

https://dspace.org/

QALYs, justice and the capabilities approach

Dulaze, Neo Nontsikelelo

2021
https://hdl.handle.net/10539/32521

Downloaded from a DSpace repository. https://dspace.org/

QALYs, Justice and the Capabilities Approach

Neo Nontsikelelo Dulaze

733666

Submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine (Bioethics and Health Law).

Supervisor: Dr Ashley Coates

Qualification: BA (Honours), MA, PHD

Position: Lecturer, Steve Biko Centre for Bioethics

Date: 28/04/2021

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Neo Nontsikelelo Dulaze (Student number: 733666, am a student registered for the degree of MSc (Med) Bioethics & Healthlaw in the academic year 2021

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature:  Date: 28/04/2021

Declaration

I declare that this thesis is my own unaided work. It is submitted in partial fulfilment of the requirements for the degree of Master of Science in Medicine (Bioethics and Health Law) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.

Candidate: Neo Nontsikelelo Dulaze

Signature: 

Date: 28/04/2021

Acknowledgements

I could not have completed this research report without the help of the following people:

I dedicate this research report to God, my loving father. I thank Him for this incredible opportunity. I thank Him for His grace, wisdom and strength and for helping me persevere in writing this report. I do not have the words to fully express my gratitude.

I wish to express my sincere appreciation to Dr Ashley Coates, my supervisor, for his encouragement, extreme patience and thoughtful counsel throughout the research process. Thank you for sharing your knowledge with me.

I wish to also express my thanks to the Bioethics and Health Law faculty staff at the University of the Witwatersrand for their passionate teaching. I would like to thank Dr Jillian Gardner and Dr Gale Ure in particular, for the guidance they provided at the beginning of this research. I would like to also thank Mr John Irvine for his guidance on how to better the report.

Finally, I would like to thank my family for their unconditional love and encouragement during the time of researching and writing this report.

Abstract

Background

Governments are responsible for ensuring access to healthcare (Bleichrodt and Quiggin, 2013). Unfortunately, due to the scarcity of medical and financial resources, medical rationing must take place. The rational allocation of healthcare resources is significant in any society and directly affects health outcomes. This raises the question of which criteria should be used to decide how medical treatments are allocated. Can age or ability, for example, be appropriate selection criteria? How can ethics inform and shape how healthcare resource allocation decisions are made? This paper studies and critiques quality-adjusted life year (QALY) resource allocation methods and does so through the lens of Martha Nussbaum's social justice framework.

Methodology

The study design employed here is normative – it investigates how governing institutions *ought* to allocate healthcare resources. Those research methods and standards typical of philosophical research will be employed. I use Martha Nussbaum's capabilities approach framework to ultimately argue that the use of QALY evaluation in healthcare is unjust.

Conclusions

Cost-effectiveness or cost-utility assessment tools (used in QALY) for allocating health care resources aim to maximise beneficial health outcomes. This raises two ethical concerns. The first is the commodification of human lives. The second is that QALYs fail to implement accurate health preference measurements for patients – especially in relation to patients with disabilities. Nussbaum's capabilities approach places particular

value on the significance of human dignity in human development. She also sees human dignity as crucial for social justice, which can be achieved through governing bodies promoting ten central capabilities. But, through their employment of preference utilities, QALYs undermine access to this minimum threshold of capabilities. In this case, people's capacities – that is their freedoms and opportunities to have the sort of human dignity intrinsic to a good life – are violated.

Table of Contents

1. INTRODUCTION TO THE STUDY 10

1.1 Introduction and Overview 10

1.2 Literature Analysis and Critique 13

1.3 Research Question 27

1.4 Rationale 27

1.5 Thesis Statement 28

1.6 Research Aim 28

1.7 Research Objectives 28

1.8 Research Methodology 29

1.9 Conclusion 31

2. PHILOSOPHICAL FRAMEWORK: NUSSBAUM'S CAPABILITIES APPROACH TO JUSTICE AND HUMAN DIGNITY 33

2.1 Introduction 33

2.2 Central Capabilities Required for Justice 40

2.3 Capabilities Approach: Dignity, Justice and Healthcare 44

2.4 Conclusion 49

3. COMMODIFYING HUMAN LIFE AND THE INJUSTICE OF QALYS 51

3.1 Introduction and Overview 51

3.2 Utility Measures: Cost-Effectiveness Threshold 53

3.3 Commodity, Commodification and QALYs: Current Perceptions 54

3.4 Nussbaum's Response 56

3.5 Conclusion 57

4. DISABILITY, CAPABILITIES AND THE INJUSTICE OF QALYS 59

4.1 Introduction and Overview 59

4.2 What Is Disability? Working Definition and Basic Accounts 60

4.3 QALYs and Disabilities: Case Illustration 64

4.4 Ethical Issues related to QALYs and Disability 64

4.5 Nussbaum's Response: Addressing Ethical Concerns 70

4.6 Conclusion 74

5. CONCLUSION AND RECOMMENDATIONS 76

5.1 Overview 76

5.2 Response to Possible Remaining Objections 78

5.3 Significance of Research, Future Research 79

5.4 Conclusion 80

6. REFERENCES 82

Appendix 99

Abbreviations

CEA	Cost-effectiveness analysis
CUA	Cost-utility analysis
GDP	Gross domestic product
HRQoL	Health-related quality of life
ICER	Institute for Clinical and Economic Review
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PBM	Pharmacy benefit manager
PIPC	Partnership to Improve Patient Care
QALY	Quality-adjusted life year
WHO	World Health Organization

1. INTRODUCTION TO THE STUDY

1.1 Introduction and Overview

It is without a doubt that public health interventions play an integral role in thriving communities and nations. These interventions, in the form of the provision of medicine or health programmes, act in the public interest by promoting or maximising health (Borghi and Jan, 2008, cited in Greco et al., 2016). The World Health Organization (WHO), states (through its international classification of health interventions tool) that public health interventions should aim to promote, improve and maintain the health of those seeking healthcare (World Health Organization, n.d.). Further elaborating on this thought, public health interventions must meet the ethical standards or principles of equity, social justice, participation, acceptability, effectiveness and accessibility (Visagie and Schneider, 2014). This is especially important for those with chronic health conditions, who require more than just a regular check-up to meet their health needs. However, this is not to say that acute health conditions are less significant than chronic conditions; both require a full suite of public healthcare interventions and the efficient allocation of healthcare funding.

The rational allocation of healthcare resources is significant in any society and directly affects health outcomes. One could argue that the rational allocation of healthcare resources is negatively impacted by poorly designed health systems (Institute of Medicine, 2003). Nguyen and Sama (2008, cited in Malakoane et al., 2020), have identified that a lack of funding directly impacts the ability of healthcare systems to meet the health needs of each citizen, especially in African countries. Coupled with

this, economic factors and stakeholder principles and values inform resource allocation decisions (Docherty et al., 2012; Harrison and Taylor, 2016). Regardless of the rationale, the reality is that a lack of resources is the breeding ground for social injustices to evolve, further complicating access to healthcare. Perhaps, then, rethinking how governing bodies ought to allocate healthcare resources is a necessary step towards realising fully efficient healthcare systems.

Although the discourse of resource allocation is currently well explored, various aspects of justice in healthcare remain controversial. For example, the lack of access to dialysis machines for treatment purposes in the public healthcare sector of South Africa is heavily debated (Etheredge and Fabian, 2017). Furthermore, in recent global events, the allocation of resources in the climate of COVID-19 has demonstrated rising concerns about how to fairly distribute healthcare resources like ventilators, testing kits and personal protective equipment (Emanuel et al., 2020). Perhaps, in the future, questions about the best process to adopt to fairly distribute a vaccine will arise. The bottom line is that resource allocation is a continuous conundrum.

With these challenges in mind, the allocation of resources for healthcare interventions and health programmes is generally dependent on publicly funded healthcare systems (Daniels, 2016). Due to the scarcity of medical and financial resources, publicly and privately funded healthcare systems must confront certain pressing questions. Which criteria will be used to decide how medical treatments are allocated? Can age or ability, for example, be appropriate selection criteria? Moreover: how can ethical reflection inform and shape the making of these decisions? One key consideration in this regard is whether the answers to these questions can be found through the

application of justice theories (Singer, 2009).

Each system is responsible for ensuring access for all (World Health Organization, 2006; 2017). It is vitally important that all implicit and explicit choices are made with the utmost consideration of all kept in mind (Scott et al., 2019). As a way of doing addressing this concern, cost-effectiveness / cost-utility assessments are traditionally recommended for setting priorities in healthcare (Nice, 2013).

These traditional methods determine the allocation of healthcare spending. However, this research report questions whether cost-effectiveness / cost-utility allocation methods like the quality adjusted life years approach (QALY) apply (any or satisfactory) ethical perspectives or principles. Hence, this report will answer the key research question: Does Martha Nussbaum's capabilities approach to justice indicate that the use of QALYs as a criterion for the allocation of limited medical resources is unjust? Based on the arguments I present in this report, I find that the use of QALYs for this purpose is indeed unjust as it undermines people's possession of the capabilities necessary to live a dignified human life. The QALY approach fails to meet the threshold required for true human functioning.

Chapter 1 serves as an introductory chapter to the research report. An analysis and critique of the literature relevant to the key elements of this report are provided. Elements such as medical costs in healthcare, medical rationing, economic evaluations, and the characteristics of the universally accepted criteria for allocating healthcare resources – QALYs – will be outlined and discussed. The chapter will also provide a literary review of current studies exploring the same challenge. Finally, this

chapter establishes the research question, aims and objectives of the project. The argumentative strategy adopted will be outlined in the research methodology discussion. As mentioned, I find that healthcare resource distribution on the QALY approach is unjust. This is because this report takes the stance that healthcare resources ought to be allocated with the aim of ensuring that all human beings have the necessary tools to function with true, human dignity. The final part of the chapter draws conclusions from this outline and evaluation of the subject.

1.2 Literature Analysis and Critique

1.2.1 Healthcare Medical Costs

The substantial inflation of medical costs incurred by healthcare users is a direct consequence of an increased demand for medical care (Nuijten and Dubois, 2011). Generally, there are two direct medical costs incurred by healthcare users. Firstly, there are pharmaceutical costs – that is the costs of prescription medications or drugs; and secondly, high administrative costs such as those for expensive treatment options or work from specialists (Nuijten, and Dubois, 2011). Over the years trends in healthcare spending illustrate a significant increase in brand name prescription treatment. For example, between the years 2012 and 2019 the cost of AbbVie's (a pharmaceutical company) rheumatoid-arthritis treatment named Humira increased, to $60,000 a year from $19,000 a year. Furthermore, the price of insulin has said to have tripled between the years 2000 and 2013 (Entis, 2019). According to Erman (2020) (drawing on Reuters reports) at the start of the year 2020, the cost of 445 separate prescription treatments produced by pharmaceutical companies has significantly increased. Unfortunately, due to patents, the production of generic versions of these

drugs is not viable until 2034 (Erman, 2020). This limits access to popular treatments. Essentially, as a collective, medical insurers / medical aid companies, pharmaceutical benefit managers (PBMs), and drug manufacturers are responsible for the price increase of treatment (Entis, 2019).

So, the cost incurred by healthcare users – whether governmental or privately funded users – for medical healthcare or treatment is driven by pharmaceutical costs, which sometimes even impacts how people pay for medical insurance (Entis, 2019). The choice of medical healthcare is affected by high medical aid and pharmaceutical costs (Entis, 2019). As a result, in the absence of a medical aid plan, healthcare users must pay out of pocket (Entis, 2019). However, those who are unable to pay rely solely on the provision of governing bodies. Unfortunately, governing bodies are faced with compounding challenges, specifically with regards to the increasing pharmaceutical costs, which have a direct impact on access to healthcare (World Health Organization, 2020). To remedy the economic consequences, governing bodies resort to medical rationing / medical allocation methods like the cost-utility analyses alluded to above (Niëns, 2014). Thus, healthcare rationing and economics are associated.

1.2.2 Medical rationing

Medical rationing is an unavoidable process, occurring as a way of managing a general fiscal scarcity (Frakes, Frank and Rozema, 2017; Scheunemann and White, 2011). It is important to, firstly, acknowledge that rationing is vital. Rationing is an economic tool for determining how limited resources will be allocated. Specifically, in healthcare, it limits or withholds life-saving and quality-of-life-enhancing treatment from

healthcare users in response to two types of scarcity: financial and physical constraints (in the form of funds for services and healthcare capacity respectively) (Scheunemann and White, 2011). To further clarify this issue, Klein, Day and Redmayne (1996) provide a detailed illustration of medical rationing. The authors describe such rationing as failing to meet healthcare needs through delaying, denying, deterring, diluting, deflecting, and terminating access of healthcare treatment. The authors also highlight that a selective process is applied where those who will benefit more receive priority care (Table 1) (Klein, Day and Redmayne, 1996, cited in Arvidsson, 2013, p.13).

Table 1: Rationing Approach

Denial: Would-be beneficiaries of services or programmes are turned away on grounds that they are not suitable or that their needs are not urgent enough. By changing the threshold of eligibility, supply and demand can be matched.
Selection: The converse of denial, but can have the same outcome. Service providers select the would-be beneficiaries who are most likely to benefit from the intervention.
Deflection: Would-be beneficiaries are directed towards another programme or service. In effect the agencies safeguard their own resources by dumping the problem in the lap of someone else. A social problem becomes redefined as a medical problem and so on.
Deterrence: Making it difficult for patients to access services, e.g. by fees, short opening hours, incomprehensible forms to fill in and so on, to discourage them from coming.
Delay: Discouraging demand by giving patients appointments months away or putting them on waiting lists.
Dilution: Services and interventions are offered to as many as possible, but the content is reduced so everyone gets less, e.g. less time with the doctor, fewer tests, or cheaper and less effective treatment, i.e. lower quality.
Termination: To end a treatment or intervention (when it still would be beneficial to the patient or client), i.e. by discharging patents or declaring a case closed.

Source: Arvidsson (2013, p.13), cited by Klein, Day and Redmayne (1996)

Levels of rationing, as reported by several scholars, take place at micro and macro levels (Frakes, Frank and Rozema, 2017; Scheunemann and White, 2011). At a macro level, Scheunemann and White (2011) report that resources are allocated nationally (or at a societal level) for specific sectors, for instance education about public healthcare. At a micro level, resource allocation can be understood as 'bedside allocation'. In other words, making decisions regarding where public funding should be allocated occurs at a macro level while decisions about how these resources are used for individual patient services occurs at a micro level. Unfortunately, as history shows, without ethical macro-funding, patients at the micro level are restricted in terms of how much healthcare they can enjoy (Scheunemann and White, 2011).

For many citizens, the concept of rationing is usually associated with limitations, shortages, reduced quality of healthcare, and the removal of individual choice (Arvidsson, 2013, p.13; American College of Physicians, 2011). This further supports the picture of rationing that Klein, Day and Redmayne (1996) provide. Healthcare practitioners are equally opposed to this approach as it further complicates their ability to meet their obligations (Scheunemann and White, 2011). Given this knowledge, the process of rationing is controversial as justifying the potential benefits of one treatment over another based on cost undermines the purpose of medicine: to treat (Scheunemann and White, 2011).

Having said this though, the combination of finite healthcare resources and an increased burden of disease gives governing bodies no rational alternative to manage the consequential increased mortality rates and lowered life expectancy across the world (National Research Council, 2011; Mondal and Shitan, 2013). So, in order to

achieve the inevitably difficult task of allocating healthcare resources and services, economic evaluations are applied. Each such approach takes into consideration price, eligibility, potential benefit, and a global budget (American College of Physicians, 2011, p.11).

1.2.3 Economic Evaluations

Economic evaluations in the medical field are often classified as being: cost-benefit analyses, cost-utility analyses (CUAs), and cost-effectiveness analyses (CEAs). These analyses all aim to maximise a specific, measured value (Centers for Disease Control and Prevention, 2019; National Institute for Health and Care Excellence, 2013; Ogden, 2017).

Perhaps the overview that the Centers for Disease Control and Prevention (CDC) (2019) provide may explain what each analysis addresses. Firstly, cost-benefit analysis compares costs to potential benefits; cost-utility and cost-effectiveness analyses (which terms are interchangeably used) compare costs to health outcomes. Various developmental governing bodies and organizations – in particular, the National Institute for Health and Care Excellence (NICE), in the United Kingdom – have progressively preferred these latter resource allocation tools to inform their policy and guide the efficient use of healthcare resources (National Institute for Health and Care Excellence, 2013; Ogden, 2017; Whitehead and Ali, 2010; Wareham, 2013, p.2). NICE relies on economic evaluations to, essentially, determine the worthiness of healthcare interventions with the aim of selecting programmes which are more likely to improve health states. According to NICE (2013, p.2), the analysis assists in

prioritising waste management and improving efficiency.

