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DOUBLE SUFFICIENCY.

REQUIREMENTS OF JUSTICE IN HEALTHCARE

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Marije Versteeg - Mojanaga

Student Number: 479589

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Abstract

Billions of people worldwide cannot access the healthcare they need, giving impetus to global and local efforts to improve coverage of healthcare. How this can be done justly remains contested. In this dissertation I seek to make a contribution to current debate. I argue that a satisfactory account of justice requires a distinction between healthcare and social justice principles. Adapting Rawls' notion of a "veil of ignorance", I propose a way of thinking about prioritised packages of healthcare corresponding to intrinsic healthcare needs over a lifetime. I conclude that justice requires "Double Sufficiency", which refers to sufficient access to prioritised packages through a threshold approach. While tragic cases remain unavoidable, this approach expresses equal concern for everyone's healthcare needs.

Declaration

I declare that this report is my own unaided work. It is submitted for the degree of Master of Arts, Applied Ethics for Professionals, in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination in any other university.



Marije Versteeg-Mojanaga

Johannesburg, 28 June 2019

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Chapter 1. Why Priorities in Healthcare Distribution?

1.1 Introduction

What does justice require in the distribution of healthcare? Worldwide, countries grapple with difficult decisions how to allocate limited financial resources to meet healthcare needs justly. The question of justice in the distribution of healthcare resources is also one of the most contested topics in the field of bio-ethics. This is not surprising, given that conditions of resource scarcity require governments to make tragic choices in healthcare distribution. Setting priorities and imposing limits on the availability and accessibility of healthcare (also known as 'rationing') are matters of life and death and impact on people's health status and overall well-being. However, priority-setting in healthcare distribution cannot be avoided. It is evident that the priority-setting criteria a government uses, whether explicit or implied, has far-reaching consequences not only for the health of the population but also for individuals. Given the impact of these decisions, they ought to be informed by just and reasonable principles. Based on our moral equality as human beings, such principles must express concern for everyone's healthcare needs.

1.2 The role of health and healthcare in our lives

Health, both physical and mental, is one of the most important goods in life. Health has both intrinsic and instrumental value. A loss of health from disease and disability inhibits normal functioning and restricts opportunities in life (Daniels, 2001, p. 2). We need to be of adequate health to perform the various tasks in life that we all have reason to value— pursuing personal goals such as learning, working, caregiving, participating in community life. As such, the state of our health influences our ability to live and our capacity to function in society. We therefore have good reason to want our health to be in such condition to achieve the goals we value.

1.3 The challenge of infinite health needs and dual scarcity

In this project I will assume that the state is primarily responsible for maintaining a system of healthcare that progressively meets the healthcare needs of its people. It must use its available resources efficiently, rationally and equitably to best meet the health needs of the population.[1] This must happen within conditions of internal and external scarcity.

Internal conditions of scarcity arise from never-ending healthcare needs. For instance, new and expensive cures and treatment technologies are constantly developed,

[1] Beyond providing healthcare as an obligation, governments also have an instrumental interest in ensuring a healthy population for economic reasons. An educated and healthy workforce is needed to maintain and grow the economy, to produce goods and services for the entire nation and to ensure there are sufficient caregivers to look after the young, elderly and dependents. This in turn contributes to political stability.

expanding our horizon of what is possible in healthcare. The external conditions of scarcity refer to the fact that governments cannot spend their entire budget on healthcare alone. Not only is healthcare but one determinant of health, health itself is also not the only good people value in life. People also need access to other vital public goods such as education, food, water, sanitation and shelter.

While governments can aspire to grow the health budget and improve efficiencies to increase available funds for healthcare, tragic choices remain inevitable (Johansson, 2014, pp. 84–85). These choices can include ethical dilemmas on how to best allocate limited health resources; for example, using funds to alleviate the suffering of a few versus funding programmes to improve the health of many.

1.4 Priority-setting within healthcare and in relation to social justice

Not all health needs can be met due to resource scarcity. Priorities must be set. To set priorities within healthcare distribution, we need to identify criteria to categorise healthcare needs, such as serious and less serious needs, or urgent and less urgent needs.

In approaching the question of priorities, I will be working with a basic distinction between priority-setting *within* healthcare and priority-setting in relation to principles of social justice.

Priority-setting *within* healthcare considers the question of our intrinsic healthcare needs. The healthcare services that people need over a lifetime depend on many factors. Some healthcare needs may be very serious, such as vaccinations against fatal childhood diseases; others less so, such as healthcare to treat a sprained ankle. Some services will require urgency such as emergency medical treatment following a car accident; others less so, such as a hip replacement. In addition there is a distinction between health needs and wants: the former (as I shall understand them) refer to the healthcare services we need to be alive, free from pain and to enable us to achieve reasonable life plans in society; the latter refers to preferences, such as a pill over an injection (where both are equally effective and appropriate in a given context), and luxury healthcare such as cosmetic surgery.

Developing a hierarchy of health needs is a first step to help prioritise healthcare services which can be combined into 'priority packages of care'.

When thinking about intrinsic healthcare principles, I assume that healthcare should be allocated for the purpose of enabling people to carry out reasonable life plans (Alvarez, 2007, p. 430). Such plans could be to be able to study and work to gain an income and live a decent quality of life, to start a family and care for one's children, or to participate in community life by being able to communicate and interact with other people. While healthcare alone cannot achieve these goals, access and availability to healthcare play a significant role.

In chapter 2, I will be employing Rawls' veil of ignorance to identify principles for priority-setting according to intrinsic healthcare needs that reasonable people, not knowing their state of health or place in society, would prioritise for themselves (Rawls, 1971). These intrinsic healthcare priorities inform the design of healthcare packages, which are comprised of the healthcare services made available by the state. A healthcare package can be defined as 'essential' (containing only high priority healthcare services) or 'comprehensive' (including a range of services to meet both higher and lower priority healthcare needs). The theory that I will present is applicable to different budget sizes for healthcare. Depending on the available budget, a government could progressively expand the content of a healthcare package following a proposed set of priority rules.

As explained above, in addition to priorities *within* healthcare, an answer to the question of just priority-setting of healthcare must also be sensitive to broader questions of social justice. As Daniel Norheim (2015) explains:

> Fairness is fundamentally concerned with the overall distribution of benefits and burdens in society. Equity in health has traditionally been most concerned with equitable access to services regardless of socio-economic status (p. 711).

As such, fairness and equity are critical concepts for justice in healthcare distribution. For instance, some diseases and health conditions are more common among disadvantaged population groups due to an uneven distribution of wealth, opportunities and privileges. A just approach to healthcare distribution takes this into account. In

addition, while a healthcare package may be available to the population, this doesn't mean it is also *accessible*. Patients can face catastrophic expenditures accessing healthcare, both in terms of fee for services as in transport costs to reach centres of care. Catastrophic expenditures are known to influence patients' health-seeking behaviour, which in turn can impact treatment outcomes, and in some cases, contribute to premature deaths and the development of avoidable, permanent disabilities.

1.5 Double Sufficiency: sufficient access to sufficient healthcare

I will argue that justice requires that healthcare users must have 'sufficient access' to the healthcare package for which they are eligible based on intrinsic healthcare priorities. With 'sufficient access' I mean substantive access consisting of three components: physical accessibility (e.g. distance, opening hours), affordability and acceptability. In this project I focus primarily on physical access and affordability, while acknowledging that healthcare must be of sufficient quality and sensitive to people's social and cultural identities and needs to be accepted and used by the population.

With respect to the second question of social justice, distribution of the healthcare package can follow different patterns. Once we have identified what we want to distribute, which I have defined as healthcare that enables people to function and achieve reasonable life plans, the next question is how to apply justice to the distribution of the healthcare packages, i.e. should the distribution be equal, sufficient, prioritise the worst-off, or focus on maximising the health of the population?

This is not a simple question to answer. While justice in healthcare distribution requires the consideration of both social justice and healthcare principles, the difficulty is that these two components can pull resource allocations into different directions; i.e. the application of healthcare principles alone may result in a broader health package, resulting in fewer resources to support adequate access to the package, and vice versa. A complex set of principles and trade-offs are thus required to achieve justice in healthcare distribution.

Despite the appeal of some of the other theories I will demonstrate their shortcomings and will argue that sufficientarianism seems promising as a principle for an account of justice in healthcare distribution. I will defend the claim that we should aim for sufficient access to sufficient healthcare, or “Double Sufficiency”, whereby a package of healthcare services covering high priority health needs is expanded to include lower priority health needs, based on available resources. Priority healthcare needs are identified on the basis of intrinsic healthcare needs and grouped into packages of higher and lower priority healthcare services. My account will not propose a single fixed meaning of sufficiency but I will propose a hierarchy of health needs with corresponding thresholds.

Chapter 2: Healthcare principles for priority-setting

2.1 Introduction

In chapter one I argued that a satisfactory account of justice in healthcare distribution requires a distinction between two sorts of principles: healthcare principles vis-a-vis social justice principles. In this chapter I focus on priority principles within healthcare. In line with my overall aim to identify principles and an approach that express equal concern for people's healthcare needs in relation to reasonable life-plans, it is important to first identify which health needs are more important than others. I argue that one way of identifying such principles is by means of an adaptation of Rawls' notion of a "veil of ignorance". On the argument as I develop it, contractors situated behind a veil of ignorance would prioritise healthcare packages based on intrinsic healthcare needs.

2.2 External and internal scarcity

It might be asked why it is necessary to identify priorities inherent in healthcare. The answer is that identifying healthcare principles for priority-setting is necessary because the available budget for healthcare is constrained. As mentioned in chapter one, people have various kinds of healthcare needs, but not all these needs can be met: resources are finite and there are other important public goods that must be funded, such as education, poverty reduction and so on. While health is a critical good, we are unlikely to want to spend all our available resources on healthcare, prioritising (for instance)

expensive treatment for minor health conditions over a good education and sufficient food (Dworkin, 1993; Daniels, 2001). Beyond the inevitable trade-offs between spending on health versus other public goods, there is also a dimension of scarcity inherent in healthcare. Even if our other basic needs were fully met, funds would still be insufficient to meet all healthcare needs. This is due to the fact that a population's health needs are infinite and continuously expanding in relation to new diseases, technologies and treatment discoveries (Dworkin, 1993; Denier, 2008).

A case in point is the Human Immunodeficiency Virus (HIV), the virus that causes Acquired Immune Deficiency Syndrome (AIDS). Since the identification of HIV in the early 1980's, millions of people across the globe died of this infectious disease due to a lack of effective treatment therapies or a cure. The first generation of treatment therapies developed for people living with HIV prolonged life, but the therapies were very toxic with severe side-effects, impairing people's daily functioning and significantly diminishing their quality of life. However, once antiretroviral therapy was discovered in the mid-1990's, HIV became a chronic condition for those with access to the life-saving drugs. Subsequent advances in treatment have further reduced the side-effects, and HIV is now a manageable chronic condition; people with HIV and who are on uninterrupted treatment can live productive lives, have children, and grow old. Despite these major strides, however, the battle is not over: new challenges have emerged, particularly in the field of drug adherence and new HIV strains resistant to available treatment.

This is but one of many examples of infinite and expanding healthcare needs. Importantly, the concept of infinite health needs should be understood at population level, covering all sorts of health needs, severe and minor, that exist within a population. Some new technologies may lead to massive health gains for an individual or population, while others only minor; but even if minor, there is some gain (Dworkin, 1993). The example of HIV shows that the goalposts of what is possible in healthcare continue to shift, demanding an on-going need for priority-setting. As mentioned in chapter one, governments do not have and will never have sufficient funds to provide to its citizens all that is possible in healthcare (WHO, 2014).

Given the fact of scarcity, whether moderate or extreme, we need healthcare principles to set priorities within healthcare. These principles will guide decisions about which healthcare services to prioritise over others, when, for whom, and so on. Such principles are also needed to guide the expansion and rationing of services when the budget fluctuates. In times of economic growth, a country can expand the healthcare budget; but, equally, in times of severe economic crisis, a country may have no choice but to reduce the healthcare package due to a significantly decreased revenue base. Therefore, it is important to develop an approach to priority-setting that can be applied to changing circumstances.

