Chapter 1
Justice and Responsibility in Health Care – An Introduction

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The cricket, having sung her song
All summer long,
Found – when the winter winds blew free –
Her cupboard bare as bare could be;
Nothing to greet her hungering eye:
No merest crumb of worm or fly.
She went next door to cry her plight
To neighbor ant, hoping she might
Take pity on her, and befriend her,
Eke out a bit of grain to lend her,
And see her through till spring: "What say you?
On insect's honor, I'll repay you
Well before fall. With interest, too!
Our ant – no willing lender she!
Least of her faults! – replied: "I see!
Tell me, my friend, what did you do
While it was warm?" "Well… Night and Day
I sang my song for all to hear."
"You sang, you say? How nice my dear!
Now go and dance your life away!"

Jean de la Fontaine

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1.1 The Question

Does a human right to health care imply individual obligations to healthy behavior? Can we refuse medical treatment to patients whose bad condition was self-inflicted? For instance, should a drunk driver bear the costs of medical care that he needs after a car accident he has caused? Should there be a difference in health care entitlements between the smoker with a heart attack who is seriously overweight and the 60-year old man who has always taken excellent care of himself and is suddenly stricken by leukemia? And how should we think about the risk-taking behavior of people engaging in extreme sports, going on a skiing holiday or on an exotic hiking trip? What should we think about parents' responsibilities for the health of their children? And how far do our individual responsibilities regarding end-of-life care reach?

These are all examples of topics raised in discussions about the role of personal responsibility in health care. On the one hand, it is most reasonable to hold people responsible for the consequences of their choices and actions. On the other hand, it is not at all clear what this idea implies in the field of health care. To what extent should we allow personal responsibility to play a role in allocating health care services or resources, or in justly distributing the costs of receiving health care?

In this book, we will explore these matters by concentrating on the following philosophical and ethical questions: How should we understand justice in health care? How should we value health? Are health care interests so important that they deserve special protection? What are its functions and do these make it different from other goods? Furthermore, how much equality should there be? Which equalities and inequalities in health and health care are unfair and which are simply unfortunate? Which matters of health belong to the domain of justice, and which to the domain of charity? And what can be a fair position of personal responsibility in these matters? Taken together, is every person to be respected as an autonomous individual in these matters, or should we think of legitimate forms of paternalism in order to promote prudent behavior, responsible decisions and healthy life styles?

As such, this book has a double objective. First, it wants to provide a comprehensive philosophical framework for understanding the concepts of justice, luck and responsibility in health care. What do we mean when using these notions? And how do they relate to each other? Our approach in this is interdisciplinary. The book brings together various lines of reasoning from the disciplines of philosophy, economics, sociology, ethics and medicine.

Secondly, it particularly wants to explore whether these concepts have practical force to guide normative discussions in the field of health care. Are they well-suited to guide us in specific contexts of health care, like the domain of prevention of infectious diseases, or in matters of reproductive technology? Most extensively: how can they help us in reflecting on our responsibilities regarding end-of-life care? What are our rights and duties in this regard? Do the concepts of justice, luck and responsibility indeed have sufficient normative force in these fields, or should we perhaps look for alternative perspectives?

1.2 Justice and Equality: Equality of What?

An important starting point for the discussion is the relationship between justice and the idea of equality. After all, the concept of 'equality' has substantial rhetorical force in the general moral discourse. The basic assumption is that ethics always starts from equality. Equality of treatment has moral priority and any departure from it is morally unacceptable unless it can be shown that it is justified because there are sufficient and good reasons for it. Proposals for equality of treatment, however, are never in need of justification. The burden of proof lies with proposals for unequal treatment. Also in our daily lives, we experience the strong force of equality as default position in ethics. Isaiah Berlin describes it as follows:

> The assumption is that equality needs no reasons, only inequality does so… If I have a cake and there are ten persons among whom I wish to divide it, then I give exactly one tenth to each, this will not, at any rate automatically, call for justification; whereas if I depart from this principle of equal division I am expected to produce a special reason (Berlin 1955–56, p. 132).

Our preference for equal treatment does not seem to need a justification. On the contrary, we generally consider it as a matter of good sense and basic politeness.

When taking a look at contemporary theories of justice, we meet the same assumption – "Equality? Yes!" – and see that the discussion focuses on the question "Equality of What?" Which kind of equality, or which conception of equality would be the best representation of a just society? Let's have a look at some highly influential theories of justice since the 1970s.

The starting point is obvious: John Rawls's *Theory of Justice* (1971). According to Rawls, a society is just when it guarantees equal basic rights and liberties to all. Social and economic inequalities between people are only justified when they are (a) 'to the greatest benefit of the least advantaged' and (b) 'attached to positions and offices open to all under conditions of fair equality of opportunity'.

In his libertarian answer to Rawls's theory, Robert Nozick (1974) poses that each individual has an equal and inalienable right to private property. Individuals have a property right in their own person (their body, talents and skills) and in the goods that they come to have through actions that conform to 'the principle of justice in acquisition' and 'the principle of justice in transfer'. Consequently, Nozick's theory is anti-redistributive: attempts to force anyone to contribute any part of his legitimate holdings to the welfare of others is a violation of that person's property rights, whether it is undertaken by private individuals or by the state. Coerced redistribution would be an unjust redistribution of private property, by illegitimately considering it to be public property.

The controversy between liberals and libertarians is well known. Rawlsians have argued that indeed they want some correction of the social and natural lottery distributing opportunities, talents and handicaps amongst individuals. This does not mean that they want to deny individual property rights over their own personhood. However, they think it to be fair that some of the proceeds of personal' talents should be redistributed to the least advantaged in society.

In 1981, Ronald Dworkin makes an important contribution to the discussion by asking whether we should talk about equality of *welfare* or about equality of *resources*? (Dworkin 1981b, c). In the first case, the object of our egalitarian concerns would be the general welfare that people experience from the resources available to them (income, time, talents and opportunities, etc.). According to Dworkin, this would be an unfavorable interpretation of egalitarianism, since it would imply – when applied to Charles Dickens's *A Christmas Carol* – that the embittered but immensely rich miser Ebenezer Scrooge should be compensated more than Tiny Tim who is crippled but nevertheless always contented. Therefore, Dworkin argues, the question concerning "Equality of What?" should focus on equality of resources. It is not because Tiny Tim has a merry nature and is always cheerful, that he does not need a wheelchair.

If, however, our egalitarian concerns are based on equality of resources, what kind of resources do we talk about? There are, after all, resources that can be allocated or distributed (like rights and liberties, income, education, health care and wheelchairs), as well as resources that cannot be allocated, but nevertheless have an important influence on the lives and opportunities of people (like talents and abilities, health, life history, social environment and cultural background). The first category is often called – in Rawlsian terms – 'primary social goods'. The point is that it is possible to distribute these goods in a just or fair way, but that is much more difficult to reflect on the second category of unalterable resources in terms of justice. In short: inequalities in the first category may be unjust. In the second category they seem to be more a matter of good or bad luck.

Two types of critique have cropped up in the debate about egalitarianism, both of which share the idea that the discussion should not focus too much on distribution of resources.

The first critique was formulated by Amartya Sen and Martha Nussbaum and entails that the debate is not so much about people possessing equal primary social goods, but about what people can *do* and *be* with these goods (Sen 1980, 1985; Nussbaum 2000, 2003). Starting point of their theory is the idea of truly human capabilities, namely what people can *do* and *be* in their lives. For Nussbaum, it is about people's real opportunities for human flourishing (like the human capability to live a good life; to be in good health; to have one's bodily integrity respected; to use one's senses, imagination and thought; to form emotional attachments; to use one's practical reason, etc.). A theory of justice should focus on the way in which people can develop their *capabilities* and are free to transform them into real *functionings*; not only having the formal opportunities, but also the freedom to actually *do* something with them. It would be utterly meaningless for Tiny Tim, for example, should he have the formal possibility to take part in the public life when the public space would not be adjusted to or accessible for wheelchairs.

