more scarcity (OR=1.11, 95%CI 1.06-1.16), or more pressure to ration (OR=2.14 95%CI 1.52-3.01), and if they agreed more strongly with rationing (OR=1.13, 95%CI 1.05-1.23). Doctors from Norway (OR=2.61, 95%CI 1.34-5.06), Italy (OR=3.62, 95%CI 1.65-7.91), and Switzerland (OR=5.1, 95%CI 2.28-11-68), were more likely to report rationing than those in the UK.

Reported rationing of time was not associated with doctors’ age, gender, years in practice since graduation, type of admitting hospital, number of patients cared for, or hours a week in inpatient care in bivariate analysis. It was positively associated with working in a rural area, in an outpatient setting, number of hours in
outpatient care, being under pressure to ration interventions, reporting less freedom to utilize resources in patients’ best interest, and reporting scarcity, rationing of interventions, and agreement with rationing. There was a negative association between the degree of reported rationing of time and working in Italy, being specialized in internal medicine, and fearing that denying care could jeopardize the doctor-patient relationship.

In a logistic regression model of factors associated with rationing of time, doctors were more likely to report rationing of time if they reported more scarcity (OR=1.1, 95%CI 1.02-1.18), and less likely to do so if they practiced in Italy (OR=0.13, 95%CI 0.04-0.43).

**Should doctors participate in limit-setting?**

As outlined above, the role that doctors should play in cost containment effort (Daniels 1985; Morreim 1991; Sulmasy 1992; Hall 1997; Bloche 1999; Ubel 2001; Strech, Persad et al. 2009) is controversial. The obligation to advocate for patients (Hiatt 1975; Loewy 1980; Levinson 1984; Sulmasy 1992; Pellegrino 1997; Weinstein 2001; Askin 2002), and a lack of trust that doctors will make the right kind of rationing decisions (Veatch 1997), have prompted reservations about doctor involvement in health care rationing. However, doctor involvement has also been defended on the grounds that doctors are entrusted with the stewardship of scarce resources (Morreim 1991), could make cost control compatible with patient advocacy (Pearson 2000; Hardee, Platt et al. 2005), and indeed may be in the best position to ration care in an appropriate and justifiable manner (Daniels 1981; Pearson 2000; Ubel 2001).

Debates regarding whether or not rationing of health care is acceptable rarely truly dispute setting *some* limits on care. Usually some threshold, such as the current standard of care, or patients’ wishes, is taken for granted, and discussion focuses on whether or not setting a more restrictive threshold would be justifiable. Rationing, as defined by Ubel and Goold (Ubel 2001), must take place because the use of every single intervention that holds the smallest possibility of minute benefit seems financially untenable. Thus, any clinical decision to place or accept a limit on benefits for a patient constitutes rationing. Examples include such mundane decisions as early discharge to follow-up when there is a very small remaining risk of complication, such as post-operative deep venous thrombosis under appropriate prophylaxis. As this example shows, some instances of clinical rationing are routinely accepted and would be difficult to describe as immoral. While some may criticize forgoing benefits in the abstract, few dispute that forgoing very marginal benefits may be reasonable.
So in one sense, there is an apparently trivial answer to our question. Involvement of doctors in these decisions is and will remain a part of clinical practice. Doctors make decisions regarding whether or not a small benefit is worthwhile. They face requests for expensive interventions with little prospect of benefit to their patients (Hurst, Hull et al. 2005). Thus, doctors contribute to setting the threshold above which an intervention is “unreasonable”. Such limit-setting is a “mechanism that allows people to go without beneficial services” (Ubel 2001).

So yes, doctors ought to participate in limit-setting. Clinical judgment ought to contribute to these decisions: there will always be a degree of indeterminacy involved here that cannot, and perhaps should not, be addressed beforehand by rules (Hall 1994).

Is setting limits contrary to doctors’ ethics?

Respondents in our four-country study do not seem to think so. Based on the scale exploring Agreement with Rationing\(^3\) in our four-country study, 82.3% of respondents showed some degree of agreement, with a median score of 10 (range =3-15). Over a third of respondents (36.6%) agreed that they should sometimes deny beneficial but costly services. Half (51.3%) agreed that cost to society was important in their decision to use or not to use an intervention. Two-thirds (68.7%) agreed that doctors should adhere to clinical guidelines that discourage the use of interventions that have a small proven advantage over standard interventions but cost much more. However, over half (61%) thought that denying costly but beneficial care would interfere with the doctor-patient relationship. There were significant differences between the four surveyed countries in reported agreement with rationing (p=0.007), as well as in agreement with guidelines discouraging the use of expensive treatments (p<0.001), and rationing-related fear for the doctor-patient relationship (p<0.001). There were however no significant differences in doctors’ agreement that they should deny services (p=0.514), or with the importance of cost to society to clinical decision-making (p=0.152).

We found little strong disagreement or strong agreement with rationing in our sample. As shown in Figure I-5, where a lower number on our 3-15 scale indicates lower agreement with rationing, most respondents indicated more nuanced attitudes. Agreement with rationing was associated with reported rationing (p<0.001), direct pressure to deny interventions (p<0.001), perceived threats on respondents jobs or financial security (p=0.007), reported underinsurance (p<0.001) or adverse events attributed to scarcity (p=0.001), and with perceiving incentives as favoring expanded services, as opposed to reducing services or neither (p=0.001).

\(^3\) Cronbach’s alpha=.60
Doctors were also more likely to agree with rationing if they perceived more discrimination of patient groups in their health care environment (p<0.001), or if they participated in allocation decisions in their environment (p=0.006), though they was no association with reported participation in an official allocation board. They were also more likely to agree that doctors should adhere to limit-setting guidelines if they worked in a rural area (p=0.001), and to agree that cost was an important factor in their decision if they reported more scarcity (p=0.001). Doctors were more likely to fear for the doctor-patient relationship if their admitting hospital was not-for-profit (p=0.002), or if they worked in an urban area (p=0.003). There was no association with respondents’ gender, age, years in practice, training in ethics, in- or outpatient practice, and fear for rationing-related harm to the doctor-patient relationship, or with agreement that doctors ought to help their patients when the health care system is unfair to them. In logistic regression, agreement that cost to society was important to respondents’ decisions was associated with pressure to ration (OR 1.5 95%CI 1.1-2). Respondents reported more agreement with limit-setting guidelines if they worked in Norway (OR 2.3 95%CI 1.1-4.7). No variables were independently associated with the full Agreement with rationing scale, or agreement that doctors ought to deny services. Fear for the doctor-patient relationship was reported less in Norway (OR 0.1 95%CI 0.05-0.3) and in the UK (OR 0.3 95%CI 0.1-0.7) than in Italy and Switzerland.
Almost all respondents (97.3%) found at least one cost-containment policy acceptable (Figure I-6). Mean number of acceptable policies were 4, with a high of 4.5 in Norway, and a low of 3.7 in Switzerland and the UK (p<0.001). Classification of referrals by degree of urgency, emphasis on evidence based practice, and waiting lists for elective surgery were the policies most frequently found acceptable. Administrative prioritization of patient groups and closing hospital beds were least frequently found acceptable, with the latter found acceptable more frequently (52%) in Italy (p<0.001). Restriction of expensive treatments and interventions, and direct treatment fees, were found acceptable by over half of respondents only in Norway (68.2% and 58.9%, respectively) (p<0.001). Overall agreement with cost-containment policies was greater in Norway and Italy than in the UK and Switzerland (p<0.001). Agreement with cost-containment policies was not associated with perceived scarcity, equity, or discrimination, or with reporting adverse effects of scarcity.

Our results thus confirm that doctors are not fundamentally averse to such policies (Myllykangas, Ryynanen et al. 1996; Ryynanen, Myllykangas et al. 1999; Rosen and Karlberg 2002). Indeed, support was greater in our sample than in the study initially using the items we included (Ryynanen, Myllykangas et al. 1999). Respondents also indicated willingness to participate in these decisions: cost-containment policies close to the bedside were the most frequently approved. This
suggests that doctors are not only ready to recognize that cost should play a role in allocating health care resources, but would rather participate in this sort of decision than not. If they are attentive to issues of fairness, they may be well situated to promote fair access to services in the face of resource constraints.

**How justifiably are doctors rationing?**

The question, then, is not whether doctor bedside rationing is ever acceptable, but which thresholds and which processes are acceptable. The way in which bedside rationing is applied is the key question when considering its acceptability. Despite some study of public and doctors’ attitudes towards theoretical rationing situations, however (Ubel, DeKay et al. 1996; Ubel, Loewenstein et al. 1996; Ubel, Baron et al. 2000), little has been said about how bedside rationing ought to be practiced. Clinicians make rationing decisions (Hurst, Slowther et al. 2006) but cannot currently refer to a generally applicable rule, or to a widely accepted social understanding. The difficulty of such a controversial topic may play a part in this, but the very danger that bedside rationing could be done in an unacceptable way makes its examination all the more important. In addition, the mere fact that individuals are making allocation decisions allocation decision on behalf of society is potentially problematic: another reason to examine this practice, and open it to critique and wider input.(Shaul and Mendelssohn 1997; DIALOG-ETHIK 1999)

The debate regarding how doctors ought to practice limit-setting was long hindered by insufficient data regarding the contexts and situations in which rationing takes place in clinical practice. To a large degree, it is still hindered by insufficient data regarding how they do so. Descriptive data about what doctors withhold, from whom, and how they make these decisions, can be crucial to make normative judgments about the ethical acceptability of bedside rationing. If one takes the normative perspective, as we do, that rationing ought to maximize fairness, data can eventually be used to examine whether doctors withhold in a discriminatory or even-handed manner and hence whether or not bedside rationing is morally problematic. If doctor reasoning is consistent with practice guidelines, and cognizant of issues of fairness, then bedside rationing might be an ethically acceptable component of the processes dictating the distribution of medical resources.

What, then, do the findings of the studies described so far tell us?

Bedside rationing is ubiquitous, its extent and patterns vary with system-wide factors, and those interventions that are reportedly rationed involve non-vital benefits and interventions for which there are clinical alternatives. While it is reassuring to see so few doctors report rationing based on poverty,
criteria such as a patient’s work status may suggest worrisome practices. While rationing criteria such as cognitive impairment may be viewed as discriminatory they may, alternatively, reflect concerns for quality of life that are shared by patients and their families. In sum, doctors report a range of criteria for forgoing medical interventions that appear to be more and less equitable. These findings highlight the need for a more detailed attention both to the factors that do, and to those that should, influence rationing decisions. One such question was mentioned above: are doctors attentive to issues of fairness? The next chapter turns to why this question is crucial.
Chapter 4 - The importance of integrating fairness

“Investigator: What does it mean for you to treat a patient equitably?” “Respondent: Hmm…I’m not sure if I understand this term there (…)” (Geneva Study, interview 17)

Fairness in allocation decisions

Clinical fairness is difficult. Our US study suggested that it rarely constituted a rationale for allocation decisions (Hurst, Hull et al. 2005). As suggested in the citation above, it is not a readily intuitive concept. However, fairness is important for several reasons: it is one of the building blocks of a fair health care system and as such it is important for the moral legitimacy of limit-setting decisions. It is necessary for public acceptance of limits, and through it for their applicability.

Fairness is important in health care

A health care system needs to be equitable for several reasons. Some of these reasons are based on ethical values, and some are more pragmatic in nature. We recognize that illness and suffering are part of our common humanity: they should be remedied for all, without discrimination. “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being” has been recognized by WHO and by member states (WHO 1946). More fundamentally, if we recognize that all should have equal opportunities to a range of life choices, then access to health care should be equitable because health is a pre-requisite to having a full range of life options. (Daniels 1985)

Even if we did not recognize the importance of equity in health care for these reasons, we would still have reasons, albeit more pragmatic ones, to promote it. First, our individual health care needs are not foreseeable. The health care needs of large groups, however, can be predicted to some degree. Thus, we all benefit from pooling risks. We also have an interest that this should apply as broadly as possible to all health risks, as we do not presently know what our individual needs will be in the future. Second, illness can damage our wealth by affecting our ability to earn an income. Thus, if we tolerate a health care system that only responds to the needs of the rich, each of us risks being among those left aside. This is not a strictly theoretical risk. A national study conducted in 2007 in the US found that 62.1% of bankruptcies were linked to medical costs, and that 92% of those so affected had insurance (Himmelstein, Thorne et al. 2009). We thus not only defend an equitable system for ethical reasons, we also need it for more pragmatic ones.

As the ability of medical intervention to affect our future, and its cost, increase,
medical expenditure also weighs more heavily as a common endeavour of communities and societies. In a way, health care can become one of the important ways in which we share resources, and signify our regard for each other. In such a situation, we should expect fairness in the distribution of health expenditure to become more disputed as concerns for access to medicine and financial contributions to the health system fuel attempts to cut costs for the disenfranchised. It is important to note, however, that medicine’s increasing ability to affect our lives at a very basic level also makes fairness in its distribution more important. As it increasingly becomes one of our important common endeavours, legitimate decision-making in the distribution of health resources also becomes more crucial.

_Fairness is important for public acceptance_

In addition, and this is again a more pragmatic concern, if we are to accept a given distribution of health care resources as applying to us, we need—among other things—to consider it fair. This was illustrated in a targeted survey we conducted on 998 enrollees in three self-funded employer pharmacy benefit plans. This study confirmed in a real-life insurance scenario an important aspect of what determines are willingness to share: a belief that others are doing the same, and that the same level of care is thus applied to everyone.

In this study, participants were randomly selected among enrollees who were over 18 years of age, heads of households, and had filled a prescription within the last 6 months. Our questions were included in a routine mailed survey of enrollees in the three pharmacy benefit plans. The survey consisted of eight closed-ended questions addressing willingness to use a less expensive option among equivalent drug therapies and beliefs regarding resource use in the pharmacy benefit plan. Responses were given on a 5 point Likert scale. We used the example of the substitution of a generic drug for a more expensive and equally effective brand name drug in a realistic strep throat scenario. This scenario had three variants. In the first, choosing the generic would save the pharmacy benefit plan $30; in the second, it would save the plan $30 and “may preserve” the respondent’s access to drug benefits for the future; and in the third choosing the generic would save the plan $30 and have a lower co-payment, saving the respondent $15. In each case, the generic drug needed to be taken both four times a day rather than once a day, and for ten days rather than five days. We also asked respondents whether they thought that the benefit plan had limited resources, whether a duty existed to use less expensive generic drugs, whether they believed that other enrollees in the same plan were using less expensive options, and where money saved would likely go. Since respondents were self-designated as heads of households, slightly less than two-thirds (63.7%) of the respondents were male, most (76.5%) were between 45 and 65 years old, and 31.2% received their pharmacy benefits through the
employer’s retiree program. A little over half (51.9%) had a college education.

<table>
<thead>
<tr>
<th>Table I-6: Beliefs regarding limited resources and the use of generics</th>
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</thead>
<tbody>
<tr>
<td>My prescription plan only has a limited amount of money to provide all the drugs needed by me and by other plan members</td>
</tr>
<tr>
<td>32.5%</td>
</tr>
<tr>
<td>All the people in the plan should use less expensive generic drugs instead of equivalent but more expensive brand-name drugs</td>
</tr>
<tr>
<td>I believe that other plan members are choosing the least expensive treatment among treatments that are equivalent</td>
</tr>
<tr>
<td>If I choose the less expensive drug, the money that is saved goes to greater benefits for other plan members</td>
</tr>
<tr>
<td>If I choose the less expensive drug, the money that is saved goes to reduced premiums for me and other plan members</td>
</tr>
</tbody>
</table>

Source: Data collected by Medco Health Solutions, Inc., March 2003

Only 22.2% of enrollees agreed that the pharmacy benefit plan had limited money to provide coverage for the drugs needed by plan members (Table I-6). A third of respondents did not believe that the plan had limited resources (32.5%), and 45.4% were uncertain about this. Overall, 33.1% of respondents rejected the idea that all plan members should use generic drugs instead of equivalent but more expensive brand name drugs, and almost a third (28.7%) were uncertain. Similarly, only 20.1% thought other plan members actually were using the least expensive among equivalent drug treatments, almost half (46.8%) were uncertain, and 26.1% thought others were not using the less expensive among equivalent treatments. Only 18.8% thought the money saved by using less expensive treatments went to greater benefits for other plan members, and 25.4% thought saved money went to reduce premiums (Table I-6).

When the benefit of using generic drugs was to save the pharmacy benefit plan sponsor money, 39.6% of respondents were willing to use a less convenient generic drug rather than a brand name drug. Only when using a generic drug provided the plan member with the personal benefit of a lower co-payment did over half of the respondents (55.2%) indicate a willingness to use a generic drug rather than a
more expensive brand name drug.

Logistic regression showed that respondents who believed that the plan had limited resources were more likely to be willing to use a generic drug to save the plan money (OR=1.51, 95%CI 1.09-2.07), as were those who agreed that all members should use generic drugs when they were equivalent (OR=3.56, 95%CI 2.69-4.71), those who thought other plan members were using the least expensive treatment among those available (OR=3.14, 95%CI 2.32-4.25), and those who believed that the saved money would go to increased benefits (OR=4.23, 95%CI 3.13-5.74), or to reduced premiums (OR=3.39 95%CI 2.56-4.50) (Table I-7).

Table I-7: Willingness to use a generic drug

<table>
<thead>
<tr>
<th></th>
<th>Odds ratio for “Agree”</th>
<th>95 percent confidence interval</th>
</tr>
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<tbody>
<tr>
<td>Plan has limited amount of money</td>
<td>1.51</td>
<td>1.09, 2.07</td>
</tr>
<tr>
<td>All should use equivalent generic</td>
<td>3.56</td>
<td>2.69, 4.71</td>
</tr>
<tr>
<td>Others use equivalent generic</td>
<td>3.14</td>
<td>2.32, 4.25</td>
</tr>
<tr>
<td>Savings go to benefits for others</td>
<td>4.23</td>
<td>3.13, 5.74</td>
</tr>
<tr>
<td>Savings go to reduce premiums</td>
<td>3.39</td>
<td>2.56, 4.50</td>
</tr>
</tbody>
</table>

Source: Data collected by Medco Health Solutions, Inc., March 2003

Respondents who believed that the pharmacy benefit plan had limited resources, that other plan members were using less expensive options when available, and that the saved money would go to reduced premiums or increased benefits, however, were more willing to use clinically equivalent generic drugs. Yet most respondents did not share these beliefs. Indeed, there was either substantial lack of knowledge, substantial skepticism, or both, about the limited resources of a pharmacy benefits plan, the willingness of other plan members to conserve resources, and that any conserved resources would benefit plan members. These levels of ignorance or distrust appear to be higher among better educated—and, presumably, higher income—individuals. This makes ignorance unlikely to be the only factor. The element of skepticism is of particular concern because it could represent profound distrust of both the health care benefit programs and also of the intentions and motivations of fellow plan members.

Given that most respondents do not believe that others are conserving resources or that conserved resources will benefit plan members, being resistant to use less expensive drugs may be prudent. Health insurance is primarily a cooperative endeavor and current accounts of human cooperation suggest that altruistic behavior is partly determined by how altruistic we perceive others to be. (Danielson 2002; Milinski, Semmann et al. 2002) Enrollees in a cooperative
endeavor only have an interest in being mindful of others’ needs if a degree of reciprocity is maintained. Additionally, fair cooperation will require them to be mindful of others’ needs only if others are doing the same. “Looking out for number one” may seem like a prudentially rational decision, or even a fair choice, for an enrollee who believes that all other plan members are doing the same, and that any savings realized will be used exclusively for purposes that do not confer any benefit to plan members. Without trust, plan members appear to think that they are justified in ignoring the effects of their decisions on others. They also appear unwilling to assume minimal burdens or inconvenience even when doing so could benefit others. This mentality drives up costs for everyone.

Moreover, this is a basic human response, and will also apply in a different –for example state-based- health care system. Clear, credible, and empirically substantiated statements that money saved will indeed go to either reduced premiums or increased benefits is needed if individuals are to accept even marginal sacrifices for themselves. We need to know limits apply to everyone in the same way.

**Doctors as canaries in the mine**

A second reason to consider fairness in clinical care is that doctors at the point of care are uniquely situated to observe the impact of priority setting decisions on patients in the form of scarcity, or less than equitable care. Their experience may thus yield useful insights and feedback about the impact of priorities on clinical care, which could contribute to evidence-based health policy (van Kammen, de Savigny et al. 2006). So we should want to know more about to their experience, and we should want them to apply fairness-based reasoning to the manner in which they are witnesses of their health care systems.