2.3 Designing principles for a healthcare package

2.3.1 Defining a healthcare package

So far I have referred to priority-setting in relation to healthcare services. Healthcare services combine to form healthcare packages, which can range from 'minimum packages' to 'comprehensive packages'. Services considered for inclusion in healthcare packages include interventions related to health promotion, prevention, curative, rehabilitative and palliative health care. Interventions can include health education, medicines, treatment technologies and medical devices. One can think of the content of a package as flexible and capable of expanding or shrinking with the available healthcare budget, starting off with coverage for a baseline of healthcare services that meet the highest priority healthcare needs, and expanding to include services that meet medium and lower priority health needs. Services within the package may be available at community, primary, secondary and tertiary care levels and might be delivered by health professionals of various disciplines such as public health, medicine, nursing, rehabilitation and dentistry. Over and above individual healthcare services, services may also be targeted at the population level, such as public health interventions that aim to reduce the negative health effects of smoking through public awareness and legal reform (WHO, 2014).

My goal in the next sections is to identify an approach to package design that adequately expresses concern for people's healthcare needs in relation to the purpose of healthcare. Given limitations of space, I will provide only a sketch of the account,

which serves to illustrate the style of reasoning that I propose; more work will be required to fill out the finer details.

2.3.2 The WHO approach to package design and considerations of cost-effectiveness

I I begin by discussing an approach to package design that has been developed by the World Health Organisation (WHO). This approach is important since the WHO, an agency of the United Nations, advises its 194 member states on issues relating to public health and urges members states to take particular actions through guidelines and resolutions. It's main objective is the "attainment by all people of the highest possible level of health" (WHO, 2006, p. 2). As stated on its website, the WHO aims to "ensure that a billion more people have universal health coverage, to protect a billion more people from health emergencies, and provide a further billion people with better health and well-being" (WHO, 2019). Advice or guidelines by the WHO on priority-setting in healthcare are taken to be authoritative; and their implementation affects billions of people across the globe.

In its report entitled 'Making Fair Choices on the Path to Universal Health Coverage (UHC)', the WHO discusses healthcare and social justice principles criteria for priority-setting and trade-offs on the "path" to UHC (WHO, 2014). The WHO bases its call for UHC on the right to healthcare for all human beings. The stated goal of UHC is to ensure that:

> …all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship (WHO, 2019).

In terms of the selection and expansion of healthcare services for UHC, the authors criticise existing approaches as "ad hoc" with many countries only using "implicit criteria" (2014, p. 23). Instead, the WHO argues, such processes should be 'systematic and based on explicit, well- founded criteria' (2014, p. 23). The WHO goes on to propose three criteria for selection of services in the healthcare package. These are as follows:

- Priority on basis of cost-effectiveness of health interventions;
- Priority to the worst-off in terms of need (worst-off in terms health and/or service coverage); and
- Priority to services which offer financial protection.

In this chapter I focus primarily on the first two criteria in terms of priorities *within* healthcare itself. Issues of service coverage will be addressed to some extent in chapter three, which deals with questions of social justice in the distribution of healthcare[2].

[2] The scope of this project does not allow me to discuss the issue of 'financial protection' separately from point two; however, in chapter three, I will argue for 'substantive access' to the healthcare package, which refers to the notion that healthcare is only available if it's also accessible, financially and otherwise.

The WHO recommends that countries divide healthcare services into three levels of priority: high, medium and low. What constitutes high versus lower priority is therefore the critical question. The WHO hints that there are different ways to categorise priority services, but it recommends cost-effectiveness as the basis for an initial classification:

> In the context of health systems, it is standard to define the effectiveness of a service in terms of the total health improvement in the population. However, because different services may require vastly different resources to be implemented, effectiveness on its own is not a sensible way to select services. It is better to consider cost-effectiveness, where benefits are normalized by their costs (2014, p. 13).

The authors go on to add:

> A fair and optimal expansion of coverage gives priority to cost-effective policies and services. These are the policies and services that generate large total benefits relative to cost. Many national and international guidelines emphasize cost-effectiveness (2014, p. 9).[3]

[3] In this quote the WHO references the following sources: Ord T. The moral imperative towards cost-effectiveness. 2013; Chisholm D, Evans D. Improving health system efficiency as a means of moving towards universal coverage. Background paper for the World Health Report 2010. Geneva: World Health Organization; 2010; Williams A. Cost-effectiveness analysis: is it ethical? Journal of Medical Ethics. 1992;18:7-1; Tan-Torres Edejer T, Baltussen R, Adam T, Hutubessy R, Acharya A, Evans DB, et al., eds. Making choices in health: WHO guide to cost-effectiveness analysis. Geneva: World Health Organization; 2003

The rational for this approach is not to achieve 'overall cost savings' but to improve population health (WHO, 2014, p.13). As such, the institution suggests that countries proceed by first generating lists of health services, thereafter ranking these on the basis of cost-effectiveness in order to maximise population health benefits.

The concept of cost-effectiveness depends crucially on the idea of a benefit. In quantifying the notion of a healthcare benefit, the WHO appeals to the idea of "healthy life years saved", and recommends using an outcome measure that incorporates both gains in life years and quality of life. The most common measure of healthy life years saved is the Quality Adjusted Life Year (QALY) calculation.

As is implied by the label QALY, one of the benefits to maximise in a cost-effectiveness approach to priority-setting could be 'healthy life years' or 'improvements in health-related quality of life' (WHO, 2014, p. 8). A QALY is calculated by multiplying years of life by a "utility value" which quantifies the quality of life lived during those years. The utility value falls between 0-1, with 0 equal to death and 1 equal to perfect health. For instance, 1 year of life lived in perfect health is equal to 1 QALY (Prieto and Sacristán, 2003). QALY's can be used to compare healthcare services for different healthcare needs; the number of QALY's are multiplied by the cost of treatment, providing a score for a particular intervention which can then be compared against the scores of interventions for other conditions to determine the most 'cost-effective' interventions[4]. In the United Kingdom, a high income country with an advanced system of healthcare

[4] It is also used to compare rival therapies for the same condition but that is not the topic of discussion here.

priority-setting based on cost-effectiveness using the QALY approach, the utility value component of the QALY is established through various stakeholder engagements and research methods involving clinical experts, patients, the general public and other stakeholders to determine people's preferences between healthcare for different diseases and conditions (Soares, 2012).

In sum, the outcome of a cost-effectiveness assessment depends 1) on how high (or low) the benefit for a treatment has been scored (in terms of quality and life years gained) and 2) the actual *cost of treatment*.

Cost-effectiveness approaches based on healthy life years such as QALYs have a number of limitations, which are ethical, contextual and methodological (Pettit *et al.*, 2016). Some of the criticisms relate to healthcare principles and others to social justice principles. In this chapter I will focus primarily on the concerns related to healthcare principles.

In the following sections I will first critique cost-effectiveness as the primary criteria for priority-setting. The second critique is the method of integration of other criteria. The third critique is the complexity of the approach, which is difficult to implement in low and middle-income countries with limited resources and poor data availability.

Quality and quantity of life are clearly relevant criteria for macro-level decision-making on priorities for healthcare packages. However, one critique of prioritisation based on

QALYs and costs is that they do not consider lives as a whole and fail to adequately address differences in patient characteristics. While it is argued, in defence, that cost-effectiveness measures are fair as they treat everyone 'equally' (Williams, 1992), patients' characteristics are not equal. When unequal cases are treated 'equally', the outcomes do not prioritise the worst-off in terms of health status or socio-economic conditions. For instance, in countries with high levels of income inequality, where some have more than enough and others live in deprivation, the impact of a healthcare service on one's quality of life is very much context dependent—for the ability to cope with disease depends on one's circumstances. In addition, a person's pre-existing health status (such as healthy life years lived) also matters. So conceived, a 'reverse' pre-existing QALY status seems of significance when deciding who to prioritise in the allocation of healthcare resources. With this I mean: if someone is worse-off in terms of health over a lifetime and in terms of overall quality of life, this should be a factor to consider in priority-setting between two people with the same condition.

Let me illustrate this with two examples. A particular cancer treatment may be very effective in extending life with 20 years and score high on the cost-effectiveness ranking. Yet, what matters in conditions of scarcity, is not only that the treatment is cost-effective in relation to the numbers of years it can save, but it also matters to give priority to the young as they have had less healthy life years than an elderly person. While cost-effectiveness calculations based on QALYs may (and do) prioritise certain treatments for the young due to the many life years that can be gained, this is not based on principle, but based on a cost-effectiveness calculation.

The assessment of ‘quality’ in cost-effectiveness measures is also a subjective process. This is not a concern in itself, as we all have our own preferences, but it can become a problem when ‘quality gained’ is translated in a numerical measure used to compare ‘scores’ between conditions and diseases. The outcome of such an approach depends on ‘who’ defines quality, on what basis and how much weight is given to diverging individual assessments. Pettit et al discuss various methodological limitations with regards the assessment of quality in ‘several subgroups’ where ‘current methodological approaches undervalue the benefits acquired by patients…’ (2016, p. 4). For instance, many studies critique the QALY approach for being biased against people with disabilities. According to Persad, the UK National Health Service considers the state of living with a mobility impairment as 0·85 times equal to living in perfect health. Yet, as he explains further:

> Even if a life-year in which a person has impaired mobility is worse than a healthy life-year, someone adapted to wheelchair use might reasonably value an additional life-year in a wheelchair as much as a non-disabled person would value an additional life-year without disability. Allocators have struggled with this issue (Persad, Wertheimer and Emanuel, 2009, p. 427).

On the basis of the lower quality of life score attributed to living in a wheelchair, the allocation of a wheelchair would receive a lower overall score in the ranking of healthcare for various conditions and diseases. Yet, studies have shown the significant

impact of wheelchair access on a person's physical and mental health, play and learning, social integration and other gains that relate to autonomous living (Shore, 2017). Furthermore, the assessment of quality gains for the same intervention does not account for differences between people in different circumstances. For instance, the impact on quality of life by having access to a robust wheelchair suitable for outdoor use depends on one's circumstances. For an impoverished disabled rural child living in inhospitable terrain an appropriate wheelchair should receive a particularly high score due to the difference the device makes in the life of the child; from being home-bound to participating in school and community-life, resulting in improved independence, development and state of physical and mental health. For a wealthy elderly person living in a well-developed urban setting, with access to support services and various means of communication to participate in society, having access to the same wheelchair will certainly have an impact but not likely of the same level as the rural child. A unique QALY score for a given intervention cannot capture such nuances.

As such, problems with the measurement of the quality/utility component including "who evaluates quality of life' is a common critique of the QALY approach. Indeed, studies have found that different population groups score the "quality/utility" component of a treatment differently, such as patients versus doctors, patients versus the generalized populations and marginalized groups versus affluent groups (Pettit et al, 2016, Whitehead, 2010).

The WHO recognizes that cost-effectiveness approaches have limitations. Therefore, after services have been categorised on the basis of cost-effectiveness, the WHO urges that additional criteria are to be incorporated to benefit the worst-off both in terms of healthcare and social justice principles. Building on a consensus statement developed by a group of ethicists and economists, the WHO reports that at least ten additional priority-setting criteria should be considered in addition to cost-effectiveness. The WHO however notes that "the actual use of some of the criteria is controversial, and most ethicists would contest some of them" (p.19,20). The ten criteria fall into three categories:

(a) disease and service criteria;

(b) criteria related to characteristics of social groups; and

(c) criteria related to protection against the financial and social effects of ill health and costly treatment.

A difficulty then arises in combining the different criteria to distinguish 'high priority' from 'lower priority' criteria. As demonstrated above, many criteria are to be considered and the question is how to weigh and integrate the different criteria in a systematic and objective manner.