The second line of critique is known as 'luck-egalitarianism', which is a family of positions associated principally with the works of Ronald Dworkin (1981b, c, 2000), Gerald Cohen (1989, 2000), Richard Arneson (1989, 1997, 1999, 2007, 2011), and John Roemer (1985, 1996, 1998). The critique entails that theories of justice should not disregard a fundamental moral intuition on just inequalities, viz. the intuition that people are responsible for the consequences of their free and conscious choices. This intuition fits in with La Fontaine's fable of the cricket and the ant. Why should the ant, having worked hard all summer long and now enjoying a nice winter stock, help the cricket who sang all summer long but is threatened by starvation during wintertime? Can the cricket make a claim of justice on the ant? According to luck-egalitarian reasoning, he cannot. The ant does not have a duty of justice to help the cricket. Should he help the cricket nevertheless, then it would be out of compassion or charity, but not out of justice.

Put differently, when John Rawls states that social and economic inequalities are justified only when they are 'to the greatest benefit of the least advantaged' and 'attached to positions and offices open to all under conditions of fair equality of opportunity', he is not concerned with the question how it comes that the most advantaged *are* most advantaged, and the least advantaged *are* least advantaged. Holding people responsible for what they choose to do with their talents and opportunities, is an important issue that, according to luck-egalitarian theorists, should be taken into consideration in our reflections on justice.

1.3 Justice and Responsibility in Health Care

In this book, we aim to explore the basic intuition of luck egalitarianism with a particular focus on health care. What is the right thing to do when someone needs a bigger piece of the cake due to special needs that arise from free and consciously made choices? What would we say when Tiny Tim has become crippled due to reckless driving and therefore needs life-long assistance? What should we do when the smoker contracts lung cancer? And what should we do when an elderly person, or a person in the beginning stages of dementia, freely chooses to live his life fully to the end, requiring the necessary care that comes with this decision? Is there a duty to die at a certain moment (Hardwig 1997)? Is there a duty to write an advance directive, thereby curbing the costs of end-of life care (Hersch Nicholas et al. 2011)? And what should happen when a pregnant couple does not wish to abort the severely handicapped fetus but decides to care for the child for as long as it takes (at a considerable cost for themselves, their family and the broader society) (Denier 2010)? Do they have a claim of justice for the necessary support? Or is this only a matter of charity, beneficence or compassion?

In mainstream bioethics, the predominant focus of questions regarding responsibility in health care has not been so much on matters of this kind. Rather, issues in the field of clinical ethics (responsibility for professional care-giving), the ethics of the patient-physician relationship (respecting autonomy, informed consent, etc.), and in the field of research ethics (use of human subjects in experiments) have been the main contexts where matters of professional responsibility (as physicians or as scientists contributing to the well-being of the patient) have been discussed.

However, a specific social focus on the relation between health care and responsibility can be found in the writings of health care ethicists and philosophers like Dan Brock (1993, 1998, 2002, 2004), Allen Buchanan (1985, 2009), Daniel Callahan (1987, 1990, 1993, 1998, 2008, 2009, 2011), Norman Daniels (1981, 1985, 1988, 2008, 2011), Yvonne Denier (2005, 2007, 2008, 2010), Gerald Dworkin (1981a), Ronald Dworkin (1993, 1994, 2000), Susan Hurley (2001, 2007), Thomas Pogge (2004), Jennifer Prah Ruger (2010), Shlomi Segall (2007a, b, 2010a, b, 2012), ter Meulen et al. (2001, 2008), Robert Veatch (1980), and Dan Wikler (1988, 2004a, b).

Taking these views into account, how then, should we think about our personal and social responsibility for health when seen from the viewpoint of social justice? Or put another way, how should we treat people who are voluntarily engaging in risky behavior and making imprudent choices? Are they to be considered as people who should bear the cost of their ‘expensive tastes’ themselves?

1.3.1 Yes, They Should!

Several arguments support the idea that people who knowingly take health risks should pay additional sums of money to carry health care costs, or should pay higher premiums for their health insurance and fend for themselves with the consequences of their imprudent choices.

1.3.1.1 Antisocial Behavior

The first argument is grounded in the antisocial character of an unhealthy life style. Just as a person can forfeit his or her right to liberty by criminal behavior, one could argue that a person can forfeit his or her right to healthcare by failing to act responsibly. It is unfair that those contributing to the insurance pool pay the extra costs of those who voluntarily engage in risky actions that increase their need for medical services, and it is fair to withhold societal funds from persons whose medical needs result from voluntary risk taking. Free riding cannot be accepted.

At the background is the idea that duties are owed to the state. Society has a right to expect a decent return on the investment it has made in public health measures, medical facilities, nursing schools, funding for biomedical research, hospital subsidies, and many other parts of the system that pertain to healthcare. This sounds reasonable, because society is not a trough filled with services and resources that should always be at our free disposal. Citizens have rights but also duties. In this sense, one could argue that sensible care for oneself and one’s health is a moral duty. It is part of what free and adult citizens with a sense of justice may expect of one another.

1.3.1.2 Voluntary Risk Taking

A second, more fundamental argument is based on the idea of moral arbitrariness. This idea refers to what we consider to be relevant or irrelevant in matters of justice. In *A Theory of Justice* John Rawls writes: "The natural distribution is neither just nor unjust. These are simply natural facts. What is just and unjust is the way that institutions deal with these facts." (Rawls 1971, p. 102, 1999, p. 87). Hence, we do not allow biological differences such as gender or race to limit our opportunities for employment and, more generally, our chances in life. We condemn gender or race discrimination because they rely on an irrelevant criterion and because these natural differences are determined by the arbitrariness of fortune. Being black or white is morally arbitrary because it is determined by the whims of nature, randomly and capriciously. One cannot be held responsible for these features, nor can one be rewarded for it. In the same line of reasoning, Ronald Dworkin's argument of the "Responsibility Cut" holds that interpersonal inequalities may be the result of preferences or ambitions but not of endowments (Dworkin 1981c, 2000). In fact, justice is about mitigating the arbitrariness of nature and fate by installing social institutions that assure equal opportunities to everyone, despite all natural and social differences.

Now, when are health inequalities between individuals unjust? At first glance, the answer is simple: when they are avoidable by just and responsible social policy (Daniels 2001; Pogge 2004). Hence, health inequalities due to determinants such as unequal access to clean water, sanitation, adequate shelter, basic education, vaccinations, and prenatal and maternal care are unjust because we believe that these inequalities are *avoidable by just and responsible social policy* that supplies these missing determinants. When health inequalities are rooted in biological differences that we *do not know* how to overcome, the situation is unavoidable, and therefore not an injustice (Buchanan et al. 2001). As such, a fair and just healthcare system mitigates arbitrary health inequalities by providing equal access to a general healthcare framework – safe environment, good quality care, support, and so on – thus contributing to equality of opportunity. If a person needs more health care (requiring hemodialysis, for instance, or a wheelchair) due to unequal bad luck, it would be unfair if society did not try to fulfill these healthcare needs and in that way reinforce unequal opportunity. Morally arbitrary health differences that we *know* how to overcome or mitigate may not determine unequal results.

Society, however, has no moral obligation to mitigate the differences in health for which we are personally responsible. When society provides the general health framework and the opportunity to be healthy, the poorer health status of individuals who *voluntarily* smoke and drink heavily is not unfair because in cases of voluntary risk taking, the differences in healthcare needs are no longer considered to be morally arbitrary. On the contrary, they are the result of gambling. For this argument, Dworkin's distinction between two kinds of luck is useful (Dworkin 2000, pp. 73ff.). If a person is made worse off because gambles he has made turned out badly, that is, because he has had poor *option luck*, then egalitarian concerns are not triggered. If on the contrary, he fares worse than others because of matters outside his control, then he is a victim of poor *brute luck*, and egalitarian concerns come to the fore.