*When are resources too scarce?*

Doctors’ situation at the point of care enables them to perceive discrepancies between need, and utilization, that may begin to serve as a more precise description of the actual availability of services. Their view may also contribute to an understanding of what a reasonable level of resources, or a more appropriate level, ought to be. Our results thus provide insights into the impact of different health care systems, with different structures and expenditures, on clinical care as viewed by physicians. General reports on working hours, number of patients, and delays are shown in Table I-8.
<table>
<thead>
<tr>
<th>Table 1-8 Four Health Care Systems: doctors’ workload and delays</th>
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<tbody>
<tr>
<td><strong>Outpatient care</strong></td>
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<tr>
<td><strong>Italy</strong></td>
</tr>
<tr>
<td>Hours a week <em>(median, range)</em></td>
</tr>
<tr>
<td>Number of patients in half a day in clinic <em>(median, range)</em></td>
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<tr>
<td>Waiting time for an appointment <em>(median)</em></td>
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<tr>
<td><strong>Inpatient care</strong></td>
</tr>
<tr>
<td><strong>Italy</strong></td>
</tr>
<tr>
<td>Hours a week <em>(median, range)</em></td>
</tr>
<tr>
<td>Number of inpatients cared for at one time <em>(median, range)</em></td>
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</tbody>
</table>

*Kruskall–Wallis: p<0.01; null hypothesis is “no difference”

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<table>
<thead>
<tr>
<th>Table 1-9: Difference in reported unavailability is parallel to health resources</th>
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<tbody>
<tr>
<td><strong>% respondents who reported unavailable rehabilitation for stroke</strong></td>
</tr>
<tr>
<td>Potential years of life lost, cerebrovascular disease/100,000 p. &gt;70 years*</td>
</tr>
<tr>
<td><strong>% respondents who reported unavailable colon cancer screening</strong></td>
</tr>
<tr>
<td>Potential years of life lost, malignant neoplasia of the colon/100,000 p. &gt;70 years*</td>
</tr>
<tr>
<td><strong>% respondents who reported unavailable mental health services</strong></td>
</tr>
<tr>
<td>Potential years of life lost, mental disorders/100,000 p. &gt;70 years*</td>
</tr>
</tbody>
</table>

a Survey responses  
b OECD country information
On the scarcity scale, mean scores were consistent with differences in national health expenditures. As regards Switzerland, doctor reports of scarcity were similar in a second -independently conducted- study of implicit rationing and access to care, which also found greater scarcity in elder and psychiatric care (Santos-Eggimann 2005). In the study as a whole, and where comparisons are possible, doctor reports of scarcity regarding specific resources based on our findings are supported by OECD mortality data, which yields identical rankings with regard to colon cancer screening and mental health services, and an almost identical ranking regarding rehabilitation for stroke (Table I-9) (OECD 2006).

It would clearly be exaggerated to draw from this the conclusion that scarcity is the major cause of the differences in mortality reported here. For example, an alternative interpretation could be that doctors are more aware of problems related to diseases that are more prevalent. These comparisons, however, give construct validity to differences in the perception of scarcity between the four countries. If doctors were reporting different degrees of scarcity for, say, cultural reasons, we would not expect scarcity and disease-related mortality to be so parallel. Moreover, most respondents (68%) reported adverse outcomes from scarcity, with this proportion lowest in Switzerland (55.3%), followed by Italy (64.2%), Norway (74.8%), and reaching 80% in the UK (p<0.001). Respondents witnessed such adverse outcomes infrequently, with a median of less than once a month in all four countries. The most severe adverse event attributed to scarcity was described as an inconvenience by a third (30.5%) of respondents. However, a minority had encountered severe adverse events, such as death (16.5%) or permanent disability (7.2%). Others reported acute life-threatening events (11%), or temporary disability (14.7%).

Although adverse outcomes attributed to scarcity were witnessed by most doctors, if infrequently, then, some were serious. This is concerning and warrants further research. However, it must be noted that we lack sufficient detail regarding the specific cases to formulate a judgment regarding the accuracy of this attribution, or its comparability across health care systems. The association between scarcity and reported adverse events may signify true lack of necessary resources. When extrapolated to the population served by general doctors, the estimate based on our respondents’ report yields 0.15 scarcity-related deaths/1000 population (OECD 2005). This is the same as the lower estimate, and 44% of the higher estimate, for deaths due to medical errors in the U.S.(Kohn, Corrigan et al. 1999). It may, however, also suggest greater sensitivity in the perception of scarcity by doctors who have been confronted with a possible adverse outcome. Either way, doctors reporting death as an outcome of scarcity are likely to be dissatisfied either with the level of resources in their health care system, with its distribution, or both.
When are the effects of health policy inequitable?

In our European study, mean score on the Perceived equity scale (range 3-15) was 9.5, with a high of 11.1 in Switzerland and a low of 7.2 in the UK (p<0.001). While 92.8% of respondents thought everyone in their country should have equal access to needed medical services, 44.1% thought that health care resources in their country were not distributed fairly, 23.6% considered that they were not given enough means to treat their patients fairly, and 50.5% did not agree that everyone in their country had equal access to needed medical services (Table I-10). In logistic regression, less equity was reported by doctors working in the UK (OR 0.1, 95% CI 0.04-0.3), reporting more pressure to ration (OR 0.7, 95% CI 0.5-0.9), or who reported more adverse events attributed to scarcity (OR 0.7, 95% CI 0.5-0.9).

We explored Perceived discrimination with an index asking doctors whether they thought that patients belonging to certain identified groups were more likely than others to be denied expensive interventions in their health care environment (Figure I-7). Mean scores on this index (range 0-8) were highest in Switzerland (3) and lowest in Italy (2.2) (p=0.003). Most respondents (78.7%) reported that at least one group of patients was more likely than others to be denied beneficial care on the basis of cost in their health care environment. The most frequently identified groups were patients who are mentally incapacitated, patients who require chronic care, illegal immigrants, and patients who are old, respectively.
There were significant differences between countries in the frequency with which each group was identified, except for legal immigrants and the elderly. On logistic regression, more discrimination was reported by respondents who reported more underinsurance (OR 1.8, 95% CI 1.2-2.7), or more scarcity (OR 1.1, 95% CI 1.01-1.12). Less discrimination was reported by Italian doctors (OR 0.4, 95% CI 0.2-0.9).

Our results suggest a link between perceived scarcity and perceived equity. Less equity was reported by doctors who attributed adverse events to scarcity, or more pressure to ration. More discrimination was perceived by those who reported more underinsurance or scarcity. This could mean that when there is less the most vulnerable are the first to get less. This view is both plausible and concerning.

Access, then, was often reported as less than equal. More specifically, some patient groups were identified as more likely than others to be denied care on the basis of cost. Although the WHO distribution of responsiveness was identical in the four studies countries, Perceived equity was different in different countries, as was Perceived discrimination. Respondents thus perceived that access, viewed as a concern that “health care resources are mobilized to meet the needs of different groups in the population” (Gulliford, Figueroa-Munoz et al. 2002) was not fully realized. Respondents’ views about equity did not vary in the same way as their views about discrimination did. Although doctors may be judging equity by standards different from the ones offered in our survey, a more likely explanation is that specific questions about patient groups were more likely to bring real cases

![Figure 1-7: Reported greater likelihood of being denied treatment](image-url)
to their minds. Thus, perceived discrimination may be a more sensitive tool to assess fairness in the distribution of health care resources. This finding also suggests that doctors, who are in a unique position to observe unequal access or discrimination in the health system, should be better equipped to address it. It is relatively easy for persons in a health care system to express a need for more resources but it is more difficult to develop an allocation process to ensure equitable distribution and resources allocated to a place to maximize benefit in terms of organizational or system objectives. Could doctors contribute to this? Mechanisms for appeals and revisions are called for by frameworks for procedural justice in health care distribution (Daniels 2000) and such processes could be enhanced if doctors had greater opportunity to bring experience from clinical practice to bear on prioritization. Our results also suggest that efforts to measure a health system’s equity might incorporate feedback from doctors about adverse events stemming from distributional decisions made at the system level. This feedback loop could be a way to connect the macro and meso levels of priority setting with the micro level. For this, however, doctors need to be able to incorporate concerns for fairness.

Our results suggest they may be going some way towards this. Comparisons with other assessments of equity and utilization show some convergence. An OECD working paper evaluated General Practitioner care utilization to be pro-poor in all four countries included in our study, but specialist utilisation to be pro-rich in all of them (van Doorslaer, Masseria et al. 2006). Reports by general doctors in our study that patients who cannot afford to pay for treatment are more likely to be denied care fits with those results. The degree of pro-rich inequity assessed by van Doorslaer and colleagues was highest in Italy, and lowest in the UK. Doctors, then, could function as ‘canaries in the mine’ as regards the effects of health policy on clinical care. While their ability to do so as regards the general level of resources as compared to their assessment of patients’ needs is rather clear, their ability to assess health system effects on fairness necessarily relies on their ability to apply fairness to reasoning about their practice in the first place. This ability is therefore important for two reasons: to help them to make limit-setting decisions in cognizance of justice-based issues, and to enable them to function as bellwethers of the impact of health policies on fairness in clinical practice. In order to do these things, they must be able to recognize scarcity-related ethical difficulties, and to think in terms of fairness.

Scarcity-related ethical difficulties are recognized

In our European study, experience of ethical difficulties in general, and scarcity related ethical difficulties in particular was explored using items worded as follows: “Below is a list of situations where medical decision-making can be
difficult. Please tell us how often you have faced each kind of situation in your work in the last two years. In the last two years, how often have you been in the following situations?” Listed situations included treatment of patients with

Figure 1-8 Scarcity related ethical difficulties compared with end-of-life decisions

When asked to describe a recent ethical difficulty, and to rate their satisfaction with the resolution of this situation, 11% of respondents gave an example in which they identified the main issue as a scarcity-related difficulty. Overall, with regard to all ethical difficulties described, a little under half of respondents (47.2%) reported a satisfaction level of at least 7 on a scale ranging from 1 to 10. A quarter (25.7%) expressed dissatisfaction (score of 3 or lower). In the subgroup describing a case that they identified as a scarcity-related ethical difficulty, 40.4% reported a satisfaction of at least 7, and 44.2% reported a score of 3 or lower. Doctors with more experience with ethical cases were significantly less satisfied with the resolution of the recent case they described. In situations where respondents identified the main issue as a scarcity-related difficulty, satisfaction was significantly lower (p<0.01).

Facing scarcity, then, is perceived as posing ethical difficulties and satisfaction with the resolution of these cases is poor.
Do physicians think in terms of fairness?

As outlined above, results from our US study suggested that justice was relatively rarely explicitly in the rationale underlying resource allocation decisions in clinical practice (Hurst, Hull et al. 2005). This contrasts with the normative literature where concern for fairness is considered important to the acceptability of allocation decisions (Daniels 2000), a position we have also argued (Hurst and Danis 2007). Three interpretations of this result were possible at the time. 1) Doctors may not perceive justice arguments as the prime rationale for rationing. 2) They could resist the idea of letting any patient go without a benefit, even if this was compatible with, or even necessary to ensure, a just distribution of resources. In this case, questions of distributive justice could seem irrelevant to them. 3) They may take fairness into account, but have a difficult time telling researchers about this, either because of the concept’s difficulty, or because of a more general difficulty in admitting resource allocation decisions.

At face value, it is far from clear that justice-based reasoning could be applied to clinical practice. Doctors often lack a global view of the health care system. They are taught to think in terms of individuals more than in terms of groups. Moreover, fairness is in itself a difficult concept. Indeed, part of the debate surrounding the manner in which health care resources should be allocated focuses on the concept of equity itself. Equity is almost as difficult to assess as it is to apply and in addition, as applied to health and health care, the very concept is difficult to define. (Daniels 1982; Culyer and Wagstaff 1993; Pereira 1993; Anand 2002; Chang 2002; Braveman and Gruskin 2003) Research in this conceptual area is coloured by the fact that “equity” is also a thick concept. In other words, it contains both a descriptive and a normative content. (Williams 1985) To say that a situation is equitable is to simultaneously describe factual characteristics about it and to express a positive value judgment. In addition, “equity” is a plural concept: the descriptive –factual- content of what it describes can change substantially depending on the user.

Moreover, it is not clear what the best concept of equity applicable to medical care would be, or that there should be only one, or the same ones, across the micro-, meso-, and macro-level of health care resource allocation. In our US study, it was reassuring that responding doctors took their role as patient advocate seriously. However, it was unclear whether or not applying justice-based reasoning in the situations they described to us was realistic. Furthermore, if justice in resource allocation seemed irrelevant to them in an environment where allocation decisions must be made, this could be concerning. Did physicians, then, apply justice-based reasoning in their practice? Our next study was conducted in part to answer this question.
II. Applying fairness in clinical practice
Chapter 5 – Clinical fairness?

(...) so after that, I don’t really have that many equity concerns, that is personally…but I think it’s something we have in an innate way, then we can think about equity…either we have it, somehow, or we don’t. I hope we do (...) (Geneva Study, interview 4)

Is clinical fairness this simple, an innate form of practical reasoning based on character? As outlined in the previous chapter, a number of factors could have suggested that, and explained why, doctors did not apply fairness to their allocation decisions. Fairness and equity are complex concepts (Daniels 1982; Braveman and Gruskin 2003). They are based on population-level thinking, while much of clinical training is based on treating single patients. It would thus have been plausible for clinical reasoning to stop short of fairness concerns. This, however, would have been concerning. In fostering fair allocation decisions, whether, and what kind, of concerns for fairness actually play out in bedside allocation decisions does seem important to the acceptability of decisions. In addition, physicians’ situations in situations of resource constraints appear more complex than the normative literature assumes, making theoretical approaches unlikely to be easily applicable at the bedside. Knowing more about if, and how, doctors include fairness in clinical reasoning was thus important for two reasons: to know how well they are doing, and to help them do better in a more realistic manner.

A physician interview study

In order to explore the question of fairness-based reasoning in clinical decisions more in-depth, we conducted 31 semi-structured interviews with in- and outpatient doctors working in a universal access health care system in Geneva, Switzerland. This study was funded by a Swiss National Science Foundation PROSPER grant (Hurst 2005-2009). An interdisciplinary team of doctors, sociologists, and ethicists developed a semi-structured interview guide based on the assumption that doctors would find it easier to talk about concrete cases, rather than abstract principles. This interview guide addressed their experience with resource scarcity and allocation, their reasoning in the face of distributive issues, and practical examples of what they considered equitable, or inequitable, allocation. Questions are shown in Table II-1.

Participation was voluntary, but because questions addressed possibly sensitive questions regarding professional integrity, the study went through a full ethics review. It was approved by the Ethics Review Committee at the Geneva University Hospitals. Our respondents were recruited by selective sampling and snowball
technique. Participants were contacted by telephone by a research assistant

<table>
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<tr>
<th>Domains</th>
<th>Initial questions</th>
<th>Follow-up questions</th>
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<tbody>
<tr>
<td>Experience in situations of</td>
<td>In certain situations, doctors can be faced with the question of whether or not to use</td>
<td>On the basis of which patient characteristics would you say that it is reasonable/</td>
</tr>
<tr>
<td>resource allocation</td>
<td>an intervention because resources are limited. Do you feel that this happens to you?</td>
<td>unreasonable to continue an expensive treatment? Why?</td>
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<tr>
<td></td>
<td>Do you have an example of a case where pressure on resources faced you with a</td>
<td>On the basis of which treatment characteristics would you say that it is reasonable/</td>
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<td></td>
<td>difficult choice in clinical practice?</td>
<td>unreasonable to continue an expensive treatment? Why?</td>
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<tr>
<td></td>
<td>Which decisions were made in this situation?</td>
<td>Should other aspects have been considered? Which ones?</td>
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<td></td>
<td>What were the reasons?</td>
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<td></td>
<td>What was your role in this decision?</td>
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<td></td>
<td>What values seemed important to you when this decision was made?</td>
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<td></td>
<td>To what extent were you satisfied with the decision that was made? Why?</td>
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<tr>
<td>Nature of concern for equity in</td>
<td>When resources are limited, it happens that doctors are led to think in terms of</td>
<td>Can you give be an example of unfair treatment? Do you have a concrete case you</td>
</tr>
<tr>
<td>clinical decisions</td>
<td>fairness.</td>
<td>experienced?</td>
</tr>
<tr>
<td></td>
<td>What does this mean for you « to treat a patient fairly/equitably »? What about</td>
<td></td>
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<td></td>
<td>« unfairly/inequitably »?</td>
<td></td>
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<tr>
<td></td>
<td>Can you give me an example of a situation where it was difficult to treat a patient</td>
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<td></td>
<td>fairly in your practice?</td>
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<td></td>
<td>In your first example, did the decision seem fair to you? In what way?</td>
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<td></td>
<td>Did you think in terms of fairness in this first example?</td>
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<tr>
<td>Training</td>
<td>How did your idea of fairness develop?</td>
<td>Which parts of your training seem to you to have been useful in helping you face</td>
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<td>To what degree did you feel prepared by your training to face questions of fairness?</td>
<td>these cases?</td>
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<td></td>
<td>In your clinical practice, what leads you to question yourself about fairness?</td>
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<td></td>
<td>Do you think questions of fairness are more present now than before in your practice?</td>
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<td></td>
<td>What does this mean in your view?</td>
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<td></td>
<td></td>
<td>And insurance in all this?</td>
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independent of the clinical hierarchy, and told about the study purpose and interview process. Of 52 doctors we contacted, 38 agreed to participate (response rate 73%) and 31 interviews were finally needed to complete the sample. Verbatim transcripts of the interviews were imported into QSR NUD*IST, version N6 (QSR International, Victoria, Australia), qualitative research software to facilitate data analysis, and analysed by an interdisciplinary team of ethicists, doctors, and sociologists, using coding and analytic elements of the grounded theory approach.

The first step in data analysis involved examining the data, breaking them down, and making comparisons and conceptualizations, which were then labeled with a set of codes.

We initially identified recurring concepts, one example being the identification of certain allocation criteria as acceptable and others as not acceptable. In the second step, we reassembled the initial concepts into groups, or categories, according to relationships identified in the data, and broadened these categories to capture their different aspects and associations. For example, one participant said that « (...) resources aren’t limited by...the fact that...we don’t want but they are limited by the fact that we think it isn’t good for the patient to do this”. (Geneva Study, interview 8) (a ‘criteria’ code). This was then seen to be part of one of several ‘definitions of equity’, in this case as identifying a threshold of ‘reasonable benefit’ and sticking to the same threshold for all patients. This category was broadened and specified to account for the different definitions described in this chapter. In the final step, we identified the core category of “gatekeeping values”, which encompasses clinical-based definitions of fairness, strategies presented for its application, and the interplay of acceptable and unacceptable aspects of clinical resource allocation as described by our respondents. Two of the investigators (Samia Hurst and Samuele Cavalli) met regularly and double coded 13% of the dataset at various stages during the project to ensure that concepts were clearly defined and appropriately derived from the data, and that codes were being used consistently. Regular discussions with the same goals were held with the entire study team.

In qualitative analysis, the appropriate sample size is reached when new data consistently fail to contribute new concepts or refinement to the emerging theory, a point in the analytical process known as “theoretical saturation”. Theoretical saturation was reached for main components of the findings presented here.

Participant characteristics are shown in Table II-2.
Use of justice-based reasoning by physicians

As it turns out, doctors use a variety of concepts for fairness in their practice of resource allocation, but show some difficulty in articulating them. In their clinical reasoning fairness can mean: application of a clinically appropriate limit, a fair decision process, doing what is morally right overall, the correct interplay of criteria, or a balanced mix of many objective and subjective considerations. These concepts can also be understood as attempts to act as a “gatekeeper of values”, and maintain the right sort of interface between the biological, interpersonal and social dimensions of their patients’ situation.

Concepts of clinical fairness

Based on our analysis, doctors use a variety of concepts for equity in their practice of resource allocation. The following citations were translated from French into English. In respondent’s clinical reasoning, fairness can mean the following:

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Doctors (N=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>29-62</td>
</tr>
<tr>
<td>Years in practice</td>
<td>1.5-35</td>
</tr>
<tr>
<td>Male/Female</td>
<td>20/11</td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
</tr>
<tr>
<td>Gen./int. medicine</td>
<td>20</td>
</tr>
<tr>
<td>Intensive care</td>
<td>4</td>
</tr>
<tr>
<td>Paediatrics</td>
<td>5</td>
</tr>
<tr>
<td>Geriatrics</td>
<td>2</td>
</tr>
<tr>
<td>Primary practice site</td>
<td></td>
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<tr>
<td>City outpatient</td>
<td>10</td>
</tr>
<tr>
<td>Hospital outpatient</td>
<td>11</td>
</tr>
<tr>
<td>Inpatient</td>
<td>20</td>
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<tr>
<td>Role</td>
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<tr>
<td>Resident</td>
<td>7</td>
</tr>
<tr>
<td>Junior attending</td>
<td>16</td>
</tr>
<tr>
<td>Senior attending</td>
<td>3</td>
</tr>
<tr>
<td>Private practice</td>
<td>9</td>
</tr>
</tbody>
</table>
1) Application of a clinically appropriate limit
This means applying a limit that is correct or reasonable, in any case that is not based on distributive concerns, but which yields a distributive outcome by being applied to all patients. In the words of an outpatient internist: “(...) yeah, I would see it like this let’s say that I rather have the impression that I, that I’m not equitable when I can’t provide care, and intervention, to someone who needs it but does not want it for « x » reasons, social, psychological ones...” (Geneva Study, interview 22). The correct limit is seen to be independent of contextual elements such as the patient’s preferences. It is not, however, independent of contextual elements such as the patient’s specific medically defined needs. In other words, the concern here is to avoid treating some patients better than others, or not as well as others.

2) A fair decision process
This meant using the same strategies to decide. For example, in intensive care: “(...) so, let’s say, it really means using the same objective and medical criteria for everybody and not to say...to tell yourself, this patient...(...)” (Geneva Study, interview 3). Avoiding personalization, here, was a way to be equitable.