This research report focuses particularly on CEAs and CUAs (Centre for Disease Control and Prevention, 2019; Wilkinson, Petrou and Savulescu, 2018). With the aim of setting priorities in the rationing of scarce healthcare resources, these evaluations compare two interventions against one another based on a best value for money principle (Rai and Goyal, 2018). The cost-effectiveness analysis calls for the comparison of incremental costs with the incremental improvement of health outcomes, all for the purpose of calculating the incremental cost effectiveness ratio (ICER) (Bertram et al., 2016; Rai and Goyal, 2018; Wilkinson, Petrou and Savulescu, 2018).

Generally, an indicator of the cost of treatment used is illustrated in the numerator of the ratio, while an indicator of positive health outcomes or years gained is illustrated in the denominator (Rai and Goyal, 2018). A cost-effectiveness ratio is calculated for each intervention, and the ratios compared. Preference is given to the treatment or programme which produces the lowest cost-effectiveness ratio (Wilkinson, Petrou and Savulescu, 2018). This simply means that interventions measured as more effective allow more individuals to be treated and more lives to be saved at less cost (Wilkinson, Petrou and Savulescu, 2018).

To reach this outcome, cost-utility analysis must be applied to measure or quantify the effects of the intervention – measuring the years gained and lives saved (Rai and Goyal, 2018; Wilkinson, Petrou and Savulescu, 2018). Quality-adjusted life years are used to express the quality of life (QoL) and quantity of life gained as the measuring

unit of health outcomes (Tengs, 2004; Wilkinson, Petrou and Savulescu, 2018). This is then imputed as the denominator of the cost effectiveness ratio. Due to the significant role QALYs play in resource allocation, this chapter further explores the key characteristics of this evaluation tool.

1.2.4 Quality-Adjusted Life Year

The quality-adjusted life year (QALY) is a universally accepted economic cost-utility evaluation (Wilkinson, Petrou and Savulescu, 2018; Pettitt et al., 2016). As previously highlighted, the purpose of economic evaluations is to compare the effectiveness of two or more interventions against one another (Wilkinson, Petrou and Savulescu, 2018; Rai and Goyal, 2018). In this case, as stated by the National Institute for Health and Care Excellence (2013), QALYs are a summary health outcome measure of quality and quantity of life, or potential life years gained for an individual as a result of the intervention or treatment. It is fundamentally important to understand the definition and application of these two concepts which inform resource allocation.

The quality of life and life expectancy of an individual is defined as follows. Quality of life (QoL) is characterised by the World Health Organization as a multidimensional concept that indicates personal conceptions and perceptions relating to individual values, goals, concerns informing physical health, social relationships and physiological states (The WHOQOL Group, 1998). In the same light, the Centers for Disease Control and Prevention (2018) define quality of life as an individual's functional status through their physical and mental health over a period, potentially influenced by public health policies. One could even theorise that the quality of life of

an individual is directly related to human capabilities. Secondly, quantity of life is the number of healthy years an individual gains through treatment; essentially it is one's remaining life expectancy (Whitehead and Ali, 2010; National Council on Disability, 2019). With this understanding, interventions are quantified by the cost per unit of utility (quality and length of life) – commonly termed 'cost-utility estimates' – in studies such as those by Virgili et al. (2010).

This economic evaluation applies and insists on two core principles (Whitehead and Ali, 2010). The first endeavours to evaluate health states or health outcomes in order to produce utility estimates (Karimi, Brazier and Paisley, 2017; Rai and Goyal, 2018). The analysis keeps in mind that individuals move through various health states within a lifetime (Karimi, Brazier and Paisley, 2017; Weinstein, Torrance, and McGuire, 2009; Whitehead and Ali, 2010). In this case each health state which, based on public opinion, is desirable or valuable is allotted a weighted preference (or higher utility) (Weinstein, Torrance, and McGuire, 2009; Whitehead and Ali, 2010; Wilkinson, Petrou and Savulescu, 2018). To retrieve these scores and conceptualise health, various capturing methods involving the opinions of interviewed individuals are used. These include visual analogue scales, time trade-offs and standard gambles (Weinstein, Torrance, and McGuire, 2009).

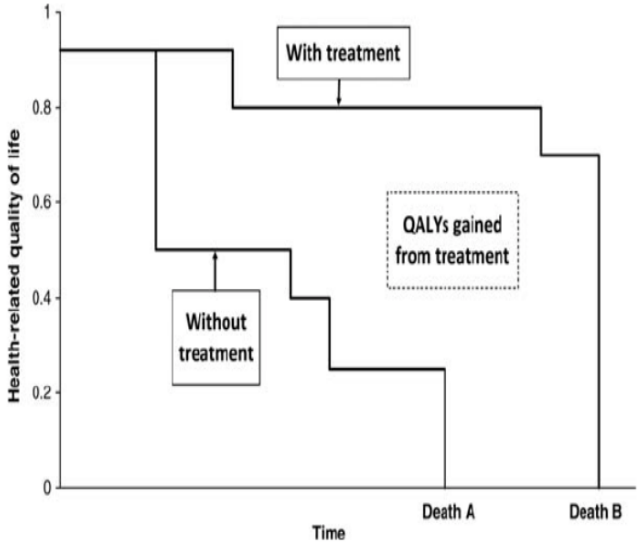
In application, the greater the desire for the health state, the higher the utility weight it will receive. Weinstein, Torrance, and McGuire (2009), call attention to the fact that QALYs do not aim to evaluate and place value on changes in health states. Instead, QALYs value the current health state the individual or community is experiencing. Often, the interventions or treatments which are most effective at maximising health

are more likely to be allotted funding, especially if they also meet a certain threshold in cost (Drummond et al., 2015; Whitehead and Ali, 2010; Wilkinson, Petrou and Savulescu, 2018). Nonetheless, health state preference weights – often defined as “health-related quality of life (HRQoL)” utilities – are captured on a numerical scale (Karimi, Brazier and Paisley, 2017; Wilkinson, Petrou and Savulescu, 2018; Whitehead and Ali, 2010). The scale ranges from 0 (indicating “Dead") to 1 (indicating a "perfect health" state) (National Council on Disability, 2019; Weinstein, Torrance, and McGuire, 2009; Whitehead and Ali, 2010).

Remembering that the common goal of QALYs is to quantify overall health observed over time (National Council on Disability, 2019; Wilkinson, Petrou and Savulescu, 2018), QALYs are then calculated through the multiplication of the quality of life (or the utility value) by the life expectancy (or length of life) (QoL x L). Life expectancy is quantified in years and quality of life (or HRQoL) is valued on a scale from 0 to 1 (Drummond et al., 2015; National Council on Disability, 2019; Weinstein, Torrance, and McGuire, 2009; Whitehead and Ali, 2010). For example, 10 years lived in perfect health (valued at “1”) will result in 10 QALYs (10 x 1); 6 years valued at “0.5” will result in 3 QALYs (6 x 0.5), etc.

Let us now focus on the second core principle studied by Whitehead and Ali (2010), the value of life years measured through the lens of mortality and morbidity. Below is an illustration of this process:

Figure 1: QALY Gain



Source: Whitehead and Ali (2010).

The second core principle QALYs endeavour to accomplish is setting a value to mortality and morbidity – that is, the time spent in a healthy state. As previously mentioned, a weighted score is assigned to each health state occurring within an individual's lifetime. A combination of publicly surveyed HRQoL and the elapsed time within a specific health state (life expectancy) demonstrates how QALYs are gained and life expectancy is valued. Perhaps Figure 1 provides a clearer understanding of how the process unfolds. Figure 1 indicates that if no treatment is administered, a deterioration in HRQoL is observed as illustrated by the lower line (Whitehead and Ali, 2010). Therefore, the time of death ("Death A") would be a faster eventuality. However, on condition that treatment or an intervention is administered, the patient's HRQoL deteriorates less quickly and life expectancy therefore increases ("Death B") in comparison to a scenario without treatment (Whitehead and Ali, 2010). The total scope of QALYs gained is indicated between the two curves, first by the improvement in

quality of life and secondly by the survival time the patient has gained with treatment (Drummond et al., 2015; Whitehead and Ali, 2010).

Remembering that the numerator represents cost and the denominator the QALY gained from the intervention, the cost-effectiveness ratio may be calculated. Quite simply: the price attached to the intervention is divided by the QALYs gained. The result from this calculation will produce a cost-effectiveness ratio. According to McCabe (2009), the results will be reviewed against a threshold incremental effectiveness ratio (considering the willingness of governing bodies to fund treatments). The threshold incremental effectiveness ratio, in essence, places value on the intervention based on cost. This process is known as the cost per QALY (Wong, 2011). This will be further explored in Chapter 3.

To summarise our discussion in this section, QALYs are a comparative analysis tool enlisted to evaluate the impact of various treatments across different clinical experiences and health states (Wilkinson, Petrou and Savulescu, 2018). They serve the following purposes: Firstly, to compare each intervention and quantify the effectiveness of medical treatments (Prieto and Sacristan, 2003; Whitehead and Ali, 2010; Beresniak and Dupont, 2017; John, Millum and Wasserman, 2016). Secondly, to compare the total gain of utilities brought about by medical treatments. This calculation assumes a utilitarian ethical philosophy, insisting that a significant objective of governing bodies or stakeholders is to integrate health maximisation principles in resource allocation (Weinstein, Torrance and McGuire, 2009). The philosophy attempts to maximise the total utility gained and maximise HRQoL with the least expensive treatment (Weinstein, Torrance and McGuire, 2009). Health interventions

and treatments that yield the highest number of QALYs are considered to maximise health, given the administration of treatment. Finally, QALY evaluations serve to compare how cost effective a treatment is in improving quality of life and adding years to it (Prieto and Sacristan, 2003).

However, the literature has raised concerns about the application of preference-based utilities (Weinstein, Torrance and McGuire, 2009) as not all individuals value their conditions the same way. In addition to this, regardless of the preference-based health measurement, an essential characteristic of conventional QALYs is the value placed on health outcomes rather than gradual improvements in health (Weinstein, Torrance and McGuire, 2009). The key point here is that the intervention is evaluated based on the intervention's "cost per QALY" (Wong, 2011). Health economists' cost-effectiveness analyses drive which treatments are funded and, traditionally, they tend to prioritise programmes or interventions with the lowest cost per QALY. This has the overall utilitarian aim of ensuring that community health is maximised (Wilkinson, Petrou and Savulescu, 2018). With all of this in place, this research report focuses on the standardised use of QALYs to compare the cost effectiveness of two or more interventions against each other (Whitehead and Ali, 2010; Pettitt, Raza et al., 2016; Wilkinson, Petrou and Savulescu, 2018).

1.2.5 Current Literature

Cost-effectiveness analysis and QALYs have, over the years, been at the centre of bioethical debates in economics. This research report will not be the first to critique QALYs (either as a decision metric or a utilitarian concept) (see Devlin and Lorgelly,

2017; Harris, 1987; Murphy et al., 2020; Neumann and Cohen, 2018; Whitehead and Ali, 2010). The literature is saturated with reports that critique the uses of QALYs. Schwartz, Richardson and Glasziou's (1993) paper communicates how QALYs are assessed and used. The authors present the utilitarian methodological and theoretical problems used in QALYs. In addition to this, Round, Leurent and Jones (2014) conduct an evaluation of a cancer rehabilitation service / intervention through a cost utility analysis. The authors support what is communicated in this report, that QALYs are useful in a practical sense. However, Round, Leurent and Jones (2014) also contribute to the many questions and concerns about QALYs.

In an effort to capture the ethical concerns surrounding QALYs, Whitehead and Ali (2010) provide a thorough report on these issues. They present concerns about the underlying theoretical assumptions of QALYs, the blindness towards equity considerations, and the utilitarian preference-based measure as areas of controversy. Schlander et al. (2014) highlight that an implication of this is the possibility that economic systems are likely to lead to an innate preference for treatment that saves lives rather than that which enhances it. This is based on the idea that long-term care and preventative interventions do not produce significant QALY gains when compared to result-driven treatments, placing specific treatments at a disadvantage.

As an example of this, consider a report by Garau et al. (2010), who use QALYs to study how health gains are produced by cancer treatments, paying close attention to the methods QALYs assume. There is a preference for HRQoL in adults; however, there is also an insensitivity to the potential progress within a health state, particularly for cancer patients. This insufficient sensitivity, often reported, fails to measure

meaningful clinical changes in utility. Cancer patients may have reduced endurance limits and short life expectancies. There is an identified gap in the literature in the consideration of various factors which play a role in overall quality of life but avoid the standard 'trade-off' (Pettitt et al., 2016; Garau et al., 2010; Knapp and Mangalore, 2007).

In contrast, Neumann and Cohen (2018) contrast the advantages and disadvantages of QALYs. The authors report that QALYs are an effective method of resource allocation in a resource-constrained society, as they measure the quality and length of life. However, the authors also conclude that the utility ratios generated by QALYs favour those who have the potential for QALY gain. Based on this, the aged and disabled are set at a disadvantage, not having many high-quality life years remaining to them. In the same light, Partnership to Improve Patient Care (2017) presents the uses, misuses, and ethical issues characteristic of QALYs. A significant finding to emerge from this study is that the significant value attached to individual lives in perfect health potentially disadvantages patients with disabilities and chronic diseases. In support of this, Garau et al. (2011) present the argument that a valuable life is not measured only by a perfect health state; one cannot conclude that an individual who uses a wheelchair cannot live a happy life.

This brief survey indicates that the main questions or issues addressed in the literature are ethical concerns regarding three of the assumptions of QALYs, namely that:

a) quality of life is a quantifiable outcome;
b) utilitarianism, the concept of utility, is acceptable; and that

c) the old or disabled have the least capacity to benefit as compared to the young or able-bodied.

Although the literature critiques QALYs extensively, it remains unclear whether these assumptions are in fact just and whether they give sufficient respect to people's dignity. This research report will help clarify this by applying to these issues an influential human development approach to social justice and quality of life, centred on human dignity – Martha Nussbaum's capabilities approach (Nussbaum, 2011). This theoretical perspective will be further explored in the next chapter.

Let me now specify the parameters of my research more precisely.

1.3 Research Question

Does Martha Nussbaum’s capabilities approach to justice indicate that the use of QALYs as a criterion for the allocation of limited medical resources is unjust?

1.4 Rationale

Understanding the value of treatments and interventions is necessary (Neumann and Cohen, 2018) especially for rationing purposes. This necessity is evident in the numerous cost-per-QALY studies presented in current research. As previously stated, rationing is an unavoidable economic process. The New York Times reports that the decision to allocate resources is not the concern, however; it is instead the decision of how to, ethically or unethically, allocate resources (David Leonhardt, cited in American College of Physicians, 2011, p.11). Serious questions remain about the ethics of using QALYs. In particular, it is unclear whether economic evaluations using QALYs truly

reflect the bioethical principle of justice that calls for “treating everyone as equal and valuing each life as equally valuable” (Rawls, 1999). Although a large body of research has been written critiquing QALYs, the current literature has not systematically explored the implications that Nussbaum’s important account of justice has for the use of QALYs. Therefore, this report will add to the existing literature on distributive and social justice applied to healthcare.

1.5 Thesis Statement

I will argue that Martha Nussbaum’s capabilities approach to justice indicates that the use of cost benefit analysis on the basis of measures of health benefit (such as the QALY) as the criterion for allocation for the allocation of limited medical resources is indeed unjust, as it undermines people’s possession of the capabilities necessary to live a dignified human life.

1.6 Research Aim

This research report aims to identify to what extent Nussbaum’s capabilities approach to justice indicates that it is unjust to use QALYs to determine how we ought to distribute limited healthcare resources.

1.7 Research Objectives

i. To present the theoretical framework of Nussbaum’s capabilities approach, as a requirement for justice and human dignity.
ii. To argue that Nussbaum’s approach indicates that the use of QALYs in healthcare rationing leads to treating people as commodities in a way that is inconsistent with

human dignity.

iii. To argue that Nussbaum's capability approach indicates that the use of QALYs in healthcare rationing has unjust implications for disabled people.

1.8 Research Methodology

This research report is holistically guided by the principles of normative study design. It further employs philosophical research standards and methods. The study design aims to define how things ought to be improved (Duignan et al., 2020). This is the study design best suited to answering the research question, which explores the ethical dimensions around the use of QALYs as a criterion for the allocation of limited medical resources. The purpose of using a normative study design, is not only based on its common use in research (Duignan, Rodriguez and The Editors of Encyclopaedia Britannica, 2020; Neumann and Cohen, 2018; Whitehead and Ali, 2010). It is also based on its appropriateness in exploring moral or philosophical standards.

Principles of bioethics such as beneficence, justice, autonomy and non-maleficence (Beauchamp and Childress, 2013) have not been violated in conducting this study. This research study does not involve human or animal subjects. No new data is collected or analysed – the information is instead gathered from secondary sources. Analysed data / literature used in this study is conducted through desktop and library-based research. For the purpose of gathering research data, the data collected is sourced from, but not limited to, PubMed, books, content-related articles, government legislation, Google Scholar as well as various other reputable academic search engines.