All in all, the third argument in favor of holding individuals responsible for the consequences of their behavior makes individual choice central. In cases of health gambling the so arisen healthcare needs are no longer generic, archetypical, and common to all, but result from personal preferences or desires. So in that case, they are "volitional" or "adventitious" needs, resulting from poor option luck (Frankfurt 1988; Braybrooke 1987; Denier 2007). Basic health care needs and special health care needs that are due to brute luck are morally arbitrary. Volitional healthcare needs are not, because they result from individual reckless behavior. So when we do not allow morally arbitrary differences to determine how social burdens and benefits ought to be allocated, personal responsibility becomes relevant.

1.3.1.3 Mitigating Moral Hazard

The fourth argument is practical. Suppose society explicitly chooses to punish risk-taking behavior (whether by excluding individuals from some healthcare entitlements or by demanding higher insurance premiums), and suppose that this would scare a considerable number of people away from smoking, drinking, unsafe sexual activities, and other forms of hazardous behavior. Suppose furthermore that this would help raise additional financing for health care services caused by voluntary bad behavior? Wouldn't this be a very efficient way to prevent unnecessary and avoidable healthcare costs? If doing so would help to maximize cost effectiveness in healthcare, why would we be against it (Rakowski 1991)?

1.3.1.4 Merit

In the final argument the criterion of personal merit is made central. Meritarian conceptions are above all grading ones. They refer to all kinds of qualities or performances with respect to which individuals may be graded. Advantages are allocated in accordance with amounts of energy spent (efforts) or kinds of results achieved (achievements). What is judged is particular conduct that distinguishes persons from one another, and not the fact that all parties are human beings. Merits are "acquired," that is to say, they represent what its possessor has made of her natural endowments and environmental opportunities.

What should be stressed is the importance of meritarian criteria in our general thinking about justice (Miller 2001). Dworkin's argument of the responsibility cut has roots in common experience and perception. People generally see a difference between nonmeritarian health crises and nonpure cases in which merit considerations do not seem wholly irrelevant. People do tend to feel and think differently about the drunk driver who has caused a car accident and the teenage cyclist who was hit in the accident and now suffers brain damage; about the smoker having a heart attack who is seriously overweight and the 60-year-old man with a healthy lifestyle who is suddenly stricken by leukemia. Furthermore, cases like that of the leukemia patient who has always taken excellent care of himself raise reactions such as "this is so undeserved!" People generally sense that benefits and burdens should be distributed in a way that is proportional (or at least related) to effort. Common sense strongly supports the idea that merit considerations are not wholly irrelevant to the allocation of health care resources. If this were not the case, the issue of responsibility in healthcare would not be a topic of discussion.

1.3.2 Counterconsiderations

Several arguments, however, maintain that even if we agree that the notion of merit plays a very important role, the idea of justice is not exhaustively characterized by it (Dworkin 1981a; Denier 2005, 2007; Prah Ruger 2010). According to this line of reasoning, the notion of merit is especially ill-suited to play a primary role in the determination of policies that should govern a system of healthcare. Why is it so ill suited?

To begin with, the practical applicability of the admission of merit considerations in the instance of healthcare delivery appears limited. A policy of withholding societal funds cannot be justified unless several conditions are met. First, it must be possible to identify and differentiate various *causal factors* in morbidity, such as natural causes, social environment, and personal activities, and it must be confirmed that a pertinent disease or illness actually results from *personal activities*, rather than from some other cause. Additionally it must be shown that the personal activities in question were *autonomously undertaken* in the sense that the actors were aware of the risks and voluntarily accepted them. Furthermore, locating the autonomous risk takers would require a rigid and complex framework of research policy. To make such a policy legitimate, considerable moral objections, for instance privacy considerations, would have to be overcome. Moreover, all this would have to be cost-effective indeed. Finally we show that luck egalitarianism clashes with a consistent understanding of the principle of fair equality of opportunity.

1.3.2.1 Unambiguous Causality?

Regarding the first condition, although it is possible to define general risks from identifiable types of conduct, it is virtually impossible to draw an unambiguous link between an example of that conduct and a particular health consequence. Medical needs often result from many influences of very different kinds varying from genetic predispositions, personal actions and habits, and environmental and social conditions (Sen 2002; Wikler 2004a, b). It is often impossible to establish the respective roles of different factors on the basis of scientific evidence. Whereas it is mostly possible to determine responsibility for an injury in mountain climbing or skiing, it is not possible to determine with certainty whether a particular individual's lung cancer resulted from smoking, environmental pollution, occupational conditions, heredity, or some combination of these. Although we know that smoking increases the risk of lung cancer, we also know that many nonsmokers die of lung cancer each year and many smokers live to old age. All in all, while we can identify conduct that increases the risk of illness or injury, it remains very difficult to conclude that a particular health crisis was actually caused by a particular lifestyle choice. In these cases, social policy may rest more on ignorance of causal factors than on knowledge.

1.3.2.2 Autonomous Choice?

Second, the argument in favor of holding risk takers responsible shows great confidence in the free, voluntary, and independent character of individual choice making. However, if we want to make choice central, we have to be sure that the participation in risky behavior is *truly* voluntary. Nicotine is now widely recognized as a potently addictive drug, and alcoholism and eating disorders are diseases in their own right. But if many people in a cultural group or class behave similarly, this behavior might acquire the quality of a social or cultural norm, in which case we might wonder just how voluntary the behavior is (Wikler 2004a, b; Marmot et al. 1997; Marmot 2004; Wilkinson and Pickett 2009). A denial of a person's right to healthcare would be unfair if the person could not have acted otherwise or could have acted otherwise but only with great difficulty. At the very least, the proposition that individuals voluntarily bring many of their illnesses upon themselves must be challenged and tested in each situation in which it is invoked. This is far from easy to achieve.

1.3.2.3 Rigid Policy?

In addition to the previous issue, problems of rigidity in policing the system become relevant. To locate voluntary risk takers, officials would have to investigate the causes of accidents and diseases. In the worst-case scenario, these officials would be authorized to invade privacy, break confidentiality, and keep records in order to document health abuses that could result in restriction of the right to healthcare. In such cases the natural jungle, in which morally arbitrary differences (as in race, gender, or health) determine the results, makes room for a social jungle, in which people could be punished by society as a result of an infinite series of responsibility questions about their health behavior. This immediately raises doubts about the ethical viability of such measures. Too much insistence on the luck egalitarian claim to discredit responsible behavior might lead to harsh and counterintuitive results.

1.3.2.4 Freedom

Furthermore, we know that in real life people routinely trade health risks for other benefits. They do so when commuting longer distances for a better job, practicing certain sports, or taking a skiing holiday. So if patients needing treatment for smoking-related diseases can be fairly penalized because they smoke, we should apply the same stricture to those who drink too much alcohol, eat too much fat, drive too fast, work too hard, go out too late, go on skiing holidays, or indulge themselves in sports like mountain climbing or boxing. Within such a policy only few of us might qualify for the treatment we require in our hour of need. Although there is some plausibility to the claim that rational people should refrain from trading their health for other goods, refusing *ex ante* to allow *any* trade-offs of health for other goods may seem unjustifiably paternalistic.

1.3.2.5 Cost Effective?

Moreover, one might wonder whether health enforcement would indeed be cost-effective. One of the major reasons for the debate on responsibility in healthcare is the problem of increasing costs. The argument is based on the idea that those who choose to run health risks cost the rest of us money, and it is fair that they should pay it back, either by paying larger insurance premiums or by forgoing healthcare for their self-induced conditions.