3) Doing what is morally right overall
Equity could mean more generally being a good person, or displaying virtuous character traits. The following is from a hospital geriatrist: “(...) so after that, I don’t really have that many equity concerns, that is personally...but I think it’s something we have in an innate way, then we can think about equity...either we have it, somehow, or we don’t I hope we do (...)” (Geneva Study, interview 4). In these cases, fairness is not viewed as something to be integrated in reasoning, but as something which flows from the doctor’s character, leading her to the right decision. Considering fairness to be a virtue, or alternately as something which should accommodate all applicable moral reasons, regardless of whether they are distributive or not, is a venerable view of equity (Sidgwick 1907). Using the term “equity” to mean this has been criticized on technical grounds as redundant with the term “good” (Hooker 2005). Finding this notion in clinical practice is, however, not entirely surprising: it suggests that fairness was, for some, implicitly integrated in the sense of excellence which doctors ought to strive for.

4) The correct interplay of criteria
This meant using only the right kind of criteria, to make the right kind of decision. The following is from a hospital pediatrician: “(...)I realize that...that sometimes I don’t speak to people the same way, or I behave differently according to who they are but I...I always try to be careful that in the end they are treated the same way.” (Geneva Study, interview 18). This quote also illustrates a part of the complexity of this definition. Our respondents’ use of distributive equity under this definition can be described using the following three domains: 1) what sort of resource is being allocated, 2) the criteria being used, and 3) the sort of equity they try to re-establish.
Each can apply to the biological, interpersonal, or social dimension, with the greatest tension being explicit attempts to avoid using criteria of an interpersonal or social nature in making allocation decisions. We could reword this as concern to accept only the right form of relationships between the biological, personal, and social spheres of a person in the face of medical need. These interplays had different aspects. Doctors reported resisting extra-medical social prioritization schemes, such as recognizing greater importance to the affluent or educated, all the while recognizing that this was difficult and unevenly applied. When it was a question of the influence of medicine rather than on medicine, tensions remained but took a different form. For example, some—but not all—respondents readily accepted that helping their patients to overcome interpersonal or social inequality could be a part of their role. The following is from an outpatient family doctor: “(...)a child who doesn’t hear well who has language difficulties and then who will have trouble in school, those are consequences, not morbidity, not hmm...normally not long-term consequences but still well, there are consequences at least direct social ones, of not intervening in a case like that.” (Geneva Study, interview 29).

5) A comprehensive mix of many objective and subjective considerations
Doctors reported the importance to them of using multiple criteria, and that this could be what equity was. In the words of an outpatient internist: “(...) little by little, with every day that passes, we realize that we can do the same things, or take the same problem, in different ways and this is where probably we get closer to, to a notion of equity, meaning that we can take several criteria into account at the same time (...)” (Geneva Study, interview 28). Briefly, but illustratively, in intensive care: “(...) It’s a little bit a mixture of all this (...)” (Geneva Study, interview 3). In way, this was a strategy for personalization, in apparent contrast with definition 2 according to which fairness lay in avoiding personalization. It can also, however, be understood as a way of going beyond this apparent tension by always taking a patient’s individual circumstances into account in the same way.

What does this study tell us?

It does seem, then, that concerns for fairness are used in clinical practice, along with reasoning strategies to apply them. This is, however, often poorly articulated and tentatively done. There was some confusion as to the sort of sort of concept meant by fairness in doctors’ reasoning, and the difficulty they show in articulating them could suggest obstacles to defending fairness under pressure, even in a health care system committed to solidarity and universal access (Hurst, Forde et al. 2007). Respondents themselves expressed concern that even sharing experience among colleagues was difficult due to the sensitivity of the topic. Making these elements of clinical decision-making explicit is important to enhance transparency, to allow clinicians to refine their decisions through shared experience, but also to equip
them better in defending fairness under outside pressure.

**Hybrid fairness**

One of the views of fairness expressed by doctors in our study was what we might call *hybrid fairness*: the view that a balanced mix of potentially competing considerations of fairness was, in itself, a potentially *right* way of applying fairness to clinical care. Is such a *hybrid* view defensible? Views of what fairness, or equity, actually is vary not just substantially but also in the level at which they address the issue. Historically, the normative philosophical literature on distributive justice revolves around two questions: *What should be a benefit of distribution?* (metric debate), and *how should a benefit be distributed?* (non metric debate). The first question deals, for instance, with notions like resources (Rawls 1971), welfare (Arneson 1989), and capabilities (Sen 1995; 2009).

The second question typically deals with the sort of principle according to which distribution would be considered fair. The most influential examples, however, all pose problems if we attempt to apply them directly to resource allocation dilemmas in clinical practice:

1. *Egalitarianism*

An egalitarian acts as someone who cares about equality, and considers that “it is in itself bad if some people are worse off than others”. Temkin writes that egalitarian does not only concern about equality but must seek equality per se, as a “non-instrumental” aim (Temkin 2003).

The positive effect of this view for physician is that, all other thing been equal, no patient has to be treated differently. This outcome indicates that inequality is bad because it has bad effects for some patients. By eluding inequality, physicians, somehow, elude bad effects.

However, when two patients are for example in need of the same limited unshareable resource (an intensive care bed for example), following traditional egalitarianism requires both to be treated equally. But the only way they can be treated equally in this dilemma is by allowing both to die, which would be absurd. The following *"levelling-down objection"* point out that eliminate inequality in fact ought to produce better circumstances — otherwise, why should equality should be desired. However, how it would be morally good if, between two candidates for life saving with an indivisible injection, the one with better off situation were rendered worse off because the other could not be offered better treatment? That would in fact be morally pernicious. Fighting inequality by bringing every patient’s treatment down contains nothing intrinsically good (Broome 1991). Depriving of treatment
those who are better off, rendering them as badly off as any other patient, is surely incoherent in medicine.

2. Prioritarianism
To one extent, prioritarianism defends that “benefiting people matters more the worse off the people are” (Parfit 2000), in some respect, it becomes an Absolute Priority View; when benefiting others, the worse-off patient is to be given absolute priority over the better off (Crisp 2003).

Here, each patient’s point of view has to be taken absolutely separately in order to achieve a decision which is in a significant sense acceptable to each patient, regardless of equality. In this regard, equality has no value. Broome support this point of view with his principle of personal good: “if one distribution gives some person more wellbeing than another distribution does, and if it gives no person less well being than the other does, then it is better than the other” (Broome, 2010).

Prioritarianism poses a problem well described by Daniels (1994): how much priority should we give the worse off? In theory, this principle could dictate that doctors should give complete priority to those whose health state is the worst, even if they fail to help them in any significant way, and sacrifice in their attempt the opportunity to help many others.

3. Desertism
To deserve to be given some specified form of treatment a patient must possess some characteristics, or have done something, which justifies the treatment. Feinberg (1970) refers to such characteristics as “desert bases”. The fact that a person should receive treatment according to her “desert bases” brings a distribution depending on how someone’s deserts compare to others patient.

The positive outcome of such position is that, as long as deservingness is intimately associated with equity, it allows physician to treat patient who deserve it. For instance, in our dilemma, suppose that there are some justifiable claims of personal desert for one of the two patients. Let us pretend that one victim is the result of a heroic child rescue. A child was attacked by a swarm of wasps, and a woman rescues him and gets bitten. The other victim is the consequence of no special circumstance. On a deservingness approach, the physician dilemma becomes a choice between saving a patient who deserves a treatment more and saving one who deserves it less.

It is important to remember that the role of desert in the determination of fair distributions must be kept in proportion in a world where individuals are born unequal. Even a perfect meritocracy cannot satisfy this basic request: to deserve a treatment, you need to have gained your desert from equal start and through an equal trajectory. Perhaps in our dilemma, some will think that the rescuer deserves a
treatment because she deserves those assets that made the rescue possible. Because she is more worthy in this sense, she deserves the treatment. However, it might be advocated that her character depends in large part upon extern social and familial circumstances for which she cannot claim credit (Rawls 1971, Nagel 1973, Wasserstrom 1976). According to this, the idea to found a treatment on desert seems to be irrelevant even on the desertist account.

4. Sufficientism
Sufficientism represents the view that: “what is important from the point of view of morality is not that everyone should have the same but that each should have enough” (Frankfurt 1987). Instead of pursuing equality, Frankfurt suggests that “if every patient had enough treatment, it would be of no moral consequence whether some had more than others”. Somehow, physician ought to give at least enough care to everyone, instead of wondering whether all patients receive the same care.

For clinical practice, however, an account of where the threshold ought to be is crucial. And no sufficientist draws a conclusive line for “how much is enough”. This major lack leaves room for arbitrary thresholds. To address this, Crisp proposes the compassion principle (Crisp 2003). “Absolute priority is to be given to benefits to those below the threshold at which compassion enters. Below the threshold, benefiting people matters more the worse off those people are, the more of those people there are, and the greater the size of the benefit in question. Above the threshold, or in case concerning only trivial benefits below the threshold, no priority is to be given”. This statement places Crisp where he believes there are certain circumstances that warrant physicians’ compassion, and that it is when compassion is warranted that physicians ought to give priority to a patient who is worse off than another, which should eliminate arbitrary thresholds. Unfortunately, this type of sufficientism leads to the conclusion that, if granting a non-trivial benefit to a patient below the threshold required bringing the rest of the patients down to the compassion threshold, then physicians are required to do so. This requirement is counterintuitive regardless of whether the reshold is high or low.

This last attempt shows philosophers attempting to do something at least superficially similar to that which doctors reported in our study: combining different considerations of fairness in what we might call hybrid views. Even though the philosophical literature emphasizes the incompatibility between each position there might be good reason not to work exclusively and separately each of the four positions of equity. For instance, Fleurbaey (2010) greatly advocates that “prioritarian will always find some egalitarian view which reaches the same practical conclusions about all possible cases, although possibly for different reasons”. In that sense, he believes that the thrust of the theoretical distinction of equity is about foundations,
Can a hybrid concept of equity be a solution to the resource allocation debate? Such ‘hybrid’ views of fairness are found in the normative literature, for example Broome’s weighing of claims (Broome 1991), Hooker’s inclusive model with side-constraints (Hooker 2005), and Crisp’s “compassion principle” (Crisp 2003). There may actually be good theoretical reasons for doing a hybridisation of the four traditional position of equity. Although the criticisms presented above seem singly negative when positions are analyzed independently, some strength has been mentioned making it worth saving some parts of each position. As such, the hybridization can be motivated by the strengths of what are being hybridized. Since they do not have enough to offer on their own, bringing these positions of equity together might have something to offer. In her paper (Casal 2007), “Why Sufficiency Is Not Enough”, Casal introduces her three Hybrids to redress the sufficiency position. She offers a systematic clarification of sufficiency principles’ possible contents, and an assessment of the role of such principles could play within distributive ethics in supplementing rather than replacing principles of equality and priority. Another example, Brown’s article “Priority or Sufficiency… Or Both?”, aims to defend that the commonly assumed opposition between prioritarianism and sufficientism is a false dichotomy (Brown 2005). According to him, “there is no need to choose between either giving priority to the worse off or giving priority to the badly off, since we might instead give priority to both”. Hybrid views are, however, not typical for the philosophical debate regarding equity. The last 30 years of philosophical literature of distributive justice have shown authors taking stand on their own position instead of trying to find compatibility between them. Most of the arguments presented have been made to reinforce each position by criticising others’ views. It was a traditional exclusivist approach used by every philosophical school. Similarly, opponents of the hybrid views might argue that, by defending a non-exclusivist argument, hybridians are simply pointing out problems in other theories which --in the end-- does not resolve any difficulties.

The pointing argument underlines that each of the four positions provides an insufficient answer. This case indicates that each theory is underdetermined as a single solution. However, against the pointing argument, hybridians emphasize what sort of restrictions can help physician’s choice to act according to their conception of fairness, instead of what sort of restriction determined their decision of treatment (which is bringing each position to their core problems). There are different ways in which fairness might be conceived under a restrictive context, but the debate about hybrid views should be able to cut across different sorts of practical choice in circumstance of constraint instead of spending too much effort by trying to resolved each position’s problems. In that sense, hybrid views may indeed bring robust outcomes. The pointing argument raises also the possibility for each of the
four positions to provide an overdetermined answer. In one case, all independent theories could answer with the same solution. Nevertheless, it would give to the hybrid views a solid advantage since it can select and use any of the four solutions. In a second overdetermined case, all independent theories might answer with different solution. Here again, it would benefit the solidity of the hybrid positions since it can evaluate the adequateness of every solution with each independent theory before deciding on the more appropriate. An example is shown in chapter 8. In both overdetermined case, hybrids increase the scope of theoretical background; therefore the robustness of the decision. The effects resulting from the use of the hybrid positions appear to be solid enough to defeat the pointing argument. A possible advantage of this approach is that each ‘ingredient’ of a hybrid view can act as a side-constraint to all the others, restricting the number of acceptable options to the sort of decisions where different theories overlap.

Hybridian’ detractors believe that an aim of distributive justice is to identify the single correct position concept that can help physicians. Perhaps that single concept is among the positions currently proposed and physicians need to determine which concept is the right one. However, hybridians take a different stand for the practicability and for the robustness of the view. They do not believe that there is a single correct concept of distributive justice. Justice of allocation resources contains a number of legitimate concepts. An alternative response to the exclusive position of the four traditional view would be that, while neither physicians nor philosophers may yet have found the correct concept of equity, and both need to wait for further progress in philosophy, hybrid views nevertheless seem very efficient in the meanwhile as a way of at least considering all ‘candidate’ principles of equity seriously, and may be a sufficiently acceptable approach.

Doctors, or course, are not well versed in the philosophical debate of equity while making medical choices in a context of limited resources. However, with or without the knowledge of these explicit philosophical arguments, the social currency of various distinct views of distributive justice informs their decisions. Ideally, the application of theories of equity in the relevant decisions made by physicians should function in such a way as to reduce arbitrariness (Hurst & Danis 2007).

Doctors seem to mix not only different valid claims for resources, but also claims which do not share the same sources of validity. In uncertainty as to which notion of fairness is best, our results suggest that they are applying different (though often poorly articulated) theories of fairness simultaneously, in very much the same way as they might prescribe different antibiotics when the identity of an infectious agent is unknown. Despite the philosophical debate that still surrounds hybrid fairness, it may be justified to consider it as many applications of basic knowledge to medicine have been in the past: an imperfect but defensible solution, likely to yield a better result than the status quo, and which it may be good to apply while waiting for
better knowledge. Applying a hybrid view of fairness to clinical care in the current context is that using a hybrid approach requires great clarity. This should give us the impulse to train physicians better as regards concepts of fairness relevant to their practice. According to the research presented above, a hybrid view of fairness does at least seem applicable, despite its apparent demandingness: doctors, after all, use a form of hybrid concept already.

Concepts of equity that embedded in clinical practice are useful because they are applicable and presumably relevant to this practice. Refining and clarifying them may be more effective in making equity-based reasoning in clinical practice more thoughtful. These decisions, however, do not happen in a vacuum. They can be influenced or even determined by many contextual elements (Hurst, Forde et al. 2007), some of which can be obstacles to moral practice,(Werner, Alexander et al. 2002) or even moral thinking (Buchanan 2002). In applying fairness to clinical care, then, concepts are insufficient by themselves. They must be complemented by knowledge of the obstacles, and by strategies. Indeed, our studies suggest that physicians do exactly that. The next two chapters turn to these obstacles and strategies.
Chapter 6 – Difficulties and obstacles

“(…)I realize that…that sometimes I don’t speak to people the same way, or I behave differently according to who they are but I…I always try to be careful that in the end they are treated the same way.” (Geneva Study, interview 18)

Respondents in our Geneva Study reported several sorts of difficulties in attempting to apply fairness in clinical practice: tensions between requirements of patients on the one hand, and of public financing and insurers on the other hand; difficulties in managing fairness between patients who ask too much and patients who ask too little; defining limits to their own responsibility, which could be viewed as more or less engaged in the public sphere. More generally, they described difficulties in thinking through fairness, and also in implementing it.

Obstacles to implementing fairness in clinical practice

The first sort of difficulty regarded the inclusion of fairness in clinical reasoning:

1) Thinking fairness between individuals and groups
The tension between individual-level and population-level thinking is present in many other areas of medicine, such as the application to individuals of collective data in the context of Evidence Based Medicine. As regards the application of fairness, this is expressed for example in the difficulty in taking collective costs into account: an effective but very expensive treatment, when it is rarely necessary, can turn out to be more cost-effective over the long term than a less expensive, less effective treatment needed by many people. Recognizing this in individual allocation decisions can, however, be difficult. As stated by one respondent: “I try to take limited resources into account at the overall level of health and I try to be cost-effective and here this is also a form of fairness because I tell myself: we need to cost less for society so something is left for the others but this…this is not really my principle here, which I identify with most when I have this sort of concern”. (Geneva study, interview 13)

Since fairness is a population-based value, it is not surprising to find this difficulty arising here. Some respondents also reported that applying it to the care of individual patients was inherently limiting, as it represented collective issues rather than individual ones.

2) Thinking through the place of patients in allocation decisions
One of the ways in which respondents thought about fairness was as the application of a clinically appropriate limit. In this sense, coming to the right decision would require respect for a patient’s views. Fairness, however, also meant
using the same threshold, process, or set of criteria for all patients. In this sense, taking a patient’s views into account could problematically hinder fairness in clinical decisions. Applying the same limit to all is in tension with the fact that some demand more than others. There was thus a tension between the right and the fair decision, as well as between fairness and respect for patients’ wishes.

When a patient did not express explicit wishes, another problem was whether –and how- to integrate elements interpreted as reflecting the patient’s subjectivity implicitly: should the impression that a patient “wants to fight” or “is tired” enter into decisions as to a fair limit? Not only is this assessment highly subjective, but it is unclear to what extent it represents respect for a patient’s priorities, and to what extent it represents a medical assessment of a patient’s physiological reserve. Basing important decisions on such fragile elements, the status of which is so unclear, was rightly perceived by respondents as problematic. However, there was also something else there: a recognition that all cannot be subsumed in objective elements, and of the attendant difficulties. One respondent described it as follows: “Sometimes we do read the patient’s chart and we feel it’s a catastrophe, he comes under futility because he is too sick, a short life expectancy, very old…and then we go see the people and we are struck with the fact that what they say, how they look contradicts these data a little and so there is a bit of an affective component, it’s true, a subjective component which says ‘with…for this patient I want to fight, he’s sending positive signals, he wants to go on, he cares for himself, he seems younger than he is, he has good reasons to want to live a few more weeks’, so this, this has an influence too, although it’s not very medical, as decisions go.” (Geneva study, interview 3)

3) Seeing and thinking in terms of budget limits
Budget limits were difficult to describe explicitly, and often to identify. Additional resources could often be mobilized, leading to an additional allocation question regarding how much time to devote to such efforts. As one respondent stated: “for those who were, that I took, that I saw late, I perhaps had to take care of them a little too fast, even though with them I did only medicine, but a little faster than I would have wanted because I had needed to take time to solve social or access to care problems for others” (Geneva study, interview 30)

The difference between inequalities strictly limited to comfort during hospitalization and those “truly affecting” clinical care –and therefore viewed as inequitable- was also difficult to define for respondents, leading to diverging views: “Some [private] patients get, get small attentions or like a visit from the chief more often but that is not a change in their care, it’s, it’s like getting a room on your own and visits when you want” (Geneva study, interview 21); “if you are a private patient you get the professor, the professor gets exams immediately, OK?” (Geneva study, interview 15)

The second sort of difficulty regarded the implementation of fairness in clinical practice:
4) Overcoming inequalities in human relations
In ordinary life, we treat people we like and people we do not like differently. This, however, is not acceptable within clinical care. Although it is more difficult to treat a patient well if the doctor has a negative affect towards him, this nevertheless remains necessary and it would be unfair to do otherwise. This difficulty was highlighted by respondents in our study, as was the importance of overcoming it: “we have,…we what to do things differently for someone likeable or not likeable, there are many subtle things that come in here more at the individual level I thing…broadly I would say, so I am conscious of these things but we try to…to fight against them.” (Geneva study, interview 12)

5) Asymmetry between medical equality and social inequality
Treating patients alike in clinical care often means disregarding inequalities in social standing we consider to be normal outside of clinical practice. Some of the respondents’ examples reflected a form of “frontier” difficulty: that of managing the domain of clinical care as a sort of enclave where the importance, and the practice, of fairness were more important than they are generally considered to be in society. This led to specific difficulties in addressing issues situated along this frontier. This was described as difficult: “people who…who speak to patients with their first names although there is no reason, they are adults, they are…it’s not because they come from another country and because they are black that should do this” (Geneva study, interview 13); it was also described as sometimes explicitly taught: “We really try to teach doctors when they arrive here how to try to…to set aside the difference to try to find the person who is behind those differences.” (Geneva study, interview 13)
A further example was how to attempt a fair outcome when a patient’s suffering clearly had social origins but was considered to be a legitimate reason for clinical care nonetheless. A point explored in the next chapter.