In illustrating how this could be done the WHO offers an example of three categories of priority services, which range from low to high cost per healthy life year. Any service that falls directly in any of the three categories can be categorized accordingly as high, medium or low priority; but services in the overlapping area (e.g. green and yellow)

need further assessment against other relevant criteria, for example, those related to priority to the worse off and financial risk protection. If the service clearly fares well against the additional criteria, it should be placed in the higher priority class in question (p.21).

Figure 3.3 Framework for integrating cost-effectiveness with other criteria when selecting services



The WHO admits that the framework provides only general guidance; service prioritization needs constant review.

I agree that the approach is an improvement over 'unsystematic service selection' (p. 22-23). But the outcome of this service prioritisation model depends on the measurement of quality of life. I have shown that a number of difficulties apply here and that a large emphasis is placed on cost of treatment. In addition, whether and to what extent other criteria such as 'worst off' are considered by decision makers (who prioritize services for priority packages at the macro-level) depends on a manual process of stakeholders assessing the relevance and weight of such other criteria in relation to each health intervention. This can be both a strength and a weakness of the model, allowing on the one hand for contextual decision-making but on the other hand also for arbitrary decision-making and/or a neglect of relevant criteria.

Lastly, the process depends on availability of cost-effectiveness data, such as the health system cost of providing a particular service (taking into account health personnel, medicines and technologies, infrastructure and others costs) which is often poorly available, particularly in low and middle income countries. Beyond methodological concerns, the model also requires significant investment in qualitative and quantitative research studies to determine stakeholder preferences, which may be unaffordable to low income countries.

In conclusion, the approach has distinct strengths, incorporating concern for the worst-off in addition to cost-effectiveness criteria, but it provides no guarantee for equal concern for people's intrinsic health needs. High priorities in terms of our health needs for autonomous living may be categorized as medium and vice versa. This means that when the budget is scarce, people with high priority healthcare needs could not receive the services they need, while people with medium healthcare needs would. This is particularly of concern in countries that face severe scarcity and where the available healthcare services may not expand beyond 'high priority', in contrast to affluent countries which are able to offer very comprehensive healthcare options to citizens including low priority healthcare.

Returning to the example of the rural child in the wheelchair, if the device has a low QALY score due to the high cost and the lower quality of life gains (due to the 0.85 score in comparison to 'perfect health') the model will place the intervention in the 'low

priority' category. While technically possible, it can only be moved to high priority through a manual process with all its related flaws. I think it is more likely that decision-makers will apply the criteria of 'prioritsing the "worst-off"' *within* the low priority group, favouring the poor rural child over others needing the same wheelchair. Yet, given its low priority status in terms of cost-effectiveness, the service will only be included after higher and medium priorities have been met.

In conclusion, while there is value in considering cost-effectiveness in relation to quality and quantity of life years, there are a number of ethical and methodological concerns that distort a natural hierarchy of health needs over a lifetime. It would instead seem that there are some high level principles that can be identified to help with priority-setting of healthcare for autonomous living over a lifetime which do not require cost-effectiveness comparisons with the related ethical and methodological constraints. For this reason, it would be useful to review the principles that define "effectiveness" in relation to the purpose of healthcare. On this basis, a hierarchy of health needs can be developed through a thresholds approach, distinguishing higher from lower priority healthcare services. Issues of cost cannot be ignored but these come into play with regards to distribution patterns, which I will discuss in the next chapter.

2.3.3 Employing Rawls Veil of Ignorance to identify intrinsic healthcare principles for package design

As discussed in chapter one, access to healthcare is a critical determinant to achieve and maintain good health, to protect us from disease and to minimize harm and

suffering caused by disease and health conditions that impair our functioning. To be able to live an autonomous life, pursuing our conception of the good life, we need to be in sufficiently good health. In this section I argue that reasonable people would define "effectiveness" of services in relation to the goal of achieving reasonable life plans.

Bearing in mind the purpose of healthcare as described earlier, the question arises as to what healthcare principles reasonable people would select for themselves. Since people rank services differently based on their state of health and position in society, an impartial approach is needed to identify principles for priority-setting in healthcare. As an alternative approach to the design of healthcare packages based on cost-effectiveness, I propose a way of thinking based on John Rawls' idea of a veil of ignorance (1971, p. 17-19). In order to explain this approach, I will need to make some brief remarks about Rawls' more general theory. I will thereafter apply Rawls' veil of ignorance to the design of healthcare packages.

In *A Theory of Justice,* Rawls develops a famous and influential theory named "Justice as Fairness" (1971), which sets out the principles for design of a just society. His theory is a version of the social contract theory, which interprets justice in terms of principles that members of a society would choose to organize themselves by, in particular, in terms of the distribution of what Rawls calls primary goods, such as rights and duties, benefits and burdens, opportunities and wealth. As Rawls develops his account, principles of justice should be chosen from a hypothetical 'original position', the defining feature of which is a 'veil of ignorance' (p. 136-137).

In the original position, Rawls's contractors are assumed to be rational agents and moral equals. They are situated behind a veil of ignorance, which means that they are entirely ignorant of their personal circumstances, positions of privilege and power, gender (p. 137); given the focus of the present dissertation, we can note that they are also ignorant of their state of health, whether or not they are living with a serious disability, whether they live in rural or urban environments, etc. The function of the veil of ignorance is to remove all conditions that enable contractors to favour their own position in the selection of principles for the distribution of primary goods. Given this interpretation of the original position, Rawls holds that rational people would take a prudent approach, attempting to benefit themselves as much as they can by securing certain primary goods for themselves, such as rights, income and wealth (p. 548).[5]

Rawls does not explicitly include health as a primary good but his theory is naturally extended to do so. In this regard, those influenced by Rawls, such as Norman Daniels, have applied the basic apparatus of the theory to health and health care (2001).[6] While

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[5] A criticism of Rawls approach is that it considers human beings as egoistic and self-centred. In defence, the contractor's choices will apply to everyone and as such is a method of impartiality. What is in the contractor's best interest is in the interest of others, as the contractor does not know his true position in society, and designs principles not knowing his wealth, race, gender, health status, and so on. As a consequence he will opt for a prudent approach to the distribution of benefits and burdens.

[6] The idea by Daniels goes as follows: if justice requires equal opportunities for all, then people would need health and health care to make use of those opportunities. While Rawls's principles provide general guidance with regards to justice in healthcare distribution, Daniels doesn't believe people would agree on principles for healthcare priorities and instead argues for procedural fairness in determining the distribution of scarce resources for health, based on four principles which are transparency for the grounds of decisions (aiming to demonstrate relevance), publicity, appeals, and enforcement. This is known as the 'accountability for reasonableness framework'. Source: Daniels, N. (2000). Accountability for reasonableness. *BMJ (Clinical Research Ed.)*, *321*(7272), 1300–1301. However, as I will argue, I believe that a number of high level principles can be identified, based on what reasonable people behind a veil of ignorance would choose.

it is noted that not everyone may design the exact same package, as people have different preferences according to their conceptions of a good life, and people will unlikely reach consensus on priorities will full knowledge of their own health needs and personal circumstances, that does not mean that there are no relevant high-level principles to guide priority-setting. These principles cannot, however, be determined from a position of unequal power, privilege and knowledge of important personal features such as health status and wealth.

Rather, the veil of ignorance approach can be employed to carry out this task. The veil I propose is partial, and in saying this, I am distinguishing the device as I will use it from the full veil of ignorance employed by Rawls. As Rawls conceives it, contractors behind the veil would have no detailed knowledge of conditions for health and disease, effectiveness of treatment and related facts. On the other hand, I will require that contractors in the original position be informed of the latest knowledge on health and disease in terms of evidence and possible needs over a lifetime, disease progression, preventable versus non-preventable conditions, cost and effectiveness of treatment. They are to think of themselves in relation to the main stages of life, and are permitted knowledge of health and disease in terms of certain and potential needs over a lifetime, disease progression, preventable versus non-preventable conditions, evidence and effectiveness of treatment. Equipped with this knowledge, they are required to choose principles of healthcare prioritisation for themselves for a whole life.

Significantly, the contractors do not know their place and personal characteristics and status in society; whether poor or rich, living rural or urban, black or white, man or female, whether they are born healthy or with a disability, whether they will grow old or die young. Under these circumstances, my question is as follows: what principles would a contractor apply to design a healthcare package for oneself over a lifetime?

For Rawls, the goal of autonomy enables people in the original position to determine the principles that govern their lives (p. 515-516). Similarly, my account, in appealing to the goals of health and health care, emphasises the importance of health in living an autonomous life. Given this assumption, the primary purpose of healthcare must be to enable people as much as possible (relative to existing health) to participate in carrying out their chosen reasonable life plans (Alvarez, 2007, p. 430). This does not entail "every kind of life plan one could imagine" but goals we all have reason to value for living a decent quality of life, such as learning, playing, working, caregiving and participating in community life. So conceived, we treat individuals as moral equals who have healthcare needs over a lifetime.

I can now, from this partial veil of ignorance, start identifying some principles that rational people from behind the veil, i.e. contractors to the social contract, would identify as higher over lower priorities. In keeping with Rawls, who says we should begin with ideal theory, the important overall rule in this exercise is that cost is constant (p. 9). The goal is not to consider the implementation of people's rational preferences, but to identify these preferences in relation to health. This means that we should be comparing

different healthcare needs for the same cost. Cost-considerations and questions of distribution will be considered in chapter 3 after establishing intrinsic health priorities. The goal is also not to pursue the question in every detail but to offer a sketch which can be developed further.

Principle 1: Prioritising serious over less serious healthcare needs

From behind the veil of ignorance, as defined above, it seems reasonable to say that contractors would prioritise serious over non-serious healthcare needs. The most serious healthcare needs relate to healthcare for diseases and conditions that are life-threatening, such as the ability to breath, followed by healthcare that prevents or treats conditions that can cause irreparable and serious harm to non-life threatening but core mental and physical bodily functions such as those identified by Ram-Tiktin[7].

Based on the above description of serious healthcare needs, it follows that if a contractor were to decide between allocating R1000 on healthcare for serious

[7] Elaborating on the work of Nussbaum and Sen's "capability accounts" (Sen, 2002b; Nussbaum, 2011)), Ram-Tiktin refers to nine key systems which are necessary for 'basic human capabilities'. These are not capabilities to achieve all that one wishes for in life, e.g. "the capability to fly" (p.151) but to achieve a level of functioning to life a good life in dignity. Central to Ram-Tiktin's account are the concepts of 'malady' and 'intactness' at the physiological level (p.149). Ram-Tiktin identifies nine key systems that need to be in tact to achieve a level of functioning to life a good life in dignity and which informs healthcare priorities. These are: 1) Thinking and emotions: The capability to perform different modes of thinking; the ability to experience a range of feelings toward the self and others; the capability to form meaningful relations with others; and the ability to understand one's own feelings and thoughts and express them to others. 2. Senses) The ability to use all five senses in order to access the world and thus enjoy and acquire new knowledge about external phenomena. 3) Circulation: The capability of blood and essential components to circulate to different parts of the body— for example, the ability to provide oxygen to tissues. 4. Respiration) The capability to supply the right dosage of oxygen to cells and expel CO2. 5) Digestion and metabolism: The capability to eat the various kinds of food that are needed for the human body. This includes the ability to digest, absorb essential materials, and excrete waste. 6) Movement and balance: The ability to crawl and stand straight at different developmental stages according to the species' functional pattern. 7) Immunity and excretion: The capability of the body to protect itself from foreign factors (antigens), to produce antibodies, and so on. 8) Fertility: The ability to reproduce. In women of a fertile age, it is also the capability to create and maintain optimal conditions for the development of the foetus until its successful delivery.
These are the physiological capabilities people require to be "in tact". However, further priorities can be set within these systems. For instance, being able to breath is more critical than the ability to walk.

healthcare need A (e.g. the ability to breath) or less serious healthcare need B (treatment for a sprained ankle), he would certainly prioritise spending the R1000 on healthcare to protect his ability to breath.