However, there is reason to believe that this strategy would lead to counterintuitive outcomes. In addition to the fact that the organization of health enforcement would carry high financial costs besides its morally unattractive features, it ironically proves that some risk taking requires less rather than more medical care, because it results in earlier and quicker deaths. Cost-effectiveness research to compare healthcare costs has shown that low-risk, nonsmoking men with low blood pressure generate far higher healthcare costs per year of life than high-risk men who smoke and have high blood pressure (Manning et al. 1989). Ironically, it seems that people with unhealthy life styles actually might save society more in overall expenditures for both healthcare and social security than they cost (Leichter 1981; Russell 1989; Schwartz 1995). Would this be embarrassing for a luck egalitarian health system? If risk-takers do not, in fact, cost the rest of us money through reckless conduct, then there is no need to penalize them (Segall 2010a).

1.3.2.6 Forward-Looking Conceptions of Responsibility?

In addition to practical problems, the concept of fair equality of opportunity remains an important element in this discussion. A human right to healthcare is of fundamental importance in order to be able to enjoy fair equality of opportunity for good positions in society and for various life styles in one's personal life (Daniels 1985, 2008). This helps us to bear in mind two things.

Firstly, moral objections against a system of full private pocket payment of healthcare fundamentally come down to the fact that it results in a *policy of exclusion* (only the healthy and wealthy will be able to purchase insurance and medical care) from a domain that is *much too important* to allow exclusion, that is, the domain of guaranteeing fair equality of opportunity for all. A *policy of inclusion* is one of the basic reasons for a moral right to healthcare. In this same line of reasoning, Shlomi Segall (2010a) has addressed the "harshness objection" to the strict luck egalitarian reading of justice, which holds that society has no obligations of egalitarian distributive justice toward those who suffer bad option luck. Such a strict reading would imply "abandonment of the imprudent" (Anderson 1999). Segall's luck egalitarian proposal implies a guaranteed minimum for all, a "sufficientarian" distribution of resources justified on grounds of the moral requirement to meet basic needs (Segall 2010a). As such, even his luck egalitarian framework conceives of health care as a *normatively non-excludable* good, a social protection that no person could forfeit.

Additionally, fair equality of opportunity is a *forward-looking* concept. It provides the moral basis for a fallback framework that contributes to all persons' receiving a fair chance in life. Because of this, it would be unfair to cut off fair equality of opportunity in the future because of past behavior. Although it sounds paradoxical, holding people responsible for their ends means that in assuming the presence of fair institutions, we are acting as if they can exercise their underlying moral power to *form* but also to *revise* their conceptions of the good and valuable.

Does this mean that society is a trough of means and services, freely available to everyone after all? Is the debate on the role of personal responsibility with regard to the right to healthcare irrelevant? Of course not.

Most theorists on the subject agree about three elements in this regard. (1) Responsibility is an important value. People's behavior has an effect on their health, and society should not hesitate to underscore the importance of a sensible choice for a healthy lifestyle by making people conscious of the influence they have on their health needs. (2) However, society should continue to be forward-looking, both in providing incentives to avoid hazardous behavior and in offering medical help. Regarding incentives, consciousness raising health campaigns show respect for individual autonomy while appealing to people's rationality to take care of their health. The same goes for cost sharing. It is fair to require individuals who engage in risky actions that result in costly medical needs to pay higher premiums or taxes. Risk takers may be required to contribute more to particular pools such as insurance schemes or to pay a tax on their risky conduct, such as an increased tax on alcohol and tobacco. These requirements may fairly redistribute the burdens of the costs of healthcare, and they may deter risky conduct without disrespecting autonomy. The return individuals may expect from taxation of unhealthy behavior is healthcare protection for themselves. (3) It would be unjust to refuse care to people in need, even if it is clear that they were responsible for their condition. Contributing to fair equality of opportunity should continue to be one of the fundamental moral goals of healthcare. This should not change because of past behavior.

1.4 Justice and the Goal of Medicine and Health Care

What do we learn from the discussion about the relationship between justice, luck and responsibility in health care? There is a relatively broad consensus about the idea that just health care should be implemented in a multi-tiered system which involves

(1) a guaranteed minimum of decent-quality care for all, organized on a basis of solidarity (universal and mandatory insurance, risk-sharing, sometimes even with a progressive, income-based contribution system), (2) allowing that additional levels or higher levels of health care be voluntarily purchased by whoever has the possibility, income and desire to do this. (Dworkin 1993, pp. 215–216; Segall 2010a; Beauchamp and Childress 2008). The additional tier is then a matter of individual choice and responsibility, organized on the basis of various conditions determined by the insurance contract. In such a system, age and lifestyle would co-determine the height of the insurance premium.

The moral acceptability of such a system depends, of course, on the level, content and quality of the first tier. What exactly is included in the guaranteed minimum of decent-quality care for all? And how can we specify this? Here, three aspects play an important role in the discussion (Callahan 1987, 1990, 1993, 1998, 2008, 2009, 2011), *viz.* (1) the fact of infinite medical possibilities, (2) the scope and content of solidarity, and (3) our public understanding of the good human life.

1.4.1 Unlimited Medical Possibilities

First of all, we have to point at the simple contradiction between endless clinical possibilities of diagnosis and therapy on the one hand and economic affordability on the other hand, which underlies the increasing gap between supply and demand in health care (Denier 2008). This contradiction is inherently linked to scientific and technological progress. The history of medicine shows an exponential increase of diagnostic capabilities and of related therapeutic possibilities (for instance in AIDS and cancer research) (Porter 1999). Furthermore, it happens that every advance in medicine creates new needs that did not exist until the means of meeting them came into existence, or at least into the realm of the possible (like the various possibilities in assisted reproduction). As such, the history of medicine and health care disclose their infinite capacity to provide patients with ever more and ever more expensive treatments (Porter 1999; Butler 1999). The nature of health care is such that supply often generates its own demand; and to spend more on the provision of health care is often no more than to stoke the fires of further demand. As John Butler puts it:

> Since to conquer one peak is merely to reveal yet others to climb, we cannot assume that a doubling or even a trebling of the volume of resources allocated to [health care] would close the gap between supply and demand (Butler 1999, p. 7).

As such, the question of responsibility in health care re-enters the stage in a different form, *viz.* by asking what we can and may reasonably expect from the health care system. Can we reasonably continue to expect physicians to honor their Hippocratic duty of doing as much as possible for any patient? And is it reasonable to expect society to support this duty (Callahan 1987, 1990, 1998, 2008, 2009)?

According to Ronald Dworkin, we should reconsider a powerful ideal of justice in health care, which is *the ideal of insulation* (Dworkin 1993, 1994). This ideal has three features. The first involves the idea that life and health are the *Summum Bonum*, or as René Descartes put it in his *Discourse on the Method*, chief among all goods, which need to be protected and promoted by all means. Everything else is of minor importance besides them (Descartes 1994, p. 87). The second component is *equality*. The ideal supposes that even in a society that is otherwise very inegalitarian, medical care should be distributed in an egalitarian way so that no one is denied the care he needs simply because of inability to pay. The third component, which in fact flows from the other two, is the old *rescue principle*. It holds that it is unacceptable when people die, though their lives could have been saved, because the necessary resources were withheld on economic grounds.

This ideal of insulation has exerted great power throughout history. It has served medical practice for millennia and although critical voices crop up from time to time (Foucault 1963; Illich 1975; Hanson 2002; Callahan 2008, 2009), it is still instinctively accepted by most people and widely supported in political rhetoric. The power of the insulation ideal is so great that people think that it might easily be thought to provide the right standard for answering two fundamental questions of justice in health care: “How much should we spend on health care?” and “What exactly should we spend it on?” (Dworkin 1993, 1994).