Literature findings are critically and ethically examined with the aim of answering the research question. Taking this aim into account, the study examines secondary literature in order to provide the clarification and definition of significant concepts as well as provide an interpretation of them. The study also identifies assumptions and criticisms presented in the relevant literature. Furthermore, with the use of an ethical-theoretical framework, an analysis aimed at articulating the most reasonable interpretation of significant concepts found in the sources is conducted. The Faculty of Health Sciences Research Ethics Committee (Medical), University of Witwatersrand, Johannesburg has approved ethical clearance for the carrying out of this research study.

1.8.1 Argumentation Strategy

The intention of this research report is to present an overview of QALY's as well as debate the policy, social and ethical challenges which arise as a result of its use in allocating scarce resources. In order to fulfil this intention, each chapter is structured to present the arguments as follows. Chapter 2 introduces the theoretical framework on which this research report will base its arguments. Nussbaum's philosophical framework develops a justification for considering the significant role of ten central capabilities she enumerates, often referred to as fundamental entitlements, which are essential to achieving a proper conception of a good or valuable life, and which are the prerequisites of a just society (Nussbaum, 2011; Robeyns, 2011; Vorhaus, 2015). The approach will be applied throughout the research report, especially in regard to justice and human dignity in human development (University of Chicago, 2013).

Followed by this foundation, the research report presents arguments to illustrate that the application of QALY evaluations in healthcare is unjust in two ways. The first ethical concern centres on the commodification of human life promoted by the use of QALYs. This is discussed in Chapter 3. The main argument in this chapter challenges the assumption that the commodification of human lives is at all acceptable. Chapter 4 then critiques the implications that the use of QALYs have on disabled populations, drawing from Nussbaum's capabilities approach. Here, it is argued that QALYs fail to implement accurate health preference measures for patients, and that this raises a second ethical concern in that it prejudices disabled and chronically ill patients. Unequal health preference measurements create unequal ranks, ensuring that the disabled remain below the threshold of capabilities necessary for dignity. Finally, Chapter 5 concludes the arguments drawn from Chapters 1 to 4. The final chapter includes a discussion of the limitations of this research report, which could be improved on for future studies.

1.9 Conclusion

Chapter 1 of this research report has demonstrated, through the use of current literature, the significance of resource allocation in both high- and low-income countries. In it, I stated that in both, traditional methods of rationing occur at micro and macro levels in determining the allocation of healthcare spending. This research report, however, questions whether macro level cost-effectiveness allocation methods such as the QALY approach are ethically justified, especially because of the significant implications its application has on justice and human dignity. As Chapter 1 has illustrated, cost-effectiveness analyses will ultimately decide which interventions to

fund and, more often than not, prefer programmes with the lowest cost-per-QALY (Wilkinson, Petrou and Savulescu, 2018). Although popular with the NICE, the literature continues to question the methodological and theoretical advantages and disadvantages of QALYs. This philosophical research study aims to argue that Nussbaum's approach indicates that the use of QALYs in healthcare rationing leads to treating people as commodities in a way that is inconsistent with human dignity, as well as having unjust implications for the disabled population.

2. PHILOSOPHICAL FRAMEWORK: NUSSBAUM'S CAPABILITIES APPROACH TO JUSTICE AND HUMAN DIGNITY

2.1 Introduction

Now that the overall constructs and debates surrounding resource allocation tools, such as QALYs, have been laid out, this report seeks to further elaborate the concerns highlighted in the literature in a more philosophical, theoretical way. In this regard, Chapter 2 aims to describe Martha Nussbaum's inspiring 'capabilities approach'. Nussbaum, in *Creating Capabilities: The Human Development Approach,* clarifies that the capabilities approach is concerned mainly with social justice issues, which are interconnected with quality of life (Nussbaum, 2011, p.19). According to Robeyns (2011), the approach is a philosophy that requires governmental (constitutional) structures to ensure the provision of a bare minimum of ten central capabilities necessary for human dignity to its citizens. This approach asks social planners to inquire about the needs valued by members within society for the purpose of converting resources into 'functionings' (Nussbaum, 2011). The approach challenges economic and social systems which rely on methods grounded on utility or per capita GDP (Nussbaum, 1995; 2011, p.1).

Shifting the conversation from pure economics to people, Nussbaum's approach appreciates that individuals may conceive of and desire to achieve lives characterised by freedom, justice and wellbeing, when the threshold of these ten capabilities is present (Nussbaum, 2011; Robeyns, 2016). In so doing, a society may be considered just on condition that each citizen is guaranteed 'fundamental entitlement' to their

necessary capabilities (Nussbaum, 2008), providing a way for each citizen to live a dignified life. The fundamental entitlements go beyond the abilities that each citizen innately has and include the opportunities and freedoms created by the combined abilities in the context of people's economic, political, or social environments (Venkatapuram, 2011).

In this chapter, I elaborate the fundamental concepts of the capabilities approach. Even though the theory originates with Amartya Sen, this research report is primarily interested in clarifying the notion of human dignity and its connection to justice from Nussbaum's perspective. Firstly, I will discuss the foundations of the theory. Then, I will present the list of those capabilities, carefully considered by Nussbaum, that frame a dignified and truly human existence. Grounded on this analysis, we can proceed to take a closer look at the relationship between justice and the demands of the capabilities approach. In doing so, I will clarify the notion of human dignity advocated by Nussbaum.

2.1.1 Key Concepts in Nussbaum's Capabilities Approach

Capability and Function Distinction

According to Nussbaum (2011), there are two key notions in the capabilities approach: the notion of 'functionings' and 'capabilities'. Although Nussbaum's capabilities approach is applicable to both human and non-human beings, as is common in the broader literature, this discussion will be restricted to human functionings and capabilities rather than the functions and capabilities inherent in non-human beings. Nussbaum's capabilities approach defines *capabilities* as freedoms to act — that is,

they are an individual's abilities or resources — whereas *functionings* are those capabilities that are accomplished (Nussbaum, 2000; Robeyns, 2016). Thus, functionings are 'beings' and 'doings' (Nussbaum, 2011; Robeyns, 2016; Saigaran, Karupiah, and Gopal, 2015). Examples of 'beings' include living a well-nourished life, being actively involved in supportive social surroundings, or being educated. Functionings are also 'doings', for instance traveling, working, caring for a child, or donating money to charity (Robeyns, 2016; Saigaran, Karupiah, and Gopal, 2015). Nussbaum states that it is often helpful to think of capabilities as facilitators or enablers for the achievement and demonstration of functionings (Kleist, n.d.; Nussbaum, 2011).

In essence, according to Robeyns (2016), functionings may be characterised as that which is realised and capabilities as potential. They are the achievements and opportunities that one may choose to exercise, respectively (Nussbaum, 2011; Robeyns, 2016). With this knowledge, although this research does not fully develop the argument around this concept, it may be observed that autonomy – an ethical concept of freedom of choice – is also central to the capabilities approach (Nussbaum, 2011). To illustrate this, Nussbaum uses the following example. When reflecting on health, specifically the function of being healthy, governing bodies are required to make available opportunities (the capabilities) for human beings to be healthy (Nussbaum, 2000; 2011; Venkatapuram, 2007). For example, governing bodies should ensure the provision of insulin to lower symptoms of diabetes or the provision of condoms to prevent sexually transmitted diseases. In each of these examples, given the capability, the individual may choose which function to exercise or not. Nussbaum insists that, ultimately, the political goal should be to prioritise capabilities rather than

functionings (Nussbaum, 2011). This shift avoids privileging certain conceptions of a good life, further ensuring that large populations access opportunities for their desired health needs to be met (Nussbaum, 2000; 2011).

To summarise this section: Nussbaum's commitment to the capabilities approach inspires the principled adoption of capabilities as a sound alternative to the sole focus on functionings, taking on an anti-paternalist approach (Kleist, n.d.; Vasbist, 2010). Furthermore, this normative conception stems from the significance of personal responsibility. In *Creating Capabilities: The Human Development Approach,* Nussbaum emphasises that the foundation of the capabilities approach is grounded on the idea of freedoms (Nussbaum, 2011, p.25). She encapsulates the notion of capabilities through choice and freedoms which she considers to have intrinsic value (Nussbaum, 2011, p.25). In this case every human being should be given the equal real opportunity to strive to realise their capabilities through beings and doings, if they wish to do so (Robeyns, 2016). Governing bodies are responsible to aid in providing and promoting these capabilities, but it is the individual's responsibility to discern how to efficiently utilise them (Robeyns, 2017). Simply put, the key point is that it is up to individuals whether or how they want to actualise their capabilities in the form of functionings. What they are owed by society is simply the capabilities that allow them to make this decision.

Capability Threshold Level

As demonstrated through Nussbaum's distinction between capability and function, what the approach is after is a society in which people are positioned to truly function as human beings (Nussbaum, 2011; Robeyns, 2016). In pursuing this objective,

Nussbaum primarily motivates the capabilities approach through the concept of 'capability thresholds' (Nussbaum, 2011). This concept stipulates that human beings, capable of active striving, are to be given a minimum benchmark (a threshold) of ten central capabilities regardless of their intelligence level, innate skills, or geographical location (Nussbaum, 2011; Robeyns, 2016; Stewart, 2013). This is to say that a person who has not been provided with sufficient central capabilities to live and engage with other human beings will fall beneath the minimum benchmark or threshold (Nussbaum, 2011). Further, it is important to note that this approach is not a distribution solution. Instead, it determines a minimum threshold level which each individual should attain.

Nussbaum gives absolute priority to interests that fall below the threshold or benchmark of the ten central capabilities (Nussbaum, 2011; Stein, 2009). The list of central capabilities, which will be stated and clarified shortly, is often referred to as a list of fundamental 'entitlements', which Nussbaum insists governing bodies ought to make available for justice to be exercised (Nussbaum, 2011). It is important to note that the approach does not provide a solution for how inequities which do not fall below the threshold of capabilities ought to be handled, as they are not fundamental entitlements (Nussbaum, 2011; Stein, 2009). So, interests falling below the threshold have absolute priority while inequities exceeding it hold second priority. Questions about distribution may be addressed once all human beings are above the threshold. Moreover, providing these capabilities would not be a meritocratic approach. It will, however, be one that encourages opportunities for individuals to be established above the threshold (Nussbaum, 2011, p.24). This philosophy could mean dedicating extra resources (or central capabilities) to a child with autism to reach the same educational

level as its peers, through specialised educational interventions.

In Nussbaum's account of justice, achieving these minimum thresholds holds more weight on the scale of importance as compared to achieving equality (Nussbaum, 2000). This position is defended by the understanding that capabilities are pursued not for certain groups of people but for every single person. This understanding, moreover, cements the idea that there is no sound rationale for those above the threshold to justify withholding resources – whether healthcare or otherwise – from those who fall below it. Failure to provide all ten central capabilities to each individual in a society suggests a prioritisation of one group over the other; Nussbaum suggests that those polices are to be rejected as they do not meet the criteria for justice (Nussbaum, 2011).

Human Dignity

Stoic philosophy holds the view that human dignity or human worth is an immutable principle inherent, equally, in all human beings (Nussbaum, 2008, p.352; Vorhaus, 2015; Leukam, 2011, p.1). The principle is further characterised as binary – an individual either has the whole of dignity or none at all (Leukam, 2011, p.1). Nussbaum agrees with her Stoic predecessors. Over the years, philosophy has attempted to determine / define the conditions, as well as the significance, of human dignity. Although not finding full clarity in its definition, Nussbaum is clear about the impact and significance of human dignity in facilitating self-respect and moral worth (Leukam, 2011, p.5; Nussbaum, 2000; 2011, p.29). To paint a picture illustrating the multifaceted principle, Nussbaum outlines the determinants of human dignity, which could be seen as a divergence from the Stoic philosophy.

Stoic philosophy holds the view that autonomy and rationality are the only conditions of human worth (Nussbaum, 2008, p355; Leukam, 2011, p.2; Vorhaus, 2015), leaving the determination of dignity in the hands of fortune (Nussbaum, 2008, p.353). However, this is where Nussbaum departs from the Stoics. In Nussbaum's view, the notion of human dignity is related to active striving (Nussbaum, 2011, p.31). She emphasises that even though human beings may differ in their potential for active striving, human dignity is always equal, for human beings are all deserving of respect from institutions and law, regardless of those differences (Nussbaum, 2011). Though recognising the value of choice and freedoms (Nussbaum, 2011, p.25; Nussbaum, 2006, p.87) – even stating that a human being should be envisioned as a being characterised by choice – Nussbaum holds to a more all-embracing approach to social justice than the narrow view of her Stoic predecessors (Nussbaum, 2011, p.30). This is for the benefit of both unimpaired and impaired human beings (Nussbaum, 2008, p.354; Vorhaus, 2015). This aspect of her thought will be further elaborated and discussed later.

Nussbaum (2011, p.30) also recognises that the living conditions and environment of human beings play a pivotal role in shaping lives of true human dignity. To facilitate human dignity, stakeholders ought to provide for and develop those who are unable to provide for themselves. Nussbaum uses debates around public schooling for disabled children as a way of illustrating this, highlighting the importance of education in developing the mind of a child. Failing to provide or create such an environment would be treating the child with less dignity they deserve (Nussbaum, 2011, p.30). At a micro level, one's political, economic, and social circumstances may influence how one chooses one's own functionings. However, at a macro level, dignity should play a

significant role in shaping policy; policies should protect rather than diminish the value of people's choices (Nussbaum, 2011, p.30). As a condition of justice, Nussbaum states that a social minimum of all ten central capabilities should be realised. These are discussed in what follows.

2.2 Central Capabilities Required for Justice

Nussbaum's capabilities approach comprises ten central capabilities which are inarguably essential and meaningful to human functioning (Nussbaum, 2000; 2011, p.33). She states that although this list is essential, it should be considered a social justice proposal — a moral basis for political and constitutional policy decision making – and not a complete theory of justice (Nussbaum, 2011, p.36). Moreover, Nussbaum's approach focuses on capabilities rather than actual functions. She holds that this protects the opportunities individuals have to pursue and achieve other functions which enhance their inherent human dignity (Nussbaum, 2011, p.25).

2.2.1 Types of Capabilities

Nussbaum's central capabilities are classified into three categories (Nussbaum, 2011, p.21; Saigaran, Karupiah and Gopal, 2015, p.192). According to her, these categories may be defined and distinguished as follows. Firstly, *basic capabilities* are the inherent predisposed characteristics an individual has that make later development possible (Nussbaum, 2011, p.23; 2000; Saigaran, Karupiah and Gopal, 2015, p.192). Secondly, *internal capabilities* are the characteristic or states of a person that are dynamic and fluid rather than fixed, to be trained and developed through one's social, political and economic environment (Nussbaum, 2011, p.21; Saigaran, Karupiah and Gopal, 2015,

p.192). Thirdly, Nussbaum defines *combined capabilities* as collective freedoms originating from personal abilities as well as social and economic environments that encourage functionings (Nussbaum, 2011, p.20; Saigaran, Karupiah and Gopal, 2015, p.192). This particular categorisation is important in capturing the intuitive idea behind human development.

As previously mentioned, capabilities or political entitlements are fundamental freedoms enabling human beings to choose particular functionings (Nussbaum, 2011, p.20). Distinguishing types of capabilities enables a society to evaluate which capabilities individuals in that society lack. For example, training and educating individuals about freedom of speech (a capability), as most societies do, but denying them the practice of freely expressing their opinions (a functioning) is incongruent with social justice. To further illustrate, Nussbaum discusses a widowed young woman strongly influenced by her cultural background who still practices and believes in female genital mutilation (Nussbaum, 2000). Although, in hopes of a second marriage, she has not been mutilated, her culture forbids her from practising her sexuality. Nussbaum (1995) explains that due to the fact that she has not been mutilated she still possesses her internal capabilities. But her combined capabilities are compromised through the denial of her freedom to practise her sexuality (Nussbaum, 2000).

2.2.2 Nussbaum's List of Ten Basic Human Capabilities

From her book, *Creating Capabilities: The Human Development Approach* (2011, pp.33-34), Nussbaum provides a descriptive list of ten central capabilities required as conditions of social justice, namely:

1. Life: the capacity to live an adequately long life.
2. Bodily health: the capacity to ensure that essential bodily health is maintained.
3. Bodily integrity: the capacity to move from one environment to another unhindered; protection from violence.
4. Senses, thinking, imagination, and reasoning: the capacity to develop and cultivate these concepts through sound education. The hope is that their development will encourage enjoyable experiences, and furthermore allow one to truly discover what it means to live in a human way.
5. Emotions: the capacity to build attachments to people and as a result create interpersonal relationships; the freedom to show the emotions of love, gratitude, anger or grief.
6. Practical reason: the capacity to formulate a concept of what is virtuous or good for one's life plans; the freedom to conceive a life not influenced by the perceptions of others.
7. Affiliation: a) the freedom to live for and show concern for others; b) the social practice of human dignity and self-respect. Affiliation entails being treated with the dignity worthy of a human being seen as an equal, ensuring that non-discriminatory practices are implemented.
8. Other species: the capacity to co-exist and build a healthy relationship with nature, plants and animals.
9. Play: the opportunity to smile or be joyful as well as take part in recreational activities one desires.
10. Control over one's environment: a) the capacity to fully participate politically (including the freedom to express political views unhindered); b) the capacity

> to own material possessions (including the ability to own and protect property, as well as seek and maintain employment while practising practical reasoning).