Why would it be reasonable to expect contractors to prioritise serious over less serious healthcare needs? Rawls says that decisions in the original position are to be made on the basis of rational prudence (Rawls, 1971, p. 24). This means that the goal is to achieve the greatest possible benefit for oneself. But we don't know what healthcare we might need over a lifetime. Given this principle it is clearly irrational for someone to choose healthcare to treat minor conditions before our serious conditions are attended to. The reason for this is that serious conditions have a much greater impact on our ability to carry out the life-plans that we value.

For instance, we would prioritise adequate nutritional intake during the development stage of a child's brain, which has serious life-long consequences on a person's ability to learn and take advantage of opportunities, over a minor condition like mild eczema which can be easily treated and does not severely impact functioning.

Let me say a bit more about the example of nutrition. In a document by UNICEF titled "First 1000 days – the critical window to ensure that children survive and thrive", UNICEF writes:

> The first 1000 days of life – between a woman's pregnancy and her child's second birthday is a unique period of opportunity when the foundations for optimal health and development across the lifespan are established. The right nutrition and care during the 1000 day window influences not only whether the child survives, but also her ability to grow, learn and rise out of poverty (….). The effects of stunting [a reflection of chronic malnutrition] last a lifetime, leading to impaired brain development, lower IQ, weakened immune systems and great risk of diseases later in life (UNICEF, 2017, p. 1)

Beyond other societal measures such as poverty reduction and social grants, the healthcare sector can prevent stunting and contribute to nutritional intake by making available an 'essential package' which includes:

> Growth monitoring, breastfeeding, Vitamin A, complementary & responsive feeding, nutrition counselling, supplementation when necessary (Saloojee, no date).

Some of these services are provided at clinic level, whereas others are offered by community health workers who can travel to difficult-to-reach communities or to communities known to have a low demand for healthcare for reasons such as lack of awareness.

There are of course many other examples of serious conditions, not all affecting the 1st 1000 days. Another example of a serious condition is a life-threatening disease such as cancer, which causes premature death and great suffering at any age. Related healthcare services would include screening for early diagnosis and treatment, curative treatment and palliative care.

Contractors would also consider healthcare that enables people with serious disabilities to restore a level of functioning that allows participation in society and autonomous living. Contractors, who would consider the risks of being born with disabilities or developing disabilities at a later stage in life, would want to protect themselves against this loss of autonomy and suffering caused by losing critical bodily functions such as sight and mobility. Healthcare would include for instance appropriate wheelchairs according to one's living conditions.

Principle 2: Prioritising serious healthcare needs earlier in life over later in life

Contractors situated in the original position defined in relation to health would, I claim, choose to prioritise serious healthcare needs earlier in life over those same (or similar) needs occurring later in life. An important implication of this is that severity is not something that applies in the same way across a life. This is for two reasons. First, when developing a serious condition later in life, tragic as that will be, we have had many opportunities to pursue and achieve our reasonable life plans[8]. The effects of the

[8] This is related to the 'fair innings' argument which holds that everyone is entitled to a reasonably long life and therefore we ought to give priority to the young who have, in Williams's words (1997), been 'cheated' from this opportunity. Williams, A. (1997) 'Intergenerational equity: an exploration of the "fair innings" argument.', *Health*

serious condition will also be shorter. What is worse, when encountering a serious condition early in life, such as stunting, the effects are irreversible, and their impact on our opportunities to achieve our life goals may have lifelong consequences. When contractors are to choose between healthcare to prevent or treat a serious condition early over later in life, they would thus prioritise such prevention or treatment earlier in life. Second, if we die of avoidable diseases or conditions earlier in life there will be no need for healthcare later in life. For instance, while cancer-related diseases are serious diseases at any stage in life, there is a relationship between severity and age. I argue that contractors would consider cancer treatment at a young age to be of higher priority than cancer treatment at old age.

An objection to this approach is that it does not treat human beings as moral equals, in that it prioritises the young over the old. In response to this objection, notice that moral equality is expressed by the veil of ignorance device. The argument for prioritising the young would be chosen by moral equals in a suitable position of equality.

Another objection to this principle is that very young people would not have life-plans as compared to say middle-aged people and thus have less to lose. This may be true but in response I argue that people from behind the veil would want each individual to have the opportunity to live a reasonable lifetime and hence would prioritise healthcare for

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economics, 6(2), pp. 117–32. Available at: http://www.ncbi.nlm.nih.gov/pubmed/9158965

serious needs such as treatments for life-threatening conditions earlier in life as compared to later in life.

Finally, it can be plausibly argued that society requires older people to look after the young and this priority could result in a society without caregivers. This is however not a question of intrinsic, physiological, healthcare needs and is a consideration that ought to be taken into account after identifying a set of core principles in relation to intrinsic healthcare needs. The principle of prioritising the young as such is not a static rule that ought to be adhered to at all times regardless of context and other principles. It is a high level principle that in turn informs priority-setting by citizen and expert panels in real life, who would require to take the local context into account.

Principle 3: Prioritising health promotion and prevention over cure and treatment for preventable conditions

Contractors situated in the original position defined in relation to health would prioritise health promotion and prevention over cure and treatment for preventable conditions. This is because illness leads to loss of functioning and a decrease in / or loss of ability to continue carrying out tasks as before. Consequences, beyond death from preventable conditions, may be wide-ranging; for instance, we may experience pain and suffering, miss school days and fall behind with learning, suffer loss of income or even loose our employment, and our ability to look after our dependents may be affected (financially and physical). These are effects reasonable people would want to avoid for their own sake, and for the impact on our opportunities to realize goals we value.

This principle challenges the rule of rescue, which holds that saving lives of identifiable patients should be prioritised over unidentifiable individuals, such as individuals whose lives may be saved in the near or distant future if we invest in evidence-based, effective prevention efforts now (Hope, 2001). From a veil of ignorance, if we were to require healthcare to prevent a life-threatening condition versus healthcare to treat a life-threatening condition, we would rationally prefer prevention.

An objection to this argument would be that rational contractors know that sometimes prevention efforts are not successful. Might rational contractors therefore prefer an allocation policy that gives priority to the worse-off (the sickest people) as a result? In response, the idea of prioritising prevention over treatment assumes that the required efforts and resources are prioritised and allocated to ensure effectiveness, even in difficult settings such as hard to reach rural populations. Where prevention efforts fail, people can claim a right to effective treatment. However, as an intrinsic healthcare priority, rational people would prioritise prevention over treatment. This includes interventions such as patient empowerment, e.g. giving people knowledge and tools to prevent illness, and immunisation for avoidable diseases.

Principle 4: Prioritising treatment at an early stage of disease rather than later

It is rational for contractors behind the veil of ignorance to prioritise treatment at an early stage of disease rather than later. The chances of recovery are increased, while suffering is - in most cases- decreased when disease is detected early and can be treated before progressing. Disease at a later stage of progression generally has an

increasingly incapacitating impact and is also be more difficult to treat. For instance, detecting HIV infection early will provide a pathway to appropriate treatment which can lead to better management of the disease, reduction of symptoms and a better quality of life. As a result, people's opportunities to pursue reasonable life tasks are better protected. To the contrary, late detection of HIV infection can be life-threatening and more difficult to treat, resulting in a significant negative impact on our life plans. This is not to argue that people at a late stage of disease should not receive treatment. Rather, if one were to choose between early versus late stage, we would prioritise early stage disease to increase the chances of preserving the core and mental bodily functions referred to in principle 1. Again, if people have not benefitted from this principle (due to failed prevention efforts), a claim can be made for late stage treatment if such treatment can restore core mental and physical bodily functions. This does however not deter from the fact that healthcare efforts should prioritise early stage treatment.

Principle 5: Incorporate the capacity to benefit in decision-making over resource allocations

From behind the veil of ignorance, contractors would consider the eventuality that their capacity to benefit from a particular priority treatment is minimal. As contractors do not know whether they will be young or old, need serious healthcare or less serious, they would want capacity to benefit to be an additional consideration. If, say, treatment for a serious condition in a young child will only extend life with a few weeks, or will only generate very minimal improvements to his quality of life, yet the same treatment could prevent serious suffering and life-threatening illness in an older person with lasting

benefits for years, then it would be rational for a contractor, not knowing his actual health, fortunes or needs, to take this into into account. It is rational to prioritise the somewhat less serious healthcare need over a more serious healthcare need if the capacity to benefit from treatment is minimal. (See for instance Ram-Tiktin, 2016, p. 160-162).

2.3.4 Preferences behind and without the veil of ignorance

Several other principles might well be identified to provide further nuances to the account. The purpose of this account is not to be exhaustive but to propose the idea of intrinsic healthcare priorities that rational agents behind the veil would prioritise over a lifetime. The purpose of doing so is to defend the claim that there is a hierarchy in healthcare needs. In line with the idea that people want to live autonomous lives, principles relate to 'preferences'; i.e. we 'prefer' treatment for serious conditions, e.g. life-saving treatment, over treatment for less serious conditions, e.g. treatment for a sprained ankle. As such, the veil has served to identify those preferences that all contractors would likely agree on.

After the priority rules have been selected, many questions remain undetermined. Some of these will be left to personal choice after the veil of ignorance is lifted. For instance, some people may fear natural birth and want birth by caesarean even if this involves more health risks. Another example concerns 'luxury' healthcare products, i.e. 'wants' for healthcare that do not relate to a healthcare need in the sense of a person's ability to

live and function in daily life, such as cosmetic surgery.[9] These matters are no longer questions of prudent package design from a place of ignorance. Answers to these questions can be left to society to deliberate whether or not to cover, and under what circumstances.

2.4 From principles to packages of healthcare

2.4.1 Designing packages through thresholds

Principles of intrinsic healthcare priorities such as proposed in the previous section can be combined to help inform the content of priority packages of care. There are many sorts of diseases and conditions. By clustering these in higher to lower priority groups, we can eliminate a level of prioritization based on irrelevant criteria in terms of intrinsic healthcare needs and avoid trade-offs between categories for reasons of cost.

A concern might be raised that such an 'intrinsic healthcare priorities approach' can lead to the depletion of the budget due to the cost of healthcare for high priorities before attending to other healthcare needs. From the perspective of the rational contractor this would be justified, because if high priority health needs are not attended to, opportunities to achieve reasonable life-goals are diminished. However, principle 5 on

[9] It is important to note that a similar procedure can satisfy a want for one person and a need for the other. Take for instance two women who both request breast surgery; the one woman needs surgery as the size of her breasts causes pain and reduces functioning whereas the other woman may want surgery to look more beautiful. If the purpose is merely 'to look beautiful' this would provide insufficient ground for a claim on available resources. There will however be some grey areas between wants and needs; e.g. what if the breast size is causing mental health problems, such as insecurity in unknown groups, impacting one's ability to confidently pursue a public leadership role? Ram Tiktin believes that people also have a responsibility to 'adjust their preferences, ambitions and tastes' as to what they can 'reasonably expect society to provide' (2016, 433). What one can 'reasonably expect from society', will also partially depend on a country's social norms.

"capacity to benefit" of healthcare for serious needs avoids the depletion of the budget if benefits are minimal.

This approach does not deny that minor conditions are important too; however, the purpose of this exercise has been merely to identify what healthcare we should provide first before progressively expanding packages in line with available resources.

The most important principle, then, that contractors would prudently choose (i.e. to avoid and reduce risks that would diminish one's opportunities to pursue one's life-plans) would be sufficient healthcare to support one's ability to pursue the goals we value in life. In the next section I will consider how this would inform the development of prioritized packages of healthcare.

2.4.2 Distinguishing between higher and lower priority healthcare needs

In this section I provide an illustration of how the principles help inform priority healthcare packages. The reasoning in this section is illustrative and not definitive and this is considered work in progress.