However, so Dworkin urges, this is a serious mistake, for it would give the advice of spending *all* the society can on health care until it has reached the level at which no more gain in health or life expectancy is to be expected. With the increasing supply of medical technology during the last decennia, meaning that we have so much more to buy, it is unreasonable that society should treat health as lexicographically prior to all other values and treat longer life as a good that must be protected at all costs. And what should we spend it on? The egalitarian impulse of the ideal seems to recommend that medical care should be distributed according to some principle of need. However, the concept of medical need is multiply ambiguous and cannot solve the matter. Its very definition is highly contested. Who should be helped first? The person who is in urgent need of the one who can profit most from the treatment? Maybe the former will die quite soon anyway and maybe the latter still has the promise of a long and fruitful life. And how should we balance needs? Does someone need an operation if it might save his life but is highly unlikely to do so? Is someone’s need for life-saving treatment affected by the quality his life would have after successful treatment? Does someone need less treatment at 70 than at 40? Furthermore, we know that, with the increasing possibilities of contemporary medicine, the fulfillment of medical needs can still be a drain on social resources (Daniels 1981, 2001). So the old ideal of insulation fails to answer our second question, as well as our first (Dworkin 1993, 1994).

1.4.2 The Content and Scope of Solidarity

Dworkin’s alternative approach to justice in health care is based, not on the insulation of health care as a separate sphere of justice or activity, but on the contrary, on the *integration* of health care in a competition with other goods. The central idea is:

> We should aim to make collective, social decisions about the quantity and distribution of health care so as to match, as closely as possible, the decisions that people in the community would make for themselves, one by one, in the appropriate circumstances, if they were

> looking from youth down the course of their lives and trying to decide what risks were worth running in return for not running other kinds of risks (Dworkin 1993, pp. 208–209).

Dworkin's *prudent insurance ideal* argues that we should allocate resources between health and other social needs, and among different patients who need treatment, by trying to imagine what health care would be like if it were left to a free and unsubsidized market that would be corrected in three ways (1993, pp. 209–210, 1994, pp. 310–312).

The first correction is that the economic structure, including the distribution of income and wealth, should be as fair as possible. In Dworkin's view, this means that the economic structure treats all members of the community with equal concern when it divides resources equally, and then leaves each member free to spend those resources designing a life that each believes valuable. Secondly, the public at large should have reliable information about the value, cost and effectiveness of different medical treatments. In other words, everybody knows what very good doctors know. Thirdly, adverse selection should not be possible for insurance companies. This means, they should dispose of no individualized knowledge about the health risks of any particular person. Information about genetic predispositions, cultural or social determinants of individual persons should not be available. No one would be in a position to say that a particular person has a higher than average probability to contract sickle-cell anemia, diabetes, or some other disease.

In this imaginary situation, each individual is free to purchase health care insurance as much or as little as he wishes to do. The question that Dworkin invites us to ponder is: which treatments would we prudently choose to be insured for, and which would we regard as not worth the cost of the insurance? What kind of health care arrangements would develop in such a community? How much of its aggregate resources would we want to be devoted to health care? And how would medical treatment be distributed?

Carrying the model through, he discusses its implications for our own society.

> Of course, what is prudent for someone depends on that person's own individual needs, tastes, personality, and preferences, but we can nevertheless make some judgments with confidence that they would fit the needs and preferences of most [individuals in industrialized societies] (1994, p. 313).

It is important to consider what arrangements the hypothetical society would generally make, Dworkin argues, because these decisions can serve as a *guide* to what we should do to improve justice in our own real, imperfect and often unjust circumstances. The prudent insurance strategy presumably allows one to determine what justice would require in the way of a *decent minimum*. Dworkin speculates that private insurance would develop into large collective insurance arrangements, which might result in something close to a comprehensive public health insurance scheme for a *basic level* of provision, with supplemental private insurance possibilities. As such, Dworkin's position combines an argument for a moral right to health care with a limitation on that right, both based on the idea of the prudential insurer.

1.4.2.1 Probably Not Including…

Consequently, he identifies a number of disparities between the choices that people would probably make in this hypothetical world and the decisions of health care providers in the real world. Let's consider some of his proposals.

Dworkin suggests, for example, that few people would insure for life-sustaining treatment in case they fell into a persistent vegetative state; yet thousands of people are kept alive in such a condition at any time (Butler 1999). The substantial sum spent year after year in insurance premiums to provide that coverage would be at the expense of education, or job training, or culture, or investment, or travel experience, and other things that would enhance someone's actual, conscious life. The opportunity cost of such insurance would be irrationally high.

Furthermore, it is reasonable to think that almost no one would purchase insurance providing for expensive medical intervention, even of a life-saving character, after he will have entered the late stages of irreversible dementia. Almost everyone would rather prefer to make life before dementia more worthwhile. Although most prudent people would want to buy insurance to provide decent-quality custodial care, in conditions of dignity and adequate comfort, if they became demented, no one would insure for expensive, life-saving intervention in this situation. The same goes for relatively old age. The prudent insurer might not be inclined to insure for expensive technology whose main results benefit people in relatively *old age*, like life-saving treatment over the age of 85 (Dworkin 1993, p. 214, 1994, p. 315). According to Dworkin, most people would prefer to enjoy life before that age.

A further suggestion is that very few people would choose to insure for very expensive medical treatment in the last months of a terminal illness; treatment which would lengthen their lives for a few additional months. Yet some 40% of medical expenditure during the last year is on people in the last 4 months of their lives (Lubitz and Riley 1993).

This is not to say, Dworkin emphasizes, that most people would not *want* those additional months. For indeed, many people want to live as long as possible, provided they remain conscious and alert, provided they do not suffer too much pain, and provided the quality of their life stays reasonably good. The point is rather that they would not want those additional months *at too great a cost* of sacrifices in their earlier, vigorous life; a cost that would be necessary if they had to make that choice. On the other hand, they would certainly want insurance to provide the much less expensive care that would keep them as comfortable and as free of pain as possible.[1]

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[1] Note, however, that the abstract ideas of age-based rationing and limiting expensive treatment in the terminal stages of life are contested. Critics contend that age-based rationing of life-extending technologies would not save substantially on resources, in part because the provision of care, including long-tem care and support services, is expensive and cannot always be sharply differentiated from the care that prolongs life. Experts argue that saving the costs of the last few weeks of life would not produce large reductions of costs overall, and they note great difficulties in predicting the final weeks of life for many patients. See: Zweifel et al. (1999), Jahnigen and Binstock (1991), O'Connell (1996).

How much further can we go down this road? How much more insurance can we be reasonably confident people would not buy in the circumstances we are imagining? Dworkin raises one further issue that is of major importance and will become increasingly more critical in the next decades. That is, how far would people in the imagined community go in making provision for access to the ultra-expensive high-tech medical equipment now in use or being developed, like the various forms of research in molecular biology (Dworkin 2000, pp. 427–452)? Undoubtedly these technologies will save *some* lives, but just as undoubtedly at a cost that would seem very high when we consider how a community might use the funds in other ways (like for instance enhancing economy and providing more jobs and a higher standard of living conditions for more people, which are, lest it be forgotten, important social determinants of health). In this line of reasoning, people might not spend to insure for highly expensive speculative technology even though it could save some lives, like for instance separating a Siamese twin when there is only a minute chance of their survival.

1.4.2.2 But Prudently Providing…

Inversely, we might use our speculations about what people in the imaginary community would consider prudent to provide for themselves, as a guide to help us define what justice demands everyone should have. As such, 'willingness to pay' becomes a strong determinant of solidarity in health care (Schokkaert 2009; ter Meulen and Jotterand 2008; ter Meulen and Maarse 2008). What should be included in the basic package of health care coverage that should be available to everyone, at a reasonable cost, and be supplied without charge to those who cannot carry that reasonable cost themselves?