Furthermore, applying fairness to clinical care requires that doctors attempt to better the health status and access to care of vulnerable persons. Health is a fundamental need, like food and shelter. However, unlike food and shelter, health care has, as it were a ‘narrow therapeutic margin’. Whereas protein will cover nutritional needs whether they come from sturgeon eggs or chicken eggs, equivalent health care often means essentially identical health care. This can run counter to social gradients, which can be very strong outside of medicine, and difficult to set aside within it: “let’s say the choice is already…it’s not very satisfying that is we are somewhat under influence of…social, sometimes political conditions are we cannot function like…hem…like we would want and so finally not everyone is equal in medical care, so it’s not always satisfactory” (Geneva study, interview 17).
That this risk is identified by clinicians highlights the tension between “medical fairness” and the inequalities we tolerate more broadly within our societies.
6) Need for specific knowledge
Applying fairness to clinical care required additional knowledge as compared to the practice of medicine in cases where concerns for justice were not prominent. Among them were familiarity with auxiliary resources and social networks: “I am thinking of, …of care centers which are more adapted for certain persons, not necessarily foreign, but for certain person than for others and which help, help us basically to get better care and which are not always mobilized either because they don’t exist or don’t exist well enough or because the doctor himself does not know about them or doesn’t have…is discouraged upfront because he’s not aware of these resources that are available” (Geneva study, interview 11)

7) Obstacles linked to institutional structures
Institutional structures could determine difficulties in applying fairness. Hospital practice and private practice were thus often contrasted, both by hospital and outpatient doctors. Outpatient medicine was described as placing greater economic responsibility in doctors’ hands, but also exposing them to greater pressure to limit care, both from insurers and patients themselves. The link with fairness could be made directly: “what do I do to be fair…time, knowledge, knowledge about money, and also hem I think…a simple thing is to be able to…yeah to be able, it’s strange what I am going to tell you because I did not think I would say that but I will say it [laughs], it’s to be able to make a living with my job because if I make a living I am a little more free, free to do, to not do, if I am…. my head barely above water hem…criteria perhaps change and I risk doing things just to be able to bring what I owe to my family, that is hem basic things, OK? I’m not saying I need a boat on the lake, right?” (Geneva study, interview 28). Hospital practice was in this sense perceived to be more sheltered from such difficulties.

Institutional structures also determine the manner in which justice-based issues will be faced. For example, justice-based difficulties were often identified during patient transfers: a confirmation that clinical thresholds deemed to be reasonable can change between individual clinicians and clinical units within an institution. This was reported in several interviews. It could lead to a form of entrapment logic: earlier decisions were viewed as difficult to question, or even to re-discuss with patients. When such discussions took place, they did so in the setting were a patient was currently being treated. This meant that during a single patient’s clinical pathway through a hospital, it was very rare for discussions regarding an appropriate limit to take place among the different responsible teams. This multiplicity of agents could be at the source of another reported difficulty: obstacles to fairness, it was often reported, come from outside. They are considered to be linked to a lack of resources, institutional decisions, or decisions made by other health care teams along the patient’s institutional journey.

Some of the difficulties expressed by respondents in our interview study can be
linked to other findings. For example, we know that doctor bias exists in clinical care: our findings suggest that doctors are often aware of this and try to decrease it. Attempts to practice medicine fairly take place within systems that often allow unequal coverage. Moreover, socio-economic factors count among the risk factors for morbidity and mortality, rendering the distinction between social fairness and medical fairness rather more problematic than has been assumed until now. These systems thus determine the context where medicine is practiced. They also influence doctors’ decisions by submitting them to various sorts of incentives and pressures.

An unlevel playing field

Doctor bias

Doctors are in a position to make difficult allocation decisions that are as respectful as possible of the context of individual lives. Knowledge of all alternatives and, more importantly perhaps, knowledge of patients’ specific individual situation inform physicians’ decisions in a way that is not possible for decision-makers who are more distant from the bedside. At the same time, however, a growing number of studies suggest that clinician bias may play a role in health care disparities. Patients’ ethnicity, gender, socio-economic status, (Fincher, Williams et al. 2004; Vaccarino, Rathore et al. 2005) have been linked to different likelihoods of obtaining similar care. Even patients’ affect can play a role. In one study, Swiss ICU doctors were presented with vignettes varying patient characteristics, and asked which they would admit to intensive care. Those described as up-beat or optimistic were, all other characteristics being equal, more likely to be admitted (Escher, Perneger et al. 2004).

The opening quote to this chapter is illustrative. Our reaction to other people is determined by a number of elements, some of which produce predictable differences in the way we react to different people. Altruistic norms, for example, are influenced by in-group bias even in experimental conditions.(Bernhard, Fischbacher et al. 2006) Affects (Hoffmann 2000) and immediate –unreasoned– reactions play a role in health care system and doctor bias (Cavalli, Burton-Jeangros et al. 2008). Part of the reason why this is a problem is precisely because we want doctors to react to different people in the same way. Despite this, our instincts can sometimes, as it were, let us down (Greene 2003). That respondents in our study seemed aware of this is encouraging. However, the degree of their success in countering their own biases remains an open question.
Unequal coverage

Even in systems with universal coverage for health care, coverage is rarely truly equal. One of the reasons for this is that most systems incorporate direct patient costs, such as co-pays and co-insurance into their structure. Consequently, the financial accessibility of health care will vary with the financial burden of this participation in health payment by individuals. When co-pays accumulate, their cost can pose a very real burden. A randomized trial of health plans with varying coinsurance levels in the US showed a decreased use of services, and a small yet significant adverse effect of cost-sharing on health. (Lohr, Brook et al. 1986) High co-payments are associated with a lower rate of seeking care for serious symptoms of chronically illnes, (Wong, Andersen et al. 2001) and reduced use of preventive services. (Solanki and Schauffler 1999) Co-payments also threaten the protection against illness-induced poverty. Among Medicare beneficiaries, 10% spent $4,800 over two years, while 1% spent over $15,000. (Goldman and Zissimopoulos 2003) Despite universal health insurance, surveys showed that a percentage of households faced catastrophic health expenditure in countries such as Belgium (0.09%), Canada (0.09%), Denmark (0.07%), Finland (0.44%), Norway (0.28%), and Switzerland (0.57%).

This means that despite being nominally equal, coverage will not be equivalent for different people. People fear being ill for many reasons. Illness can kill or maim us, and cause us to suffer. It can remove us from aspects of our lives that we value and take options away from us (Daniels 1985). Health care can prevent or alleviate some of the effects of illness, but at a cost. So we also fear that, when ill, we will not be able to afford needed care or that its cost could leave us impoverished (Hurst and Danis 2006). The World Health Organization and various health policy analysts who have explored the nature of health insurance have considered the function of health insurance to be to make health care available, and to shield us from the risk of illness-induced poverty (Maynard 1999; WHO 2000; Kawabata, Xu et al. 2002). For health insurance to function effectively for enrolled individuals, it must be designed in a way that allows it to fulfill its intent for all individuals who are enrolled regardless of their financial or health status. Health insurance limits the impact that illness can have on our lives. We need it because illness can strike us unpredictably, and because some of the consequences of illness can be limited by financial input.

Especially for the poor and chronically ill, co-payments can allow impoverishment by illness to occur through lack of sufficiently comprehensive coverage. Costshifting essentially decreases the scope of health insurance as a cooperative endeavour. It can cause health insurance to fail to function in situations for which enrollees purchase insurance: the occurrence of a chronic disease, and the ensuing poverty as a result of disease. Here too, some patients start out at a disadvantage in
their contact with the health care system. In applying fairness to clinical care, doctors must act within these initial inequalities.

The socioeconomic determinants of health

It has long been known that outright poverty was bad for our health. Only 56% of persons living in Sub-Saharan Africa have access to an improved drinking water source, and most live in urban areas. (WHO 2006) In 2005, the longest human life expectancy was 2.3 times the shortest one, an interval of 49 years (WHO 2007). Poverty is strongly associated with greater childhood malnutrition, less access to clean water and sanitation, and greater indoor air pollution (WHO 2002). We have known and described these associations for a long time.

More recently, however, a growing body of literature (Marmot 2004; Daniels 2008), including studies conducted in Switzerland (Spoerri, Zwahlen et al. 2006), has started to highlight that the “social gradient in health” actually affects all socioeconomic groups in all societies, including industrialized societies. Marmot, one of the researchers who pioneered this area, imagines a ride from Southeast Washington DC and Montgomery county, Maryland, on the Washington metro’s red line: life expectancy is longer by twenty years for the rich whites at the end of this journey, than for the poor blacks at its beginning (Marmot 2004). His initial study enrolled 17'530 British male civil servants aged 40-64 in an epidemiological study of coronary heart disease. They were asked all sorts of questions about their medical and family history, risk factors, anything that could be associated to their coronary risk. After 7 years of follow-up, it turned out that after accounting for all known risk factors there remained a greater risk of angina, EKG anomalies, and cardiac mortality which was associated with lower hierarchical status (Rose and Marmot 1981).

This “status syndrome” (Marmot 2004) has been found repeatedly in different societies. Marmot attributes it to two sorts of toxic stress: lack of control over one’s life, and lack of gratification for one’s work. This may in turn be mediated by increased long-term levels of inflammatory markers, which have been found to be associated with perceptions of ‘organizational injustice’. Two aspects of it vary: the gradient can be steeper or less so depending on how egalitarian a society is, and it can be associated with different socio-economic markers. In the US, for example, status is highly correlated with income (Marmot 2004). In Switzerland, education seems to be the better marker (Spoerri, Zwahlen et al. 2006). One aspect of it, however, does not change: the gradient is there.

This also tends to make the playing field unequal. “Inequalities are interactive” (Powers and Faden 2006): those who are worse off socially are also likely to be less
educated, poorer, in other words worse off in terms of a whole cluster of socioeconomic determinants of health relative to others in their society. Data also suggest that inequalities in the effectiveness of communication can compound existing health inequalities in such contexts. Persons belonging to socially disadvantaged groups are, for example, more likely to smoke and less likely to quit; but in addition, the effectiveness of smoking cessation interventions is also socially stratified, leading to the risk that “stop smoking” services will increase, rather than decrease, health inequalities (Low 2007). This is another way in which the playing field for fair resource allocation is not level.

**Systems influence doctors**

In our four-country study, doctors reported significantly different levels of resource availability, perceived health care equity, and discrimination, in Italy, Norway, Switzerland, and the UK. In the face of scarcity, and despite scarcity-related adverse events, doctors accepted cost-containment policies, and were willing to participate in cost-containment decisions. While one might expect fewer perceptions of underinsurance and discrimination among doctors in countries with greater health care expenditure, this was not the case, suggesting that organizational factors and allocations decisions in the health care system may have an effect as well.

**Pressures and constraints**

Perceived pressure to ration was reported to have occurred in the prior six months by 46.2% of respondents, with the greatest proportion in Switzerland (65%), followed by the UK (62.7%), Norway (47.7%), and (26.8%) (p<0.001). In addition, despite universal coverage, 45.6% of respondents reported instances of underinsurance. These results, and their association with clinical rationing, strongly suggest structural determinants of rationing by doctors.

We also found this systemic aspect scarcity as manifested through pressure in our US doctor study (DuVal, Clarridge et al. 2004; Hurst, Hull et al. 2005; Hurst, Hull et al. 2005). In the reported cases involving resource allocation, most responding doctors reported that the source of difficulty was pressure of some kind. The clearest indication of systemic influence on clinical rationing, however, was provided by the contrast between two findings in our European study. When asked whether their job or financial situation was threatened by current pressures to contain costs in health care, 44% agreed, with marked variations in the four countries. Despite this, 73.3% felt free to utilize resources in their patients’ best interest, again with marked and almost symmetrical variations (Figure II-1).
Health care systems are complex structures that are maintained to address the medical needs of a population in specific ways. How they are constructed will affect how vulnerable persons are taken care of, how much the healthy will pay for the sick, how much citizens can expect to be helped when they become ill, and how much their health-related concerns will be taken into account at that time. Thus, the shape given to health care systems, and the way in which they change, can pose a number of ethical problems and difficulties.

For example, underinsurance was reported less in the UK than in the other three countries, as was freedom to use resources in patients' best interest. Perception that respondents' job or financial situation was threatened by pressures on health care costs was much more prevalent in Switzerland and Italy, than in Norway or the UK. Indeed, this may provide context for the otherwise puzzling finding that doctors working in Switzerland, the richest health care system at the time of our survey, reported the greatest prevalence of doctor bedside rationing. In comparing the four countries as regards the prevalence of rationing, our data suggests a stronger association with perceived pressure, rather than available resources. In a very tentative manner, our data suggest the following characteristics for the four health care systems, as perceived by doctors.

**Norway: rules in conditions of plenty**

Doctors seem less concerned than in the other countries that rationing may be a problem for the doctor-patient. One possible reason may be a situation where resource allocation was abundantly discussed in the public sphere, and where
patients are expected to understand. Norwegian doctors also reported greater trust of guidelines and administrative allocation decisions (Hurst, Forde et al. 2007). We remain puzzled by the high underinsurance report in a rich health care system. As different aspects of health care are covered, or not covered in different European countries, this may have a very local explanation. A greater degree of cost-shifting from health care coverage could lead to such a response: this would not be mutually exclusive with the previous hypothesis, as rationing questions specifically excluded limits due to cost-shifting.

**UK: rules in conditions of scarcity**

Financial coverage is reported as high, but more frequently than elsewhere resources are reported as not available when indicated. Doctors report less freedom, suffer less indirect pressure, and make personal rationing decisions less often than in the other three countries. One of the reasons they seem to agree with clinical rationing rather less may be that they feel enough strictures are in place already. That they report themselves as less equipped to treat their patients fairly, and are more frequently troubled enough to think of leaving clinical care, would seem to fit with this. Their trust in guidelines is the smallest.

**Switzerland: freedom under pressure in conditions of plenty**

Swiss doctors reported a high degree of freedom, a higher availability of resources, but also high direct and indirect pressure to ration. In our study this was associated with the highest rate of reported rationing. Despite high pressure, Swiss doctors are the second happiest with the limits in their system. Despite the lack of effective guidelines regarding resource allocation, trust in such guidelines was high. Indeed, this may be due to a perception that such guidelines are lacking and would be useful. A recent Swiss Academy of Medical Sciences report seems to indicate this (Swiss Academy of Medical Sciences 'Rationing' working group 2007).

**Italy: freedom under pressure in conditions of scarcity**

Italian doctors simultaneously reported important limitations in the availability of resources, feeling personally at risk due to pressures on health care costs, and personally deciding to refrain from using interventions with the 2nd highest frequency in our sample. Based on our data, we would predict that doctors in Italy do not feel that there are many explicit limits as to how they can use resources. These pressures and health system differences are relevant to attempts to make clinical allocation fairer. One reason is that pressures disproportionately
affect the vulnerable. As these patients are more likely to suffer greater obstacles to access to care in the first place, this means that the unlevel playing field of health care and the ways in which systems influence doctors, submit such patients to a ‘double-whammy’ effect, forming synergies against them. Within such a context, applying concerns for fairness to clinical care will necessarily present clinicians with added difficulties.
Chapter 7 – Learning strategies for equity from the bedside

(…) understanding but, but it’s sometimes diff…because we are still human beings like all the others and we are much more motivated to help people who are nice to us, than people who aren’t nice, so I think that the alcoholic, alcoholised in acute phase and who’s aggressive…hmm…it’s important to still consider him as someone who has a health problem, even if we calls us a bastard (…) (Geneva Study, interview 11)

Negotiation and creativity

Findings from our US study (Hurst, Hull et al. 2005) suggest that doctors are sometimes able to negotiate alternatives (Table II-3). This reflects the reality that clinicians will struggle first with the question of whether or not to allow a patient to go without a benefit, in some cases even when this benefit is small. In so doing, it seems that they are sometimes able to come up with alternatives that are not on the radar screen if the question is “to give or not to give” a particular resource. The situations described were often handled by negotiating a solution, rather than primarily withholding an intervention. This contrasts with the manner in which the issue of bedside rationing is sometimes addressed in the conceptual literature. It has also been pointed out that conflicting obligations perceived by doctors can lead them to “game” the system, with potentially dangerous consequences. (Morreim 1991; Wynia, Cummins et al. 2000; Werner, Alexander et al. 2002) On this point also, it seems that the decision is not a simple dichotomous choice, either to apply a rule unquestioningly or to “game” the system. While our respondents did report being pitted between conflicting obligations, most of them found overt ways of negotiating solutions without resorting to covert rule breaking.

The use of negotiation is often underplayed by the normative literature on rationing, which seems to envision doctors as making solitary decisions regarding clinical resource allocation. While some strategies entailed decisions made by doctors on their own, most involved negotiations with patients, families, third party payers, administrators, colleagues and other participants in the health care system.

Thinking through equity in clinical practice

Based on our Geneva Study (Hurst 2005-2009), doctors seem at least sometimes to be able to overcome the apparent contradictions that follow from the diversity of concepts of fairness used in clinical practice. They do this by resorting to specific
reasoning strategies, such as the use of extreme examples as comparison points, and targeted management of empathy to attempt to equalize their concern for their various patients.

| Table II-3: Strategies reported by US doctors as responses to resource constraints |
|---------------------------------------------------------------|---|
| **Open-ended responses**                                      | N=55 |
| Interacted with the system                                   | 45% |
| Negotiated the system                                        | 33% |
| Pressured the system                                         | 7% |
| Manipulated the system                                       | 2% |
| Refused to manipulate the system                              | 4% |
| Expanded resources                                            | 2% |
| Interacted with patient or family                             | 22% |
| Discussed with the patient                                   | 5% |
| Confronted the patient                                       | 4% |
| Negotiated with the family                                   | 13% |
| Used the family’s support                                     | 2% |
| Assumed responsibility for care                               | 22% |
| Chose to shift authority                                     | 7% |
| Reported to board or authority                                | 7% |
| Fired colleague                                               | 2% |
| Went to ethics committee                                      | 5% |
| Acquiesced to request                                        | 5% |
| Refused request                                               | 16% |
| Suggested an alternative                                      | 4% |
| Negotiated an alternative or compromise                       | 11% |
| Simple refusal                                                | 2% |
| Accepted limitation                                           | 20% |
| Did not accept limitation                                     | 33% |

<table>
<thead>
<tr>
<th>Closed-ended responses</th>
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<tbody>
<tr>
<td>Initiated a meeting with the team</td>
<td>38%</td>
</tr>
<tr>
<td>Discussed with the patient or family</td>
<td>85%</td>
</tr>
<tr>
<td>Discussed with the department head</td>
<td>37%</td>
</tr>
<tr>
<td>Discussed with hospital lawyer</td>
<td>13%</td>
</tr>
<tr>
<td>Requested a formal ethics consultation</td>
<td>13%</td>
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**Extreme examples**

Doctors used rare, often striking, examples to ‘weigh’ whether or not an intervention was deemed reasonable in a more consistent manner. These examples
were very diverse; some had taken place in Geneva, but some were situated on different continents. They filled two roles. First, they exemplified learning occasions, stories of how the respondent had become aware of the justice-based issues raised in clinical practice:

“In Zimbabwe I was a primary care doctor so the...yes in fact in Zimbabwe ... hmm ... especially with the political class...hmm...resources started to be increasingly limited and then...in effect access to care was reduced, access to drugs was reduced (...) so there you start really to...to ask yourself what you are doing there as a doctor, when you no longer have basic medicines to work correctly, hey? No X-ray, no lab reagents, no...anti-malarials (<laughs>) so there...hmm...then it becomes an emergency humanitarian program (...) what do we do for people who did not have resources and who could not pay? So there was a sort of ... small reserve (...) so the difficulty becomes knowing who...who will benefit from this fund and how to determine who will benefit and who will not.” (Geneva Study, interview 15)

Secondly, these examples served as yardsticks for the justice issues faced by respondents in their current setting; cases to which to compare other cases, as if to keep the setting constant when weighing fairness –or unfairness- in individual situations:

“(...) because what I mean is, there are lots of people who need organs and if it’s not done in the country, ha, they’ll come here to do it and then the folks with their child who needs a liver they’ll say: yes but my child is on the list for two years, there’s someone who arrives from another country where that’s not done (...))” (Geneva Study, interview 2)

Managing affect

The second strategy described by respondents was to exercise specific control over the emotions they spontaneously experienced in response to different patients. In some cases, the issue was to decrease an emotion –usually negative- viewed as too strong. An example is given in the quote which opens this chapter:

“(...) understanding but, but it’s sometimes diff...because we are still human beings like all the others and we are much more motivated to help people who are nice to us, than people who aren’t nice, so I think that the alcoholic, alcoholised in acute phase and who’s aggressive...hmm...it’s important to still consider him as someone who has a health problem, even if we calls us a bastard (...)” (Geneva Study, interview 11)

In other cases, the difficulty could be to find reasons to enhance empathy for patients with whom it came less easily:
“I try to find something seductive in… (laughs) well, seductive, to, to like in everyone, otherwise I can’t work with everyone.” (Geneva Study, interview 18)

Equalizing affect could mean withdrawing into the strictly biological, and this was viewed as simultaneously beneficial and problematic:

“When I review cases, I know who the patient is, I know him, but we look at ‘case X’ it’s a case of pneumonia in a patient known for this, this, this and it’s a case of infarction in a patient known for this, this, this...then we treat like that, be they nice, obnoxious, blond, green, yellow I don’t know we don’t care that’s it, we treat...the defect is that we treat a pneumonia and not a patient but the advantage is we treat everyone the same” (Geneva Study, interview 3)

Equalizing empathy and affect was important as a distribution tool: it was a strategy to treat patients fairly, by equalizing respondents’ motivation. But there was an added aspect: doctors’ affects themselves were treated as a resource to allocate. In effect, respondents were treating their empathy as though it was the sort of thing that comes with a volume control, and the sort of thing that patients need to receive. The second is clearly true in most cases. The first is an interesting open question.