Healthcare that meets all identified principles will be considered highest priority. The principles identified thus far in the previous section were:

Principle 1: Prioritising serious over less serious healthcare needs

Principle 2: Prioritising serious healthcare needs earlier in life over later in life

Principle 3: Prioritising health promotion and prevention over cure and treatment for preventable conditions

Principle 4: Prioritising treatment at an early stage of disease rather than later

Principle 5: Incorporate the capacity to benefit in decision-making over resource allocations

1. **Highest priority healthcare**

Services in the highest priority healthcare need category would be those services for diseases and conditions that are either life-threatening or that cause irreparable and serious harm to core mental and physical bodily functions. In contexts of resource scarcity, priority is given to the young if the capacity to benefit is reasonable and it is preferable to prevent than to treat. Priority would be given to strategies that aim to detect diseases at an early stage so as to avoid people requiring treatment at more advanced stages of disease. Some of these healthcare needs are more prevalent among poor people, and rural people, due to socio-economic factors. Contractors do not know if they will be poor or rich, urban or rural, and therefore as a matter of prudence will include healthcare services for all serious conditions.

Examples of services that would be covered in the package of 'highest priority need' are essential pre-, peri-natal and post-natal care; immunisation against fatal childhood diseases such as measles and diarrhoea; access to essential life-saving medicines such as antibiotics; pain relief; screening and treatment for life-threatening conditions such as TB, HIV and childhood cancer; and nutritional support in the first 1000 days of life. Different modes of healthcare service delivery may be required depending on the

characteristics of the population groups. For instance, to ensure coverage of the 1st 1000 days in rural areas, CHWs are known to be a cost-effective intervention to reach out to inhospitable areas.

2. **High priority healthcare**

High priority healthcare is healthcare for serious conditions where capacity to benefit, in terms of age or effectiveness, is lower. The exact cut-off age, both in terms of a bottom and upper ceiling, could be discussed by a citizen panel. From a veil of ignorance, we do not know what conditions we may encounter over a lifetime nor whether we would develop any serious conditions early or later in life. It would then appear evident that contractors would prioritise the prevention of avoidable serious healthcare needs later in life by timely health promotion and prevention and early detection of diseases. It would be reasonable to also include treatment of non-avoidable conditions at an early stage of disease before they become life-threatening. Finally, contractors would prioritise healthcare that has a high impact on their ability to function with a serious disability.

Examples include preventative measures, such as screening and treatment for conditions like HIV, TB, cancer, asthma and other common serious conditions for adults. Contractors would also include healthcare for serious mental health illnesses and care and assisted devices that can significantly improve functioning.

3. **Moderate priority healthcare**

Included as part of moderate priority healthcare would be healthcare for moderately serious, non-life threatening conditions which have some impact on functioning; for example, moderate mental health problems, moderate asthma symptoms, influenza and migraines. Due to the disproportional impact of such health problems on the development of children affecting future health and well-being, these conditions in the case of children would fall in the higher priority category.

4. **Low priority healthcare**

Treatment for conditions that are not serious, i.e. conditions that are not life-threatening; do not impact people's ability to achieve life goals; do not cause pain and/or suffering; and those which do not require medical attention, or require very little, would be considered 'low priority'. Examples include mild skin conditions, a sore throat or a sprained ankle.

2.4.3 Closing remarks

As a general remark, contractors would choose the most cost-effective measures in each group in terms of rival treatments and methods of delivery, without significant compromises on quality of care. This would save funds for other healthcare needs in the same priority group, and where possible, for lesser priority healthcare needs.

In conclusion, on the basis of a rational prudent approach to priority-setting in healthcare, we should prioritise those services that can promote health and prevent, detect, and treat, serious diseases and conditions, with priority given to the young. The

most appropriate platform to provide the majority of these services is at the primary healthcare level; this is the ‘entry’ level to the healthcare system and the pathway to higher levels of care for advanced stages of disease. At the primary healthcare level individual and population-level public health measures can be used to prevent and/or detect disease early, to reduce harm and allow for timely referral when needed.

Having established intrinsic healthcare principles for a prioritised package approach the next question concerns the patterns of distribution; how can the package be distributed fairly and equitably, within and between categories of priority, taking resource constraints into account? This involves questions of social justice and will be discussed in the next chapter. Here I will argue against utilitarian approaches which prioritise benefits at the “aggregated level”, arguing instead for an approach that aims to give people sufficient access to sufficient healthcare over a lifetime.

Chapter 3. Principles of Distributive Justice

3.1 Introduction

In the previous chapter I applied Rawls' notion of a veil of ignorance in order to identify principles for healthcare priorities. The application of this device generated a hierarchy of intrinsic healthcare needs corresponding with higher and lower priorities of healthcare packages, based on rational prudence. I will henceforth refer to this as the "prioritised packages approach" to setting priorities within healthcare.

In this chapter I discuss principles for the distribution of healthcare packages defined in this way. I will compare and interrogate the morality of rival theories of distributive justice: the utilitarian principle, egalitarianism, prioritarianism, pluralism and sufficientarianism (Johansson, 2014, p. 87). By so doing I hope to identify principles for the just distribution of healthcare packages that express equal concern for everyone's healthcare needs.

My method is as follows. In each section I begin with a sketch of the distributive approach; thereafter, I discuss some of its objections, before applying the approach to the idea of structured, hierarchical packages.

3.2 Utilitarianism

Utilitarianism is an ethical theory that defines the right in terms of the good. When applied to the distribution of healthcare, utilitarianism assesses the justice of a

distribution in terms of the ‘good’, i.e. ‘utility’, it produces. There are many forms of utilitarianism, but the basic idea is that a just distribution will produce the greatest net benefit, as a balance of benefits over harms. This is different from deontological approaches to healthcare, which might claim that people have a right to healthcare.

Applied to healthcare, a morally good outcome for utilitarianism is an outcome which produces the best possible health outcome for the population. It is not concerned with prioritizing access to healthcare for the worst-off or with equal distribution, but with the total aggregated outcome of benefit. This is also referred to as health-maximising (Persad, Wertheimer and Emanuel, 2009)As explained in chapter 2, when needing to trade-off different healthcare interventions, principles of cost-utility are applied and the most cost-effective intervention is the right intervention. This is done through formula’s considering gains in quantity and quality of life such as QALYs and Incremental Cost Effectiveness Ratios (ICERs), which compare the cost-effectiveness between interventions for the same or different conditions (see for instance Bognar, 2015).

In chapter 2 I discussed some of the concerns with this approach. In particular, a lot depends on how “benefit” and “utility” is defined. But the greatest problem for considerations of equal healthcare needs arise when cost-effectiveness calculations are used to calculate aggregated population benefits. Such calculations can lead to minor conditions producing a higher overall health gain in comparison to serious conditions due to their higher prevalence among the population. Persad et al. explain how the use

of QALYs multiplied by population numbers can distort the natural hierarchy of health needs:

> Treatment of a serious disease such as appendicitis gives a few people many more QALYs, whereas treatment of a minor problem like uncapped teeth gives many people a few more QALYs. Even though the two strategies [might] produce equal numbers of QALYs, they treat individuals very differently (Persad, Wertheimer and Emanuel, 2009, p. 6).

As this example shows, a utilitarian would not distribute healthcare packages along a hierarchy of intrinsic healthcare needs. As such, utilitarians would also not design packages on basis of higher and lower priority healthcare needs but along the principle of be 'highest net benefit'. To establish highest net benefit, health gains are compared against various costs. These include the cost of treatment but also the cost of making services accessible to people who need them. As such, a utilitarian approach to healthcare distribution would not be intrinsically concerned with the exclusion of, say, remote rural communities to high priority healthcare if rural cost drivers and low population densities make care inefficient and therefore reduces the maximising effect within the available budget. Based on the higher cost of providing a particular intervention to hard to reach populations, such populations fail to have adequate access[10] to high priority healthcare, while other populations enjoy easy access to high

[10] In this instance, access that is affordable and timeous. While one may argue in theory that rural populations may travel to urban centres for healthcare, living conditions and cost of travel undermine real access. Furthermore, high

and even lower priority healthcare needs due to the higher overall aggregated health gain. Where high priority healthcare services are delivered to rural populations, this would be in result of a cost-effectiveness analysis which takes indirect costs into account, perhaps showing that delayed health-seeking behaviour, and related social costs, is ultimately more costly to the health system and society and resulting in a lower aggregated benefit over time. The determining principle is not health rights or needs.

While the above concerns should be acknowledged, it is important to remember that the core idea behind utilitarianism as a distributive theory is that goods should be distributed so as to produce the greatest net benefit. We can therefore consider a version of utilitarianism as applied to the distribution of healthcare packages. Let's say a utilitarian agrees with the proposed hierarchy of the prudent healthcare package; but would argue that the package as a whole needs to be distributed in a utilitarian manner; maximising end outcomes within the constraints of the hierarchy.

The utilitarian might decide to prioritise the distribution of the healthcare package in dense urban populations, which are easily accessible, with higher economies of scale and lower costs of delivery as compared to rural populations. A utilitarian might also decide to expand from high to medium priorities in such urban areas before reaching adequate coverage in rural areas if this leads to a higher overall net benefit at population level.

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priority healthcare aims to prevent life-threatening conditions so that travel for diseases at an advanced stage is not necessary.

A major objection to the utilitarian principle to healthcare distribution is that it does not create equal or sufficient healthcare for all and can in fact deepen existing inequalities in health access of marginalized population groups such as rural populations. Supporters of the health-maximising principle may argue that their approach is fair as it is impartial. Every individual is counted equally; but given the goal of bringing about as large a benefit as possible some individuals will have less healthcare access than others. The reasons that certain healthcare needs or population groups would bring down the overall maximising effect, such as past social and health injustices, or the immediate additional cost of rural healthcare, are morally irrelevant for the strict utilitarian.

This approach does not treat people with equal concern. It will leave some people with a lot of healthcare for medium and low priorities and others with no healthcare for high priorities, including people of young age in rural areas. This is unjust as people have a right to healthcare on the basis of the fundamental role of healthcare in our lives and people's health needs cannot simply be ignored on the basis of a utilitarian calculation.

In conclusion, allocating healthcare on basis of the highest utility principle has both practical and moral flaws. But the idea that we should aim to generate as much health for society remains important. Having demonstrated the problems with the utilitarian approach, the question remains how to distribute healthcare packages ethically in conditions of scarcity. In answering this question, concerns of *access* to the healthcare package must be incorporated, as without adequate access, a healthcare package would equal no healthcare package at all.

3.3 Egalitarianism

Egalitarians hold that the morally right distributive approach is the principle of equality. Egalitarians are concerned with 'equality as comparability', as opposed to other conceptions of equality found across distributive theories, namely equality as universality and equality as impartiality (Ram-Tiktin, 2012, pp. 339–340). Egalitarianism can be applied to different currencies, such as outcomes (e.g. health status), inputs (e.g. resources), outputs (e.g. access, opportunities) and packages.

Despite its intuitive appeal there are a number of problems with the egalitarian approach. A problem with the emphasis on equal health outcomes, for instance, is that health outcomes are influenced by various social determinants of health, genetic make-up, and individual life-style choices. Therefore it is not possible for a government to equalize actual and potential health attainments for all (Sen, 1992).

The equal input approach, in turn, does not treat people with equal concern. Giving everyone the same budgetary amount per person (or 'per capita' in health systems language) would disadvantage smaller economies of scale and communities that are at a lower base for socio-economic reasons. For instance, 'diseases of poverty' are conditions that are more common among deprived communities on account of the broader socio-economic conditions in which people live, undermining their capabilities to live healthy lives (e.g. a lack of safe water, which causes life-threatening diarrhoea in children; a lack of sufficient food, which causes malnutrition and thus weakened immune systems to fight off disease). In addition, as mentioned before, remote rural

communities face higher per capita costs of healthcare due to the smaller economies of scale and the higher delivery costs caused by conditions such as poor roads and longer distances. As a result, some people would deplete 'their budget' sooner for reasons grounded in structural inequities. This would be unjust.