Informed and reflective people in the imagined society, ultimately deciding for themselves how to allocate their resources, might make the following decisions. They might pay to provide for life-saving techniques for diseases that tend to occur relatively *early in life*, particularly when these techniques have a high probability of success. As such, most people would consider it prudent to insure for immediate and expert treatment for handicapping conditions in childhood, including treatments which are traditionally in short supply such as those for children with speech or learning difficulties (Butler 1999, p. 22).

The point of the prudent insurance principle is that if *most prudent* people would buy a certain level of medical coverage in a free market if they had average means – that is, if nearly everyone would buy insurance covering primary medical care, hospitalization when necessary, standard prenatal and pediatric care, routine examinations, inoculations and other preventative medicine, and finally, respectful, decent, and attentive long-term care – then the *fairness* or unfairness of our real time society can be measured according to the number of people that do not have such coverage now. The above quoted elements of medical coverage would constitute the basic package that any responsible health care system would establish.

If, at the contrary, very *few prudent* people would want to buy insurance covering a much higher level of coverage – like some heroic medical technologies – it would be unjust to force everyone to have such insurance through a mandatory scheme. There are of course exceptions to the prudent insurance principle: some people have special preferences and would make decisions different from those of most others. It seems fair however, to construct a mandatory coverage scheme on the basis of assumptions about what all but a small number of people would consider appropriate, allowing those few who want to spend more on special care to do so, if they can afford it, through supplementary insurance (Dworkin 1993, pp. 219–212, 1994, p. 315).

1.4.3 What Is a Good Human Life?

The discussion about how to deal with scarcity in health care and what forms of care are appropriate towards the end of our life ultimately points to deep philosophical questions: What is a good life, and maybe even more important: What is our public understanding of a good human life (Callahan 1990)?

1.4.3.1 A Healthy Life?

For a long time the primary focus of public policy has been on realizing equal access to health care for equal need. The reason for this has been that health was considered to be essentially a matter of natural or genetic factors of which we did not really have much control. Recently one has become aware of the fact that health depends only to a minor degree on the quality and quantity of health care, and much more on various social determinants that can be influenced by public policy (Marmot 2004; Wilkinson and Pickett 2009). Hence the focus has shifted to equality in health (Segall 2007b, 2010a, b; Daniels 2008). Significant inequalities in health between people trigger us to continuously reflect on the influence of social structures on people's health status. In this regard, incentives for health promotion can be considered as an important part of a just society. A very strong argument for this is the fact that health has an important instrumental value: it determines to a significant extent the possibility of forming and realizing our life projects. Nearly everything we want to do or be in life depends on our good health. Health is surely not our only concern in life, but definitely, health is special and it deserves special protection within a just health care system.

1.4.3.2 A Free Life?

Does this mean that it is the just society's assignment to get everyone as healthy as possible? After all, attempts to change unhealthy behavior through education, exhortation, penalties, taxes, restrictions, or prohibitions do involve or border on coercion and therefore must continue to be the subject of moral reflection. The fact that good health may be valued by every person does not by itself justify these interventions, since for some people health risks seem to be less important than the benefits derived from risk-taking behavior.

Freedom is an important aspect of the good human life, and each encroachment on individual autonomy is commonly regarded as standing in need of justification (Wikler 2004b). Three kinds of justification generally come into play: (1) paternalist concerns for the person's good; (2) protection of others from burdens involuntarily imposed by the risk-taking behavior, and (3) the public's stake in the nation's health. As such, interventions aimed at altering lifestyle choices have to be evaluated along the lines of (1) the harm for the person and the question whether or not it is a truly free choice with which the person identifies (e.g. the happy smoker) or an addiction, a handicapping taste (the unhappy addict); (2) the harm to others (e.g. AIDS-prevention); and (3) the health of the nation (e.g. compulsory vaccination against infectious diseases).

Within these lines of reasoning, continuous attention must be given to the precarious balance between health and liberty, thereby being careful not to overemphasize the goal of health at the expense of other important goals. The moral perspective from which lifestyle interventions are urged, has been criticized as *healthism*, a view whereby health is being elevated from a self-interested goal to a virtue, thereby entering into the conviction that healthy people (or at least those who choose health) are better people (Skrabanek 1994). Or, as Dan Wikler has put it:

> the behavior in question may be difficult to change without considerable meddling in the individual's culture and milieu, whether these champion "wine, women, and song", or risk taking or violence, or quiet (and unathletic) contemplation. The life of the fitness-loving moderate is not for everyone, even if it is most conducive to long life and good health (Wikler 2004b).

1.4.3.3 A Long Life?

Is a good human life a long life? Is living longer living better? And how long then, should it be? Should it be a certain minimum amount of life years, based on the society's average life expectancy, a certain form of normal life span (Daniels 1988, 2008), or an aggregation of quantities of well-being (Broome 2004)?

Or put another way: Is a short life less good? Although we might spontaneously be inclined to think it is, this is probably not always the case. Yes, we want to live long and grow old, but only and at least under favorable conditions of good health. Hence, it is not so much a matter of loose additional life years, but of Qualitative Life Years (QALY's), Disability Adjusted Life Years (DALY's), or Healthy Life Expectancy (Segall 2010a). As such, we generally believe that living well is favorable over merely living longer (Temkin 2011). But how then, should we interpret living well? Probably this is related to our desire to lead a meaningful life. And this has to do with living a life that is more or less 'to the point', i.e. appropriate to the various challenges each individual is confronted with.

1.4.3.4 A Meaningful Life?

In general, people strongly believe that death at a certain age, when having lived a full life to a good end, is easier to cope with than the death of a young person, who still had hopes to fulfill many important projects in life. As such, a good life indeed implies a certain number of life years, up to a point where it can be said that one's life has been complete and that everything has been fulfilled or accomplished.

In this regard, medicine and health care have achieved enormous results in expanding the life expectancy of people. We are able to let people grow much older than in previous centuries. The flipside of this, however, is the fact that medicine and health care cannot offer a perspective of a meaningful life. Medicine and health care are able to prolong the lives of people, but they cannot offer a meaningful life. As such, new problems crop up. How should we deal with people who are convinced that their lives have been lived to the fullest extent and are now ready to die (Hardwig 1997)? What should we do with people who say that they do not want to endure physical and/or mental deterioration, simply because such a situation would be contrary to their conception of a meaningful life? And what should we do, on the other hand, with people who wish to live their lives to the fullest extent? Can we expect society to support long-term care at a very old age? And how can we make a distinction between intensive treatment and intensive care for people at high age? What would be a meaningful thing to do for physicians in such cases (Callahan 1987, 1993, 2008, 2011)?

1.5 Outline of the Book

In the succeeding chapters of the book, all the above-raised questions are being dealt with in a particular way. All together, they provide a thorough reflection on the theme of justice, luck and responsibility in health care.

In the first part of the book the contributors tackle this theme from a more fundamental philosophical and ethical perspective. Daniel Hausman sketches how inequalities in health and health care may contribute to injustice, thereby providing a critical analysis of luck egalitarian considerations of health and health care. Shlomi Segall provides a defense of radical affirmative action in health. Yvonne Denier inquires into the question of prospective parents' moral responsibility in reproduction matters. Finally, Jeroen Luyten takes the matter onto the level of our mutual moral obligations in the prevention of infectious diseases.