Learning fairness

In our interview study, we specifically asked about how respondents considered their views on fairness to have developed. Three important points emerged from their responses. First, they stressed that this aspect of their practice, though important, was not addressed during their formal medical training. Fairness and equity were described as learned through experience and practice. Second, their stories as to how they had learned to include justice-based considerations in their practices often began with a story of awareness-raising. These stories could be very personal, and usually involved a rather extreme example of unfairness, either as experienced professionally in Swiss or foreign settings, or regarding an encounter with the health system as a patient either by the respondent or a family member. Third, the inclusion of fairness in clinical practice was described as an ongoing process of refinement over time, in a way similar to the refinement of clinical experience itself. Indeed, one of the difficulties in applying fairness to clinical practice is found in many areas of clinical practice: the requirement to think simultaneously at the level of individuals and populations. As a value, equity is population-based. As noted by one respondent:

“Yeah, we talk about it more, generally we talk about it more than before, we talk about treating individuals first against, independently of society, so equity there, there is at once the question of equity, the value of the individual and then the advantage of the individual
Although the necessary balance between individual and group data and concerns is of course an important part of medical training, its explicit inclusion at the pre-graduate level is variable. Moreover, while this is taught in clinical reasoning and the application of Evidence Based Medicine, this balance between individuals and groups is rarely explicitly linked to ethical and fairness concerns. The citation given here also illustrates the difficulty not just in respecting this balance, but in naming it as regards fairness in clinical practice.

This difficulty should give us pause. We repeatedly found that respondents had a hard time articulating what they meant by fairness, and although it was important to them they also often gave confused accounts as to why this is so. This suggests that this value could, in the current state of medical education, prove difficult to defend should doctors be placed under pressure to do so. And indeed results from a previous study show precisely this: doctors working in the Swiss health care system make resource allocation decisions under considerable pressure (Hurst, Forde et al. 2007).

Sharing experience

As shown in the above citation, some respondents reported sharing experience with colleagues in order to refine their practice of fair allocation. This should not surprise us: many difficult issues in medicine are brought forward in this way, through shared experience in discussions, rounds, and continuing education. However, many respondents also reported that they did not. Even young doctors, who were expected to discuss all clinical decisions with their supervisors, reported discussing the application of fairness concerns only in case of uncertainty. Some seemed surprised to be having this conversation for the first time with a research assistant rather than with a mentor or peer. This should not surprise us either: in the controversy surrounding the role of doctors in resource allocation, reluctance to admit uncertainty as to how to practice it is entirely understandable. Indeed, this is one of the reasons our results are important: we hope that showing such concerns to be broadly prevalent can decrease reluctance in addressing them openly.

Equalization strategies

Until this point, we have mostly looked at concerns for equity that doctors may have when faced with a situation where they need to allocate resources, and ask themselves how to do this fairly. But striving for equality in the delivery of health care can require something more: that doctors should strive to equalize their
treatment of patients within the unequal playing field of health care systems. In attempting to equalize response to health needs, and ultimately their patients’ health, doctors deploy efforts to equalize access to health care. Our respondents describe attempts called for in the literature. For example, acting against biases built into the health care system (Institute of Medicine 2002; Bullas 2003; Barr and Wanat 2005; Wellstood, Wilson et al. 2006), by mobilizing resources for patients with insufficient coverage or language barriers. They also report trying to minimize biases in their own reasoning (Escher, Perneger et al. 2004; Vaccarino, Rathore et al. 2005), by controlling their affects, and sometimes by focusing on diseases rather than patients. In doing these things, they are in effect attempting to realize equal treatment for equal need as fully as possible (Betancourt 2006; Smith, Betancourt et al. 2007).

An additional aspect is that some interventions, like motivational discussions for smoking cessation, are not equally effective across the socioeconomic gradient (Low, Unsworth et al. 2007). To equalize this, doctors sometimes need to treat patients with similar medical needs differently to reach the same health-related outcome, for example by designing specific strategies for disadvantaged patients. This sort of intervention might also for example include giving an appointment sooner if it is known that a patient had to overcome greater obstacles to arrive at the point of contact with the health care system (Thorson and Johansson 2004). Although rarer, this strategy was also present in our study. Some respondents accepted that helping their patients to overcome interpersonal or social inequality could be a part of their role, though it always remained a problematic one. In one example, a respondent reported that he went to visit a patient simply so that she would not be alone, and wondered whether this was still a part of his role:

“this person I’m thinking of, it’s going to be extremely hard but I’ll be the only one at her burial, the day she’s buried, there’s no one else, there’s only me and now a nurse but that’s it (…) I go from time to time I do a minimum, because in any case that’s all I do there’s nothing else to do medically speaking” (Geneva Study, interview 28)

Gatekeeping values

As reported in chapter 6, respondents reported difficulties in managing the tension between “medical fairness” and “social fairness”, and ultimately in attempting to treat patients of different socio-economic levels in the same way. Part of the reason for this is that medicine is a domain within which we consider a greater level of egalitarianism to be right that within society at large. As outlined in chapter 4, we have good reasons to defend greater equality in health care than we do more generally in society. This emerged in our interviews as a concern that we have called ‘gatekeeping values’. Doctors described behaviour and reasoning consistent
with active resistance to the intrusion of social differences within allocation decisions. This did not in any way mean that they rejected these social differences as citizens (our questions did not address this point). However, as doctors they reported great care not to let these –otherwise often socially accepted- variations in socioeconomic standing among patients intrude into the clinical domain. They defended a more egalitarian space within clinical care. A striking example is given in this story, where the contrast between social differences and medical lack of differences is played out in an pre-hospital emergency setting:

“I’m thinking of an African patient at the airport who was in a corner,…hem…in a drowsy state like that and who the…security only approached with his foot, didn’t talk to him, ask him what is happening, because he only spoke English and then the paramedics finally came, with about the same attitude, that is without trying to understand what was really happening and then finally someone called us, we arrived, I talked to the patient, I ended up realizing that, so, he had a myocardial infarction, well? His heart was blowing itself up and we took him on much too late because of … hem… all these barriers there (…) So I came and established the diagnosis, we, we left for the hospital right away and then everything ended very well, he could have ended very very badly, so there I know it’s not me personally who was…hem…who was involved in, in the negligence of the problem because of barriers, it was others but it could have been me in another context, easily.” (Geneva Study, interview 11)

‘Gatekeeping values’ meant keeping the relationships between acceptable biological allocation criteria, and problematic social and relational ones, in the right order. These dimension applied to resources which doctors allocated, the criteria they used to do so, and sometimes the sort of fairness they tried to re-establish in the face of inequalities inherent in their health care system or society. As shown in Figure II-2, this included protecting an enclave within medicine against differences accepted ‘outside’ within society. It also included resisting doctors’ own biases. This last example, which ends with “it could have been me”, illustrates this well.

Doctors, then, use diverse strategies in attempting to apply fairness in clinical practice. They compare, weigh, call upon contrasting, sometimes extreme examples. When they identify bias in their practice, they resist it. They describe considerable efforts to regulate their own empathy and affect to achieve more equal motivation with their very different patients. They try to compensate, through their practice, some of the initial inequalities in access to care.

The practical strategies for implementing fairness found in our study are thus complex. Any attempt to help doctors do better must take this reality into account. Are their efforts successful? In part perhaps they may be, but certainly not entirely. According to Swiss doctors themselves, some patient groups are more likely than others to be denied beneficial care on the basis of cost. Among them, illegal
immigrants, persons with cognitive deficit, the elderly, or those who cannot afford to pay their share of the cost (Santos-Eggimann 2005; Hurst, Slowther et al. 2006).

As outlined above, and all other things being equal, we also know that optimistic persons are more likely to be admitted to intensive care (Escher, Perneger et al. 2004). In short, there is still room for improvement. Moreover, even the most egalitarian doctor will remain unable to render a health care system, with all its multiple actors and interests, fair as a whole.

How can we do better? Our Geneva study shows a ‘half-full glass’ set of results, and suggests ways in which improvements could be made. Doctors take fairness into account without formal training in doing so, and may do better were the exercise more structured. Sharing experiences during continuing medical education is a traditional way of clinical learning: not including justice-based difficulties is certainly a missed opportunity. Training could also increase the ease with which doctors could articulate and thus defend fairness in the health care system. In the next section, we turn to a few initial proposals to improve fairness in clinical rationing.
III. Doing better?
“(...) so, let’s say, it really means using the same objective and medical criteria for everybody and not to say…to tell yourself, this patient… (...)” (Geneva Study, interview 3)

One way of making clinical rationing more legitimate would be to open its processes to critique and revision. This, however, requires some attempt at describing approaches to rationing by clinical judgment, which can then form the basis of a discussion on acceptable, and less acceptable, aspects. Such an approach must recognize that setting limits at the bedside can occur in a variety of ways. As Truog and colleagues have outlined (Truog, Brock et al. 2005), clinicians ration generally by three mechanisms: in accord with external constraints, by rules of medical practice, or by exercising clinical judgment where the first two mechanisms do not apply. In this chapter we examine the third of these mechanisms (Hurst and Danis 2007).

**Tiers in clinical rationing**

Rationing by clinical judgment itself also comes in three forms. First, it can occur as triage, where locally available resources are in obvious and immediate short supply and must be allocated between identified patients who are in competition with each other. Examples are decisions regarding the last available ICU bed, or organ transplantation (Table III-1).

Second, rationing by clinical judgment can occur in a situation where resources are strained or subject to fixed limits. While there is no immediate competition between identified patients, candidates for an intervention are nevertheless compared to other patients who may potentially need the same resource: residents of a community served by a hospital, or population covered by a health plan (Table III-2)(Lee 2004).

Third, rationing by clinical judgment can be based on an opinion that using a specific intervention in a specific case will bring an incremental gain in benefit that is not worth the additional human or financial effort that this intervention will cost. Here, the clinician judges that the contemplated intervention, as reported in the literature for a population of like patients, shows a benefit, but that this benefit is, in the light of the expected cost, too small to put the intervention over a certain threshold that is deemed reasonable. This is different from rationing by rules of clinical practice, because it involves an individual case assessment, in contrast to a general cost-effectiveness analysis (CEA) on a population. For example, a clinician
could judge that although a single drug was shown to be effective in his patient’s condition, the incremental cost-effectiveness of adding this drug to the many others already prescribed is low (Tinetti, Bogardus et al. 2004).

In these three circumstances, the clinician is situating the patient at hand in the context of increasingly wider circles of competing patients and deciding about the use of constrained resource pools with regard to these populations (Table III-1, III-2, III-3).

**Table III-1: Examples - triage in the ICU**

| Limited time | The ICU team goes on rounds for 90 minutes each morning and has ten beds in the ICU. Inevitably many of the patients require more than 9 minutes of the team’s attention to fully evaluate their status, consider the options, decide on a plan of care and communicate this to the ICU staff. The patients in the first beds often get more time on rounds and the last ones barely get adequate attention. The staff wonders about how to best ration their rounding time. Should they move from bed to bed every nine minutes? Give more time to the patients who are more unstable? Give most time to the patients who are likely to benefit the most from their care? Should they simply reverse the rounding order so they start at the back end of the ICU on alternate mornings? |
| Limited beds | The ICU team often receives patients admitted from the Emergency Department during the night. When these patients need ICU care the unit is often full and the question therefore arises as to whether there are any patients who could be transferred out of the ICU earlier than would otherwise occur. The team must review the ICU census and consider who is least likely to suffer adverse consequences if transferred. Should the patient with the poorest prognosis be moved? The patient who is most stable? The patient who is receiving the least monitoring? |
| Limited staff | The ICU has 5 nurses staffing each shift. This provides an average of one nurse for every two patients in the 10 bed unit. During one shift a patient in respiratory failure is so difficult to ventilate that the team judges that it is necessary to paralyze the patient and put him on volume control ventilation with a high I:E ratio. This will require that the patient have 1:1 nursing. The charge nurse must decide how to reassign the nurse in the ICU. Three patients will need to be assigned to one nurse to accommodate the nursing care needs of the patient in severe respiratory failure. Should a patient who is terminally ill and getting palliative care be one of them? Should a patient who is an acute asthmatic be one of them? |
Importantly, many difficult end-of-life choices regarding when to initiate or continue “cure-oriented” treatments are not rationing decisions in this sense. Clinical judgment that an intervention will cause the patient more harm than good is a different consideration. However, when an intervention contemplated in end-of-life care is indeed expected to bring more good than harm, but too little good to be indicated or reasonable, then forgoing it constitutes rationing by clinical judgment under this framework.
Conditions for fairness and legitimacy in rationing by clinical judgment

One of the fears regarding rationing by clinical judgment is that it may be susceptible to subjectivity and bias. It has been noted that concerns about justice infrequently come into doctors' rationales for decision in the facing scarcity (Hurst, Hull et al. 2005). This is concerning, as it does suggest that links between general concerns for fairness and the clinical practice of bedside rationing may be weak. Models have been proposed to increase consistency, openness, and participation by those affected in limit-setting decisions (Daniels and Sabin 1997; Pearson 2000). Outlining an approach that respects general conditions for fairness in rationing by clinical judgment faces several difficulties. First, it must be consistent, and attentive to justice. In addition, it must be sensitive to relevant individual variations. These first two conditions can conflict with one another. In addition, any consistently applied framework must be revisable in the light of new theoretical and practical insights (Daniels and Sabin 1997), some of which will arise in the application of the process itself. All these features will be necessary for it to be a trustworthy process, able to lend moral legitimacy to rationing decisions by individual clinicians. The final difficulty is that a framework for rationing by clinical judgment must in practice be applicable in the three different kinds of cases outlined above, each of which poses certain specific difficulties.

Elements of a framework for rationing by clinical judgment

A general framework must recognize that a legitimate diversity of values will be at play in rationing by clinical judgment. In this sense, Daniel and Sabin’s Accountability for reasonableness, is convincing and influential (Daniels and Sabin 1997). However, applying it to rationing by clinical judgment is not straightforward. First, the substantial content of a reasonable rationale is too vague for use in clinical practice. Additionally, the reasoning strategy that could be used to apply it in this setting is unspecified. Based on Daniels and Sabin’s four conditions of publicity, relevance, revisions and appeals, and enforcement, a justifiable model seems to us to require the consistent presence of six minimal elements (Figure III-1).

1) Doctor reasoning based on general considerations of justice
Doctors should be prepared to reason about rationing in the light of general considerations of justice, if they are to be able to give reasons which would be deemed ‘relevant’ under the Accountability for reasonableness model. It is essential that clinicians appreciate the concept and importance of fairness and apply considerations of justice to rationing decisions. This does seem to require them to be aware of the various traditional theories of justice. First because these concepts provide a clearer account of the sorts of intuitions they would rely on if they applied
Daniels’ and Sabin’s model directly, and second because they need to understand the underlying assumptions of conflicting points of view regarding a fair decision if they are to discuss it openly. They should understand the basic elements of utilitarian, egalitarian, and prioritarian theories, and be aware that different theories of justice will lead to different outcomes. The requirement that doctors become knowledgeable regarding theories of justice may seem demanding. However, it is no more so than for other conceptual tools that medical practice now requires, such as the use of decision analysis in diagnostic approaches, or evidence-based medicine. Furthermore, doctors are already expected to have some understanding of medical ethics in general. They are quite familiar with issues of patient autonomy, beneficence and non-maleficence. They are also taught some non-principlist approaches to bioethics such as virtue ethics and casuistry. However theories of justice are insufficiently taught. As it is necessary to address the competing duties to different patients in an even-handed way, an important clinical outcome, this educational requirement appears justified.
2) **Respect for individual variations**
Respect of individual variation within a certain range can be in tension with general considerations of justice, as it seems to contradict the demand for consistency. On the other hand, the degree of indeterminacy involved in these situations seems to require this flexibility. In addition, it seems that the assurance that individual circumstances have been taken into account would be important to most of us in accepting limit-setting decisions if we were affected, and thus falls under the relevance condition. It is also required as a basic admission of humility given the uncertainty inherent in applying population data to individual cases. Indeed, much of the value of doctor involvement in rationing lies in their ability to do just this: to balance respect for individual variation and consistency. No other locus seems better for achieving this balance.

3) **Decisions based on reciprocity**
Rationing by clinical judgment should only take place where reciprocity prevails. The process thereby becomes defensible to all affected by being applicable not merely to the patient who forgoes a potential benefit for the sake of others, but also, and similarly, to others for the benefit of this patient. Reciprocal sacrifice is a basic benchmark if we are to justify sacrifices made for the benefit of others. It is a justified requirement because health care resources are shared resources, making them a common good to which rules of cooperative fairness will need to apply (Rawls 2001). This requires that the decision take place in a closed system in which it would be possible for the patient to benefit from a reciprocally offered sacrifice.

4) **Consistent application of the same process**
The same process should be applied in every case to introduce a minimal procedural equity into rationing by clinical judgment (Daniels and Sabin 1997). This is also necessary if the process is to be justified by reciprocity. Consistency is a limiting condition for the application of a process that could otherwise be applied in several different ways.

5) **Explicit process**
The process should be sufficiently explicit to be examined by patients, doctors, and those who fund care (Daniels and Sabin 1997). In other words, the process must be outlined in a way that is understandable and accessible for examination by all those affected.

6) **Iterative re-examination of the process and its application**
There should be an iterative re-examination of the process, so that new theoretical and practical insights can be included as they are brought to light (Daniels and Sabin 1997). There should also be an iterative re-examination of practices, so that they can 1) be evaluated for application of the process and 2) be a source of insight for new input into the process.
Applying this framework
A framework for rationing by clinical judgment must be applicable in practice. For this purpose, knowledge is important (Rest and Narvaez 1994; Eastman, Eastman et al. 2001), but insufficient. Bringing considerations of justice, respect for variation, reciprocity, consistency, explicitness, and revisability to bear on actual decisions requires the use of specific reasoning strategies, akin to a reasoning strategy for ethical thoughtfulness. This is similar to other reasoning strategies learned by doctors, such as decision analysis or Evidence-Based Medicine. Difficulties identified in getting doctors to use the reasoning strategies of EBM in clinical decision making include a persistent gap between theory and practice (Slawson and Shaughnessy 2005). A similar gap exists between theory and practice in resource allocation (Hurst, Hull et al. 2005). Thus, we outline proposals for the application of the elements outlined above to rationing by clinical judgment.

The application of general considerations of justice raises several questions. Must all clinicians, or at least any given doctor, always apply the same theory? One might argue that consistency in applying theory will lead to greater fairness. Doctors might consider which patients would benefit the most from resource use or who would face the least risk from having a resource withheld, using utilitarian logic. They might give priority to the patient who is the worst off. They might take an egalitarian approach and attempt to limit care on as even handed strategy as possible.

However, there will not necessarily be a uniquely applicable or justifiable theory of justice for every case. Indeed, the existence of these different views of distributive justice, all of which can be defended to some degree by reasonable people, makes this unlikely. The essential guide here should be that application of theories of fairness by individual clinicians should function in such a way as to reduce arbitrariness. Always applying the same theory might be one way, but individual patients treated by different clinicians may still be treated very differently. Alternatively, clinicians might agree that they will vary the theory they each apply according to the situation, but do this in a predetermined and consistent manner. One approach could be to always take all these views into account. The likely benefit from resource use, the degree of risk faced from having a resource withheld, and how badly off different patients are, will each vary from case to case. This means that, in some cases at least, the degree of unfairness linked to setting aside one kind of consideration of justice will vary, and some theoretical approaches will thus weigh more heavily than others in a given case. For example, one could be considering the two following patients in a triage situation: one stands to gain slightly more from the intervention, but the second is much worst off. In this case, setting aside the prioritarian consideration to favor the worst off would result in a much higher degree of injustice on this view, than giving up a slightly higher
overall benefit would constitute on the utilitarian view. Thus, priority should be given to the worst off patient in this case. For this to be a consistent process, it is necessary to be prepared to reach the opposite conclusion in opposite circumstances, namely, if one patient was only slightly worst off, but the other stood to benefit much more. This is different from proportional satisfaction of moral reasons (Broome 1991), because these are situations where the resource cannot be meaningfully split. It is also different from choosing the best consequences, which would lead to the opposite conclusion in our example. What this amounts to is choosing the smallest available wrong.

This also illustrates one of the ways in which the requirement for consistency will constrain the process. It will limit how reasoning in terms of justice can be applied to real cases. For example, it could dictate that the same theory of justice should be applied to all situations or that the strategy of weighing different theories of justice should be applied to all situations. In addition, there is a degree of tension between consistent application of the same process and respect for individual variations. Consistency will also dictate that the same kinds of individual characteristics of patients, such as preference, likelihood of benefit, degree of need, be considered in all circumstances.