Given concerns of this sort, some egalitarians have shifted emphasis from equal resources to equal opportunities. In chapter two I briefly noted Normal Daniels (2001), who extended Rawls's work on Justice as Fairness (1971) to health and healthcare. Daniels argues that the relevant sort of equality is that of opportunity: what matters is for people to have an equal opportunity to be healthy. Daniels argues for 'substantive' equal opportunity, which requires that health systems address socio-economic and other barriers that undermine people's equal opportunities to benefit from available healthcare services (p.3). Daniels' account is in some ways similar to Amartya Sen and Martha Nussbaum's so-called "capabilities account" (Sen, 2002a; Nussbaum, 2011)

While the idea of substantive opportunities or capabilities is important, 'equality' as a pattern seems an unsatisfactory goal. It does not matter, ultimately, if people have 'equal' opportunities when these opportunities are minimal, or when the egalitarian requirement pulls everyone below the minimum threshold. What seems of primary importance, instead, is that people have *enough* opportunities to be healthy and for these opportunities to be substantive.

Other egalitarian theorists have argued for "equal *access* to healthcare based on equal need." On this view, the obligation is to ensure everyone with equal needs has equal access to available healthcare. This approach is vulnerable to an objection that is similar to the objection against the equal opportunities approach: it places an emphasis on comparative and not absolute needs. On this account, for example, if one cannot ensure that all rural communities have *equal* access to radiation oncology services as compared to their urban counterparts, then one should level down urban communities in order to achieve 'equal access based on equal need'. Equal access to radiation oncology is however difficult to achieve, as there are not enough specialists for every district. An undesirable implication of the equal access approach is that the entire population could fall below the level of acceptable healthcare for all (Alvarez, 2007, pp. 339–340).

The above example demonstrates that the requirement of equality in a context of scarcity requires that health systems "level-down" to the worst-off groups (Alvarez, 2007, p. 427; Johansson, 2014, p. 91). What this means is that it is morally better if everyone is badly off then when some are better off than others. This seems hardly justifiable and unnecessary to express equal respect to the needs of rural communities. What matters is that reasonable measures are taken to ensure rural communities access radiation oncology services timely, and in a dignified manner. This can be achieved through a functional referral pathway.[11]

[11] Such a functional referral pathway would prioritise prevention, early detection and adequate transfer facilities to higher levels of care to the patient, including patient transport and overnight accommodation facilities for patients who require so.

Another concern here is that the egalitarian goal of elevating the worst-off to the level of the best-off groups, within a context of infinite health needs, would lead to the "bottomless pit" argument of resource needs (Daniels, 2001, p. 4). For example, to ensure all rural communities have equal access to radiation oncology services within the district within a scarce budget, resources need to be diverted from important goods to increasing training outputs. Yet radiation oncology is not the only specialist healthcare service communities need; and there are simply insufficient resources to meet all healthcare needs.

These problems seem less severe when thinking about egalitarian distribution in terms of packages. This is because sufficiency type principles are already built into the account; need is categorised between higher and lower priorities based on a prudent package. The distribution should aim to bring about a state of affairs where everybody (and this is the egualitarian component) has access to highest priority needs before expanding to lower priority healthcare needs. As such, this approach partly avoids the levelling down objection as there is no obligation to provide the same healthcare to all. However, *within* packages, or thresholds, concerns of the levelling-down objection remain. In conditions of scarcity, resources may not be enough to ensure everyone has equal access to the highest priority healthcare package. On an egalitarian account this would mean that it is morally better if no one has access to high priority healthcare, than that some have and others don't. This remains unsatisfactory as an account. What matters is that people have sufficient healthcare, not that they have the same level of healthcare.

3.4 Prioritarianism

Prioritarianism may have an answer to the concern of the bottomless pit and leveling down-effect. Combining a health maximising with an egalitarian approach, it holds that it is morally more important to *prioritise the worst off* in distributing healthcare than a strict application of equality. The goal of prioritarianism is not that everyone should have an equal share (which could result in levelling down), or to achieve the best possible total benefit, but to increase the share of the worst-off. As Parfit explains:

> [W]e ought to give priority to the worst-off, this is not because we shall be reducing inequality. We do not believe that inequality is, in itself, either bad or unjust. But, since this view has a built-in bias towards equality, it could be called egalitarian in a second looser sense. We might say that, if we take this view, we are non-relational Egalitarians (Parfit, 1991, p. 25).

Thus, for prioritarians the moral problem with the worst-off is not the fact they are worst off in relation to others (relational equality), but that they "are at a lower absolute level" (Parfit, 1991, p. 27). While prioritarianism is concerned with maximising health benefits, it holds that it is morally more important to make small gains for worst-off groups than possibly more cost-effective larger gains for better-off groups. As Parfit puts the point: "[for utilitarians] the moral importance of each benefit depends only on how great this benefit would be"—but, for prioritarians, "benefiting people matters more the worse off these people are" (1991, p. 19).

Prioritarianism's focus on improving the condition of the worst-off seems a more reasonable account than relational egalitarianism or utilitarianism; its focus on improving the worst-off expresses concern for everyone's healthcare needs, yet it does not face the levelling down or bottomless pit objection. The main difficulty with the prioritarian account that I want to note is that it does not define "how much priority" should be given to the worst-off. As long as there is "some improvement", it seems that the outcome would be deemed morally acceptable. So the application of prioritarian principles might leave certain individuals or communities below a level of adequate healthcare.

The above concern with the prioritarian account can be illustrated as follows. Certain countries demonstrate, by law, a prioritarian commitment to progressively realising healthcare within available resources for everyone with priority to vulnerable groups such as deprived rural communities. Under this account they can correctly claim to be improving the situation of rural communities without ensuring that rural communities also access a minimally acceptable standard of healthcare. Consider, for instance, a scenario where a country improves the essential immunisations coverage of rural children with 10% from 40 to 50%, while the better-off continue to access all or most of the healthcare they need, including healthcare for minor conditions. This would meet prioritarian requirements. Yet it does not seem just. Under a prioritarian account, the improved state of affairs of the worst-off could remain insufficient, too slow, or leave too wide a gap with the better-off. Prioritarianism therefore seems to lack a sense of

appropriate urgency and needs a minimum baseline with thresholds above the minimum to direct the pace and extent of improvement of the worst-off.[12]

At a structural level, these appear to be some of the substantial weaknesses and difficulties with the prioritarian account. Would the prioritarian account in terms of the distribution of hierarchical packages address some of these concerns? It seems to be partially the case. The advantage of a prioritarian package approach is that it already includes healthcare priorities in its design. As a result, a prioritarian approach would need to follow the built-in threshold design if it were to prioritise the worst-off (i.e. it would not be prioritizing the worst-off if it prioritized the medium over the higher priority package). In conditions of extreme scarcity, however, it is possible that the highest priority package will be unaffordable in its entirety; further priorities would then have to be set within the highest threshold. For instance, life-saving treatment at the early life stages is a high priority intervention (see chapter two), but it is possible that the available budget would not be able to cover certain treatments. In this circumstance, it would be absurd to continue prioritisting the worst off by depleting the budget without achieving any gain. As a result it may make moral sense to spend resources on the next level of priority package benefitting some or many. In such cases there is no moral

[12] An objection to the above could that a redistribution of resources could cause people who are only slightly better-off to fall below a level of adequate healthcare. While not the result of egalitarian requirements, the prioritarian approach in this scenario could nonetheless result in levelling down. This is unjust and no one benefits. However, it seems reasonable to accept levelling down under *certain* other conditions, not to achieve equality, but to lift up the worst-off. For instance a levelling-down that pushes better-off below the level of priority healthcare seems unacceptable. But a levelling down of some who access low priority healthcare to bring up others to the level of high priority healthcare seems just. This does not need to mean taking healthcare away, but one could for instance consider user fees for the better-off for minor conditions.

justification to prioritise the worst-off over the -somewhat- better off, without actual gain for the worst-off.

Challenges with regards to the extent of prioritization also apply to *access* to the package for the worst-off in terms of socio-economic and typo conditions. For instance, rural communities' access to the package may be prioritized through added investments in overcoming rural barriers and delivery costs, but the investments may remain insufficient to achieve substantive access to highest priority healthcare.

All of this points to the concern that the idea of priority appears important but cannot be the primary currency of healthcare distribution. What ultimately matters is not whether people are better off from what they were before, if "better off" remains insufficient. What matters is that they have enough.

3.5 A pluralist account

I have thus far presented moral objections to three main distributive theories. However, as shown, each theory also has elements that appear to be important. I have argued that we should try to benefit more people rather than fewer, when all else is equal, that healthcare should be distributed to *everyone* based on need, and that it matters morally to prioritise the worst-off. This raises the question whether a pluralist account might provide an answer to the question of justice in healthcare distribution. Pluralism is an approach that combines different principles that can take different priority dependent on the situation.

The pluralist view has been defended in the literature. For instance, Hessler argues that while the aim of public health is to maximize population health, “ethical public health respects rights as “side-constraints” or limits on utility maximization” (Kristen Hessler, 2008, p. 2). Norheim et al. (2014) in turn hold that health-maximising approaches are important in achieving universal access to healthcare but argue for the inclusion of equity criteria in line with the WHO approach (WHO, 2014). Persad et al. agree that health-maximising principles such as ‘saving the most lives’ is a critical consideration and argues that few would disagree that when all else is equal, we should save 5 instead of 1 lives (Persad, Wertheimer and Emanuel, 2009, p. 425). However, as he rightfully states, “all else is rarely equal’ (p.425); and, as I argued in Chapter 2, other principles such as lifetime cycle are relevant too beyond saving lives.

An example of a pluralist account is the WHO model (WHO, 2014) introduced in chapter two. As I have shown, this model holds that health-maximising is important to achieve the goal of improved population health outcomes. But achieving adequate healthcare for everyone and prioritising the worst-off in terms of health status is also important. An approach is subsequently provided to rank services based on cost-effectiveness, using approaches such as QALYs to measure health gains against costs, and then ‘worst-off’ criteria in terms of need, severity and/or urgency can be applied to manually shift some services between categories of priority. Subsequently, the packages of priority (categorised from high to low) need to be distributed fairly and equitably among the

population towards coverage for everyone. To avoid the "inverse care law",[13] when deciding which population groups to prioritise first, the WHO makes the following recommendation:

> [C]ountries should strive to first reduce barriers for the following groups: low-income groups; rural populations; other relevant groups to the extent that they are disadvantaged in terms of service coverage or health [equity]. This strategy of reducing inequalities in service coverage is integral to the pursuit of raising the general level toward universality (30).

Furthermore, the goals of fairness and equity require that access to the priority package be affordable, based on the ability to pay and not need (p. 9).

In Chapter 2 I raised the concern that the WHO approach to priority-setting of healthcare principles is not based on 'instrinsic healthcare priorities' and that the balancing of criteria of health-maximising and health need gives rise to both moral and practical difficulties. Moreover, while the theory allows prioritarian criteria to trump cost-effectiveness criteria (if it is felt that there is a need to do so) this is done through a manual process by local stakeholders. Dependent on the cost-utility outcome and whether or not decision-makers apply other criteria, intrinsically high healthcare

[13] According to the Inverse Care Law "the availability of good medical care tends to vary inversely with the need of the population served", which is applicable in many high and low income countries and particularly applicable to rural communities across the globe due to the unique access barriers. Julian Hart (1971) quoted in WHO (2014, p. 26).

priorities can be given low priority. As a result vulnerable groups such as (impoverished) rural communities may be disadvantaged. This possible outcome of the pluralist approach is expressed in the following quotation:

> In many cases, the demands of fairness and benefit maximization go together. (…) In other cases, the policy considered the most fair is not the one that maximizes benefits. For example, treatment for hypertension may be more cost-effective than pneumococcal vaccine, while the vaccine targets conditions with a larger individual disease burden. Similarly, fairness may recommend that coverage is extended first to a rural population that has lesser coverage, has worse health, and is poorer than an urban population. At the same time, the rural population may be more costly to reach with a given set of services, the services may be less effective in that population, or both. The objective of benefit maximization may therefore give priority to the urban population. In situations where the two objectives diverge in what policies they recommend, it is, again, crucial that countries assess alternative policies with respect to both objectives. Only then can the objectives be carefully balanced and the best policy overall be identified (WHO, 2014, p.8).