2.2.3 In Defence of Universal Capabilities

Nussbaum (2000) strongly advocates for the universal use of all capabilities on this list, based on the following rationale.

Firstly, insisting on the provision of all ten central capabilities ensures that trade-offs of capabilities are avoided. This limits a deadlock from occurring when deciding which capability is most critical in a society that cannot provide them all (Nussbaum, 2000; St. Clair and Gasper, 2010). Perhaps it will cause policy makers to rethink the applicability of evaluation methods such as CEA and CUA in policy decision making. Secondly, the multiple realisability of each capability allows different religious, cultural, and secular views to be considered, in line with the norms and values of culture, when considering what shapes a dignified life (Nussbaum, 2000; Robeyns, 2016). Thirdly, treating capability as a goal results in a political principle which promotes capabilities rather than functionings, respecting individuals' freedom of choice to pursue the relevant functionings or not (Nussbaum, 2000; Robeyns, 2016). Fourthly, each capability gives all human beings the power of choice. This promotes liberty and practical reason, aligning with other prominent principles of justice (Nussbaum, 2000; Robeyns, 2016).

Fifthly, political liberalism, touched on in the last point, is promoted through the

insistence on the use of all ten capabilities. Political liberalism is a political concept acknowledging that human beings have different conceptions of the good (Nussbaum, 2000). Nussbaum's list advocates and prioritises open conceptions of the good life on a large scale. This principle helps answer accusations Nussbaum's approach of being biased towards westernised traditions and values (Saigaran, Karupiah and Gopal, 2015, p.195). Sixth, Nussbaum advocates this list as constituting the *core* capabilities that must be the foundation, at the least, of any policy or constitution implemented by governing bodies (Nussbaum, 2000). Once they are implemented, governing bodies may choose to promote further capabilities better suited to their norms and traditions (Nussbaum, 2000; Robeyns, 2016). Setting these capabilities as political goals should be understood as an aspirational benchmark; its function is aspirational rather than utopian. (Nussbaum, 2000; Robeyns, 2016).

2.3 Capabilities Approach: Dignity, Justice and Healthcare

This research report has, so far, outlined the conceptual basis for Nussbaum's capabilities approach. A discussion aimed at clarifying the principles of capabilities, threshold levels, and human dignity has been conducted. Although all of these principles are integral to the theory, Nussbaum particularly highlights the significance of human dignity in creating a just society. Fundamentally, the capabilities approach is a social justice theory based on the idea that justice requires individuals to be allocated the minimum ten central capabilities (Robeyns, 2017). When these are provided, individuals have the opportunity to be treated with respect and human dignity (Robeyns, 2017). In this final section of the chapter, I will explore the correlation between human dignity, social justice and the ten central capabilities, particularly in healthcare.

2.3.1 Capabilities and Human Dignity

Nussbaum defends central capabilities for the holistic purpose of not only assisting in creating just societies but also helping us grasp what human dignity demands. In Nussbaum's version of the capabilities approach, she places particular attention on fundamental entitlements or the areas of freedom which are integral to ensuring that all people live as dignified human beings (Nussbaum, 2006 p.166; 2011, p.31). Although all capabilities / entitlements are crucial, Nussbaum holds two out as particularly significant: a) affiliation, which requires the social practice of human dignity and self-respect; and b) practical reason which Nussbaum believes "suffuses all the others, and this, in turn, constitutes a truly human pursuit" (Nussbaum, 2011, p.39; 2000; Robeyns, 2016; Kleist, n.d.). Through these she demonstrates that at the core of human function lies a dignified human being with the ability to construct its own idea of a dignified life, unshaped by the perceptions and expectations of others.

Generally, human dignity calls for the recognition of one's worth or the value of one's choice and being treated with the courtesy one deserves (Nussbaum, 2006, pp.87–92). Nussbaum insists that placing the emphasis on the provision of the ten central capabilities will become a source for meeting the primary goals of any liberal and pluralistic society, as each individual is placed above the threshold level of capabilities (Nussbaum, 2008, p.361; 2011, p.19; Robeyns, 2016). In this way, all persons are treated with respect and are exempt from humiliation (Nussbaum, 2006, p.174; 2011, p.16). Throughout the literature, Nussbaum insists that human respect requires freedom of choice to be respected as well. That is, human beings must be able to freely choose which capabilities to exercise. However, circumstances may inhibit this

choice. For example, Nussbaum observes how cases of discrimination (whether based on religion, race, and gender) or even rape compromise central capabilities. She argues that the act of rape compromises the development and functioning of a human being's mental, emotional, and bodily state. In this case, the compromised development will inhibit the affected individual from fully living a life of dignity (Nussbaum, 2008, p.358).

Nussbaum boldly claims that in the absence of a practised central capability for functioning, although it may sound extreme, the human being is stripped of their humanity and cannot be considered a human being any longer (Nussbaum, 2000). Her social justice theory acts as a platform for inquiring what constitutes a dignified life. Nussbaum states that respect for human dignity is evident only if all human beings meet the threshold of possessing all ten capabilities (Nussbaum, 2011; Robeyns, 2016; Stewart, 2013). Their absence is an indication of a lack of human dignity and compromised social justice (Nussbaum, 1995; 2011; Gluchman, 2019). Furthermore, these specific goals ensure the promotion of equality, which all societies must have, to a considerable degree. Governing bodies, according to Nussbaum (2011) ought to implement policies which ensure dignity for all (Nussbaum, 2011). It is the responsibility of social institutions to provide each of their citizens with each central capability, at least up to the minimum threshold.

2.3.2 Capabilities and Justice

The fundamental principle which Nussbaum grounds her approach on is social justice. The approach aims to assess and address social justice issues affecting the quality of

life of individuals (Nussbaum, 2011, p.18). It poses questions about the injustices and inequalities which may arise from, for example, marginalisation or discrimination, which can escalate into a spectrum of issues (Nussbaum, 2011, p.19).

As we have seen, thresholds of capabilities hold a particularly significant role in Nussbaum's approach to social justice. Her approach states that a society is just to the extent that every citizen is constitutionally guaranteed these central capabilities at the right threshold (Nussbaum, 2011). As a reminder, a capability enables a human being to achieve a function (Nussbaum, 2000; 2011, p.20). The approach not only guides us to social justice but also ensures the creation of an environment where citizens can choose to function as fully human beings. In this just society, governmental bodies are not responsible for people's happiness; instead, they are responsible for providing opportunities for people to make themselves happy (DeMartino, 2011, p.41; Lamont and Favor, 2017). According to Kleist (n.d.), two different individuals with equal opportunities to practise the capability of play may choose to enjoy their capabilities in different ways: one may choose to volunteer at a homeless shelter while the other chooses to swim. This essentially means that two people with equal capability thresholds experience different levels of utility; they remain responsible for that difference themselves. But, at the very least, this capability has been provided.

Nussbaum’s insights present moral arguments for a threshold of capabilities, that is, a basic minimum of 10 central capabilities, for the purpose of setting the standard of just societies (Nussbaum, 2011). As a criterion for justice, a threshold of capabilities is fairly vague, which may result in inconsistencies in judgements about justice. I accept that there may be cases where it is not clear whether the threshold has been met.

However, I also think that the notion of the threshold is sufficiently intuitively clear to act as a moral compass pointing towards justice in many cases. The way it can do this will become clearer as I apply the notion over the following chapters.

With this said, Nussbaum admits that on occasion social conditions may present challenges in delivering the threshold level of central capabilities, forcing societies to make trade-offs, as two or more capabilities compete (Nussbaum, 2011, p.36). Trade-offs ensure that societies are forced to make tragic choices (Nussbaum, 2011, p.37). The healthcare sector, especially recently, has had to make trade-offs involving the provision of certain forms of care for individuals due by economic strain (Nuijten and Dubois, 2011). To do so, governing bodies have resorted to cost-benefit evaluation methods. Nussbaum states that cost-utility or cost-effectiveness evaluations compromise social entitlements for the development of a fully just society (Nussbaum, 2011, p.37). This claim will be further elaborated throughout this report.

2.3.3 Capabilities and Healthcare

As demonstrated earlier, health and healthcare are accounted for in Nussbaum's central capabilities list, namely through the capabilities of: a) life: the capacity to live an adequately long life; b) bodily health: the capacity for ensuring that essential bodily health is maintained; and c) bodily integrity: protection from violence, or the capacity to move from one environment to another unhindered. These capabilities certainly afford the opportunity to each human being for a healthy and full life. They can perhaps be understood as facilitators for achieving the other capabilities, further cementing the idea of the interconnectedness of all the capabilities. Without the capacity to be

healthy, one cannot engage in play or even interact with others within their environment (Venkatapuram, 2007, p.89). Pregnant women, for example, require forms of healthcare such as nutritional or prenatal healthcare services in order to fully function as human beings, not only for themselves but for their unborn children as well (Venkatapuram, 2007, p.91; Nussbaum, 2011, p.23).

2.4 Conclusion

Chapter 2 has extensively illustrated Nussbaum's capabilities approach to social justice and human development. In it I have explained that capabilities are freedoms to achieve something, and functionings are the resulting achievements (Nussbaum, 2011, p.19). With this in mind, Nussbaum (2000) strongly advocates for the universal use of all capabilities, versus functionings, as each capability holds significance in its own right. As a political goal, Nussbaum's capabilities list provides each human being the freedom to conceive a life that they value (Nussbaum, 2011, p.39; Robeyns, 2016).

Nussbaum insists that a threshold level of the provision of all ten central capabilities is required for justice and human dignity to be achieved (Nussbaum, 2011, p.36). For example, practical reason, which is the ability to construct one's own ideas of a good life, is essential to a life of dignity (Nussbaum, 2011, pp.33–34). If this capability is not facilitated, one falls below the standard that a dignified life requires. This ethical framework requires the equal and sufficient allocation of resources to ensure that individuals are able to function fully (Venkatapuram, 2007, p.91). To facilitate justice in a society, every individual must be entitled to central capabilities at a level sufficient to make a dignified life possible (Nussbaum, 2000; 2011, p.36).

Now that the framework for understanding and elucidating how Nussbaum conceptualises human dignity and social justice in public policy is in place, we can ethically evaluate rationing tools such as QALYs, by applying Nussbaum's theory. I do so in the following chapter.

3. COMMODIFYING HUMAN LIFE AND THE INJUSTICE OF QALYS

3.1 Introduction and Overview

This report has established that economic evaluations such as the QALY approach have become gradually ever more crucial in health policy due to a climate of diminishing resources. QALY, as an evaluation method or a cost-utility analysis, employs neo-utilitarian ethics to govern resource allocation policies (Pettitt et al., 2016). However, this practice is not without its concerns. One concern lies in the formulation – the criterion which economic evaluations typically employ. As established in Chapter 1, the QALY method is an attempt to produce a single numerical index by placing a value on HRQoL (utility) and life expectancy based on the cost of treatment (Weinstein, Torrance, and McGuire, 2009; Whitehead and Ali, 2010).

In reference to Chapter 1, cost-utility QALYs are an economic framework used to guide the rationing of limited healthcare resources (American College of Physicians, 2011, p.11). QALY evaluations adopt a multi-attribute utility framework favouring two criteria: length of survival and quality of health status (Drummond et al., 2015; National Council on Disability, 2019). QALY gains are observed when the improvement of quality of life and survival time the patient has gained with treatment (Drummond et al., 2015; National Council on Disability, 2019; Pettitt et al., 2016; Weinstein, Torrance, and McGuire, 2009; Whitehead and Ali, 2010). The numerical index indicating QALYs gained will then be divided by the cost of treatment to present the cost-per-QALY ratio or the cost-utility of treatment (McCabe, 2014; Wong 2011). This leaves the

impression that monetisation – the placing of monetary values on health outcomes – is a fundamental element of QALYs.

The idea of monetisation, however, has created an uneasy tension between economic interests and respect for the value of human lives. The justification for placing a monetary value on human life is perennially debated in social policy and bioethics (Bayles, 1978). These debates are often centred around the idea that the existence of economic limits or the need for medical rationing suggest that monetisation is a plausible method of allocating life-enhancing healthcare resources (Scheunemann, and White, 2011). Importantly, it is becoming increasingly difficult to ignore the assumption that medical rationing practice accepts that monetary value should be placed on human lives, purely based on the utility those lives bring to their societies (Huang et al. 2018). This chapter will challenge the assumption that QALYs which maximise utility for medical rationing allocation, essentially encouraging the commodification of human lives, are ethically justified.

I begin by illustrating the composition of utility measures to provide a thorough understanding of how resource allocation is achieved through QALYs. Secondly, commodity and commodification in relation to QALYs will be defined. Once our understanding of utility measures and commodification in relation to QALYs has been enhanced in this way, Nussbaum's theory of justice (employing the principle of thresholds of capabilities, as well as human dignity) will be used to support the argument made.

3.2 Utility Measures: Cost-Effectiveness Threshold

As explained, the purpose of a cost-utility analysis, according to McCabe (2014), is to determine a cost-per-QALY ratio (QALY gain / cost) (Wong, 2011; Zilberberg and Shorr, 2010). To determine how resources will be allocated, NICE compares the results of the cost-utility analysis to a budget of between £20,000–£30,000 for one QALY gained by residents in the United Kingdom (Cleemput et al., 2011; National Institute for Health and Care Excellence, 2013). For the United States, a budget of $50,000–$100,000 is used (Neumann, Cohen, and Weinstein, 2014; Nuijten and Dubois, 2011). A medical intervention is considered to be of good value if it falls below this 'budget' (Cleemput et al., 2011). In other words, maximum funding for medical interventions per QALY created for a patient is capped at £30,000 (Kirkdale et al., 2010; Nuijten and Dubois, 2011).

Essential medical interventions above the £30,000 and $100,000 threshold may not be funded. Ensuring that medical interventions are cost effective may sound reasonable, however, using the thresholds set by the United States and United Kingdom commodifies lives by putting a monetary value on human lives based on the utility they produce. So, treatments for rare diseases and orphan diseases which are generally more expensive to produce (Wareham, 2013, p.1), targeted for smaller populations, will not fall high on the priority the UK's and US's list due to the lack of utility produced. Perhaps it is valuable to define and clarify the terms 'commodity' as well as 'commodification' at this point and illustrate the connection between these concepts and QALYs.

3.3 Commodity, Commodification and QALYs: Current Perceptions

Commodification, at the most abstract level, is a process in which various items are quantified and made exchangeable or equivalent through the use of money (Christiansen, 2017). Simply put, it is the process by which something becomes a commodity. Furthermore, Marxist theory adds to this definition by highlighting that a commodity often has the sole purpose of satisfying the needs and wants of individuals (Pashukanis, 2017; Fleetwood, 2002). Walsh (2019) defines commodification as the transformation of ideas, services, goods, and people into commodities or objects for monetary exchange within a capitalist economic system. Due to the increase of privatised, digitised, and monopolised world, commodification may manifest itself in the sale of basic human necessities like water, education and long-standing healthcare. These basic goods are viewed as commodities and are then sold to consumers (Christiansen, 2017, p.84; Pellegrino, 1999).

Neumann and Cohen (2018) argue that healthcare commodification, while it compromises the health of vulnerable populations by limiting access to healthcare (Christiansen, 2017, p.84), does have countervailing benefits. They elaborate on this point by arguing that valuing human life through rational and explicit measures like QALYs could potentially improve the quality and quantity of healthcare delivery for each patient. Card and Mooney (1977, p.1628) support this position and suggest that utility measures by estimating cost and utilities in monetary terms, have the potential to a) recommend the best course of treatment; and b) determine whether an expensive diagnostic test will be worthwhile.

To further illustrate this point Card and Mooney (1977) report, in order to determine a

diagnosis particularly for large bowl cancer, the American Cancer Society recommends and conducts six tests costing $47 million per case (Card and Mooney,1977, p.1628). This is problematic. The authorisation of six expensive tests by the American Cancer Society meant that no money was left for other large-scale cancer interventions. Although the study is not particularly current, Card and Mooney (1977) raise queries then that societies still are faced with today. Queries concerning the principles which inform decision making in public health. The researchers stress that health systems can spend money to saving lives. However, there is a limit to how much is to be spent on health in each case. In other words, the cost of saving an individual life may take away from the potential to better another life (Card and Mooney, 1977, p.1628). This consequence sets up value preferences in healthcare, which will be further explored and debated in Chapter 4. Nonetheless, this approach seems ethically problematic.