In the second part of the book, we focus on the implications of these philosophical and ethical debates for an ethics of end-of-life care. It opens with a contribution of John Hardwig, who as advocates the idea that at a certain moment in life we might come to the point where we are confronted with something like a moral duty to die. In the following chapter, Martin Gunderson provides an analysis of our duty to care based on the theory of democratic equality and stresses the importance of people's freedom to choose. In his contribution, Chris Gastmans analyses the theme of advance euthanasia directives and defends the idea of dignity-enhancing care for people who suffer from dementia. In his answer to Chris Gastmans, Govert den Hartogh provides a thorough analysis pro advance euthanasia directives in the case of dementia. In the final contribution to the second part of the book, Thomas Nys discusses the question whether the principle of respect for autonomy can still be relevant in guiding our conduct for people who suffer from severe dementia, and offers an thorough analysis of what exactly frightens us when we talk about old age and dementia.

1.6 About Crickets and Ants…

When taking a general look – like the Owl of Minerva – at the issue at hand, we cannot but consider the past, present and future of the discussion. In this regard, we have to bear in mind that the story of the cricket and the ant has already been present in peoples' minds for centuries. Considering the fact that the fable's most early versions were present in the Aesopica (620–560 BC), that there are versions of it in ancient Indian philosophy (Sendabar, 100 BC), in Greek philosophy (Babrius, third century AC) and Latin literature (Avianus, fifth century), in the Hebrew Bible, in the late renaissance period with Faerno (1564) and L'Estrange (1692), and with Jean de La Fontaine in the seventeenth century, until its twentieth century adaptations by William Somerset Maugham (1924), James Joyce (1939) and John Updike (1987), it is clear that the question regarding the relationship between personal responsibility and justice offers thoroughly fundamental and dateless food for thought.

New evolutions and altered expectations in the field of medicine and health care ("a new life", "a new death") have made us ask the question again: Why should the ant provide support to the cricket? Answers to this question are not univocal; and they probably they never will. What is important, however, is the presence of a continuing debate on these matters, motivated by the urge to find the most humane and dignified solution for the problem at hand.

References

Anderson, E. 1999. What is the point of equality? *Ethics* 99: 287–337.

Arneson, R. 1989. Equality and equal opportunity for welfare. *Philosophical Studies* 54: 79–95.

Arneson, R. 1997. Egalitarianism and the undeserving poor. *Journal of Political Philosophy* 5: 327–350.

Arneson, R. 1999. Egalitarianism and responsibility. *Journal of Ethics* 3: 225–247.

Arneson, R. 2007. Desert and equality. In *Egalitarianism: New essays on the nature and value of equality*, ed. K. Lippert-Rasmussen and N. Holtug, 262–293. Oxford: Oxford University Press.

Arneson, R. 2011. Luck egalitarianism – A primer. In *Responsibility and distributive justice*, ed. C. Knight and Z. Stemplowska, 24–50. Oxford: Oxford University Press.

Beauchamp, T.L., and J.F. Childress. 2008. *Principles of biomedical ethics*. Oxford: Oxford University Press.

Berlin, I. 1955–56. Equality as an ideal. *Proceedings of the Aristotelian Society* 56: 301–326.

Braybrooke, D. 1987. *Meeting needs*. Princeton: Princeton University Press.

Brock, D. 1993. *Life and death: Philosophical essays in biomedical ethics*. Cambridge: Cambridge University Press.

Brock, D. 1998. Justice health care and the elderly. *Philosophy and Public Affairs* 18(3): 297–312.

Brock, D. 2002. Priority to the worst off in health care resource prioritization. In *Medicine and social justice*, ed. M. Battin, R. Rhodes, and A. Silvers, 362–372. New York: Oxford University Press.

Brock, D. 2004. Ethical issues in the use of cost effectiveness analysis for the prioritization of health care resources. In *Public health, ethics, and equity*, ed. S. Anand, F. Peter, and A. Sen. Oxford: Oxford University Press.

Broome, J. 2004. The value of living longer. In *Public health, ethics, and equity*, ed. S. Anand, F. Peter, and A. Sen, 243–260. Oxford: Oxford University Press.

Buchanan, A. 1985. *Ethics, efficiency and the market*. Oxford: Oxford University Press.

Buchanan, A. 2009. *Justice and health care: Selected essays*. Oxford: Oxford University Press.

Buchanan, A., D. Brock, N. Daniels, and D. Wikler. 2001. *From chance to choice: Genetics and justice*. Cambridge: Cambridge University Press.

Butler, J. 1999. *The ethics of health care rationing. Principles and practices*. London: Cassell.

Callahan, D. 1987. *Setting limits: Medical goals in an aging society*. Washington, DC: Georgetown University Press.

Callahan, D. 1990. *What kind of life. The limits of medical progress*. Washington, DC: Georgetown University Press.

Callahan, D. 1993. *The troubled dream of life: In search of a peaceful death*. New York: Simon & Schuster.

Callahan, D. 1998. *False hopes. Overcoming the obstacles to a sustainable, affordable medicine*. New York: Simon & Schuster.

Callahan, D. 2008. Finite lives and unlimited medical aspirations. In *The contingent nature of life. Bioethics and the limits of human existence*, ed. M. Düwell, C. Rehman-Sutter, and D. Mieth, 159–167. Dordrecht: Springer.

Callahan, D. 2009. *Taming the beloved beast: Why medical technology costs are destroying our health care system*. Princeton: Princeton University Press.

Callahan, D. 2011. End-of-life care: A philosophical or management problem? *The Journal of Law, Medicine & Ethics* 39(2): 114–120.

Cohen, G. 1989. On the currency of egalitarian justice. *Ethics* 99: 906–944.

Cohen, G. 2000. *If you're an Egalitarian, how come you're so rich?* Cambridge: Harvard University Press.

Daniels, N. 1981. Health-care needs and distributive justice. *Philosophy and Public Affairs* 10(2): 146–179.

Daniels, N. 1985. *Just health care*. Cambridge: Cambridge University Press.

Daniels, N. 1988. *Am I my parent's keeper? An essay on justice between the young and the old*. Oxford: Oxford University Press.

Daniels, N. 2001. Justice, health, and healthcare. *The American Journal of Bioethics* 1(2): 2–16.

Daniels, N. 2008. *Just health: Meeting health needs fairly*. Cambridge: Cambridge University Press.

Daniels, N. 2011. Individual and social responsibility for health. In *Responsibility and distributive justice*, ed. C. Knight and Z. Stemplowska, 266–286. Oxford: Oxford University Press.

Denier, Y. 2005. On personal responsibility and the human right to healthcare. *Cambridge Quarterly of Healthcare Ethics* 14(2): 224–234.

Denier, Y. 2007. *Efficiency, justice and care. Philosophical reflections on scarcity in health care*. Dordrecht: Springer.

Denier, Y. 2008. Mind the gap! three approaches to scarcity in health care. *Medicine Healthcare and Philosophy* 11(1): 73–87.

Denier, Y. 2010. From brute luck to option luck? On genetics, justice and moral responsibility in reproduction. *The Journal of Medicine and Philosophy* 2(35): 101–129.

Descartes, R. 1994. *Discourse on the method*, ed. and trans. Heffernan, G. Notre Dame: University of Notre Dame Press.

Dworkin, G. 1981a. Taking risks, assessing responsibility. *The Hastings Center Report* 11(5): 26–31.

Dworkin, R. 1981b. What is equality? Part 1: Equality of welfare. *Philosophy and Public Affairs* 10(3): 185–246.

Dworkin, R. 1981c. What is equality? Part 2: Equality of resources. *Philosophy and Public Affairs* 10(4): 283–345.

Dworkin, R. 1993. Justice in the distribution of health care. *McGill Law Journal* 38: 883–898. Reprinted in *The ideal of equality*, eds. M. Clayton, and A. Williams, 203–222. Basingstoke: Palgrave Macmillan.