As shown, the model in itself does not provide moral direction on how to weigh off principles of fairness and equity with cost-effectiveness criteria. Perhaps the advantage of this approach is that it allows decision-makers to take into account local factors. However these factors can be morally questionable or even irrelevant. It is well known

that governments are constantly pressurised and lobbied by donors, political parties, and other stakeholders, to improve efficiencies, higher aggregated population health outcomes or other health related objectives.

To address the concern of uneven or slow progress towards universal healthcare access, the WHO has identified “unacceptable trade-offs”, which are “to expand coverage for low- or medium-priority services before there is near universal coverage for high-priority services” (Norheim, 2015, p. 712). However, this appears to contradict the earlier quote which stated that in case of conflicting objectives [fairness and cost-effectiveness], governments have to balance both objectives without stipulating that rural populations should be given priority if their coverage is less.

While the pluralist approach has important strengths, such as the threshold approach between higher and lower priorities, which addresses one of my concerns of prioritarianism, it provides no guidance in the balancing of different criteria. This makes it vulnerable to unjust decision-making and people with intrinsically high priority healthcare needs could be unfairly disadvantaged. The response to pluralism is that it is always better to give a unified account of the plurality of factors that the pluralist regards as incommensurable. A theory that foregrounds the principle of sufficiency may be better able to unify the different considerations in an account that gives equal concern to everyone’s healthcare needs within budget constraints. At any rate, this is the idea I want to explore.

3.6 Sufficientarianism

3.6.1 An introduction

Sufficiency as a theory for distributive justice is less well known than the other theories discussed thus far. The theory of sufficiency is promising both on its account of moral significance and its ability to address some of the concerns with the other theories. In this section I start by discussing some of the main elements of the theory before arguing for an account of sufficient access to priority healthcare packages. Sufficiency, much like the other theories, faces some challenges that need to be addressed. In the remainder of this chapter I discuss tragic cases including questions of insufficiency within thresholds.

3.6.2 Main tenets of the sufficiency account

A sufficientarian account maintains that what matters most morally is for people to have enough of a given currency of justice such as healthcare, welfare or capabilities. As such, the sufficiency account is based on the idea that justice requires that people achieve a threshold level of some good. This is known as the positive thesis (Fourie, 2016).

The doctrine of sufficiency was introduced by Harry Frankfurt (1987). Frankfurt states that "[w]hat 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). Distinctive of Frankfurt's account of sufficiency (which is not endorsed by all sufficientarians) is his rejection of the moral value of relational equality. He writes:

> … what is of genuine moral concern is not formal [as in everyone's right to an equal share of social good X] but substantive. It is whether people have good lives, and not how their lives compare with the lives of others [that is important] (Frankfurt, 1997, p. 6)

Since Frankfurt introduced the principle, it has been developed further, with different accounts on the currency and pattern of the sufficiency principle being proposed (Fourie, 2016, p. 14). Huseby, for example, proposes the following version of sufficientarianism:

> It is, in itself, bad if a person is not sufficiently well-off. It is worse the farther below a sufficient level a person is, it is especially bad if a person's basic needs are unmet, and worse the more people that are not sufficiently well off (Huseby, 2016, p. 72).

This principle can be applied to healthcare. I will discuss this further in the next section.

3.6.3 Applying sufficiency to healthcare distribution: the prioritised packages approach

Extending Huseby's description of sufficientarianism to healthcare, it is reasonable to claim that it is bad when people's health needs are not met. It is worse the more serious

the health needs are that are not met. It is especially bad if people die prematurely or suffer from serious unmet health needs and conditions that significantly reduce their abilities to pursue reasonable life plans. And it is worse the more people suffer from such serious unmet healthcare needs.

This claim can be further expanded to the priority packages approach that I developed in chapter two. On this approach, I argued that healthcare priorities can be set according to intrinsic healthcare needs, leading to higher and lower priority healthcare packages. Connecting this account to Huseby's remarks above, it can be said to be bad when people's low priority healthcare needs are not met, but even worse when their high priority healthcare needs are not met. This suggests an account of justice in the distribution of healthcare according to a prioritised packages approach. We should first attend to people's needs for highest priority healthcare, after which we can expand access to medium priority healthcare, followed by low priority healthcare. As such, my account does not propose a single fixed meaning of sufficiency; rather, I am proposing distribution based on a hierarchy of health needs with corresponding thresholds. On this account, justice in healthcare distribution requires a progressive realisation of enough healthcare for everyone along a threshold approach of intrinsic healthcare needs over a lifetime.

Whether in conditions of moderate or extreme scarcity, the starting point for distribution is sufficient access to the highest priority healthcare package. The prioritised packages approach provides an answer to the critique that 'a minimum core in healthcare' would

serve as a ‘ceiling’ after which there is no moral or legal need to expand. To the contrary, the minimum threshold of healthcare would be the very first threshold, but this is not where justice ends.

Conceived in this way, I claim that sufficient healthcare through the distribution of prioritised packages using a threshold approach is more plausible than any of the other theories discussed. I will briefly revisit the other theories to support my claim. To begin, the approach is more plausible than a utilitarian distribution of healthcare as, on a utilitarian account, the high priority healthcare needs of some would be traded-off in favour of lower priority healthcare needs of others *if* this leads to a higher net benefit in terms of population outcomes. This is also the case on a utilitarian distribution of prioritised packages. A utilitarian might decide to prioritise the roll-out of prioritised packages in urban dense populations over rural communities, and even expand from high to medium priorities in urban areas before reaching adequate coverage in rural areas if this leads to a higher overall net benefit at population level. As mentioned before, a major objection to the utilitarian approach is that it does not create equal or sufficient healthcare for all and can in fact deepen existing inequalities in health access of marginalized population groups such as rural populations.

The egalitarian claim, as we have seen, maintains that what matters most is that people have equal healthcare. However, if people were given a choice between ‘equal healthcare’ or ‘enough healthcare’ as the principle pattern for distribution, it seems clear to me that one would choose to have enough healthcare. This is because, as argued

before, ‘equal healthcare’ can mean ‘insufficient healthcare’. It is true that when applied to the packages approach, the levelling down objection can be avoided as there is no obligation to provide equal healthcare to all, only equal *priority* healthcare. However, the account would still face the challenge of levelling down objection within the threshold. When resources are insufficient to provide *everyone* in the same threshold with equal healthcare, an egalitarian account would then require that no one has access to high priority healthcare, rather than some having access and others not.

Given these concerns and constraints, I maintain that the goal of distribution should be to ensure that everyone has *enough* healthcare. Therefore, we ought to prioritise the worst-off in the distribution of healthcare resources. How does this differ from the prioritarian account? While the accounts have similarities, the main difference is that the prioritarian account does not indicate ‘how much’ priority should be given to the worst-off. And, as I have argued, this can, and does, leave scores of people without access to highest priority healthcare. The priority packages approach resolves this problem. The aim ought to be that no one falls below the highest sufficiency threshold[14] and to ensure that everyone eligible has access to high priority healthcare, before expanding to lower priority healthcare. This approach avoids the scenario provided before, where a 10% of increase for the worst-off is deemed “sufficient”, yet leaving scores of people below the highest priority threshold.

[14] With exception of tragic cases, see 3.6.5

The advantage, in turn, of the prioritised packages approach over the WHO model is that it gives clear moral guidance on how to prioritise the distribution of healthcare services; in this regard, it is clearly preferable to a pluralistic approach based on cost-effectiveness and other criteria, which leaves the balancing of different criteria to individuals. The WHO approach, as discussed, can result in the prioritisation of lower over higher priority healthcare needs.

3.6.4 Double Sufficiency

Having enough healthcare does not imply enough healthcare in terms of package design and priority only, but also in terms of 'access' to the package. If societal barriers such as stigma and arbitrary discrimination or the costs and distance of healthcare prevent people from accessing the package, then we cannot consider the package to be available. Therefore, justice requires sufficient access to the prioritised healthcare packages.

I will illustrate this with the oncology example. Cancer treatment would likely be categorized as a high priority healthcare service for children. From a sufficiency perspective there is no moral obligation to create 'equal access' to treatment—this would have a levelling down implication for all children needing cancer treatment. What matters from a social justice perspective is that children have *adequate* access; access that is dignified, in time for it to be effective, and affordable to the patient, regardless of distance and socio-economic status. In a rural context this would require adequate staffing at the different levels of healthcare for diagnosis and referral, and a functional

referral pathway between centres of care which may be situated far apart and requiring subsidized transport and overnight accommodation for families of lower income groups.

I refer to this as a "Double Sufficiency" account": sufficient access to sufficient healthcare to follow reasonable life plans. The access component enforces the social justice requirement of package distribution; not only is it required that we prioritise people with the highest priority healthcare needs and ensure they have enough before we expand the package, the package itself must also be accessible in the broad meaning of the word (physical, acceptable, financial access).

In conclusion, the prioritised package approach gives moral direction to the distribution of healthcare resources, both in terms of healthcare and social justice principles. The account, like the other accounts, does not claim that everyone's healthcare needs can be met. In the next section I discuss how we could approach tragic cases justly within a prioritised packages approach.

3.6.5 Addressing insufficiency within and between thresholds

My account foregrounds 'sufficiency' as the primary principle for distribution. This principle may not be 'balanced' or 'traded-off' with other principles. As such, my account of sufficiency is founded on the positive thesis identified above: what matters most morally is that people have sufficient healthcare to pursue reasonable life plans (and not that they have equal healthcare). The other distributive principles play a supporting role towards achieving threshold sufficiency. As such, it is worthwhile noting that the

prioritised packages approach has an egalitarian component: it matters that we must first address the healthcare needs of people in the category of high priority healthcare needs before expanding access to the next category of healthcare packages. This is however not because it is morally important that everyone has the same, but because it is important that no one falls below the sufficiency threshold.

I now move on to questions of insufficiency within the high priority thresholds. These are tragic cases. When resources are insufficient to meet everyone's healthcare needs in the high priority categories, some people in this category will lose their lives and/or face life-long severe permanent disabilities and other harms. The fact that we cannot meet everyone's healthcare needs due to conditions of scarcity does however not count against the sufficiency approach. Conditions of scarcity affect *all* distributive accounts. The moral importance, and distributional direction, of ensuring that people have enough healthcare stands.

In the following paragraphs I will describe a few principles and examples on how my sufficientarian account could address such tragic cases. Let me re-emphasise that the first priority on my sufficiency account is to distinguish on basis of priority healthcare needs. Some accounts only have one threshold, but the advantage of my account is that it provides prioritised packages of healthcare. As such, the prioritised package approach already ranks healthcare needs from higher to lower priorities, hereby avoiding trade-offs between packages of care in different thresholds.

In terms of insufficiency *within* the threshold, justice requires that we consider both intrinsic health and social justice considerations. From the point of view of social justice, special consideration should be given to the worst-off in terms of levels of deprivation of basic needs (such as access to water and nutrition), as high levels of deprivation affect people's abilities to cope with disease and disability and and can push them into further insufficiency of health and healthcare. For instance, TB affects a poor person disproportionately as compared to an otherwise well-off person with TB. The immune system of an impoverished person is likely to be weaker due to conditions of poverty and unaffordability of a balanced diet. She is also likely to be spending a higher proportion of a limited disposable income in seeking healthcare treatment, due to transport costs and other expenses. Her children will be impacted too due to the risks of infection in the house and a reduced household budget for other needs due to the indirect and/or direct medical expenses. All this demonstrates that it is fair to give more weight to the socio-economically worse-off when resources are scarce to meet everyone's needs *within* a priority threshold.