Basically, while the merits of commodification seem ethically problematic, some scholars argue that in order to rationally allocate healthcare resources, commodification must take place. So, it is assumed that quality of life is a quantifiable outcome and therefore the concept of utility is acceptable. Using a formula which essentially determines whether a human being's quality of life – their state of being – is worth the value of a particular course of treatment is concerning. Based on this, people are commodified in the sense that the value of investing money in them is taken to be entirely determined by the amount of utility that those people can produce. People, just like objects that are bought or sold in a market, have their worth fixed entirely by how much utility they produce.

3.4 Nussbaum's Response

In the following discussion, I will use Nussbaum's theory to illuminate the problem unpacked in the previous section. In the first place, Nussbaum's theory indicates that commodification of the sort just discussed is unjust as it seriously violates human dignity. Nussbaum's theory indicates that being treated as a commodity, in the relevant respect, undermines the social bases of self-respect and, so, undermines the critical capability of affiliation, which is at the core of truly human functioning (Nussbaum, 2011, p.39; Nussbaum, 2000; Kleist, n.d.). As indicated in Chapter 2, the role of affiliation is crucial to living a true human life as it provides opportunities for human beings to form a conception of lives worthy of human dignity (Nussbaum, 2011, p.39; 2000; Robeyns, 2017; Kleist, n.d.).

Given this, Nussbaum would insist that QALYs' standard interpretation reduces the value of human dignity to a single measure. In a way, this strips away the value of human life; a life treated as priced may be exchanged for another as its equivalent, a process which goes against the binary nature of human dignity (Leukam, 2011, p.1). On this scheme people are treated as mere commodities rather than with human dignity. This realisation cements the significance of making questions about capabilities central.

Secondly, the act of making judgments based on the production of utility also implies that these judgments are not justified on the foundations of the threshold level of central capabilities. Nussbaum aims to philosophically provide an account of basic principles (capabilities) that may be applied to resource allocation policies. It follows that governing bodies ought to provide a threshold of central capabilities to meet the

conditions for true human functioning and social justice (Robeyns, 2017; Nussbaum, 2011). Consequently, according to Nussbaum (2000), injustice occurs when individuals are below the threshold of capabilities. On the grounds of Nussbaum's approach to social justice, it is plausible to infer that it is unacceptable to commodify human lives.

Nussbaum's approach allows us to potentially provide a rational principle for distribution that is in line with human dignity by being based on the threshold level of the capabilities. The social practice of human dignity means ensuring that human beings are equipped with the capabilities they need to live a dignified life, whether or not doing so is the most efficient way to maximise utility. Nussbaum would insist that at the core of truly human functioning is a dignified human being who is given the capability to achieve a life that has intrinsic value (Nussbaum, 2011, p.39). Although Nussbaum's approach does not agree with the use of cost utilities in medical rationing, it is not to conclude that she does not agree with rationing as a whole. Indeed, Nussbaum's approach seems to leave room for rationing. Instead of cost-utility measures, however, governing bodies ought, as a first concern, to provide a threshold level of central capabilities when rationing. This approach will guide how to ensure that people can live dignified lives rather than ensuring maximisation of utility.

3.5 Conclusion

In this chapter, I have argued that rapid growth in healthcare expenditure has caused the practice of rationing medicine to be scrutinised not only in terms of its effectiveness but also its ethics. Healthcare, finance, and human lives are all viewed as valuable, but not interchangeably. The trade-off of prioritising healthcare costs over a dignified

human beings life creates consequences for self-respect and the central capability of affiliation. The commodification of human lives assumes that the amount of utility produced determines the value of a human life.

Nussbaum asserts that QALYs reduces the value of human dignity to a single measure, stripping away the value of human life. It was also shown that, according to Nussbaum, utility-based judgments ignore capability thresholds, so that people consequently fall beneath the minimum thresholds required for living human lives. Perhaps, then, allocation methods that prioritise human dignity and the central capabilities ought to be considered in order to facilitate justice. The findings of this research report support the belief that the cost-utility analysis that QALYs employ is unjust, based partially on what was unpacked and debated in this chapter. An account of the second ethical concern – injustices over disabilities occasioned by the use of QALYs – is provided in the next chapter.

4. DISABILITY, CAPABILITIES AND THE INJUSTICE OF QALYS

4.1 Introduction and Overview

This report has so far stated that Nussbaum's central capabilities approach considers the act of treating human beings as mere commodities, through the maximisation of utilities, as undermining the capability of affiliation and therefore undermining human dignity. In the same light, questions of concern have been raised in the literature regarding where the principle of health maximisation leaves disabled populations since they likely produce fewer QALY utility scores. Nussbaum, throughout her writing, passionately sheds light on the significance of justice for the disabled community, drawing on her own family experience. Her vision of social justice is one that is inclusive of all human beings. As briefly discussed in Chapter 2, the approach responds to and caters for those who are not able to autonomously and rationally make decisions for themselves (Nussbaum, 2011, p.24; Vorhaus, 2015, p.2). For this reason, as well as for the purpose of equality (Vorhaus, 2015, p.2), Nussbaum advocates the same ten central capabilities be applicable to disabled populations (Nussbaum, 2011, p.18).

In this chapter, Nussbaum's capabilities approach will be used to argue that disabled populations are unjustly disadvantaged within a QALY-based healthcare system. The main argument made here is that the preferences QALYs set unjustly divert resources away from disabled people and towards the able-bodied. Nussbaum’s approach, on the other hand, requires governing bodies to direct more resources towards disabled people than towards the able-bodied for the criteria of social justice to be met

(Nussbaum, 2011, p.24). This will be further elaborated throughout the chapter. The first section will begin with the fundamentals: defining and outlining basic accounts of disability as well as theoretically conceptualising it. In the second section, case examples will be presented to promote an understanding of the concerns raised. These ethical concerns will also be outlined and discussed. The last section will explore Nussbaum's response to each ethical concern with the aid of a thorough analysis. This will entail drawing on Nussbaum's concept of thresholds and social justice discussed throughout this research report.

4.2 What Is Disability? Working Definition and Basic Accounts

4.2.1 Working definition

To the general public, disability is commonly understood as "the inability to do something" (Wasserman et al., 2016). Within the scope of medicine and science, no settled definition is assigned to the term and there is no single, distinct way to measure it. Nevertheless, for the benefit of forming an understanding, this section will present conceptions of disability from various models / paradigms. Perhaps a thought to take note of is the common perception these paradigms often express: disability is a binary phenomenon; an individual may be characterised as either disabled or abled-bodied (National Council on Disability, 2019; Wasserman et al., 2016).

To begin, within the scope of sociology, "being disabled" is associated with a mental incapability caused by disease. It is also understood as a physical incapability resulting from injury or acquired at birth (Goering, 2015). Within the economic scope, particular focus is placed on how much utility or value a human being produces for the broader

society (Wasserman et al., 2011). Crow (1996, cited in Goering, 2015) notes that within the scope of medicine the term ‘disability’ is ascribed to impairments that affect the function of a human being, with a widely accepted notion that disability is a pathology to be treated or eliminated so that patients are restored to ‘full health’. At its core, medicine perceives disability as an issue to be rectified instead of valuing the opportunity it provides for diversity. The recent rise in disability advocates, focusing on ensuring anti-discrimination policies are in place, is attributable to this conception (Blustein, 2012).

Apart from these models, there are institutional conceptions worth mentioning. According to sociologist Saad Nagi (1965), disability is the representation of a mental or physical restriction. Nagi highlights that this restriction is often demonstrated through the way in which disabled individuals interact with their social environments (Institute of Medicine, 1991). Often the lack of capabilities one has significantly impacts one’s ability to fully and actively interact with one’s physical and social environment (Nagi, 1965; 1976; Institute of Medicine, 1991). In all fairness, this is no fault of the disabled individual. If the environments created by governing bodies become more inclusive, disabled individuals may have an increased chance to efficiently interact with them.

Nevertheless, the Section 6 of United kingdom’s Equality Act (2010) defines a disabled person, similarly to Nagi (1965), as a human being showing mental or physical incapacities that have an impact on how the individual completes normal day-to-day activities (Parliament of the United Kingdom, 2010). For example, routine day-to-day capacities include remembering to do a task, having the ability to learn or understand,

physical coordination and general mobility (Parliament of the United Kingdom, 2010). The World Health Organization (2018) also defines the term disability as an overarching expression denoting individual who experience restrictions in interacting with their environments or with society on an equal basis to others, as a result of a bodily impairment. The World Health Organization (2001) additionally notes that social perceptions of disability may further limit the ability of disabled individuals to participate fully in society. Vorhaus (2015) notes that social norms often dictate the identity of disabled individuals, forcing them to claim a passive and incapable status.

So, the working definition of 'disability' can be said to be the lack or limitation of internal capabilities for active interaction with the social environment, ranging from slight to severe, and being mental or physical in nature (National Council on Disability, 2019; Nagi, 1965; Wasserman et al., 2016; World Health Organization, 2001; Disability Discrimination Act, 2010). In reality there are significant influential factors which play a deeper role depending on which paradigms disabled individuals experience on a day-to-day basis.

4.2.2 Basic Accounts of Disability: Understanding the Definition of Disability through the Capabilities Approach

The definition of disability is not extensively accounted for in Nussbaum's capabilities approach framework, so the following is a short summary of what is interpreted and presented by various authors in broader literature of Nussbaum's approach. To begin, the idea of human nature is not theorised, but an account of human nature which highlights where individuals in societies fall short is developed. Nussbaum refers,

throughout her writing, to the disabled as being human beings with mental or physical incapacities impairing their ability to actively function (Mitra, 2018; Mitra, 2006, p.241). According to Mitra (2006, p.241), the capabilities approach characterises and defines disability as falling within two categories: a) as a deprivation of capabilities (potential disability); and b) as the deprivation of functionings (actual disability). Mitra (2006) notes two observations in alignment with this categorisation. Firstly, the occurrence of disability occurs where a lack of practical opportunities and freedoms (capabilities) exist as a result of a physiological, mental, or structural loss or impairment (Mitra, 2006, p.241). Secondly, an individual is disabled on the condition that their impairments have an impact on the way they function or participate in their day-to-day activities.

Mitra further reports that disability occurs as a determinant arising from an individual's gender, age, race, the characteristic of the impairment, and available resources, healthcare or otherwise (Mitra, 2006, p.243). To elaborate further, first, a disability is observed when there is a shortage of provisional healthcare resources (Mitra, 2006, p.241). Secondly, disability may be observed when an actual impairment is present (Mitra, 2006, p.241). However, the combination of all these determinants could lead to both a functioning and capability deprivation (Mitra, 2006, p.241). One could even argue that capability deprivation, for an already predisposed individual, will result in a twofold disadvantage. It would result both in the denial of the individual's capabilities as a result of external factors (their impairments), personal factors and their environment, and subtract from their ability to function as a human being, given the lack of provisional resources necessary to do so (Mitra, 2018).

4.3 QALYs and Disabilities: Case Illustration

Let us consider two programmes: one designed to reduce the viral load of HIV in patients through antiretroviral therapy (ART), and the other aimed at reducing the symptoms of a motor neuron disease, often causing physical disability, called amyotrophic lateral sclerosis (ALS) (Bowen et al., 2016). Both are life-changing programmes. However, with the application of the principles of QALYs, one will be favoured over the other. The quality of life amongst those who have more advanced HIV/AIDs (lower CD4 count) is poor. So is the quality of life of those who exhibit symptoms of ALS. However, the patient with HIV has higher chances of improved quality of health over time on ART. The majority of participants report 'perfect' health after one year of ART (Bowen et al., 2016). As a result, HIV testing strategies that increase timely access to ART for HIV-positive individuals will result in HIV/AIDs patients gaining more QALYs as compared to ALS patients. An ALS patient's quality of life will continue to deteriorate and move increasingly far from perfect health (Bowen et al., 2016).

4.4 Ethical Issues related to QALYs and Disability

The case illustration presented above demonstrates ethical issues particularly impacting the disabled population, arising from the application of QALYs in the healthcare system.

4.4.1 Ethics of Misinformed Perceptions: Valuing Health

As highlighted by the National Council on Disability (2019), one of the precepts of QALYs is to consult the *healthy* population to rank the value of various health states. As outlined in Chapter 1, the healthy public assigns a numerical value (between 0-1) to all health states by way of a questionnaire (Revill and Maheswaran, 2019; Weinstein, Torrance, McGuire, 2009; National Council on Disability, 2019). A 'tariff set' converts these responses to the QoL weight. The results influence a range of policy outcomes, particularly the development of new treatments and efficient access to medical resources. These tariff sets in essence determine a "rate of discount" which establishes how long a population group is willing to live with a certain health condition (Singer et al., 1995, p.144). The population could express the desire to trade two bedridden years for one year of full health (Singer et al., 1995, p.144). Disability advocates are significantly concerned that QALYs / QoL weights, based on the epistemic perceptions of those living without disabilities, determine the value and worth of disability conditions. In so doing, they project views which are not sensitive to the specific characteristics of certain disabilities.

Essentially, the preference for 'perfect' health states over functionally impaired ones endorses the premise mentioned earlier, that the quality of life of individuals with disabilities is less important than those in 'perfect' health (Garau et al., 2011; Pettitt et al., 2016; National Council on Disability, 2019). The continued reliance on surveying the preferences of a healthy community to represent the whole population is problematic as the general population forms a negative perception of the quality of life of disabled people.

Scott et al. (2016) demonstrate, in a study conducted in the United States of America

on public attitudes, that of 2044 participants, 47% ranked blindness as the worst health condition as compared to heart disease, arthritis, the loss of a limb, or even AIDS. This finding reflects the social model mentioned earlier applied to policy decision making. Goering (2015), urges policy makers to sway from perceiving an impairment as negative, highlighting that a person who is born with blindness does not view their state of being as problematic but rather as natural or 'normal'.

Perhaps our understanding is deepened when we take into consideration the above illustration. Skewed perceptions such as those illustrated there have detrimental effects on disabled populations' access to the best possible healthcare. Medical treatments and interventions that primarily treat those who are disabled or who require extra care (palliative) are assigned a lower QALY gain / ratio compared to treatments that extend life precisely the same amount in other cases (National Council on Disability, 2019). As seen in the above illustration, if two patients seek treatment to improve their quality of life, one with HIV/AIDs and the other with ALS, the patient with favourable quality of life health outcomes will be favoured. Although both patients begin with a poor quality of life, the administration of ART's which act to reduce viral load, produces more QALYs for the HIV/AIDs patient. Whereas the form of treatment required for ALS patients is palliative, where no drastic changes to health outcomes are made. Access to this kind of care is not placed at the same value as with its' competitor treatment.

4.4.2 Ethics of Health Maximisation: Health Utility Preferences

QALYs set preferences on the value of medication based on who will benefit from it

most. The principle of QALY maximisation stipulates that the goal is to produce the greatest utility outcomes given a medical intervention. The application of this will practically redirect all resources to patients who will gain the greatest number of QALYs (Singer et al., 1995, p.147). It is important, perhaps, to highlight that QALY maximisation is particularly focused on incremental quality of life through treatment rather than current quality of life. So, expected or possible utility is unattached from the health state the patient is currently experiencing. While this seems fair, it raises concerns for those who are disabled and have slim chances of their condition changing.

In the pursuit of valuing “perfect health” over “less than perfect health” (Pettitt et al. 2016) an automatic preference and privilege is set for abled-bodied persons over disabled individuals. Doing so ensures the preservation of one group over the other. To elaborate: in most cases patients with chronic conditions, seniors, and persons with disabilities do not function in the same way as the socially described ‘healthier’ population. For these people, functioning at the same level as a ‘normal’ individual may come as challenge. For example, a paraplegic individual and an individual with two fully functional legs would each have a different conception of a good life. Their utility, which is their ability to perform certain tasks – essentially, their usefulness – would be different.

The QALY approach is a utilitarian, benefit maximising one, which places public interest over individual preference (Scheunemann and White, 2011). Although this is noble at face value, its application undermines minority groups for the advancement of the larger population. In deciding where to allocate healthcare resources, the guiding

criterion is the question of where the greater public would benefit the most. This fashions an unequal hierarchy, which places those who are already in disadvantaged health states in even more compromised health states. Importantly, Singer et al. (1995) further draw attention to the unfortunate circumstance disabled individuals face. Not only are impaired human beings limited by their disability, but they are also affected bey low health care priority, which could potentially endanger their lives and health.