Dworkin, R. 1994. Justice and the high cost of health, first appeared as will Clinton's plan be fair? *New York Review of Books* 41(1–2): 20–25. Reprinted in Dworkin, R. 2000. *Sovereign virtue. The theory and practice of equality*, 307–319. Cambridge: Harvard University Press.

Dworkin, R. 2000. *Sovereign virtue. The theory and practice of equality*. Cambridge: Harvard University Press.

Foucault, M. 1963. *Naissance de la Clinique*. Paris: Presses Universitaires de France.

Frankfurt, H.G. 1988. Necessity and desire. In Id., *The importance of what we care about*, 104–116. Cambridge: Cambridge University Press.

Hanson, R. 2002. Why health is not special: Errors in evolved bioethics institutions. *Social Philosophy and Policy* 19(2): 153–179.

Hardwig, J. 1997. Is there a duty to die? *The Hastings Center Report* 27(2): 34–42.

Hersch Nicholas, L., K.M. Langa, T.J. Iwashyna, and D.R. Weir. 2011. Regional variation in the association between advance directives and end-of-life Medicare expenditures. *Journal of the American Medical Association* 306(13): 1447–1453.

Hurley, S. 2001. Luck and equality. *Proceedings of the Aristotelian Society* 75(supp vol): 51–72.

Hurley, S. 2007. The 'what' and the 'how' of distributive justice and health. In *Egalitarianism: New essays on the nature and value of equality*, ed. K. Lippert-Rasmussen and N. Holtug, 308–334. Oxford: Oxford University Press.

Illich, I. 1975. *Medical nemesis – The expropriation of health*. London: Calder & Boyars.

Jahnigen, D.W., and R.H. Binstock. 1991. Economic and clinical realities: Health care for elderly people. In *Too old for health care? Controversies in medicine, law, economics, and ethics*, ed. R.H. Binstock, S.G. Post, and L.S. Mills, 13–43. Baltimore: Johns Hopkins University Press.

Leichter, H. 1981. Public policy and the British experience. *Hastings Center Report* 11: 32–39. Reprinted in Leichter, H. 1991. *Free to be foolish: Politics and health promotion in the United States and Great Britain*. Princeton: Princeton University Press.

Lubitz, J., and G. Riley. 1993. Trends in Medicare payments in the last year of life. *The New England Journal of Medicine* 328: 1092–1096.

Manning, W., E. Keeler, J. Newhouse, E. Sloss, and J. Wasserman. 1989. The taxes of Sin. Do smokers and drinkers pay their way? *Journal of the American Medical Association* 261(11): 1604–1609.

Marmot, M. 2004. Social causes of social inequalities in health. In *Public health, ethics and equity*, ed. S. Anand, F. Peter, and A. Sen. Oxford: Oxford University Press.

Marmot, M., C.D. Ryff, L.L. Bumpass, M. Shipley, and N. Marks. 1997. Social inequalities in health: Next questions and converging evidence. *Social Science and Medicine* 44(6): 901–910.

Miller, D. 2001. *Principles of social justice*. Cambridge: Harvard University Press.

Nozick, R. 1974. *Anarchy, state and utopia*. New York: Basic Books.

Nussbaum, M. 2000. *Women and human development*. Cambridge: Cambridge University Press.

Nussbaum, M. 2003. Capabilities as fundamental entitlements: Sen and social justice. *Feminist Economics* 9(2–3): 33–59.

O’Connell, J.M. 1996. The relationship between health expenditures and the age structure of the population in OECD countries. *Health Economics* 5: 573–578.

Pogge, T. 2004. Relational conceptions of justice: Responsibilities for health outcomes. In *Public health, ethics and equity*, ed. S. Anand, F. Peter, and A. Sen, 135–162. Oxford: Oxford University Press.

Porter, R. 1999. *The greatest benefit to mankind: A medical history of humanity*. New York: Norton.

Prah Ruger, J. 2010. *Health and social justice*. Oxford: Oxford University Press.

Rakowski, E. 1991. *Equal justice*. Oxford: Clarendon.

Rawls, J. 1971. *A theory of justice*. Cambridge: Harvard University Press.

Rawls, J. 1999. *A theory of justice*, revth ed. Cambridge: The Belknap Press of Harvard University Press.

Roemer, J. 1985. Equality of talent. *Economics and Philosophy* 1: 151–188.

Roemer, J. 1996. *Theories of distributive justice*. Cambridge: Harvard University Press.

Roemer, J. 1998. *Equality of opportunity*. Cambridge: Harvard University Press.

Russell, L.B. 1989. Some of the tough decisions required by a national health plan. *Science* 246: 892–896.

Schokkaert, E. 2009. Willingness to pay and solidarity. In *In sickness and in health. The future of medicine: Added value & global access*, ed. M. Wynants. Brussels: VUB Press.

Schwartz, R.L. 1995. Life style, health status, and distributive justice. In *Justice and health care: Comparative perspectives*, ed. A. Grubb and M.J. Mehlman, 244–248. New York: Wiley.

Segall, S. 2007a. In solidarity with the imprudent: A defense of luck egalitarianism. *Social Theory and Practice* 33(2): 177–198.

Segall, S. 2007b. Is health care (still) special? *Journal of Political Philosophy* 15(3): 342–361.

Segall, S. 2010a. *Health, luck and justice*. Princeton: Princeton University Press.

Segall, S. 2010b. Is health (really) special? Health policy between Rawlsian and luck egalitarian justice. *Journal of Applied Philosophy* 27(4): 344–358.

Segall, S. 2012. Why egalitarians should not care about equality. *Ethical Theory and Moral Practice* 15(4): 507–519. doi:10.1007/s10677-011-9306-7 (Online First™).

Sen, A. 1980. Equality of what? In *Tanner lectures on human values*, ed. S.M. McMurrin, 195–220. Salt Lake City: University of Utah Press.

Sen, A. 1985. *Commodities and capabilities*. Amsterdam: North-Holland.

Sen, A. 2002. Why health equity? *Health Economics* 11: 659–666.

Skrabanek, P. 1994. *The death of humane medicine and the rise of coercive healthism*. London: Social Affairs Unit.

Temkin, L. 2011. Is living longer living better? In *Enhancing human capacities*, ed. J. Savulescu, R. ter Meulen, and G. Kahane, 350–367. West Sussex: Wiley-Blackwell.

ter Meulen, R., and F. Jotterand. 2008. Individual responsibility and solidarity in European health care. *The Journal of Medicine and Philosophy* 33(3): 191–197.

ter Meulen, R., and H. Maarse. 2008. Increasing individual responsibility in Dutch health care: Is solidarity losing ground? *The Journal of Medicine and Philosophy* 33(3): 262–279.

ter Meulen, R., W. Arts, and R. Muffels (eds.). 2001. *Solidarity and health care in Europe*. Dordrecht: Kluwer Academic Publishers.

Veatch, R.M. 1980. Voluntary risks to health. *Journal of the American Medical Association* 243(1): 50–55.

Wikler, D. 1988. Ought the young make health care decisions for their aged selves? *The Journal of Medicine and Philosophy* 13(1): 57–71.

Wikler, D. 2004a. Personal and social responsibility for health. In *Public health, ethics and equity*, eds. S. Anand, F. Peter, and A. Sen, 109–134. Oxford: Oxford University Press. A shorter version of this essay is available. *Ethics and International Affairs* 16(2002): 47–55.

Wikler, D. 2004b. Lifestyles and public health. In *Encyclopedia of bioethics*, ed. S.G. Post, 1406–1409. New York: Macmillan.

Wilkinson, R.G., and K. Pickett. 2009. *The spirit level: Why more equal societies almost always do better*. New York: Bloomsbury Press.

Zweifel, P., S. Felder, and M. Meiers. 1999. Ageing of population and health expenditure: A red herring. *Health Economics* 8: 485–496.