In applying reciprocity, it should be understood that any organizational entity may support reciprocally offered sacrifices. In the US, this could mean that any insured patient could be considered as part of one pool where reciprocal sacrifices will be accepted. On the face of it, a universal health care system appears to be a better environment for reciprocal rationing. However, it is not a necessary condition. A set of patients could be reciprocally sharing health care resources even in its absence. It could mean that all beneficiaries of hospital services in a given area form such a group. Applying rationing to them could take place in a closed system, and be fair. This sort of system, however, could not be viewed as closed as regarded any person not within this circle. Rationing from someone who was not covered would thus not take place within a closed system; although it could sometimes be described as necessary, on our framework it would not be fair. Importantly, a universal health care system is not a sufficient condition for reciprocal rationing either. It only represents a more favorable set of initial circumstances. It does not, for example, preclude systematic discrimination against a specific group by a majority of health care providers.

Explicitness would require that doctors document these decisions, at least retrospectively. For example, Intensive Care Units must regularly refuse patients who do not meet their criteria for inclusion, or who are in competition with other patients whose needs are, for example, greater. Some ICUs keep logs of refused referrals with documentation of the reasons. This can serve as a basis for review and critique later on. Such a system could be applied by surgical services to delays
for elective procedures, or by hospital pharmacies for non-formulary requests. Decisions for rationing by clinical judgment could also be documented in patients’ charts.

Clearly, all decisions could not be documented in this way all the time. If we wish to open these decisions to examination, however, we must start somewhere. Additionally, even if only some interventions are logged in such a way, or consigned to patients’ charts, doctors will become better accustomed to thinking and justifying their decision in those terms in applying this process, and will be better able to compare their decisions with those of others. This is likely to improve rationing practice even in non monitored interventions. Documentation and examination would constitute a kind of quality control for the process. One could also, as a quality improvement effort, select certain routine decisions for review, such as hospital or ICU admission, or dialysis. The process should also be publicly available in some form, and thus accessible to critique by those affected. Iterative re-examination could be done as a self-evaluation by a group of doctors of their rationing practices, with a result disclosed to individual doctors only along with a comparison to the typical practices of colleagues in similar situations. It should be explicit that this typical practice is not a norm in the moral sense. It may very well be that doctors could legitimately depart from typical practices. This evaluation should not serve to enforce a return to the mean, but to foster regular thoughtful re-evaluation of rationing practices.

Like other reasoning strategies, such as those incorporated in Evidence-Based Medicine, this framework could serve as a checklist for intuitive conclusions, or used to move forward in difficult situations. This would require that doctors take pause and at least briefly question each point when making rationing decisions. It could also serve to guide doctors’ general reflections on how to ration by clinical judgment. Time could be set aside every now and then to share experience, as it is for other difficult decision-making skills such as diagnosis. Indeed, if rationing by clinical judgment is part of doctors’ role such time should be set aside. This practice should be examined in the same kind of circumstances as other interventions are: continuing education time should be allocated to it.

Specific difficulties for different types of rationing by clinical judgment

Unique issues will arise during rationing by triage, comparison to other potential patients, and using a threshold.
**Triage of identified patients**

During circumstances when triage is necessary the notion of reciprocity is not straightforward. When immediate demand exceeds fixed resources the circumstances do not permit immediate reciprocity and may not permit reciprocity in the future particularly in life-threatening circumstances. Thus the demand for reciprocity cannot dictate that reciprocity should be literally feasible at the given moment a rationing decision must be made. It would not be possible to adequately give in return at the moment that a critically ill patient must forgo some share of a potentially beneficial intervention such as a doctor or nurses’ time. It should however be the case that if the patient who is about to forgo this resource were in the opposite situation, in the situation of the patient who will benefit from the sacrifice, the clinician would, upon reflection, be willing to parse out the necessary resource to her.

In such cases, reasoning based on general considerations of justice must take place in very limited time. This may imply using a simplified algorithm in certain cases. While this is clearly a less than optimal way to use general considerations of justice, any improvement in the systematic application of such considerations to triage is certainly desirable (Repine, Lisagor et al. 2005).

**Comparison to other potential patients**

In situations where rationing by clinical judgment occurs by comparison to other potential patients who could benefit from the resources involved, the urgency of the rationing decision is not as obvious. The competition for resources is not as frenzied, which makes the notion of reciprocity more imaginable. Again, the clinicians should consider whether it is the case that if the patient who is about to forgo this resource were in the opposite situation, in the situation of the others who will benefit from the sacrifice, the clinician would, upon reflection, be willing to parse out the necessary resource to her.

An added feature of this level is the risk that the “potential patients” used in this hypothetical comparison could be defined very differently. Consistent application of the same process would seem to require that the type of patient doctors use in these comparisons be explicitly examined. It is not realistic to expect these hypothetical patients to be identical for all doctors. However, they should not be allowed to vary on points that could lead to discrimination. One simple example is that, were doctors to systematically compare their patients to people who were the same age as themselves, marginal benefits would be more likely to be denied to
patients by those doctors not in their age range. They should also avoid comparison on the basis of characteristics considered morally non relevant (race or gender for example).

**Using a threshold**

In this circumstance, clinicians may judge that using a specific intervention in a specific case will bring an incremental gain in benefit that is not worth the additional human or financial effort that this intervention will cost. While the reasoning that the clinician will use under these circumstances uses the logic of cost-effectiveness, the available literature does not suffice to answer the question of whether or not to intervene because the patient does not exactly match the patient population reported in the CEA literature. The difficulty here is to maintain respect for individual variation when making a decision using analysis based on population data. An added difficulty is that there are in practice two thresholds. The first is the amount of expected benefit required to consider that an intervention is indicated, the second is the cost-effectiveness ratio required to judge that implementing an intervention is “reasonable”. Each threshold can be examined at the level of rule-setting, or at the level of clinical judgment. The specificity of the threshold problem at the level of clinical judgment is that the tension between data gathered from groups and the care of individual patients is more palpable at this level (Saarni and Gylling 2004).

**Clinical Judgment of expected benefit**

Clearly, the benefit expected of a specific intervention will contribute to determining whether or not it is indicated. Thus, it is important to know what prospective benefit can be expected for this particular patient. Comparisons must be made between the individual patient and the study group. This is a standard necessity, and a standard difficulty, in the application of Evidence Based Medicine (Slawson and Shaughnessy 2005).

The result of this is an assessment of the amount of benefit expected from an intervention. Knowing if this benefit is sufficient for the intervention to be indicated will further require that there be an agreement on the level of expected benefit sufficient to warrant treatment. This is a value judgment that will vary individually. When costs are not considered, the main stakeholder is clearly the patient. The setting of clinical discussion can thus be legitimate and sufficient to set this first threshold on a case by case basis.
Clinical judgment regarding expected cost-effectiveness for a patient

In making a clinical judgment regarding cost-effectiveness and the reasonableness of paying for an intervention, a layer of complexity is added. The first question here is the prospective cost-effectiveness level in this particular case. Here too, the best available evidence must be examined in the light of relevant patient characteristics. This is more complex than examining the question of benefit, because there are several parts to a cost-effectiveness ratio: the prospective benefit in terms of years of life gained, the prospective benefit in terms of quality of life, and the cost of the intervention. The standard unit of CEA is the cost per Quality Adjusted Life Year (QALY). The QALY is the number of years gained on average through the intervention, multiplied by the assessed value for the quality of life of the patient (V). This is a number between 0 and 1 where 0 is death, 1 is perfect health and anything in between is life in less than perfect health.

The number of years gained from an intervention is based on data gathered from a study population. Thus, it is important to assess whether this patient differs from the study group. This is similar to the kind of clinical judgment required when applying any evidence based practice guideline to individuals who do not quite fit the study populations. Here, the legitimacy of considering individual cases in the light of clinical judgment is relatively straightforward.

The assessed cost of the intervention or of the alternative it is being compared to can also differ from the costs in the study group. As with the evaluation of differences between an individual patient and a study population on the question of a prospective health benefit, cost may not apply precisely to details in a particular clinical situation. Thus, there are circumstances where the literature on cost-effectiveness suggests that a treatment is not cost-effective and yet the cost of the intervention may be less than that indicated in the literature, placing this treatment above the threshold deemed reasonable. The opposite could happen in situations where the cost is greater than in the study population. For example, the indication of many preventive interventions, such as screening, is based on cost-effectiveness ratios. A doctor, who is deciding whether to schedule colonoscopies, or mammographies, will be basing her assessment on population-based data. If either the prevalence of the disease or the cost of the intervention in her area differs from that of the study population, the cost-effectiveness ratio may need to be tempered by this information. Currently, however, many cost-effectiveness analyses give clinicians insufficient elements to make this judgment. A clinician will typically be told the age range of the study group, whether they were male, female, or both, some information regarding prevalence of the studied disease, comorbidity and similar information. The same type of general information about costs in the study should also be made available to clinicians if they are to apply CEA with the same kind of thoughtfulness as evidence-based medicine.
The assessed value for the quality of life of the patient, V, could also be different for an individual patient if she differs sufficiently from the kind of patient used in reaching this evaluation. Here, however, a problem arises. In clinical practice, it is considered important to leave the assessment of quality of life to the patient herself. In placing the value of V for CEA, however, this assessment is not left to the patient alone. Indeed, there is substantial controversy regarding what the best viewpoint for this assessment would be (Ubel 1997; Menzel, Gold et al. 1999; Nord, Pinto et al. 1999; Ubel 1999; Ubel, Nord et al. 2000; Ubel, Richardson et al. 2000; Ubel, Loewenstein et al. 2001; Ubel, Loewenstein et al. 2003). In adapting the value of V to an individual patient who does not quite fit the study population, the difficulty regarding the best viewpoint from which to assess V is imported into clinical practice. If patient input is legitimate, then the clinical setting is the appropriate locale in which to allow this.

Importantly, then, there are elements of cost-effectiveness assessment that are compatible with respect for individual variations: the number of years gained, and the added cost of the intervention. Using input from clinical judgment in rationing through cost-effectiveness thresholds is thus already possible, and would be important. If a consensus could be reached regarding what constitutes a legitimate input by the individual patient on the assessment of V, this element may be adaptable as well.

Knowing how to adapt cost-effectiveness assessment to individual patients, however, goes only part of the way to deciding whether or not it is “reasonable” to implement an intervention in a specific case. Knowing if this level of cost-effectiveness is sufficient for the intervention to be “reasonable” will further require that there be an agreement on the level of cost-effectiveness sufficient to for this to be so. This is a value judgment that will vary individually. At this point, however, the patient is no longer the only stakeholder. Whether or not she remains the main stakeholder is controversial. If any limit whatsoever is placed on potentially beneficial interventions, even where the chance of benefit is small and remote, then the clinician will be considering the cost born by third parties: all enrollees into whichever program pays in a third party system; enrollees in a plan, or tax-payers in a state system. Importantly relying on published thresholds for cost-effectiveness analysis, even as a baseline for individual adaptation, is problematic. In the frequent cases where the cost-effectiveness literature mentions a threshold, it is usually as follows: interventions which cost less than $50’000 per QALY gained should be used, those which cost more than $100’000 per QALY are too expensive, and judgment should be exercised in between. Even setting aside methodological difficulties associated with measuring QALYs (Ubel, Richardson et al. 2000), however, this answer is misleading. Not only was this $50-100’000 level never agreed upon as a threshold (Ubel, Hirth et al. 2003), but since it represents a
balancing of values there is no reason to suppose that it would be the same in every part of the world (Hurst and Danis 2007). Also, it seems to have somehow escaped inflation (Ubel, Hirth et al. 2003). One reason why this threshold is so consistently cited may be precisely because it offers the illusion that we can escape a hard question, or that its answer is objectively measurable. In fact, setting a threshold for how much benefit warrants a given opportunity cost is not an objective measurement, but an assessment of values requiring us to think through our priorities.

Considering that some threshold will be used, the question is then how to legitimately decide where it should be. Whether the clinician’s judgment carries legitimate authority that is sufficient to answer this question is contingent on the presence of the six elements we have outlined at the outset of our discussion.

**Conclusion**

The framework we have outlined here contains minimal requirements for fair rationing by clinical judgment. It is intended to begin attempts to refine the practice of rationing by clinical judgment. It needs to be judged realistic by other clinicians, as well as theoretically robust. By adopting minimal requisite conditions for rationing by clinical judgment, clinicians could practice bedside rationing more fairly. They would not cease using their personal values, or intuitions, but would be able to complement them and subject them to more systematic examination. They may also be able to advocate more effectively for their patients in situations where pressure could be exerted on them to ration without meeting these requirements. In addition, this framework could serve as the basis for clinical tools for bedside rationing. To the extent that rationing is unavoidable, and that making it more explicit and equitable is desirable, such a tool would be valuable. Finally, in including iterative re-examination of the process and its application, this framework could serve as an assessment tool for clinical rationing. This evaluation should help to foster regular moments of thoughtful re-evaluation of rationing practices.

The framework outlined in this chapter could go some way to limiting arbitrariness in clinical resource allocation, and in helping doctors to integrate considerations of fairness more explicitly into these decisions. In attempting to apply fairness to health care more generally, however, it suffers from one major limitation in focusing on patients who are already ill, and already at the point of care. We know, however, that we are not all equal in facing the risk of becoming ill in the first place. Should doctors include this knowledge in allocation decisions and give priority to those more at risk of becoming ill? This question is examined in the following chapter.
Chapter 9 - Priority to the (socially) worse off?

“(…)a child who doesn’t hear well who has language difficulties and then who will have trouble in school, those are consequences, not morbidity, not hmm…normally not long-term consequences but still well, there are consequences at least direct social ones, of not intervening in a case like that.” (Geneva Study, interview 29)

A different way of making clinical limit-setting more fair could be to take into account the unlevel playing field. Given what we know about the socio-economic determinant of health, concerns for equity in clinical care may need to expand to include some way to ‘re-establish’ fairness. This is controversial. However, as it was suggested in our Geneva study that doctors sometimes do include considerations aimed at re-establishing fairness in their allocation decisions, discussion of this point is needed. In this chapter, then, rather than look at how doctors should attempt a strategy, we will look at whether they should attempt it. This strategy is giving priority to the socially worse off (Hurst 2008).

There are really two different strategies here. The rather more modest proposal is that, since some conditions can worsen existing socioeconomic inequalities, treating them can sometimes alleviate these inequalities. Taking this into account could mean bolstering the indication for an intervention targeting such a condition. For example, treating a child for a hearing impairment will give her a better chance of academic achievement than she would have had otherwise. Were it not for the possibility of problems in school, an intervention may not be indicated in all such cases. So its indication could increase if the child were otherwise disadvantaged, for example if her parents had little education themselves (Davis-Kean 2005).

The more provocative possibility examined in this chapter is that, because we live in a society where the socio-economic determinants of health are unfairly distributed, doctors could contribute to equalizing unjust health inequalities by giving some priority for needed interventions to the socioeconomically worst-off. For example, they could allocate more time in outpatient consultations where trade-offs are often made between different preventive interventions that all take time, or give some priority in waiting lists for elective interventions. A more extreme example might be to use low status as a tie breaker for patients with equal need in situations where for example only one operating room was available.

Should doctors do this?

Priority to low socioeconomic status?

Is ordinary medical fairness too modest? If medicine is “the ambulance waiting at
the bottom of the cliff” (Daniels 2008), does protecting fairness require that doctors
give priority to those more likely to fall from the cliff earlier, or harder?
Growing data on the socioeconomic determinants of health pose a novel challenge
to clinicians attempting to apply a concern for equity in their practice. Given our
knowledge of the importance of wealth, education, or social status to health, is
fairness in medicine served better by continuing to avoid considering our patients’
social status in setting clinical priorities, or by attempting to equalize existing
health inequalities by giving priority to the socioeconomically disadvantaged at the
point of care? I believe that, at least for the moment, doctors should not try this. But
examining exactly why is important, because some of the points which we must,
for now, take into consideration may not apply in all health care systems, or at all
times.

In a recent book, the philosopher Norman Daniels proposed to apply ‘a population
view’ of equity to public health concerns, namely that health inequalities are unjust
when they result from ‘an unjust distribution of the socially controllable factors
affecting population health and its distribution’ (p 27) (Daniels 2008). But what of
clinical practice? One of the most traditional difficulties in medicine is to adopt the
population and individual perspective simultaneously (Gigerenzer, Swijtink et al.
1989). And, doctors are in fact expected to integrate the population view into their
reasoning at the bedside. They do so when they apply population statistics, concern
for public health, evidence-based medicine, and their own experience over
hundreds, sometimes thousands, of similar cases.

This means that reasoning about the socioeconomic determinants of health can, in
principle, be applied to clinical care. Hence the following challenge: given what we
know about the importance of wealth, education, or social status to health, is
fairness in medicine served better by remaining neutral to our patients’ social status
in setting clinical priorities, or by attempting to equalize unjust health inequalities
by giving priority to the socioeconomically disadvantaged at the point of care?
Although our initial intuition may be that such a thing would be outrageous, this
may not be based on sound justification. The reason may simply be that we have
been socialized in the current form of medical fairness, which precludes any
priority based on social status. I know that I was. Given the ubiquitous inequalities
associated with the socioeconomic determinants of health, continuing to attempt
neutrality to social status may seem not so much counter-intuitive as misguided in
the light of recent evidence. In this chapter, I will indeed argue that doctors should
remain as neutral as possible, and not attempt to give priority to low status.
However, recent data on the socioeconomic determinants of health do challenge us
to rethink this position, and either to ground it in arguments that take these data
into account, or revise it.
‘Ordinary’ medical fairness

Our starting point for this question is what we could call ‘ordinary medical fairness’. The current view which can be stated approximately like this: ‘treat all equally according to their health-related needs’. This is quite a high demand, illustrated in our Geneva study by concepts of fairness based on a clinically reasonable limit, and on a correct interplay of criteria. Among other things, it means that doctors are required to set aside considerations of status and ‘personal value’, even if these happen to be otherwise prevalent in their societies. Though data unsurprisingly suggests that this is incompletely achieved (Cooper, Hill et al. 2002), it does seem to be successful at least to some degree (Weisfeld and Perlman 2005). The challenge posed to ordinary medical fairness by the socioeconomic determinants of health can be stated as follows. If medicine were deployed on a level playing field as regards disease, then ordinary medical fairness could indeed be our best approach to fostering just health. But bring in data on the socioeconomic determinants of health, and this is no longer the case. We could now reword ordinary medical fairness as follows: ‘avoid increasing health-related inequalities among those who reach the point of care’. This is much more modest than the previous wording. Attempting to reach a fair distribution in the response to health related needs may now seem to require much more than that.

Practical difficulties and their limits

Although practical difficulties do exist, none of them is insurmountable. Giving priority to low status would require that we be able to identify unjust health inequalities -those stemming from unjust social inequalities. This may be difficult. As we lack broad consensus on whether some types of social inequalities are unjust, it may be restricted to those we can agree on. However, it does seem likely that some would exist. In turn, identifying unjust health inequalities could require identifying causal pathways between unjust social inequalities and effects on health (Daniels 2008). Some are currently insufficiently investigated to be applied to clinical reasoning, but this may be transitory. Nevertheless, as long as some general causal pathways are known, doctors would merely be addressing inequalities incompletely, rather than inaccurately. It would obviously be difficult for doctors admitting a patient with myocardial infarction to their ward to know whether this specific myocardial infarction was caused by socioeconomic disadvantage. This, however, would not be a fatal flaw in the approach as long as it could be identified that some groups started out at a disadvantage, and should be given compensatory priority at the point of care. Finally, giving priority to low status would present clinicians with a version of the unsolved priority problem (Daniels 1994). Equalizing outcomes through priority to low status could also sometimes mean that we sacrifice efficacy, making this a form of the “best outcomes/fair chances”
problem too. Again, however, this would not resolve whether doctors should give any priority to low status per se. Furthermore, priority to low status may sometimes increase efficacy, as could for example happen if persons of low status were given priority in screening and prevention programs for pathologies that affect them more frequently. What the compound effect might be is an empirical question.

**Should we give priority to low status?**

Several arguments can be put forward in favor of asking doctors to give priority to low status in the delivery of clinical care. After all, as long as unjust health inequalities exist in our societies, the claim that they require compensation, including through priority in treatment, seems initially at least as convincing as the claim that they require measures aimed at decreasing them at the source. Both strategies share the same outcome as their goal.

Moreover, if the better-off groups were partly responsible for the plight of the less well-off, or had benefited from this plight, then as Daniels states “we should not be complicit in sustaining the advantage they illegitimately acquired by refraining from giving more priority to those they have harmed” (Daniels 2008). As he points out later “Other people also have claims of justice on measures that protect their health” (Daniels 2008), but the trade-off is one that reasonable people will disagree about.

Furthermore, health systems are a space common to all parts of society. One of their roles can be to enhance social cohesion. By giving priority to low status, doctors could compensate the sometimes legitimate impression of being left aside other social spaces. On the other hand, this could also decrease the role of health care systems as spaces where all are treated equally and thus perhaps also their role in enhancing social cohesion.

In addition, doctors are in a unique position to see unequal treatment (Hurst, Forde et al. 2007), and some of the results of socioeconomic inequalities, in their health care system. As gatekeepers, they have the means to give priority to some over others.