4.4.3 Scope of the Problem

The main ethical issue we have identified relates to QALYs' purpose of maximising health gains based on the preferences of society. Due to this, the value of medical treatment for the disabled population is low. This creates complexities for the billion human beings across the world currently that have impairments of some kind. In 2018, the World Health Organization reported an estimate that the disabled population made up no less than 15% of the global human population (World Health Organization, 2018). It also reported that from the age of 15 upwards, difficulties in functioning are observed in about 2.2% to 3.8% of earth's population (World Health Organization, January 2018). Translated, that is between 110 million and 190 million people (World Health Organization, 2018). The World Health Organization predominately attributes this to the increase of chronic conditions in the aging population (World Health Organization, 2018).

Nonetheless, as we all are human, just as abled-bodied individuals require certain essential healthcare services so do disabled individuals. This suggests that healthcare

is a universal requirement for all. Ultimately, the foundations set by the medical community through their ability to define and distinguish normal from abnormal create broader cultural and social assertions reflecting negatively on disabled populations by assigning low values to the lives of those who are disabled (Johnson, 2016).

With this in mind, it is essential to note that human beings with disabilities have an extraordinary need of resources. Pro-QALY advocates will probably use this as a basis for their argument. Take bioethicists, Peter Singer, for example, in the article “Why We Must Ration Healthcare,” where he advocates for the adoption of QALYs. He states that:

> “If…a year with quadriplegia is valued at only half as much as a year without it, then a treatment that extends the lives of people without disabilities will be seen as providing twice the value of one that extends, for a similar period, the lives of quadriplegics" (Singer, 2009).

This idea will aid the discussion on QALYs and Nussbaum’s approach later on in this chapter. As a brief summary, the main ethical issues that the discussion thus far has raised are centred around health maximisation. Utilitarianism is a benefit maximising theory. In rationing limited healthcare resources, the philosophy of utilitarianism seeks health maximisation (Cubbon, 1991; Whitehead and Ali, 2010) – that is, prioritising and directing resources to those who are expected to gain more QALYs or utility (Whitehead and Ali, 2010). In essence, this means prioritising those who will be returned to full health. Thus, two scenarios play out: at a macro level, resources are allocated to health interventions which will benefit the majority of the population –

those interventions that will be the most effective. At a micro level, interventions are given, firstly, to those who will be returned to full health. The challenge with this is the potential for stakeholders or decision makers to exclude anyone who cannot gain substantial utility due to impairments.

4.5 Nussbaum's Response: Addressing Ethical Concerns

Throughout her writing, Nussbaum has explored the intricate relationship between capabilities not only for a specific group of people but for all, including the disabled. She shares, through her theoretical perspective, guidance on how healthcare resources ought to be allocated for the purpose of meeting the criteria of social justice for all. Moreover, Nussbaum's theory of social justice recognises the potential for all human beings, regardless of their health states or internal capabilities, to flourish, especially those with severe impairments. She, in fact, promotes the idea that capabilities are achievable on condition that environments make allowance for connecting to people's "natural endowment" (Mitra 2018; Terzi, 2009; Wasserman,1998). This potentially enhances the opportunity for human rights to be observed, human dignity to be consistently experienced, and social justice to be achieved (Venkatapuram, 2014; Díaz Ruiz, Sánchez Durán and Palá, 2015).

Taking into consideration the values that ground Nussbaum's capabilities approach, health and the capability to be healthy are advocated for and protected (Nussbaum, 2011, p.33; Tengland, 2019). As reported in Chapter 2, health is amongst the ten central capabilities that Nussbaum suggests are crucial. This section will apply Nussbaum's capabilities approach in order to critically evaluate QALYs' relationship to health and disability. The main idea communicated is that disabled people, like anyone

else, have a claim to a minimum threshold level of central capabilities. The argument developed here will draw on the conceptual framework built and discussed in Chapter 2. I argue that QALYs do not allow disabled populations to reach a minimum threshold of capabilities. This will consequently prohibit the realisation of capabilities and impair flourishing, dignity, and justice.

Once again, Nussbaum's capabilities approach stipulates that all human beings have the right to a threshold level of all ten central capabilities. This comes through acknowledging the importance of capabilities over functionings. Just like majority of a population, these capabilities should be actualised in disabled members of society (Spring, 2009). If resources are required to facilitate this actualisation, Nussbaum calls for governing bodies to aim to provide disabled individuals with each capability at the minimum threshold. She stipulates that "where direct empowerment is not possible, society ought to give capabilities through a suitable arrangement of guardianship" (2006, p.193). The QALYs approach, though, seem to allow disabled people to fall below this threshold. In fact, it might legitimise directing resources to those who are already above the threshold on the assumption that the life span and quality of life of a disable person are not as consistent as that of an abled-bodied person.

With the understanding that disabilities involve deprivations of capabilities, disabled populations often need more resources than others to reach this level. For example, Nussbaum suggests that governing bodies provide the necessary capabilities for an immobile individual to be made mobile through access to prosthetics and vehicular interventions (Spring, 2009). Similarly, a human being lacking hearing or vision may be provided with hearing aids or corrective eye surgery (Spring, 2009). Furthermore, an

individual with intellectual impairments may build cognitive skills by participating in cognitive building activities (Spring, 2009). Lastly, an individual with emphysema could be provided with access to lung capacity interventions (Spring, 2009). In essence, all these interventions could increase the capacity of the individual to have control over their material environment as well as to exercise the key capability of affiliation – both of these being part of Nussbaum's capability set (Nussbaum, 2006).

Utilitarian bioethicists Peter Singer (1995), for example, may still object to Nussbaum's approach as it requires that a significant portion of resources belonging to a society are devoted to raising those who fall below the threshold up to meet it. In addition to this, utilitarians might further argue that because those who are disabled will not be returned to full health, devoting valuable resources to the disabled could, all things considered, be a waste. Health conditions that guarantee good quality of life and increase life expectancy are more deserving of the allocation of already limited resources and dedicating these elsewhere would seem unfair to those who may be returned to full health if allocated to them (Spring, 2009). It is here that utilitarianism and the capabilities approach do not find common ground.

Utilitarianism is also understood as an economic decision-making tool which conceives, under one umbrella, the overall satisfaction of a society through the production of the greatest ‘amount’ of utility (University of Chicago, 2013; Mill, 1863, p.95; Marseille, 2019). Unfortunately, the consequence of this consideration is a neglected minority. This is true for QALY evaluations, which tend to direct resources away from disabled people who formulate the minority – those who are already below the threshold level. It is worth mentioning that utilitarianism does not adequately

account for adaptive preferences – that is the consideration that human beings, over time, change their preferences with every environment they experience, and that hence measuring people's preferences may be problematic. Nonetheless, Nussbaum points out that the idea of satisfaction fails to give weight to autonomy or agency (University of Chicago, 2013). It does not consider that people may want to choose to participate actively in decisions made at a policy level. In Nussbaum's version of the capabilities approach she emphasises that human dignity calls for the recognition of one's ability to choose and for being treated the courtesy one deserves (Nussbaum, 2006, pp.87–92). Furthermore, the conception of a threshold of capabilities allows for human dignity to be facilitated.

Nussbaum has a clear understanding of resource scarcity and acknowledges the challenges which arise from it (University of Chicago, 2013), as discussed in Chapter 1. However, she insists that governing bodies can provide the ten central capabilities, at least up to the threshold level (University of Chicago, 2013). To argue this, Nussbaum uses a southern Indian state, Kerala, as an example. Its economic capacities are poorer than most states in India. However, despite this challenge, the state maintains 99% literacy and overall good health for both children and adults (University of Chicago, 2013). This demonstrates that thresholds of capabilities are achievable. Through failing to provide the threshold of capabilities, a state or governing body fails to meet the standard of human dignity and social justice.

It is unjust to disregard the minority. The reality of dependency has always existed in our society on a continuum, with natural human conditions like aging (old or young), being sick constituting deficiencies affecting the minority of us (National Council on

Disability, 2019; Lindemark, Norheim and Johansson, 2014). We need to provide for those who lack our capabilities. We should realise that as the capabilities on Nussbaum's list are interconnected, so are we, as humans. Through the adoption of new policies, we ought to raise disabled members in societies above the threshold, as Nussbaum suggests.

4.6 Conclusion

To conclude, this chapter has argued that there is a critical difference between making decisions about resource distribution based on utility maximisation and making them based on ensuring a dignified level of functioning through protecting the capabilities essential to human beings. In resource allocation, QALYs do not allow disabled populations to reach a minimum acceptable threshold of capabilities. This plays a detrimental role in human development. As outlined in Chapter 2, Nussbaum's human development approach to social justice seeks to award human beings their freedoms and the opportunities to actualise lives characterised by human dignity (Nussbaum, 2011, Trani et al., 2011). Although QALYs are argued by some to be beneficial (Neumann and Cohen, 2018), the QALY approach sets preferences to interventions and groups of people who will be returned to full health (National Council on Disability, 2019).

This ensures that disabled individuals often remain below the minimum threshold of Nussbaum's set of capabilities. It is important to remember that falling below the capabilities threshold compromises human dignity, while meeting it meets the criterion for social justice. Perhaps *after* the threshold is reached, economists and stakeholders could consider and evaluate interventions based on their economic value. In moving

towards a just society for all, Nussbaum's capabilities approach has been proposed in the preceding discussion as an alternative to cost-utility / cost-effectiveness assessment measures like QALYs. The approach asks healthcare resources are allocated in a way which enhances human dignity through the provision of freedoms and opportunities (Nussbaum, 2011).

5. CONCLUSION AND RECOMMENDATIONS

5.1 Overview

This paper began by hypothesising that Martha Nussbaum's capabilities approach to social justice indicates that the use of QALYs as a criterion for the allocation of limited medical resources is unjust. It sought to identify the extent to which QALYs are in accordance with Nussbaum's capabilities approach to justice and human dignity and considered this through the lens of determining how we ought to distribute limited health resources. It was mainly concerned with the version of QALYs that evaluates interventions based on the cost-per-QALY produced by the intervention. Adopting this approach means that cost-effective analysis will decide which treatments or interventions to fund. A comparative analysis will determine the worth of each treatment or intervention based on its cost-utility (McCabe, 2014). Throughout this report, it has been illustrated how resource allocation arguments adopt utilitarian rationales.

Arguments presented by Singer (1995), for example, argue in favour of QALYs premised on the fundamental idea of promoting a considerable number of positive health outcomes. However, this research report has shown that Nussbaum’s approach to justice indicates that QALY maximisation is unjust because a) QALYs commodify those human lives which produce the greatest utility (and the commodification of human life undermines the possession of Nussbaum’s affiliation capability) and b) QALYs systematically violate human dignity as they fail to raise disabled human beings above a threshold of capabilities required for truly human functioning.

The first ethical concern raised was the injustice of valuing human lives based on monetary principles and the overall amount of utility they produce. In this regard, priority is placed on interventions or treatments which facilitate the “greatest good for the greatest number of people” (University of Chicago, 2013; Mill, 1863, p.95; Marseille, 2019) – usually favouring human beings whose treatment is less expensive (Brock and Wikler, 2006; Wong, 2011). Furthermore, the trade-offs between utility and capability have detrimental consequences as they strip people of the capability of affiliation – undermining respect for the equal worth of people and for their dignity. This means that those with disabilities are put at a disadvantage because the interventions aimed at improving their lives and meeting their needs are expensive (Brock and Wikler, 2006). The fundamental point is that when we think about people as commodities in this way, we are not thinking about the capabilities that are owed to them as a matter of human dignity and justice. This consequentially redirects health resources away from certain human beings on the basis that their commodity value is low. This is problematic as justice requires that all human beings be given those resources required for a life worthy of human dignity.

The second ethical concern this research report has raised regards the injustice of valuing health based on utility preferences. As demonstrated in in Chapters 2 and 4, QALYs tend to place significant worth on individuals who will be returned to full health (Navarro, 2017; Whitehead and Ali, 2010). Consequently, the worthiness of disabled and chronic patients is not equal to those who may be returned to 'perfect' health. For example, patients with HIV/AIDS, chronic heart diseases, or physical or mental disabilities have a lowered HRQoL as well as shorter life expectancies (Bowen et al.,

2016). As a result of the QALY calculation factoring this in, treatment and interventions for patients with disabilities will not be as readily funded as there is no significant QALY gain. All else being equal, healthcare for people with disabilities will produce fewer QALY gains compared to healthcare for those without. This undermines access to threshold levels of capability in respect of the life, health, and social bases of self-respect for the disabled.

The argument outlined above leads to the conclusion that, given Nussbaum's view, QALY evaluations are unjust. Basically, QALYs are guilty of making utility production central to questions about resource allocation, thereby treating people as mere commodities rather than in accordance with human dignity. According to Nussbaum's approach, it is unjust not to try to raise people up to the threshold levels of each central capability. This is primarily an ethical concern for patients with chronic conditions and disabilities, as they will often not have access to each central capability.

5.2 Response to Possible Remaining Objections

Throughout the research report, I have assumed Nussbaum's view and used it to criticise QALYs. Therefore, one might argue that the report only raises problems for QALYs if we accept Nussbaum's view. That view can be seen as controversial, as it is merely one among many proposed conceptions of justice. However, due to space constraints, I cannot argue about the correct view of justice. The purpose of this research study is simply to demonstrate the injustices of QALYs in resource allocation through the lens of an influential philosophical view. This is especially important because, as discussed in Chapter 1, the connection between Nussbaum’s capabilities approach and QALYs has not received much sustained attention.

Nussbaum's approach allows us to capture what seems intuitively problematic about QALYs. It helps clarify the inherent problem with treating people as commodities and the intuitive injustice this causes to people with disabilities. Moreover, Nussbaum's approach, with its emphasis on a dignified human life, provides an excellent tool for identifying the principles that governing bodies ought to apply in the distribution of healthcare resources. With this said, even if Nussbaum's theory is not obviously the best general theory of justice, as compared to, for example, Rawls', it is a useful tool in the present context for illustrating how QALYs fall short.

5.3 Significance of Research, Future Research

This research report set out to fill the gap in understanding the comparative value of healthcare interventions and to answer pressing questions that remain about the ethics of using QALYs. In particular it was unclear whether economic evaluations using QALYs truly reflect the bioethical principle of justice that calls for all persons to be equally acknowledged and given an equal share of capabilities according to their needs (Beauchamp & Childress, 2013; McCormick, n.d.; Rawls, 1999). Although a large body of research written with the aim of critiquing QALYs exists, as shown in this report, it has not systematically explored the implications that Nussbaum's important account of justice has for the use of QALYs. Therefore, this report has aimed to add insight to the distributive and social justice literature applied to healthcare through its evaluation of QALYs from a capabilities approach point of view.

The report, in particular, has shown how Nussbaum's conception of justice indicates that the criteria QALYs adopt in preference setting creates problems for justice and dignity.

The conditions of setting healthcare preferences (valuing perfect health over disability) as well as utility preferences (producing the greatest utility at the best cost) are stringent and, on Nussbaum's view, do not uphold social justice or dignity. They fail to respect the equality of people's lives, health, and self-respect, and fail to meet the threshold of her central capabilities.

The aim of this research was to provide a criticism of QALYs rather than proposing an alternative to QALYs. Nonetheless, the work done in this report could encourage future research in developing criteria for health resource allocation that do not violate human dignity in the way that this report argues that QALYs do. Given this research, health economics could potentially use the philosophically sophisticated foundation of Nussbaum's theory for economic evaluation, as it provides a method of addressing long-standing general concerns about the use of utilitarian economic methods and proposes the alternative of valuing capabilities and the freedom to choose which capabilities to exercise (Bleichrodt and Quiggin, 2013).

5.4 Conclusion

I have, in this paper, critiqued cost-effectiveness / cost utility assessment tools – specifically, the QALY approach to allocating health care resources – from the perspective of Nussbaum's social justice framework, based on capabilities. The result of the study is the conclusion that quality-adjusted life year evaluation is grounded on unethical assumptions. I draw this conclusion from the following arguments. Firstly, Nussbaum's capabilities approach places particular value on the significance of human dignity, which may only be achieved through meeting a threshold of providing ten central capabilities to people to ensure their ability to live human lives. The QALY evaluation,

however, commodifies human life, based on the best-value-for-money approach. Through the use of utility preferences, it also keeps disabled individuals below the threshold of capabilities. In both instances, this undermine people's capacity to conceive of a life that is good and dignified. It also appears to undermine access to threshold levels of life, health, and the social bases of self-respect for the disabled. Therefore, on Nussbaum's approach, the implementation of QALYs as a tool of resource allocation fosters an unjust healthcare system.

6. REFERENCES

American College of Physicians. (2011). 'How Can Our Nation Conserve and Distribute Health Care Resources Effectively and Efficiently?' [policy paper]. Philadelphia, PA: American College of Physicians.

Arvidsson, E. (2013). *Priority Setting and Rationing in Primary Health Care*. Linköping: Linköping University.

Bayles, M. (1978). 'The Price of Life', *Ethics,* 89(1), pp.20–34 [online]. Available at: www.jstor.org/stable/2380129 (Accessed: 10 February 2020)

Bendik-Keymer, J. (2014). 'From humans to all of life: Nussbaum's transformation of dignity' in F. Comim and M.C. Nussbaum (eds.) *Capabilities, Gender, Equality*. Cambridge: Cambridge University Press, pp.175–191.

Bertram, M., Lauer, J., De Joncheere, K., Edejer, T., Hutubessy, R., Kieny, M. and Hill, S. (2016). *Cost–effectiveness thresholds: pros and cons*. World Health Organization [online]. Available at: https://www.who.int/bulletin/volumes/94/12/15-164418/en/ (Accessed: 8 February 2020).

Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics* (7th ed.). New York: Oxford University Press.

Bleichrodt, H. and Quiggin, J. (2013). 'Capabilities as menus: A non-welfarist basis for QALY evaluation', *Journal of Health Economics*, 32(1), pp.128–137. Available at: https://doi.org/10.1016/j.jhealeco.2012.10.004

Blustein, J. (2012). Philosophical and ethical issues in disability. Journal of Moral Philosophy, 9, 573–587. doi: 10.1163/17455243-00904002

Borghi, J. and Jan, S. (2008). 'Measuring the benefits of health promotion programmes: application of the contingent valuation method', *Health Policy*, 87, pp.235–248.

Bowen, L.N., Tyagi, R., Li, W., Alfahad, T., Smith, B., Wright, M., Singer, E.J. and Nath, A. (2016). 'HIV-associated motor neuron disease: HERV-K activation and response to antiretroviral therapy', *Neurology*, 87(17), 1756–1762. Available at: https://doi.org/10.1212/WNL.0000000000003258

Brock, D. and Wikler, D. (2006). 'Ethical issues in resource allocation, research, and new product development' in D.T. Jamison et al. (eds.) *Disease Control Priorities in Developing Countries.* 2nd ed. Washington, DC: The International Bank for Reconstruction and Development / The World Bank, pp.259–260. Available at: https://www.ncbi.nlm.nih.gov/books/NBK11739/

Beresniak, A., and Dupont, D. (2016). Is there an alternative to quality-adjusted life years for supporting healthcare decision making?. *Expert review of pharmacoeconomics & outcomes research*, *16*(3), 351–357. https://doi.org/10.1080/14737167.2016.1184975

Card, W.I. and Mooney, G.H. (1977). 'What is the monetary value of a human life?' *British Medical Journal*, 2, pp.1627–1629. Available at: https://doi.org/10.1136/bmj.2.6103.1627

Centers for Disease Control and Prevention (2018). 'Health-Related Quality of Life (HRQOL)' [fact sheet]. National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health.

Centers for Disease Control and Prevention (2019). 'Economic Evaluation Overview' [online]. Available at: https://www.cdc.gov/policy/polaris/economics/index.html

Christiansen, I. (2017). 'Commodification of Healthcare and its Consequences', *World Review of Political Economy,* 8(1), pp.82–103. Available at: https://doi.org/10.13169/worlrevipoliecon.8.1.0082

Cleemput, I., Neyt, M., Thiry, N., De Laet, C. and Leys, M. (2011). 'Using threshold values for cost per quality-adjusted life year gained in healthcare decisions', *International Journal of Technology Assessment in Health Care* (27)1, pp.71–76.

Cubbon, J. (1991). 'The principle of QALY maximisation as the basis for allocating health care resources', *Journal of Medical Ethics*, 17(4), pp.181–184 [online]. Available at: https://jme.bmj.com/content/medethics/17/4/181.full.pdf (Accessed: 4 July 2019).

Daniels N. (2016). 'Resource Allocation and Priority Setting', in D.H. Barrett et al. (eds.) *Public Health Ethics: Cases Spanning the Globe*. Cham, CH: Springer, Chapter 3. Available at: https://doi.org/10.1007/978-3-319-23847-0_3

Devlin, N. and Lorgelly, P. (2017). 'QALYs as a measure of value in cancer', *Journal of Cancer Policy*, 11, pp.19–25. Available at: https://doi.org/10.1016/j.jcpo.2016.09.005

DeMartino, G. (2011) Capabilities, Equality, and Class Justice: A Reply to Wilde, Global Discourse, pp. 39-47, DOI: 10.1080/23269995.2011.10707881 Available at: https://doi.org/10.1080/23269995.2011.10707881

Díaz Ruiz, A., Sánchez Durán, N. and Palá, A. (2015). 'An Analysis of the Intentions of a Chilean Disability Policy Through the Lens of the Capabilities approach', *Journal of Human Development and Capabilities*, 16(4), pp.483–500. Available at: https://doi.org/10.1080/19452829.2015.1091807

Docherty, M., Cao, Q. and Wang, H. (2012). 'Social values and health priority setting in China', *Journal of health organization and management*, 26(3), pp.351–362. Available at: https://doi.org/10.1108/14777261211238990

Drummond, M., Sculpher, M., Claxton, K., Stoddart, G. and Torrance, G. (2015). *Methods for the Economic Evaluation of Health Care Programmes.* 4th ed. Oxford: Oxford University Press, pp.41–83.

Duignan, B., Rodriguez, E. and The Editors of Encyclopaedia Britannica (2020). 'Normative ethics', *Encyclopaedia Britannica* [online]. Available at: https://www.britannica.com/topic/normative-ethics (Accessed: 20 August 2020).

Emanuel, E., Persad, G., Upshur, R., Thome, B., Parker, M., Glickman, A., Zhang, C., Boyle, C., Smith, M. and Phillips, J. (2020). 'Fair Allocation of Scarce Medical Resources in the Time of Covid-19', *New England Journal of Medicine*, 382(21), pp.2049–2055 [online]. Available at: https://www.nejm.org/doi/full/10.1056/nejmsb2005114 (Accessed: 16 June 2020).

Erman, M. (2020). 'Novartis, Merck And Allergan Join Those Raising U.S. Drug Prices For 2020', *Reuters*, 3 January [online]. Available at https://www.reuters.com/article/us-usa-healthcare-drugpricing/novartis-merck-and-allergan-join-those-raising-u-s-drug-prices-for-2020-idUSKBN1Z21P3 (Accessed: 13 June 2020).

Entis, L. (2019). 'Why Does Medicine Cost So Much? Here's How Drug Prices Are Set'. *Time,* 9 April [online]. Available at: https://time.com/5564547/drug-prices-medicine/ (Accessed: 8 December 2020).

Etheredge, H. and Fabian, J. (2017). 'Challenges in Expanding Access to Dialysis in South Africa – Expensive Modalities, Cost Constraints and Human Rights', *Healthcare,* 5(3), p.38. Available at: https://doi.org/10.3390/healthcare5030038

Fleetwood, S. (2002). 'A Marxist theory of commodity money revisited', in J. Smithin (ed.) *What is Money?*. London, UK: Routledge, pp. 184–203. Available at: https://doi.org/10.4324/9780203072691

Formosa, P. and Mackenzie, C. (2014). 'Nussbaum, Kant, and the Capabilities Approach to Dignity', *Ethical Theory and Moral Practice,* 17(5), pp.875–892 [online]. Available at: www.jstor.org/stable/24478719 (Accessed: 15 April 2020).

Frakes, M., Frank, M. and Rozema, K. (2017). 'The Economics of Healthcare Rationing', in G. Cohen, A. Hoffman and W. Sage (eds.) *The Oxford Handbook of U.S. Healthcare Law*. Oxford: Oxford University Press. Available at: https://scholarship.law.duke.edu/faculty_scholarship/3652

Garau, M., Shah, K., Mason, A., Wang, Q., Towse, A. and Drummond, M. (2011). 'Using QALYs in Cancer: A Review of the Methodological Limitations', *Pharmacoeconomics*, 29(8), pp.673–685. Available at: https://doi.org/10.2165/11588250-000000000-00000

Gluchman, V. (2019). 'Human Dignity as the Essence of Nussbaum's Ethics of Human Development', *Philosophia*, 47(4), pp.1127–1140 [online]. Available at: https://0-link-springer-com.innopac.wits.ac.za/article/10.1007/s11406-018-0034-2 (Accessed: 12 January 2020).

Goering S. (2015). 'Rethinking disability: the social model of disability and chronic disease', *Current Reviews in Musculoskeletal Medicine*, 8(2), pp.134–138. Available at: https://doi.org/10.1007/s12178-015-9273-z

Gold, M., Stevenson, D. and Fryback, D. (2002). 'HALYs and QALYs and DALYs, Oh My: Similarities and Differences in Summary Measures of Population Health', *Annual Review of Public Health*, 23(1), pp.115–134. Available at: https://www.doi.org/10.1146/annurev.publhealth.23.100901.140513

Greco, G., Lorgelly, P. and Yamabhai, I.(2016). 'Outcomes in Economic Evaluations of Public Health Interventions in Low and Middle-Income Countries: Health, Capabilities and Subjective Wellbeing', *Health Economics.* 25(1), pp.83–94. Available at:

https://doi/org/10.1002/hec.3302

Harris J. (1987). QALYfying the value of life. *Journal of medical ethics*, *13*(3), 117–123. https://doi.org/10.1136/jme.13.3.117

Harrison, K. L. and Taylor, H. A. (2016). 'Healthcare resource allocation decisions affecting uninsured services', *Journal of Health Organization and Management*, 30(8), pp.1162–1182. Available at: 'https://doi.org/10.1108/JHOM-01-2016-0003

Huang, L., Frijters, P., Dalziel, K. and Clarke, P. (2018). 'Life satisfaction, QALYs, and the monetary value of health', *Social Science and Medicine*, 211, pp.131–136 [online]. Available at: https://www.sciencedirect.com/science/article/pii/S0277953618303095 (Accessed: 13 October 2019).

Institute of Medicine (1991). 'Disability concepts revisited: Implications for prevention', in A.M. Pope and A.R. Tarlov (eds.) *Disability in America: Toward a National Agenda for Prevention.* Washington, DC: National Academy Press. Available at: https://doi.org/10.17226/1579

Institute of Medicine (2003). 'Chapter 2: Challenges Facing the Health System and Implications for Educational Reform' in A.C. Greiner and E. Knebel (eds). *Health Professions Education: A Bridge to Quality*. Committee on the Health Professions Education Summit [online]. Washington, DC: National Academies Press (US). Available at: https://www.ncbi.nlm.nih.gov/books/NBK221522/

John, T., Millum, J. and Wasserman, D. (2016). 'How to Allocate Scarce Health esources Without Discriminating Against People with Disabilities', *Economics and Philosophy,* 33(2), pp.161– 186. Available at: https://doi.org/ 10.1017/s0266267116000237

Johnson, E. (2016*).* 'Disability, Medicine, and Ethics', *AMA Journal of Ethics.* 18(4), pp.355–358. https://doi.org/10.1001/journalofethics.2016.18.4.fred1-1604

Karimi, M., Brazier, J. and Paisley, S. (2017). 'How do individuals value health states? A qualitative investigation', *Social Science and Medicine*, 172, pp.80–88 [online]. Available at: https://www.sciencedirect.com/science/article/pii/S0277953616306451 (Accessed: 21 July 2020).

Kirkdale, R., Krell, J., O'Hanlon Brown, C., Tuthill, M. and Waxman, J. (2010). 'The Cost of a QALY', *QJM: An International Journal of Medicine,* 103(9), pp.715–720. Available at: https://doi.org/10.1093/qjmed/hcq081

Klein, R., Day, P. and Redmayne, S. (1996). *Managing Scarcity*. Buckingham: Open University Press.

Kleist, C. 'Global Ethics: Capabilities Approach', *The Internet Encyclopaedia of Philosophy* [online]. Available at: https://www.iep.utm.edu/ge-capab/ (Accessed: 11 September 2019).

Knapp, M., and Mangalore, R. (2007). 'The trouble with QALYs…' *Epidemiology and Psychiatric Sciences*, 16(4), pp.289-293. Available at: https://doi.org/ 10.1017/s1121189x00002451

Lamont, J. and Favor, C. (2017). 'Distributive Justice'. *The Stanford Encyclopedia of Philosophy,* Winter 2017 Edition, Edward N. Zalta (ed.). Available at: https://plato.stanford.edu/entries/justice-distributive/

Lee, L.W. and Tseng, H.L. (2018). 'Citizen Participation and e-Government Usage Satisfaction in Taiwan' in R. Bouzas-Lorenzo and A. Cernadas Ramos (eds.) *Proceedings of the 18th European Conference on Digital Government*. Reading: Academic Conferences and Publishing International, pp.119–124.

Leonhardt, D. (2009). 'Health Care Rationing Rhetoric Overlooks Reality', *New York Times*, 17 June. Available at: www.nytimes.com/2009/06/17/business/economy/17leonhardt.html

Leukam, M. (2011). 'Dignified Animals: How "Non-Kantian" is Nussbaum's Conception of Dignity?' [thesis]. Atlanta, GA: Georgia State University. Available at: https://scholarworks.gsu.edu/philosophy_theses/89

Lindemark, F., Norheim, O. and Johansson, K. (2014). 'Making use of equity sensitive QALYs: a case study on identifying the worse off across diseases', *Cost Effectiveness and Resource Allocation*, 12(1), p.16. Available at: https://doi.org/10.1186/1478-7547-12-16

Malakoane, B., Heunis, J.C., Chikobvu, P., Kigozi, N.G. and Kruger, W.H. (2020). 'Public health system challenges in the Free State, South Africa: a situation appraisal to inform health system strengthening', *BMC Health Service.* 20(1), p.58. Available at: https://doi.org/10.1186/s12913-019-4862-y

Marseille, E., Kahn, J.G. (2019). 'Utilitarianism and the ethical foundations of cost-effectiveness analysis in resource allocation for global health', *Philosophy, Ethics and Humanities in Medicine,* 14(5) [online]. Available at: https://doi.org/10.1186/s13010-019-0074-7

McCabe, C. (2014). *What is cost–utility analysis?* Newmarket, UK: Hayward Medical Communications. Available at: http://www.bandolier.org.uk/painres/download/whatis/What_is_cost-util.pdf

McCormick, T. (n.d.). *Principles Of Bioethics*. [online] UW Medicine : Bioethics & Humanities. Available at: <https://depts.washington.edu/bhdept/ethics-medicine/bioethics-topics/articles/principles-bioethics> [Accessed 21 December 2020].

Mill, J.S. (1863). *Utilitarianism*. Volume 3. London, UK: Parker, Son, and Bourn, West Strand. pp.9–11.

Mitra, S., (2006). 'The Capabilities approach and Disability', *Journal of Disability Policy Studies*, 16(4), pp.236–247.

Mitra, S. (2018). *Disability, Health and Human Development*. New York, NY: Palgrave Macmillan. Available at: http://dx.doi.org/10.1057/978-1-137-53638-9

Mondal, M. N., and Shitan, M. (2013). 'Impact of Socio-Health Factors on Life Expectancy in the Low and Lower Middle-Income Countries', *Iranian Journal of Public Health*, 42(12), pp.54–62.

Murphy, R. P., Boyce, C. J., Dolan, P. and Wood, A.M. (2020). 'Valuing the Q in QALYs: Does providing patients' ratings affect population values?' *Health Psychology*, 39(1), p.37.

Nagi S. (1965). 'Some conceptual issues in disability and rehabilitation', in M.B. Sussman (ed.) *Sociology and Rehabilitation.* Washington, DC: American Sociological Association.

Nagi S. (1979). 'The concept and measurement of disability', in E.D. Berkowitz (ed.) *Disability Policies and Government Programmes.* New York, NY: Praeger Publishers.

National Council on Disability (2019). *Quality-Adjusted Life Years and the Devaluation of Life with Disability: Part of the Bioethics and Disability Series*. Washington, DC: National Council on Disability, pp. 23–44. Available at: https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf

National Institute for Health and Care Excellence (2013). *How NICE Measures Value For Money In Relation To Public Health Interventions*. London, UK: National Institute for Health and Care Excellence, pp.1-2. Available at: https://www.nice.org.uk/Media/Default/guidance/LGB10-Briefing-20150126.pdf

Neumann, P.J., Cohen, J.T. and Weinstein, M.C. (2014). 'Updating cost-effectiveness – the curious resilience of the $50,000-per-QALY threshold', *New England Journal of Medicine*. 371(9), pp.796–797.

Neumann, P.J. and Cohen, J.T. (2018). 'QALYs in 2018 – Advantages and Concerns' *The Journal of the American Medical Association,* 319(24), pp. 2473 [online]. Available at: https://mfprac.com/web2019/07literature/literature/Misc/QUALYs_Neumann.pdf (Accessed: 11 November 2019).

Niëns, L.M. (2014). *Affordability in Health Care: Operationalizations and Applications in Different Contexts*. Erasmus University Rotterdam. Available at: http://hdl.handle.net/1765/50314

Nuijten, M.J.C. and Dubois, D.J. (2011). 'Cost-utility analysis: current methodological issues and future perspectives', *Frontiers in Pharmacology,* 2(29), pp.1-5 [online]. Available at: https://www.frontiersin.org/articles/10.3389/fphar.2011.00029/full (Accessed: 8 June 2019).

Nussbaum, M.C. (1995). 'Human Capabilities, Female Human Beings', in M,C. Nussbaum and J. Glover (eds.) *Women, Culture, and Development: A Study of Human Capabilities*. Oxford, UK: Clarendon Press.

Nussbaum, M.C. (2000). *Women and Human Development: The Capabilities Approach*. Cambridge, UK: Cambridge University Press.

Nussbaum, M.C. (2002). 'Capabilities and Disabilities: Justice for Mentally Disabled Citizens', *Philosophical Topics*, 30(2), pp.133–165.

Nussbaum, M.C. (2006). *Hiding from humanity: Disgust, Shame, and the Law.* 1st ed. Princeton, NJ: Princeton University Press.

Nussbaum, M.C. (2008). 'Human Dignity and Political Entitlements', in *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics*. Washington, DC: The President's Council on Bioethics, pp.351–380. Available at: http://bioethics.georgetown.edu/pcbe/reports/human_dignity/

Nussbaum, M.C. (2011). *Creating capabilities: The Human Development Approach*. Cambridge, MA: The Belknap Press of Harvard University Press.

Ogden, J. (2017). 'QALYs and their role in the NICE decision-making process', *Prescriber,* 28(4), pp.41–43c[online]. Available at: https://0-onlinelibrary-wiley-com.innopac.wits.ac.za/doi/epdf/10.1002/psb.1562 (Accessed: 13 July 2020).

Parliament of the United Kingdom. (2010). *The Equality Act 2010*. England and Wales; Scotland. Available at: https://www.legislation.gov.uk/ukpga/2010/15/contents

Partnership to Improve Patient Care**.** (2017). 'Measuring Value in Medicine: Uses and Misuses of the QALY: Ethical Issues with QALYs and Alternative Measures of Value' [white paper]. Washington, DC: Partnership to Improve Patient Care. Available at: http://www.pipcpatients.org/resources/white-paper-uses-and-misuses-of-the-qaly-ethical-issues-and-alternative-measures-of-value

Pashukanis, E. (2017). *The General Theory of Law and Marxism*. New York, NY: Routledge.

Pellegrino, E.D. (1999). 'The commodification of medical and health care: the moral consequences of a paradigm shift from a professional to a market ethic', *The Journal of Medicine and Philosophy*, 24(3), pp.243–266.

Prieto, L. and Sacristán, J. (2003). 'Problems and solutions in calculating quality-adjusted life years (QALYs)', *Health and Quality of Life Outcomes*, 1(1), pp.1–80. Available at: https://doi.org/10.1186/1477-7525-1-80

Rai, M. and Goyal, R. (2018). 'Pharmacoeconomics in Healthcare', in D. Vohora and G. Singh (eds.) *Pharmaceutical Medicine and Translational Clinical Research*. 1st ed. London, UK: Academic Press, pp.465–472.

Revill, P. and Maheswaran, H. (2019). 'An Introduction to Using Cost- Effectiveness Analysis to Inform Spending Decisions On HIV Testing' [presentation]. Available at: https://www.slideshare.net/CarmenArlene/an-introduction-to-using-costeffectiveness-analysis-to-inform-spending-decisions-on-hiv-testing

Robeyns, I. (2016). 'The Capabilities approach', in E.N. Zalta (ed.). *The Stanford Encyclopedia of Philosophy* (Winter 2016 Edition). Available at: https://plato.stanford.edu/archives/win2016/entries/capability-approach/

Robeyns, I. (2017). *Wellbeing, Freedom and Social Justice: The Capabilities approach Re-Examined.* Cambridge, UK: Open Book Publishers. Available at: http://dx.doi.org/10.11647/OBP.0130

Round, J., Leurent, B., Jones, L. (2014). 'A cost-utility analysis of a rehabilitation service for people living with and beyond cancer', *BMC Health Services Research*, 14(1), p. 558. Available at: https://doi.org/10.1186/s12913-014-0558-5

Sama, M. and Nguyen, V. (2008). *Governing Health Systems in Africa*. Dakar, SN: Council for the Development of Social Science Research in Africa.

Scheunemann, L.P. and White, D.B. (2011). 'The ethics and reality of rationing in medicine', *Chest*, 140(6), pp.1625–1632. Available at: https://doi.org/10.1378/chest.11-0622

Schlander, M., Garattini, S., Holm, S., Kolominsky-Rabas, P., Nord, E., Persson, U., Postma, M., Richardson, J., Simoens, S., Solà Morales, O.D. and Tolley, K. (2014). 'Incremental cost per quality-adjusted life year gained? The need for alternative methods to evaluate medical interventions for ultra-rare disorders', *Journal of Comparative Effectiveness Research*, 3(4), pp.399-422.

Schwartz, S., Richardson, J. and Glasziou, P.P. (1993). 'Quality-adjusted life years: origins, measurements, applications, objections', *Australian Journal of Public Health*, 17(3), pp.272–278.

Scott, A.W., Bressler, N.M., Ffolkes, S., Wittenborn, J.S. and Jorkasky, J. (2016). 'Public Attitudes About Eye and Vision Health', *JAMA Ophthalmology,* 134(10), pp.1111–1117.

Scott, P.A., Harvey, C., Felzmann, H., Suhonen, R., Habermann, M., Halvorsen, K., Christiansen, K., Toffoli, L., and Papastavrou, E. (2019). 'Resource allocation and rationing in nursing care: A discussion paper', *Nursing Ethics*, 26(5), pp.1528–1539. Available at: https://doi.org/10.1177/0969733018759831

Singer, P. (2009). 'Why We Must Ration Health Care', *New York Times,* 15 July. Available at: https://archive.nytimes.com/www.nytimes.com/2009/07/19/magazine/19healthcare-t.html

Singer, P., McKie, J., Kuhse, H. and Richardson, J.(1995). 'Double jeopardy and the use of QALYs in health care allocation', *Journal of Medical Ethics*, 21(3), pp.144–150.

Spring, J. (2009). 'An Analysis of Martha Nussbaum's Capabilities Approach with Attention to Her Use of the Term "Threshold"'. Undergraduate Thesis, University of Pittsburgh, (unpublished).

St. Clair, A.L. and Gasper, D. (eds.) (2010). *Development Ethics* , New York, NY: Ashgate Publishing .

Stein, M.S. (2009). 'Nussbaum: A Utilitarian Critique', *Boston College Law Review*, 50(2), pp.1–13, Available at: http://lawdigitalcommons.bc.edu/bclr/vol50/iss2/4

Stewart, F. (2013). 'Nussbaum on the Capabilities Approach', *Journal of Human Development and Capabilities,* 14(1), pp. 156–160 [online]. Available at: https://www.researchgate.net/publication/277446982_Nussbaum_on_the_Capabilities Approach (Accessed: 11 August 2019).

Tengland, P. (2019). 'Health and capabilities: a conceptual clarification', *Medical Health Care and Philosophy.* 23, pp.25–33. Available at: https://doi.org/10.1007/s11019-019-09902-w

Tengs, T.O. (2004). 'Cost-Effectiveness versus Cost–Utility Analysis of Interventions for Cancer: Does Adjusting for Health-Related Quality of Life Really Matter?' *Value in Health*, 7, pp.70–78. Available at: https://doi.org/10.1111/j.1524-4733.2004.71246.x

Terzi, L. (2009). 'Vagaries of natural lottery? Human diversity, disability, and justice: A capability perspective', in K. Brownee and A. Cureton (eds.), *Disability and disadvantage*. Oxford, UK: Oxford University Press.

The WHOQOL Group (1998). 'The World Health Organization Quality of Life Assessment (WHOQOL). Development and psychometric properties', *Social Science in Medicine*, 46, pp.1569–1585. https://doi.org/10.1016/s0277-9536(98)00009-4.

Trani, J. F., Bakhshi, P., Bellanca, N., Biggeri, M. and Marchetta, F. (2011). 'Disabilities through the capabilities approach lens: Implications for public policies', *ALTER: European Journal of Disability Research,* 3, pp.143–157.

Rawls, J. (1999). A theory of justice. Cambridge, Massachusetts :The Belknap Press of Harvard University Press,

Saigaran, N.G., Karupiah, P. and Gopal, P.S., 2015. The Capability Approach: Comparing Amartya Sen and Martha Nussbaum. *Proceedings of Universiti Sains Malaysia*, *1*.

University of Chicago Law School (2013). *Martha Nussbaum, "Creating Capabilities: The Human Development Approach"* [YouTube video]. Available at: https://www.youtube.com/watch?v=sYfFGDhbHUk

Vasbist, L. (2010). 'Martha Nussbaum's Capabilities Approach: Perils and Promises', *Journal of the Indian Law Institute,* 52(2), pp.230–266 [online]. Available at: www.jstor.org/stable/43953495 (Accessed: 15 April 2020)

Venkatapuram, S. (2007). 'Health and Justice: The Capability to be Healthy'. Doctoral thesis, King's College, University of Cambridge.

Venkatapuram, S. (2011). *Health justice: An Argument from the Capabilities Approach*. Cambridge, UK: Polity Press.

Venkatapuram, S. (2014). 'Mental disability, human rights and the capabilities approach: Searching for the foundations', *International Review of Psychiatry*, 26(4), pp.408–414.

Virgili, G., Koleva, D., Garattini, L., Banzi,R. and Gensini G.F. (2010). 'Utilities and QALYs in health economic evaluations: glossary and introduction', *Internal and Emergancy Medicine*, 5, pp.349–352. Available at: https://doi.org/10.1007/s11739-010-0420-7

Vorhaus, J., (2015). 'Dignity, Capability, and Profound Disability', *Metaphilosophy*, 46(3), pp.1–22 [online]. Available at: https://core.ac.uk/reader/79539920 (Accessed: 23 September 2020).

Walsh, A. (2019). 'Commodification', in *International Encyclopedia of Ethics* [online], pp.1–8. Available at: https://doi.org/10.1002/9781444367072.wbiee712.pub2 (Accessed: 13 Oct. 2019)

Wareham, C. (2013). 'Expensive Life-extending Treatments', *Nuffield Council on Bioethics*, pp.1–2 [online]. Available at: https://www.nuffieldbioethics.org/publications/expensive-

life-extending-treatments (Accessed: 8 June 2019).

Wasserman, D., Asch, A., Blustein, J. and Putnam, D. (2016). 'Disability: Definitions, Models, Experience', in E.N. Zalta (ed.) *The Stanford Encyclopaedia of Philosophy* (Summer 2016 Edition). Available at: https://plato.stanford.edu/entries/disability/

Weinstein, M.C., Torrance, G., McGuire A. (2009). 'QALYs: the Basics', *Value in Health*, 12, S5–S9. Available at: https://doi.org/10.1111/j.1524-4733.2009.00515.x

Whitehead, S. and Ali, S. (2010). 'Health outcomes in economic evaluation: the QALY and utilities', *British Medical Bulletin*, 96(1), pp.5–21. Available at: https://doi.org/10.1093/bmb/ldq033

Wilkinson, D., Petrou, S. and Savulescu, J. (2018). 'Expensive care? Resource-based thresholds for potentially inappropriate treatment in intensive care', *Monash Bioethics Review,* 35, 2–23 Available at: https://doi.org/10.1007/s40592-017-0075-5

Wolff, J. (2009). 'Disability among equals', in K. Brownlee and A. Cureton (eds.) *Disability and Disadvantage*. Oxford, UK: Oxford University Press.

Wong, D. (2011). 'Rationing Treatments Based on their Cost per QALY', *AMA Journal of Ethics* [online]. Available at: https://journalofethics.ama-assn.org/article/rationing-treatments-based-their-cost-qaly/2011-04 (Accessed: 9 February 2020).

World Health Organization*. International Classification of Health Interventions (ICHI)* [online]. Available at: https://www.who.int/classifications/ichi/en/ (Accessed: 10 December 2020).

World Health Organization (2001). *International Classification of Functioning, Disability, and Health* [online]. Available at: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health (Accessed: 10 December 2020).

World Health Organization (2006). 'Constitution of the World Health Organization', in *Basic Documents,* 45th ed. Geneva, CH: World Health Organization. Available at: https://www.who.int/governance/eb/who_constitution_en.pdf

World Health Organization (2017). *Human rights and health* [fact sheet]. Available at: https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health

World Health Organization (2018). *Disability and health* [online]. Available at: https://www.who.int/news-room/fact-sheets/detail/disability-and-health (Accessed 26 November 2019).

World Health Organization (2020). WHO guideline on country pharmaceutical pricing policies. 28 September 2020. Available at: https://www.who.int/publications/i/item/9789240011878

Zilberberg, M. and Shorr, A. (2010). 'Understanding cost-effectiveness', *Clinical Microbiology and Infection*, 16(12), pp.1707–1712. Available at: https://doi.org/10.1111/j.1469-0691.2010.03331.x21q

APPENDIX

Appendix A

Copy of ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PROTOCOL ASSESSORS MEETING

Candidate Full Name: Neo Dulaze

Student Number: 733666 Date: 17.7.2019

School / Department / Division: Bioethics

1. Type of study *(tick all that apply)*:

- ○ Quantitative
- ○ Qualitative
- ○ Mixed Methods
- ○ Laboratory
- ○ Clinical
- ○ Other, please specify: Normative study

2. Is title of the study appropriate *(preferably fewer than 20 words)*? [✓] Yes [ ] No

Comments:

3. Are the study objectives clear and linked to the research aim and title? [ ] Yes [✓] No

Comments: Introduction - need short introduction to Martha Nussbaum capabilities approach.

4. Is the design of the study appropriate to meet the study objectives? [ ] Yes [✓] No

Comments: Make objective 2 your primary objective Maybe combine objective 3 & 4 other objectives secondary.

11 March 2019/MP

1

5. **Are the proposed methods and tools appropriate to meet the research objectives?** Yes ✓ | No

Comments: _____

6. **Is the study feasible within the resources of:**
   a) The applicant? Yes ✓ | No
   b) The department? Yes ✓ | No
   c) The time frame? Yes ✓ | No

7. **If this is a PhD protocol assessment:**
   a) Is the content original? Yes | No
   b) Does the content show the scope and depth of a PhD? Yes | No

Comments: _____

Do you recommend:

i. Additional revision/amendment of the protocol? Please be specific on the recommendations being made:

_____

ii. The appointment of the proposed Supervisor? Yes ✓ | No

Nominee/s: _____

iii. The appointment of the proposed Co-Supervisor/s and/or additional co-supervisors? Yes [ ] No [✓]

Nominee/s: _____

_____

_____

iv. Has the Chair of the Assessor Group signed the RECOMMENDATION FOR APPOINTMENT OF SUPERVISOR(S) OF RESEARCH REPORT, DISSERTATION OR THESIS form? Please attach. Yes [✓] No [ ]

v. Has the Chair informed the student and supervisor about the Wits ethics requirements, and that if required, they must have either a Wits Human Research Ethics clearance certificate or a Wits Animal Research Ethics clearance certificate? Yes [✓] No [ ]

vi. Based on the protocol provided (including any proposed changes by the protocol assessor group), does the student require:

1. Human Research Ethics clearance certificate	Yes	No
2. Animal Research Ethics clearance certificate	Yes	No
3. No human or animal ethics certificate is required	Yes [✓]	No
4. Unclear, will seek appropriate guidance from the HREC/AREC committees	Yes	No

vii. Has the Postgraduate student and supervisor/s signed the ethics declaration form Yes [✓] No [ ]

Overall recommendation regarding the protocol:

i. Revision of the protocol to the satisfaction of the Supervisor (**NB: if HoD approval is also required, please specify**): Yes [ ] No [ ]
*(**Candidate**: one copy, list of corrections with page numbers and Supervisor approval letter – submit to PG Office).*

ii. Revision of the protocol to the satisfaction of the Assessor Group/Chair: Yes [ ] No [ ]
*(**Candidate**: one copy, list of corrections with page numbers, Supervisor approval letter – submit to PG Office and PG Office to forward to the Assessor Group Chair).*

iii. Revision of the protocol and resubmission of the revised protocol to the next Assessor Group Meeting: Yes [ ] No [ ]
*(**Candidate**: six copies, list of corrections with page numbers, Supervisor approval letter – submit one copy to PG Office / 5 to school assessor group administrator / for PhD, all six copies to be submitted to the PG Office).*

iv. Candidate goes ahead (*no revision required*): Yes [✓] No [ ]

11 March 2019/MP

Details of Assessors:

Name:	Email:	Sign:
Denise Franzsen	denise.franzsen@wits.ac.za	
Jeanine Vellema	Jeanine.Vellema@wits.ac.za	

Details of Assessor Group Chair:

Name:	Email:	Sign:
JE Maree	Lize-maree@wits.ac.za	

Date: 17/7/2019