In terms of healthcare principles, I argue that principle 5 "capacity to benefit', introduced in chapter 2, places a critical role in addressing insuffciency within and also between thresholds. We give priority to healthcare needs in relation to people's abilities to pursue reasonable life plans over a lifetime. If the prognosis of survival for a person is very poor, and extending treatment will not make a significant difference on his or her life plans, or if the size of the benefit is minimal in terms of its impact on the health condition, then it could be justifiable not to provide the treatment in the 'prioritised

package' and instead prioritise the needs of other people in the same threshold or even the next priority threshold. For instance, If resource X (which can be the cost of medicine but could also be the time of a healthcare professional) can extend the life of person A in the highest priority threshold with one day, or the same resource X can attend to the medium priority healthcare needs of person B in the next threshold with a much better prognosis, then reasonable people would agree that it is permissible to expand the healthcare package even though we are unable to help person A. Exactly where to place the limit of 'sufficient prognosis' in each threshold is something that needs deliberation by experts and citizen panels.

Some of these difficulties will be resolved on a more detailed account of principles for healthcare. As stated in chapter two, I only provided a broad sketch. The inclusion of additional relevant principles will assist in resolving competing cases of insufficiency that are currently placed within the same priority threshold.

The number of people that we can bring to sufficiency also matters (Ram-Tiktin, 2016, p.160-161). Here, cost-effectiveness is clearly an important criteria, with effectiveness defined in relation to threshold sufficiency. Cost-effective interventions can maximize sufficiency for the greatest number of people *in the given threshold*. For instance, if resource X can benefit 100 people with condition X in the high priority category or 2 people with condition Y of equal severity, then fairness would stipulate that we prioritise the 100 people. This is not so for reasons of aggregation. The goal is to get people to

sufficiency. It is better if more people have sufficient treatment than for fewer people to have sufficient treatment.

This section has shown that non-relational egalitarianism, health maximising and prioritarianism can have a place in an account of sufficiency. The sufficiency principle however remains the primary principle. This is different from a pluralistic account.

3.6.6 What about inequality above the low priority healthcare threshold?

In addition to the positive thesis, some sufficientarians such as Frankfurt support the negative thesis (Frankfurt, 1987). The negative thesis holds that equality and priority do not matter above a critical threshold. In other words, once people have enough it does not matter if some have more than others. The negative thesis has been much discussed and criticised; but the scope of this project does not allow a thorough evaluation of this literature (see for instance Casal, 2007; Deveaux, 2017). Sufficientarian theories do not have to endorse the negative thesis (See for instance Casal, 2007; Ram-Tiktin, 2016; Deveaux, 2017;). It can integrate other views while maintaining sufficiency as the priority principle.

I nonetheless need to make a few comments about the negative thesis. I agree that Devaux's claims that inequalities above a critical threshold, e.g. a basic level of welfare for all, can be of moral importance for substantive reasons such as social cohesion and social mobility (2017). While I agree with this statement I am not sure that the concern

as it applies to wealth inequality above sufficiency threshold has equal force to healthcare inequality *above the low priority healthcare needs threshold*.

Let me explain this in a little more detail. In my prioritised packages approach, the threshold for low priority healthcare includes conditions such as a sprained ankle. There is good reason to put the threshold this high. A sprained ankle can be a minor concern for a generally healthy affluent person in an urban area, who can move around in his or her own vehicle and work from home while recovering. The impact on a poor person may be much larger, having to navigate by foot over rough terrain to catch public transport and being unable to carry out vital day-to-day tasks at work and at home.

In my account, needs above the low priority threshold are health care *wants* such as cosmetic surgery or *preferences* without medical indication such as a caesarean section (e.g. to allay fears for pain or because it is more convenient to choose the day of birth). Intuitively it feels wrong that some people can afford to pay for cosmetic surgery or for a non-medical caesarean while others cannot. Some gain benefits and others do not for reasons of non-affordability. However, governments face dual conditions of scarcity and cannot meet everyone's healthcare wants and needs. The key issue here is the relation of healthcare services to people's capabilities to pursue reasonable life plans within the context of a country's local conditions and societal norms. I do not think healthcare at this level, beyond minor healthcare needs, forms part of a comprehensive package of healthcare that everyone needs in order to follow reasonable life plans.

3.6.7 Conclusion

The essence of my response to justice in healthcare distribution is captured in figure 1. Justice in healthcare distribution requires a progressive realization of healthcare needs through a prioritized packages approach along intrinsic healthcare priorities, ensuring sufficient access to the highest priority healthcare needs before expanding to the next level and so continued. The aim of distribution is to ensure that no one falls below the corresponding sufficiency thresholds.

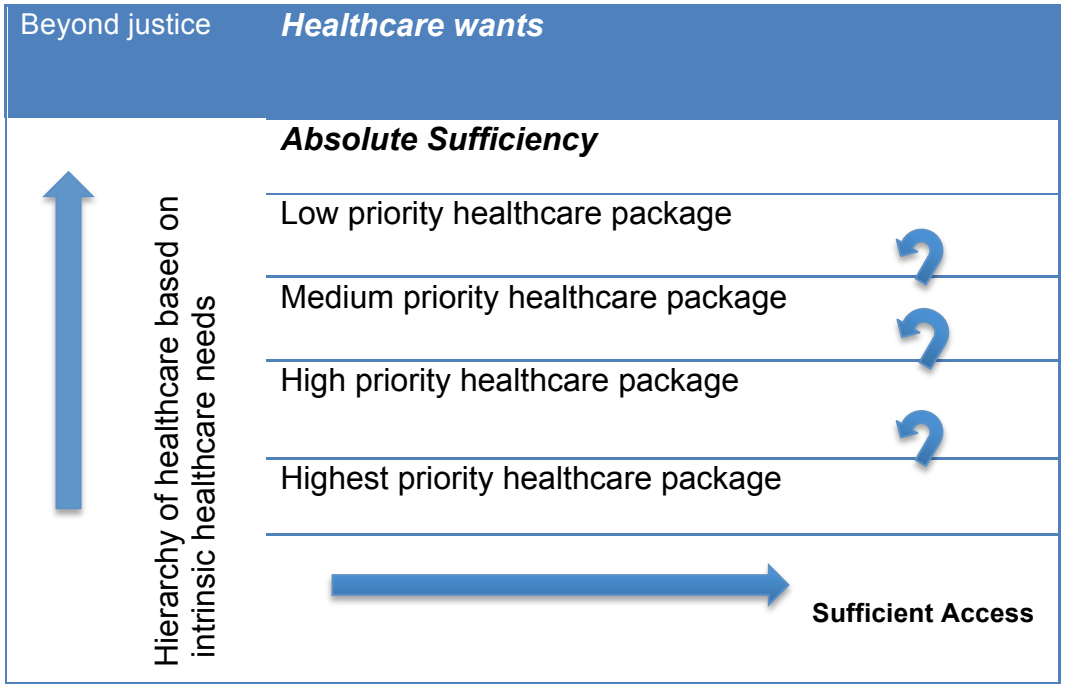


Figure 1: Double Sufficiency

On this account, Double Sufficiency is the requirement of justice in healthcare distribution.

In the next chapter I address some limitations and possible objections to my account.

Chapter 4: Objections and Limitations

4.1. Double Sufficiency and the capabilities approach

A possible critique from the capabilities approach could be that the categorisation of healthcare into higher and lower priority packages cannot be done in isolation from the broader context in which people live. It can be plausibly argued that it is the actual context, for instance poverty or lack of healthcare literacy, that can cause a lower priority healthcare need to become a more serious impairment to the healthcare user.

I agree that this is the case. Therefore I challenged the QALY approach which has a 'fixed' value for utility (quality of life) for each condition, regardless of patient circumstances. I believe my account should be interpreted in support of the capabilities approach. From a capabilities approach 'healthcare' alone cannot achieve sufficient health or sufficient capabilities; it is merely one of many social determinants of health. This is true and I have not argued to the contrary. My account is based on the idea that governments have to make decisions on how to alloate their healthcare budget; and the allocation of the healthcare budget must be done to support people's abilities to pursue reasonable life plans. Sufficient access to sufficient healthcare over a lifetime plays a critical role. This does not take away from the fact that decision-makers in health and other sectors ought to collaborate in addressing the impact of and relation between the various social determinants of health in order to achieve best possible health for its population in a fair and just manner.

In terms of the example of a sprained ankle, it is indeed so that people in more deprived circumstances are more likely to experience a greater negative impact for reasons explained. Nonetheless, the condition is not as serious, or life-threatening, as a fatal childhood disease. The benefit of the double-sufficiency approach is that it makes it explicit that we need to achieve full coverage of high priority healthcare needs before expanding to lower priority healthcare. This counts for everyone. What it does is to avoid prioritisation on the basis of utilitarian calculations, leaving the high or medium healthcare needs of the impoverished rural person unmet due to the 'higher gains' of meeting lower priority healthcare needs for many, for instance people living in concentrated urban areas.

It must further be re-iterated that the veil of ignorance also addresses the issue of context. As disussed in chapter two, from behind the veil, priorities are set without knowledge of one's personal circumstances. On basis of rational prudence, people will categorise treatment for serious diseases of poverty as 'high priority': in our priority-setting process we would take into account the possible inhospitable living conditions and levels of deprivation that we may live under. But we would not identify a sprainked ankle as a high priority health need for ourselves.

The concern from a capabilities approach may also be partially addressed by the adequate access requirement of the Double Sufficiency approach. Adequate access refers to financial, physical and quality access. Once a service is classified as 'high priority', it must be accessible and not push people into poverty. The same applies to

access of services in lower priority thresholds. Lastly, living conditions are also accounted for in the prioritarian distribution *within* the threshold, giving special consideration to the worst-of socio-economically.

4.2 Ageism

My account could be seen to be discriminating against the elderly, by prioritising healthcare needs that arise earlier in the lifecycle, I do not think this is the case. I maintain that this approach gives equal concern to everyone's healthcare needs. The principle of prioritizing younger people is one I believe reasonable people would identify from behind the veil of ignorance. Certain healthcare services, however, should be available to all as part of highest priority healthcare. These are pain relief and palliative care to minimize suffering during serious disease and the process of dying. Lastly, it must be noted that this account is meant to provide moral guidance in any condition of scarcity. In many countries, treatment for serious diseases of the elderly, including life-expanding treatments, is available and advanced and this is proper when higher priority needs have been met. However, I believe few would disagree that in conditions of severe scarcity, we ought to prioritise the serious healthcare needs of the younger generations.

4.3 Application

The Double Sufficiency theory is a theory based on ideal theory. As mentioned, Rawls argues that we first need to develop ideal theory in terms of what a 'perfectly just

society' would look like (Rawls, 1971, pp. 8–9). On my account in terms of the distribution of healthcare this would be "Double Sufficiency". The next step would be the application of the account to deal with non-ideal conditions in the real world. Finding answers to these non-ideal conditions must be grounded in the moral goal of Double Sufficiency. For example, while it is rational for an individual to prioritise intrinsic healthcare needs over a lifetime, in certain dire circumstances (eg an epidemic targetting the economically active population) this could mean that a country would be left with a young population without caregivers and productive citizens. This in turn will clearly affect the well-being and even survival of the young. As such, what is rational for individuals behind the veil may not be rational for a Government who has to respond to a non-ideal situation. In such cases, a panel of experts and citizens, using transparent processes of decision-making, on the basis of the sufficiency principle, may agree to specific trade-offs against the intrinsic hierarchy of healthcare needs over a lifetime. Such a trade-off could be to include life-saving healthcare to the productive population in the highest priority category. This will safe-guard "future sufficiency". The translation of ideal to non-ideal theory is important but beyond the scope of this project. I hope to do further work on this in the near future.

On the basis of the Double Sufficiency theory, governments need to respond with urgency to bringing people who are below the higher sufficiency thresholds to sufficiency. Beyond priority-setting based on the principle of Double Sufficiency, governments can seek to increase the health budget, by improving efficiencies, avoiding wasteful expenditures and increasing budget allocations to healthcare. Many different

options can and must be pursued. Financing models can be introduced that include user fees for high-income groups, or higher taxes based on income, to fund healthcare access for everyone needing high priority healthcare. Savings can be achieved by improved efficiencies in the use of human resources for health and so on. All must be geared towards Double Sufficiency, urgently.

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