**Against priority to low status**

This last point does lead us to some arguments against priority to low status, only some of which can be answered.

First, this is a proposal for reverse discrimination. Does this mean it is unfair? Not
automatically (Nagel 1973); and if we accept Daniels’ arguments we have to consider that we do indeed owe everyone an equal chance of being healthy, to a degree that is currently not realised. So such reverse discrimination may be justified. As with all such proposals, it could be difficult to identify who ought to get priority (Sher 1979). However, studies in the socioeconomic determinants of health have used rather simple variables, so it may not be excessively difficult to determine who should be given priority on the basis of their income quartiles, job and educational level. Another problem is that reverse discrimination can be viewed as retribution, and thus outside the remit of medicine (p 342) (Daniels 2008). However, even if this argument stands, it will only defeat priority to low status if its intention is indeed retribution, rather than equalization of health

Another concern is that ordinary medical fairness fosters a somewhat different value system within medicine as the one outside it. Doctors act as the guardians of an enclosed space where socioeconomic status ought to play no role. There is no inconsistency per se in defending greater egalitarianism within medical care than outside it. It represents recognition of our common biology, and vulnerability to disease. It also recognizes that to strive for equality in health is to attempt greater equality of resources, rather than outcomes, as regards our opportunities in life more generally (Daniels 1985). If doctors, however, attempted to compensate for inequalities in the socioeconomic determinants of health, would this not become a form of proselytizing? In effect, they would be compensating for social injustices that took place outside the remit of medicine. Inasmuch as they are currently likely to have varying conceptions of what constitute unjust health inequalities, they would also confront the victims of this proselytising with a high risk of arbitrariness in their decisions. It could be objected that this would only be the case were doctors to act on their own. If there were inequities that we as a social group wanted to decrease, then we would not only have already adopted a more intelligible view of what these inequities were, but also a more egalitarian value system outside of medicine.

On a more pragmatic note, priority to low status might alienate the powerful. If this happened, the strategy could become counterproductive for the very people it aimed to help. If the typically rather well-off persons in charge of funding decided to give dramatically less to health care, the worst off could in the end get less that they currently do even if we gave them priority. There are three answers here. First, this could be a matter of degree: some priority may be possible without risking a worst outcome for those with low status. Also, it is an empirical question: after all the powerful may still prefer to have a functioning health care system even if they get somewhat less priority within it. The degree of priority this would allow may, however, still be insignificant. We should expect the resilience of health care systems based on solidarity to grow more fragile as they increasingly become exceptions to broad inequalities accepted in other areas. Very little may suffice to drive the well-off away, especially at a time of increasingly globalised high-end
health care offer. The incentive to fund public health systems generously would then decrease among the well-off. Finally, however, this argument rests on the idea that we should do as well as possible by the worst off. Accepting it has other consequences: we ought to channel funding from well-paid and sought-after intervention into coverage for the poor to a greater degree.

A related point is that shaping health care delivery in such a counter-cultural way will cost even more resources than the current levelling of social biases. A predictable pitfall would need to be avoided: if we unblind clinical reasoning to social status we may make doctors more likely to follow the biases of their society and give priority to the well-off, rather than the opposite. To the effort required to unblind clinical reasoning would then be added a further effort to help doctors give priority to low, rather than high, status. This makes it more likely that this approach will fail in the balance of the “best outcomes vs. fair chances” problem. However, as this problem is still unsolved, the question cannot be closed in this way.

Finally, however, under ordinary medical fairness, we protect two different values by treating all alike: 1) aiming for equal health, 2) showing equal regard. Norman Daniels speaks of “the neutrality that seems appropriate in medical contexts.” (p 334) (Daniels 2008) There is value in treating all alike. Data on the socioeconomic determinants of health may shift our view on the first of these goals, but they do not invalidate the second goal. At most, they will force a choice. To justify giving priority to low status, we must give priority to equal health over equal regard in the delivery of care. Deciding which of these values to prioritize would hinge not only on how important we think each is, but to what degree it is likely to be affected by giving priority to low status. If the resulting compensation was small in terms of health, it might not be worth sacrificing the equal regard shown through neutrality. This would apply if only little priority could be given to low status in practical scenarios, or if priority resulted only in small health benefits for those who received it. This would also apply if the equalizing effect was very uncertain. As things stand, we cannot expect the health effects of priority to low status to be large. So I would argue that unless we thought equal regard to be of very little importance indeed, we should not trade it off by giving priority to low status.

**A more fundamental question**

Some of these questions rest on a deeper one. Are we aiming for just health, or social justice, or both? If our purpose is more justice in health, and if we consider that social justice is good primarily because it is good for our health, then it may actually not matter so much if we consider that priority to low status is a fair means or not. It would contribute something to a fairer outcome. Equal regard would
indeed be of little importance. Doctors, however, would be acting with a rather broader aim than the one they currently endorse. It may be a broader aim than we want to entrust them with, or that they wish to endorse.

If our purpose is social justice through health, however, things may work out differently. The legitimacy of medical intervention would be greater, as would the importance of equal regard. Giving priority to low status may then be far less important than attempting to decrease the negative impacts of current disease on social justice. Priority to low status could be judged excessive, as maintaining sufficient functioning for a fair range of opportunity may then be considered sufficient without evidence that more health would lead to more fairness for the socially less favoured. It could conceivably still be justifiable in restricted circumstances; perhaps only inasmuch as it could prevent a “double-whammy” effect where disease was expected to deepen an existing social injustice.

We may be aiming at both. Social justice and just health are increasingly shown to be more intricately bound that we ever previously thought. Indeed, if the effects of the socioeconomic determinants of health reflect the way in which we live our very social life and dependence on others (Marmot 2004), then this could even turn out to be a distinction without a difference. Even if this were so, however, it could mean that we cannot lightly make trade-offs for one goal in the name of pursuing the other goal. Giving priority to low status would thus not be justified in this case.

Conclusion

Justified claims that we should address the socioeconomic determinants of health could prompt the question of giving priority to patients of low socioeconomic status at the point of care. Although this strategy could go some way towards compensating unjust health inequalities, and the impression of being left aside in other social spaces, in my view even selflessly egalitarian doctors should not attempt it. Under current circumstances, such priority would risk being given arbitrarily, could represent a form of medical proselytizing, risk leaving the worst off with less than before, and require teaching doctors to act in strongly counter-cultural ways. Crucially, however, we protect both equal health and equal regard by treating all alike according to need: priority to low status would promote the first somewhat, but at the expense of sacrificing the second. This does not preclude other measures to equalize response to similar need, such as designing specific strategies when this is required to reach the same effectiveness, and acting against biases both in doctors’ reasoning and in the health care system.
Chapter 10 - Protecting vulnerability

“I’m thinking mostly of...of persons of different ethnic groups, foreign to ours, with whom we have all sorts of barriers with language, culture...hmmm...etc and for whom probably there are resources available which can help to...to do further investigation and get...get a diagnosis and treat correctly; I’m thinking of translators, I’m thinking of...of centers better adapted to certain persons (...) than for others, and who help, who basically help us to do better management but which aren’t always solicited either because they don’t exist or don’t exist well enough or because the doctor himself is not aware or isn’t...is immediately discouraged precisely because he isn’t aware of the available resources, so for him there is a pressure on resources.” (Geneva Study, interview 11)

Fairness and vulnerability

The theoretical complexity, and practical difficulty, of applying equity-based consideration in health care may require that some minimal criterion be more precisely established, to distinguish between “nice to have” aspirational equity and “need to have” equity which should be a real goal in clinical practice.

One way to address this could be to attempt to provide –at minimum– protection for specific claims to protection for vulnerable populations. This seems convincing because even though we may not agree on what ideal equity in health care should be, we usually broadly agree that the vulnerable should be afforded some kind of special attention, or protection. Defining vulnerable persons or populations, however, has proved more difficult than we would like. Attempts to define vulnerability have differed in their scope (Ruoff 2004). At the broad end, we find a European ‘principle of vulnerability’, which should be considered as a universal expression of the human condition (Levinas 1961) and requires us to respect ‘the right balance between this logic of the struggle for immortality and the finitude of the earthly presence of human suffering’ (Rendtorff 2002). This and other such broad definitions (Callahan 2000) encompass humanity in its entirety. At the restrictive end of the spectrum, ‘vulnerability’ in research on human subjects is often applied to individuals who are unable to give informed consent or who are more likely to be exploited (Lott 2005). These restrictive definitions are very narrow, not clearly applicable to clinical care, and have been critiqued even in the context of research as both ‘too broad and too narrow’ by authors who proposed to replace the concept entirely. This, however, would remove a needed moral safeguard (DeMarco 2004).

To clarify the problem of vulnerability, I have proposed that vulnerability as a claim to special protection should be understood as an identifiably increased likelihood
of incurring additional or greater wrong (Hurst 2008). Vulnerability in this sense is not restricted to the likelihood of faulty consent or even to the limited capacity to defend one’s own interests. If we understood the worst, or perhaps the only, wrong to be lack of respect for self-determination, and that no harm is done to the willing, then this definition would be identical to previous ones. The examples of research and clinical care, however, show us situations where we do not expect even ordinary patients or subjects to protect all their interests themselves. When even ordinary, non-vulnerable people are not expected to protect their own interest, then additional elements become visible. Some interests are more likely than others to be placed at risk. They may be harder to achieve and thus to defend. This affects some individuals even when they would be completely capable of defending their own interests in other settings. Even for those able to consent, an increased likelihood of incurring additional or greater wrong means that we expect self-determination to do more work in their case. If a claim exists that we should afford the same protection to all regarding a claim we consider valid, then additional requirements other than complementing faulty consent will be required.

This converges with one of the concepts described in Chapter 5 (Hurst 2005-2009). In the interview part of this study, one of the concepts put forward was that that equity can be understood as the application of a clinically appropriate limit, applying a limit that is correct or reasonable, in any case that is not based on distributive concerns, but which yields a distributive outcome by being applied to all patients. The underlying assumption is that there exists a claim that no lower threshold be used, and thus that if a patient is presented with a lower threshold this is not only medically inappropriate, but also unfair.

This definition is limited in the sense that it does not identify all forms of vulnerability, such as those associated in general with being human, fallible, mortal, and capable of suffering. In this sense, it is a relative definition of vulnerability. It is, however, relevant in an important way, as it is circumscribes the forms of vulnerability requiring additional attention as compared with the care we usually take to avoid perpetrating wrongs. It is also limited as a definition in that it does not provide a clear cut-off line between the vulnerable and the non-vulnerable. Inasmuch as some individuals and groups will indeed be identifiably more likely to suffer wrongs, however, it provides a framework both for recognizing these groups systematically and for designing ways to address their specific kinds of vulnerability.

Defining vulnerability in this way helps to clarify an aspect already pointed out in previous debates: that vulnerability seems to be both broad and narrow. It does so in a way which shows that, rather than being problematic, this is an accurate description of the sort of concept vulnerability as a claim for special protection actually is. Under the definition proposed here, many –perhaps most- people are
vulnerable in some way. However, they are not vulnerable in the same way. Distinguishing how they are vulnerable is just as relevant as identifying that they are vulnerable, as the strength of their claim and the required protections may vary. We need a definition able to both define a common concept of vulnerability, and make relevant differences. This definition does just that.

If an identifiably increased likelihood of incurring additional or greater wrong exists, including any wrongful harm, then there is an increased risk of moral transgression. Vulnerability in this sense is thus a two-way street and affects those who practice health care as well. This will be the case any time that an identifiable agent acts in way that predictably affects vulnerable persons.

Applying this definition of vulnerability could take the form of a four step approach:

1) Is there an identifiable potential wrong?
2) If yes, are some people identifiably more likely than others to incur this wrong, or likely to incur it to a greater degree?
3) Who shares in the duty to minimize, or avoid, this wrong, and does it include us in any way?
4) What should we do to minimize this increased likelihood or degree, or to compensate for it in ethically justifiable ways?

The mere definition of vulnerability does not identify those with a share in the responsibility for protecting the vulnerable. Applying this definition thus requires the addition of step 3 (Figure III-2). Depending on the sort of wrong identified, those responsible for preventing it will vary.

Figure III-2: Vulnerability as a claim to special protection
Applying this definition to clinical care

Basic requirements for the ethical conduct of research with human subjects are relatively uncontroversial. The nature of valid claims in clinical care is debated to a greater degree. Application of the concept of vulnerability proposed here to this field can be expected to reflect this. Importantly, however, this does not invalidate the use of this notion. We should expect greater controversy as to what constitutes a valid claim; but once we admit a claim as valid, we become able to identify vulnerable populations as those more likely to be denied fulfillment of this claim, and to identify measures likely to prevent this.

Examples of requirements proposed for ethical clinical care are shown in Table III-4. They include having access to healthcare, adequate financial coverage, not being harmed, self-determination, confidentiality, getting fair consideration in resource allocation, and having a voice as a stakeholder in healthcare. Access can be further divided into the elements proposed by Penchansky and Thomas: availability, or the degree to which the provider has the necessary resources to meet the patient’s needs, accessibility, or the ease with which the patient can physically reach the location of health services, accommodation, or the degree to which the health service is organized in ways that meet the constraints and preferences of patients, affordability, or how the provider’s charges fit with the patients’ ability and willingness to pay, and acceptability, or the extent to which patients are comfortable with the characteristics of the health services and vice versa (Penchansky and Thomas 1981; McLaughlin and Wyszewianski 2002). Examples of vulnerability linked to these requirements are shown in Table III-4.

Whenever resources are allocated, vulnerability also applies to those more likely to see their claims transgressed or discounted in allocation processes. Importantly, this may not mean that anyone less likely to have resources allocated to them is vulnerable in this way: it would depend on their risk of having their claims discounted, rather than on the final result. For example, if decisions about admission to intensive care for people with short life-expectancies were likely to be based on an evaluation that their needs should count for less, then this would constitute vulnerability. If the same decisions were systematically made with the same sort of considerations afforded anyone, such as likelihood of benefit and quality of life, then they might still be allocated intensive care less frequently, but their claim would not have been discounted.

Clearly, some populations will only be considered vulnerable in the sense proposed here if they do, indeed, have a valid claim to whatever it is they are more
likely to be denied. On some counts, this may be more controversial than in others. For example, some populations are more at risk of becoming ill in the first place (Marmot 2004). If we have a right limited to access to health care, then this would constitute a part of normal human fragility, not vulnerability as a claim to special protection. If, however, the claim to provide health care is based on a requirement to equalize health itself as a precondition of fair equality of opportunity (Daniels 1985), then a greater likelihood of becoming ill would constitute vulnerability, a claim to special protection as outlined here.

Table III-4: Protecting the vulnerable in health care

<table>
<thead>
<tr>
<th>Examples of requirements</th>
<th>Examples of vulnerability</th>
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<tbody>
<tr>
<td>Access</td>
<td></td>
</tr>
<tr>
<td>1. Availability</td>
<td>• Patients with rare diseases, need for interventions requiring expensive technology</td>
</tr>
<tr>
<td>2. Accessibility</td>
<td>• Distance from health service, responsibility for dependent relatives</td>
</tr>
<tr>
<td>3. Accommodation</td>
<td>• Long or inflexible working hours</td>
</tr>
<tr>
<td>4. Affordability</td>
<td>• Poverty, uninsured, underinsurance, distance (high transportation costs)</td>
</tr>
<tr>
<td>5. Acceptability</td>
<td>• Populations with reason to distrust the health care system</td>
</tr>
<tr>
<td>Adequate financial coverage</td>
<td>• Greater likelihood of being denied insurance, such as pre-existing conditions, or risk factors.</td>
</tr>
<tr>
<td>Not being harmed</td>
<td>• Patients more likely to be treated in unusual ways, such as health care providers and their families, or patients from whom litigation is feared.</td>
</tr>
<tr>
<td>Self-determination / Autonomy</td>
<td>• Difficulties in receiving or understanding the relevant information: not knowing the language used, or how to read</td>
</tr>
<tr>
<td></td>
<td>• Difficulties in requesting a role in decision-making</td>
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<tr>
<td></td>
<td>• Lack of decision-making capacity: some children, some patients with mental disorders, comatose patients.</td>
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<tr>
<td></td>
<td>• Lack of freedom to make a voluntary choice</td>
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<tr>
<td></td>
<td>o Through limited freedom: prisoners</td>
</tr>
<tr>
<td></td>
<td>o Through social weakness: minorities, refugees, sometimes women</td>
</tr>
<tr>
<td></td>
<td>o Through hierarchical weakness: hospital employees, students</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>• Public figures, health care providers, families of health care providers</td>
</tr>
<tr>
<td>Getting fair consideration in resource allocation</td>
<td>• Patients at risk of seeing their interest discounted, such as:</td>
</tr>
<tr>
<td></td>
<td>o terminally ill patients,</td>
</tr>
<tr>
<td></td>
<td>o elderly patients,</td>
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<tr>
<td></td>
<td>o cognitively impaired or handicapped persons,</td>
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<tr>
<td></td>
<td>o disenfranchised or socially marginalized persons.</td>
</tr>
<tr>
<td>Being a stakeholder</td>
<td>• Disenfranchised or socially marginalized persons.</td>
</tr>
<tr>
<td>Avoiding illness?</td>
<td>• Persons with less access to health literacy</td>
</tr>
<tr>
<td></td>
<td>• Persons at the bottom of socio-economic spectrum.</td>
</tr>
</tbody>
</table>

Attempts to ground obligations directly in vulnerability have been made both in
continental philosophy (Levinas 1961) and in bioethics (Thomasma 2000). Concern could exist that if we do not have a requirement to respect a principle of vulnerability, then the vulnerable could lack protection. This concern, however, presupposes an existing claim to protect the vulnerable. Clearly, then, such a claim cannot originate in the principle itself, as it seems to ground the very need for it. The present proposal accepts that the vulnerable have a claim to protection; but this claim is grounded in other claims that we recognize anyway. If a claim for anything exists, then the higher likelihood that this claim will be transgressed generates a requirement for greater attention that this claim be fulfilled whatever this, preexisting, claim may be. The obligation to avoid wrongdoing is not derived directly from a principle of vulnerability but from another source; specifically, from a valid claim that some wrong should be avoided, including the wrong we incur when a good to which we have a valid claim is denied us. If vulnerability increases the likelihood of being wronged, it also increases the attention required to avoid any wrong that we should avoid for other reasons.

However, applying this sort of protection to the vulnerable in health care is not straightforward. We could wonder whether the strength of the pre-existing claim might not be affected by the added difficulty. There are, after all, instances where duties exist in part because the burden to the agent is not too great, as in the rule of rescue (McIntyre 1994). As this suggests, however, this would depend on the sort of claim considered. In research with human subjects, for example, a claim that was too difficult to fulfil might have to lead to the exclusion of potential subjects from the protocol. This is because we do not actually have a claim to participate in research per se. In health care, this would play out very differently. If we have any claim to health care, then added difficulty would not affect it directly. How much added effort is required when more is needed is indeed an open question, but this is due to the need to balance claims against those of others (Daniels 1994), rather than because the claim itself is diminished. But this just brings us back to the original problem of fair allocation.

This definition of vulnerability is silent as to whose duty it is to fulfill existing claims. The simple answer might be that whoever had this duty in the first place still has it in the case of vulnerable persons. This, however, should mean anyone who shares in the duty to avoid the identifiable wrong (Figure III-2). Asking who is the agent responsible, as if there had to be a single one, is simplistic, as we consider that different people may have different sorts of duties to fulfill the same claim. A child’s parents may have a duty to make sure she does not fall into a pond but this does not relieve me of a duty to rescue her if I happen to be there when she does. Finally, the definition of vulnerability proposed here does not address differences in the way that people may have become vulnerable. As has been proposed, differences between vulnerabilities that originate in injustice, or misfortune, or that are the fault of the vulnerable person herself, could well be relevant (Brock 2002).
According to the view proposed here, however, this would affect the legitimacy of the claim being considered, rather than the definition of vulnerability itself. But again, this is currently a limitation to the application of such a protection to the vulnerable in health care, and thus requires further exploration.
Chapter 11 - Should ethics consultants help?

“But the therapeutic decision I’d say that in none of these situations I took it alone, so, it seems that we always look for a little help, did I...because, at least me and I think my colleagues as well are a little like that from what I’ve heard, we don’t want to remain with the doubt, with this dissatisfaction telling ourselves...with the question: did I do everything? Did I try all solutions? Did I perhaps forget something? So we try in any case to look around us for our supervisors, colleagues, specialists, social workers, or others” (Geneva Study, interview 17)

Despite experiencing ethical difficulties in allocating resources as fairly as possible, clinicians seldom use the assistance of ethics support services in facing scarcity (DuVal, Clarridge et al. 2004). Indeed, in contrast to end-of-life decisions, such as the one depicted in the quote above, they rarely discuss allocation issues among colleagues either. In this chapter, we will examine whether ethics support services could help doctors in facing scarcity (Hurst, Reiter-Theil et al. 2008). Three questions can arise. First, are doctors aware of ethical difficulties in facing scarcity? This was discussed in Chapter 4, and it clearly seems that the answer is “yes”. Second, would they perceive the kind of assistance offered by ethics support services as helpful? As we shall see, data from our European study suggests that this is the case. Third, are there reasons to think that the assistance of ethics support services would indeed help doctors in facing scarcity? We will look at this trickier question last.

Doctors’ perception of help

One of the aspects explored in our European study (see Chapter 2), was doctors’ attitudes towards possible strategies to approach scarcity-linked ethical difficulties. We asked doctors “In reflecting back on the case, could you have used:…”, and then listed forms of help including clarification of the issue, help in reviewing standard of ethics, help in weighing possible outcomes, alternative suggestions and the provision of ethics literature, but also professional reassurance that the decision was correct (Hurst, Perrier et al. 2007).

Most respondents (81%) thought that at least one type of help would be useful in the case they had described. Interestingly, doctors who reported difficulties with scarcity were as likely as others to find that help would be useful in facing ethical difficulties. The types of help most often identified as potentially useful were: professional reassurance that the decision was correct (47.5%), someone capable of providing specific advice (41.1%), help in weighing outcomes (36%), and clarification of the issues (35.9%). The types of help less often identified as useful
were: provision of relevant ethics literature (20.9%), help in talking things through with the patient (24.3%), and mediation of conflict (29.4%). There were few differences between countries regarding the perceived usefulness of help.

Clarification of the issues and mediation of conflict were perceived as less useful in Switzerland, help in talking things through with the patient was perceived as helpful more often in Italy, as was provision of relevant ethics literature in Italy and the UK. A discussion in advance was perceived as less useful in Norway. Doctors who identified their case example as a scarcity-related ethical difficulty were slightly more likely to think that specific advice would be useful (p=0.044).

So doctors in the countries we surveyed indeed report facing scarcity-related ethical issues, and also perceive the kind of help that ethics consultation can offer to be potentially useful in solving these situations.

**But would ethics consultants actually help?**

The fact that doctors seem to view the kind of help offered by ethics consultation as potentially useful in facing scarcity-related ethical difficulties suggests that such help may be useful. However, as this kind of perception can be mistaken, it goes only part of the way. So could ethics consultants indeed help doctors face scarcity in their practice? Would such help truly be useful? While there is growing evidence of the usefulness of ethics support services in general (La Puma, Stocking et al. 1992; Orr and Moon 1993; Day, Smith et al. 1994; McLung, Kramer et al. 1996; Heilicser, Meltzer et al. 2000; Schneiderman, Gilmer et al. 2003), these assessments have focused on the US and have not addressed this question. In attempting to assist doctors who face scarcity, ethics consultants could have two different, though overlapping, aims. First, they could provide assistance to doctors in the process by which these doctors make resource allocation decisions. In other words, they could make the process less difficult. Second, ethics consultants could foster resource allocation decisions that are more ethically justifiable thus contributing to a better result of the decision-making process. In this sense, they would be making both the process and the outcome more ethically sound. Both kinds of help would correspond to the guidelines formulated by the American Society for Bioethics and the Humanities in 1998 (ASBH Task Force on Standards for Bioethics Consultation 1998). Ethics support can take different forms at different institutions, ranging from advice from an individual consultant to formal deliberation within an entire committee. A core of common understanding of what ethics support is, however, is shared across these differences. For example, ethics support is not a substitute for decision-making by those who are in charge of a clinical case discussed in an ethics consultation. The aim is to respond to requests for assistance in considering the ethical implications of a difficult situation, and in using acceptable processes for
decisions when reasonable persons disagree. At no stage should stakeholders be dispossessed of their role and responsibilities in the case.

Neither do ethics support services bring something one could call a ‘superior expertise’ in the right principle to apply to resource allocation cases. As stated earlier, there are several different, and mutually incompatible, philosophical views on what constitutes fairness or, for that matter, health. This of course means that providing ethics support in situations of resource scarcity is a difficult exercise. This situation, however, is not very different from other ethically difficult cases where the tools of clinical ethics support can be applied. Making competing claims explicit, helping those involved in the situation to weigh them within the specific case, and helping them to select the ‘least worse’ one is part of the task of clinical ethics support. This may in a way be frustrating, as the identification of the right principle to apply to a difficult case may be among the expectations of clinicians towards ethics support services. However, help in combining different principles of fairness is a way of at least considering all ‘candidate’ principles of equity seriously. As shown in chapter 5, it may be a sufficiently acceptable approach. Moreover, it is also a way to start with one of the approaches already used by clinicians in the ‘comprehensive mix’ view of clinical fairness, and to build upon it by helping physicians to think through the different aspects of a hybrid view more explicitly. An example of what such a combination might look like is shown in chapter 8.

**Making the process less difficult**

The first kind of help can only be useful if doctors indeed perceive difficulties in facing scarcity. Thus, our findings at least partially indicate a need for a process that might make decisions less difficult in scarcity-related ethical difficulties. In addition, it is interesting to note that in describing how doctors make resource allocation decision, two common assumptions are made. First, these decisions are perceived as dichotomous choices: the resources is either given, or not given to the patient. Second, doctors are perceived as making these decisions on their own. Based on findings from our prior research, both of these assumptions may turn out to be false (Hurst, Hull et al. 2005). In analyzing case examples of ethical difficulties centered on resource allocation as given by 55 American internists, we found that most of these discussions involved negotiation with various affected parties, and that they were not handled as dichotomous choices. Rather, they included attempts to devise additional solutions within the complex constraints of the respondents’ health care environment.

The tasks of ethics consultation typically includes facilitation of discussion in ethically difficult situations involving different affected persons (Agich and Youngner 1991; ASBH Task Force on Standards for Bioethics Consultation 1998;
Reiter-Theil 2003). Devising alternative scenarios is also a frequent part of the consultation process. In this sense, then, ethics consultation may indeed be useful in helping doctors face scarcity. However, of the two possible aims outlined above, making the process less difficult is both the easiest to attain and the less important one. Whether or not ethics consultants would help doctors make more ethically justifiable allocation decisions is a more controversial, and more important question.

**Making decisions more ethically sound**

It must first be noted that our two questions are not wholly unrelated. Inasmuch as the process leading to a decision has ethical relevance, in making this decision more or less reflective, participatory, and legitimate, process-related assistance could in and of itself be useful in obtaining a decision that was more ethically sound. There are however several other points on which ethics support could prove useful in reaching more ethically sound decisions.

Resource allocation decisions are a matter of distributive justice, so it seems clear that ethics consultants have something to contribute to making them more justifiable. However, this begs the question of the ethical justification of ever denying useful services to patients based on scarcity. If rationing were or is considered not acceptable, then the involvement of ethics consultants would simply serve to rubber-stamp the practice and lend it an appearance of respectability, an approach of “alibi ethics” that would obviously contradict ASBH guidelines as well as opinions of practicing ethics consultants.

Setting some limits to health care is increasingly recognized as inevitable (Ubel 2001). It can arguably even be desirable. Justifiable decisions could conceivably be made to sacrifice marginal health care benefits for other important social goods, such as education for example.

This line of reasoning, however, does not provide a threshold for the type of care that can justifiably be denied. So it does not provide a straightforward rule to judge whether the limit set in an individual case is acceptable or not. Regardless of whether we are convinced that some limit to care is acceptable or not, we will encounter situations where the actual limit that is set will seem unacceptable. If we are convinced that some limit is acceptable, we will encounter situations where we are uncertain whether or not the actual limit in a specific case is or isn’t justifiable.

This outlines the first kind of help that ethics consultation could provide to doctors facing scarcity. Doctors are often highly aware of the amount of benefit that can be expected from an intervention and its alternatives, as well as of the degree of
uncertainty attached to those assessments. They are typically less aware of the concerns regarding how to define how much benefit is enough to say that an intervention is necessary, or useful, or marginal. Concepts such as “effectiveness”, “efficiency” and “appropriateness” all involve implicit thresholds that doctors may not be accustomed to thinking through. Another example is “futility”. Ethics consultants, then, could assist doctors in evaluating what may or may not count as marginal care in specific cases. In doing this, they would not be bringing any straightforward rules to bear on the definition. Rather, they would be bringing a set of considerations different from, and complementary to, the considerations readily available to doctors who are making these decisions today. For example, considerations of medical necessity are based on concepts of what constitutes sickness and health. Exactly where medical care ceases to aim at curing disease and starts to promote the enhancement of health, however, is a notably difficult question. This is because there are several ways in which we can think of health, such as normal functioning (Daniels 2000), the best attainable functioning, the lowest risk group for health-related consequences, or the absence of suffering. Furthermore, there are situations where our conclusions regarding marginal care will change depending on the concept we are using. To the degree that ethics consultants are familiar with these debates, this is one example of how their input could complement considerations brought into these decisions by doctors.

When imposing a limit is deemed acceptable in theory, issues of justice typically arise. This is a second area where ethics consultants may indeed offer useful help to doctors, who are often ill equipped to think in terms of justice and indeed rarely formulate such considerations in explaining how they reached resource allocation decisions (Hurst, Hull et al. 2005). Ethics consultants are equipped to consider questions of justice in difficult cases, and may thus help doctors come to more reflective, ethically more transparent, and ultimately better justifiable decisions. Again, this does not necessarily mean that consultants would be bringing a straightforward rule that could be applied to resource allocation cases in any simple way. Here also, they would be bringing a different and complementary kind of consideration to bear on allocation decisions. In the study presented here, we were struck by the diversity of criteria reported as relevant for denying medically beneficial but expensive services. This diversity may reflect variations in the experience of respondents, or adaptation to individual patients’ circumstances. Thus, it is not necessarily undesirable. Alternately, however, it may suggest insecurity or tension regarding how to address issues of scarcity. One consequence might be that this diversity results in inequitable access to these services as provided by different doctors. In order to overcome this variability, one possibility might be to attempt to unify the criteria by somehow developing rules stipulating which criteria are ethically acceptable and which are not. This will only go part of the way, as acceptability of criteria may vary with circumstances. In certain cases, a judgment as to the acceptability of criteria will per force have to take place on a
case to case basis. But this, in turn, does not mean that the acceptability of these
criteria is a question for which considerations of justice are irrelevant
(Hoedemaekers and Dekkers 2003). Bringing these elements to bear on decision-
making in these cases will thus again be helpful in fostering more ethically
justifiable outcomes.

A case where such assistance was helpful took place at a Swiss university hospital.
A couple from an Eastern European country was referred for diagnostic procedures
to eventually prepare for assisted reproduction. Their health insurance, however,
only covered acute treatment necessary to restore health. Had the centre accepted
the wishes of the couple, the resulting costs would have been paid by the
institution. This stimulated debate regarding the duty to offer the service or the
duty to contain costs. In this case, an interdisciplinary grand round was initiated
and the case discussed with two clinical ethicists. Their contribution focused on
discussing possible criteria for a decision. Reflection centred on whether it was
justified to make an exception to provide the expensive procedure without
payment. In this case consensus was reached that arguments of justice would not
justify making this exception. Rather, it seemed more just not to finance the
extraordinary measures through the budget of the institution which was held to
serve more the urgent needs of patients whose health was threatened. In this case,
then, a limit was deemed to be ethically justifiable, and its application in this case
was considered to be acceptable also.

There are instances in which the actual limit is not acceptable. In such situations,
one concern might be that the very involvement of ethics consultants lends a
misleading air of ethical respectability to unacceptable acts. Before concerns of this
kind become a legitimate reason for refusing involvement, however, ethics
consultants may be able to assist doctors in a number of ways. In such situations,
ethics consultants are challenged to articulate the concerns, give reasons why the
option is ethically not justified and, try to support those in charge of decision-making
to find other solutions and to communicate the problem to the relevant
bodies. In addition, even when resources are limited in an unjust or otherwise
unacceptable way, doctors are still confronted with difficult situations in which
declining to make a choice is not an option. Moreover, making resource allocation
decisions in situations of unjust limits is not itself morally problematic. Making
these decisions well is important in these settings, and may even be more important
as unjust scarcity is likely to be more pressing (Wikler 2003). Ethics consultants
could thus assist doctors facing unjust limits by helping them to bear witness to
these situations. Doctors and other health care professionals are in a special
position to witness the effects of scarcity on daily patient care. Arguably, the very
uniqueness of their perspective means that they have some degree of duty to make
any problems that arise more visible to decision-makers other than themselves. As
outlined above, however, identifying an unjust limit, as opposed to a merely
frustrating limit, can require normative considerations of justice of the kind that ethics consultants are more accustomed to dealing with. This means that the help that ethics consultants can bring in identifying unjust limits as such could be helpful to doctors in bearing witness also.

Finally, ethics consultants could help doctors by participating in the prevention of these difficulties. Resource allocation at the institutional level certainly has some impact on the frequency with which doctors encounter scarcity (Hurst, Forde et al. 2004). In this regard, institutional level allocation decisions are value-laden to a greater extent than is sometimes realized. In a UK study exploring the ethical difficulties faced by managers in primary care organizations, resource allocation decisions were identified as among the most ethically difficult that managers faced (Slowther 2004). Were they to take on a more explicit advisory role in resource allocation at the institutional level, ethics consultants could thus contribute to reducing the scarcity-related ethical difficulties encountered by doctors. This role would need to be clearly defined as the contribution of making values explicit, and bringing a different and complementary kind of consideration to bear on these decisions. There are examples in the UK of primary care organizations establishing priorities committees specifically to bring an ethical perspective to decisions about resources (Hope, Hicks et al. 1998). Some of these committees also contribute to decisions in individual cases where there is a request for treatment as an exception to the agreed limit set by the organization for the local community.

The input of ethics consultants would at all these levels would necessarily be limited. Consultants have no authority to decide about allocation of resources. They are not necessarily positioned in the chain of command that dictates allocation decisions. More importantly, the role of ethics consultants is to offer support in considering the ethical implications of a difficult situation, and in using acceptable processes for decisions when reasonable persons disagree. This role is not intended to take the decision-making role away from those whose responsibility it is. According to our findings, perception that the type of help offered by ethics support services would be useful was the same for scarcity-related ethical difficulties and other kinds of ethical difficulties. Despite this, research has shown that doctors rarely refer scarcity-related ethical issues to ethics support services. This is probably a missed occasion: ethics consultants could indeed assist doctors in facing scarcity, both by making the process less difficult, more transparent, and balanced, and by contributing to decisions being more ethically justifiable. In addition, the limit placed on resources that doctors must work with is indeed sometimes unjust. However, recognizing an unjust limit, as opposed to a merely frustrating limit, can be difficult. The expertise of ethics consultant in bringing considerations of justice to bear on real cases could be useful in making these judgments also. In none of these contributions would ethics consultants be taking over decisions, as this is not a part of their role (ASBH Task Force on Standards for
Bioethics Consultation 1998). Nor would they contribute the only decisive elements. Their role would be to bring a different and complementary kind of consideration to bear on the difficult decisions that doctors must face in situations of scarcity.

There are several reasons why scarcity-related ethical difficulties might not be referred to ethics support services. Firstly, doctors may feel powerless in situations of scarcity. Secondly, they may not realize that economic issues are value-laden and that ethical considerations explicitly or implicitly enter into all allocation decisions. Finally, they may expect ethics consultants to respond to scarcity-related ethical difficulties by setting impossibly ideal standards, such as giving the advice to set no limit at all. That this need not, and indeed ought not, to be the case should be clear from the considerations outlined here.

Though these situations are unlikely to be among the most frequently referred to ethics support services, ethics consultants should be prepared to address them. They should also see as part of their role a contribution to making doctors better equipped to face these difficult problems.

Can we help ethics consultant to help?

A recent study showed that clinicians and managers in the US Veterans' Administration shared concerns regarding limited resources while ethics committee members focused largely on other issues (Foglia et al 2009). In our own studies, we too have found that clinicians commonly face limited resources and the need to ration "at the bedside", yet rarely seek advice from ethics consultants to address the attendant ethical concerns (DuVal, Clarridge et al. 2004; Hurst, Forde et al. 2007; Hurst, Reiter-Theil et al. 2008). In our study of doctors' perception of scarcity in four European countries, most respondents (87.7%) perceived some resources as scarce, and most (78.7%) also reported some patient groups as more likely than others to be denied beneficial care on the basis of cost. Almost all respondents (97.3%) found at least one cost-containment policy acceptable. The types of policies preferred suggest that respondents are willing to participate in cost-containment, and do not want to be guided by administrative rules (70.5%) or restrictions on hospital beds (71%).

In these various surveys, the fact that clinicians and managers were concerned with resource allocation points to the reality that resource allocation is a challenge at all levels of health care – from the bedside on up. The findings suggest that organizations do well to include clinicians in discussions of resource allocation decisions for several reasons: clinicians themselves have an important role in
allocating resources; they can provide valuable feedback on consequences of allocation decisions made at the institutional level; they are willing to exercise allocation decisions, and their active inclusion in the process makes them valuable partners rather than disenfranchised and disillusioned players.

How can clinical ethicists contribute to addressing concerns about resource allocation more effectively than they appear to do in these surveys? Ethicists “will require added skills”, to address these issues. To that end, there is indeed a need for theoretical and practical development. Clinical ethicists can help address organizational allocation decisions as well, but the ground is not well trod for applying a comprehensive framework to meso-level resource allocation. A number of ingredients, however, do exist which could form part of such a process. The first ingredient necessary to promote sound resource allocation for a health care organization is clarification of its mission (Jennings, Gray et al. 2002). This should comply with more general social norms, and respect expectations that a health care organization provide adequate medical care without, for example, prioritizing diseases with more prestigious treatments at the expense of other equally valid health care needs.

A second ingredient is a process - be it a survey, focus groups, or discussions in routinely held meetings in various component units of the organization – that allows, through a give and take process, for gathering of information about the resource limitations that providers encounter in their day to day work.

A third necessary ingredient is the availability of an ongoing, iterative process that allows for realignment of resources in keeping with the organizational mission and thus reduces mismatches between assigned resources and needs. The IntegratedEthics Initiative at the VA might be such a vehicle although it is not designed specifically for this task. Daniels and Sabin have recommended a strategy of accountability for reasonableness (Daniels and Sabin 2008), and highlight instances where their framework has been applied (Daniels and Sabin 2008, 67-83). However, these examples do not cut across an entire organization. Hence their framework would do well to be merged with the more comprehensive approach to health services management provided by Shortell and colleagues (Shortell et al. 2000). Shortell envisions health care organizations as entities offering fully integrated services across a continuum of healthcare needs. So, for example, a perceived shortage of resources in the dialysis unit might be addressed by examining whether the care of patients at risk for kidney failure is sufficient to prevent end stage renal disease at the same time that an increase in dialysis beds is contemplated. Such an approach yields coordinated resource allocation and would fit well with integrated ethics approach. It requires, however, true integration across different domains of health care.
Conclusion

We conducted studies showing that doctors ration care and realize that they do so, that they attempt to include various concerns for fairness in their allocation decisions, and use various strategies for doing so. Some of these strategies are exactly the sort which we would expect to target known inequalities within health care. All these results should at least partly reassure us as to the acceptability of clinical rationing.

However, there remains considerable room for improvement, both in our knowledge and practice of clinical fairness. Exploring strategies and reasoning for fairness in clinical care, and how minimal requirements such as the protection of vulnerable people are fulfilled, will remain important. One reason will be to refine our knowledge of clinical allocation decisions. Another reason, however, is that attempts to do better must still take clinical reality into account. Looking at strategies and reasoning which were refined in practices is, moreover, useful. Here too, sometimes the insight comes from the bedside.

Another path for further study is more philosophical in nature. Practice-based concepts of fairness may be applicable, but are they robust enough for us to use in building more explicit approaches to clinical fairness? If we are to help doctors do better in integrating fairness into their allocation decisions, this needs to be part of the next steps also.

Such efforts at making fairness a more explicit concern in clinical practice will in any case be important. Neither respect for patients’ autonomy nor a concern to do all the good we can is able to morally justify a ban on rationing (Hall 1994). Moreover, rationing is inevitable: avoiding it could not form a part of a credible moral demand. The crucial ethical question, then, is not whether it should be practiced, but how. Moreover, ethical approaches to distributive justice have recently come under critique for failing to propose substantive principles on which to base such decisions (Ashcroft 2008). Our study, with its ‘half-full glass’ findings, suggests both ways in which fairness could be improved in implicit rationing, but also possible causes for alarm. Doctors take fairness into account without formal training in doing so, and may do better were the exercise more structured. Sharing experiences during continuing medical education is a traditional way of clinical learning: not including justice-based difficulties is certainly a missed opportunity. Training could also increase the ease with which doctors could articulate and thus defend fairness in the health care system. We need more detailed discussion of frameworks and of the practice of rationing by clinical judgment; and the inclusion of developing clinical ethics support services could also be of assistance.
I have already gone over these more optimistic aspects regarding how we could build on strategies already used by our respondents earlier in this thesis. Let me point out a more concerning point now. As shown in our European study, we have in Switzerland a health care system under pressure. Anxiety generated by health care costs leads insurers to tighten the degree of freedom afforded to clinicians. Doctors report feeling threatened, and also report that they set limits: almost as though this were a form of defensive medicine. They further report unequal success in defending justice-based values, although they consider them important to their practice. In such a context, articulating what fairness in clinical care means, and why it is important, takes on a special kind of urgency. Therein may be a hope of opening a necessary debate on what we consider to be reasonable and fair ways of setting limits in the health care which will be available to us.


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133


Appendices

Selected papers:


