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April 10, 2023

Compassionate Care: Towards a New Ethical Approach for Allocating Healthcare Resources

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An abstract of a thesis submitted to the Faculty of Emory College of Arts and Sciences of Emory University in partial fulfillment of the requirements of the degree of Bachelor of Arts with Honors

Philosophy, Politics, & Law

2023

Abstract

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In a world of finite resources, how do we decide who deserves what in health care? Do we decide to spread the resources amongst people that will create the greatest overall population? Or do we allocate them to those who need it most? Do we concern ourselves with the well-being of the individual patient or society as a whole?

One approach taken by health economists is simply aiming to increase overall population health statistics using efficiency. However, this utilitarian approach does not do enough to recognize humanity as its focus is almost entirely on the numbers. By recognizing the importance of individuals within the system, we can provide individualized care that improves the dignity and respect afforded to patients. However, this cannot be solved by simply prioritizing the absolute duty to each individual patient over all else as Kant would argue since there will always come a point when decisions must be made between the duties to each patient.

Reconciling compassionate, individualized care with the goal of efficiency, the Dalai Lama's ethics of compassion addresses the shortcomings of the utilitarian and deontological approaches to research allocation. The approach taken by the United Kingdom's National Institute for Clinical Excellence aligns with this ethics of compassion since its guidelines first fall back on consequentialism, but in hard cases medical professionals can apply these guidelines based on the individual circumstances of the patient.

By applying an ethics of compassion, systems can become closer to finding a proper balance between the 'inconsistent triad' of cost, quality, and access in healthcare. The application of the ethics of compassion to decisions regarding resource allocation must be supported by a compassionate healthcare system. With these improved decision-making modes and compassionate systems that similarly aim to respect the dignity of individual patients, healthcare systems can take important steps towards creating an improved sense of justice in healthcare. Compassionate Care: Towards a New Ethical Approach for Allocating Healthcare Resources

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Acknowledgements

Many thanks to Noelle McAfee, Anna Grimshaw, Karen Hegtvedt, and Brendan Ozawa de Silva for not only serving on my committee but for the parts they have played in shaping this thesis. The topic of this paper is very personal to me and over the course of my academic career at Emory I have taken deeply thought-provoking courses in various disciplines that have shaped my understanding of healthcare ethics– many of these with members of this committee.

I would also like to thank my mother and father for providing me with the opportunities and education that allowed me to complete this thesis, as well as the love and support they have given me throughout my life, which has driven me in all aspects of my life, especially academically.

Lastly, I want to thank my sister, Sophie. You have shaped me into the person I am today. Your story and your attitude towards life have helped inspire me to write about this topic. Thank you for showing me hard work and persistence throughout the years— without you I truly could not be where I am today.

Table of Contents

1)	Introduction	1
	a) Chapter Overview	3
2)	Chapter 1: Utilitarianism & Healthcare Economics	6
	a) Introduction	
	b) Defining Health & Healthcare	
	c) Importance of Ethical Guidelines in Making Health Care Decisions	
	d) The Role of Priority Setting in Health Care	
	e) Health Economics & Utilitarianism	
	f) Quality-Adjusted Life Years	
	g) The Problems with Quantifying Life Using QALYs	
•	h) Conclusion	22
3)	Chapter 2: Deontological Ethics & Prioritizing the Duty to the Individual Patient	
	a) Introduction.	
	b) The Problem of Supply & Demand for Individuals: The Case of Child B	
	c) Deontological Ethics & Morality	
	d) Duties in Healthcare	
	e) The Right to Healthcare	
	f) The Doctor-Patient Relationship	
	g) Individualism & Autonomy	
	h) Quality Care for All Costs	
4)	i) Conclusion	
4)	Chapter 4: The Ethics of Compassion	
	a) Introductionb) The Ethics of Compassion	
	c) Compassion & Patient-Centered Cared) Efficiency & Patient-Centered Care	
	e) The Effects of Compassion on Healthcare Providers	
	f) Compassion Training	
	g) Implementing Compassion on a Large Scale	
	h) Conclusion	
5)	Chapter 3: Towards Solving the Inconsistent Triad of Healthcare	
5)	a) Introduction	
	b) Access, Quality, and Cost: An Inconsistent Triad	
	c) US Healthcare vs. National Health Service	
	d) A World of Conflicting Values	
	e) A NICE Solution: The National Institute for Health and Care Excellence	
	f) Concerns about NICE	
	g) Conclusion	69
6)	Conclusion	71
,	a) Introduction	71
	b) The New Models' Incompatibility with American Healthcare	72
	c) The Larger Solution: Changing the System	73
	d) An Attempt at Changing the System: The Affordable Care Act	76
	e) Systems Affect Individuals	
	f) Conclusion	79

Introduction

During the COVID-19 pandemic, the world was faced with countless issues with supply and demand. As the news first hit the United States, like many others, my family began to stock up a bit on what we could, especially toilet paper and cleaning supplies. However, shortages immediately became widespread due to mass panic. I remember going to the grocery store to find every single shelf nearly empty. Stores began to limit products to one or two per customer to help ration. The question of distribution became a central question in our lives, especially as hospitals became overrun and healthcare resources became increasingly scarce. Vaccines, for example, were first allocated to the elderly and immunocompromised. However, resource allocation remains a prevalent issue no matter the circumstances.

In a world of finite resources, how do we decide who deserves what in health care? Do we decide to spread the resources amongst people that will create the greatest overall population? Or do we allocate them to those who need it most? Do we concern ourselves with the individual patient or the society as a whole? These questions have long been debated as governments created health care systems and health care policies. The ways in which a healthcare system attempts to solve this problem has ethical implications that affect entire populations.

It may seem easy to decide based on your values- why not distribute healthcare resources to increase the overall health of the population? This was my initial inclination, as well; however, I quickly reconsidered when I thought of my sister, Sophie. Sophie and I grew up practically attached at the hip, although she is two years my senior. At the age of nine, she was diagnosed with a rare lymphatic disease that was known as lymphangiomatosis. Since then, Sophie began being treated by incredible pediatric specialists across the country. She joined a clinical trial and had an incredible response to the new drug. Now, apart from her regular

1

doctor's appointments and blood tests, she lives a rather normal life for a twenty-two-year-old. Having recently graduated from Emory University's Goizueta Business School, Sophie moved to Charlotte, NC, where she is now working in sports marketing and putting down roots in the new city.

Despite the relative normalcy she enjoys, Sophie knows that most other children diagnosed with a generalized lymphatic anomaly (GLA) are not so lucky. Due to the limited prevalence of the disease, very few researchers will invest time into researching it: there is no money there. My family is fortunate that we could afford her care and that she responded well to treatment. However, since she was diagnosed, I have seen countless pediatric patients at children's hospitals and patient conferences who will never see remotely near the normalcy that Sophie enjoys. I can't help but think of Sophie and these other patients when the question of health care allocation comes to mind. In an introductory anthropology course at my university, for example, I learned about cost-utility analyses, which I understood as the math of people's lives. However, instead of "people" in general, my mind couldn't help but wander towards the children I had seen lining the halls of children's hospitals throughout my childhood.

The ethical dilemmas that are presented by resource allocation are ones that have important policy implications, but it cannot be thought of only in abstract terms: this dilemma affects all those children I saw at patient conferences and children's hospitals. It affects my sister. It is important that in discussing these ethics, we do not lose the fact that we are talking about people with real lives, real families, real hopes for what their lives could be like. When it comes to policy, I can understand why we have sought out a way to decide what medical issues to focus on and where to allocate our resources as a country; however, in this work I will propose that these should not be either/or decisions. Rather, I argue that we should aim for decision-making processes that allow for efficiency *and* patient-centered care for all by effectively balancing the healthcare systems goals of cost-effectiveness, high quality care, and access for all.

Chapter Overview

Utilitarianism and deontology are two prevailing ethical approaches that often guide decision-making processes in healthcare resource allocation. In the first two chapters, I outline these two approaches, focusing on utilitarianism in the former and deontology in the latter. The third chapter discusses a different method that combines the strengths of the utilitarian and deontological approaches together. Lastly, the conclusion emphasizes that, for the best outcomes, better ethical approaches to resource allocation should not occur in a vacuum.

The first chapter begins with a discussion of health and healthcare, emphasizing the gravity that decisions that affect these have. Healthcare decisions therefore should be grounded in ethical principles. I then turn to the inevitability of priority setting in healthcare given the current medical culture. The following section discusses the approach of the health economist, utilitarianism, which aims to increase efficiency using cost-utility analyses called Quality-Adjusted Life Years (QALYs). To illustrate both the strengths and weaknesses of the utilitarian approach to resource allocation, I begin a more in-depth discussion of QALYs, noting the deeply flawed ethical assumptions that they are based on. In this chapter I ultimately argue that the focus on efficiency that occurs with utilitarianism forces the healthcare system to lose sight of the individual, seeing them simply as numbers in their calculation.

The second chapter turns to Kantian deontology, beginning with a case study known as 'the Case of Child B' to further illustrate the downfall of utilitarianism for the individual patient. To address the shortcomings of utilitarianism, I then delve into a discussion of morality and deontological ethics and how they relate to healthcare. I discuss how duty and rights are essential to the running of a healthcare system as they create trust in the healthcare system.

In the next section, I explore how focusing on the individual patient– as well as the relationship with that individual patient– occurs when trust is at the center of healthcare. Given the realities of finite resources, it would be impossible for everyone to receive all the care they could possibly ever need. Since deontology requires that all duties are absolute, I argue that priority setting presents the fundamental flaw in Kantian ethics. Thus, I ultimately argue that the deontological approach is insufficient for guiding resource allocation as it does not offer any guidance when duties conflict.

In the third chapter, I aim to find a different approach to making decisions about priority setting in healthcare that avoids the downfalls of the utilitarian and deontological approaches. To further illustrate the approaches taken, I present cost, quality, and access as an "inconsistent triad" in healthcare, using the United States and the United Kingdom's healthcare systems to demonstrate. Employing Albert Weale's work, I then acknowledge that there is no one clear cut solution that will solve the issue of cost, quality, and access for all since the world is full of conflicting values. Instead, I argue that healthcare decision-making should not be informed by absolute principles, but by a hierarchy of social and cultural values, like compassion. The following sections discuss how NICE has successfully taken into account clinical effectiveness, cost-effectiveness, and social values, but falls short in its ability to recognize differences between patients. I ultimately argue that decision-making processes should take into account cost, quality, access, and social values, like NICE, but also work to solve this shortcoming to promote patient-centered care in healthcare.

Finally, in the conclusion I discuss the difficulty and value of implementing compassion on a large scale. Compassion should not only occur in doctor-patient relationships, but also throughout the system. However, I show that the idea of a compassionate system is largely at odds with the capitalist model of healthcare used by the United States. Private healthcare leads to competition that drives healthcare professions to prioritize their own interests over those of the patient. Additionally, I further illustrate how the profit-motive affects healthcare systems, by describing how increasing privatization in the United Kingdom has led to the near collapse of the NHS. Thus, using the ACA to demonstrate, I propose that the improved decision-making processes for resource allocation must be supported by changes to the healthcare system as a whole to promote just healthcare in the form of high quality, low cost, and easily accessible care. With decision-making processes guided by the principles of patient-centered care with focuses on cost, quality, and access, changes to the systems as a whole can create lasting positive change for patients around the world.

Chapter 1: Utilitarianism & Healthcare Economics Efficiency in Decision-Making

Introduction

In healthcare, there are two main approaches that guide medical professionals and policymakers in making decisions about healthcare rationing: utilitarianism and deontology. In this chapter I will focus on the former and the following chapter will delve into the latter. This chapter begins with a discussion of health and healthcare, highlighting the gravity that healthcare decisions have on individuals. Due to the weight of the decisions being made, I then highlight the importance of ethical guidelines in making healthcare decisions, providing the reader with a background in prevailing beliefs in healthcare ethics. The following section turns to the role of priority setting in healthcare, noting particularly its inevitability given the current medical culture. I go on to discuss how health economists take the utilitarian approach to make recommendations to policymakers and medical practitioners, using cost-utility analyses called Quality-Adjusted Life Years (QALYs). The metrics used to calculate QALYs are further examined to shed light on the fundamental flaws in the assumptions being made about health and the worth of life in utilitarian approaches to health economics. I ultimately argue that the focus on efficiency and cutting out waste in healthcare under the purely utilitarian approach forces healthcare professionals and policymakers to lose sight of the individuals that are seeking treatment, seeing them simply as numbers in their equations.

Defining Health & Healthcare

Throughout life, every human being is constantly aware of their health and wellbeing and the care that they receive to maintain that health. Often some of our first memories consist of holding back tears after a shot or getting a sticker after being brave. Maybe we meet a new family member in the maternity ward of a hospital or visit a grandparent in hospice care. Our health and healthcare are central to the human experience, yet we often take these things for granted. Still, as most grow up, they start to understand the depth of the idea of health and the breadth of health issues that can afflict us.

The typical dictionary definition of health, however, only specifies the absence of disease or any "deviations from *normal* physical and chemical functioning."¹ As simple and straightforward as this definition may seem, it evidently lacks so much. In the 21st century, sizable strides in the area of mental health have been made that alone are able to discredit this definition as it neglects to highlight the importance of our mental and social well-being. Instead of merely the absence of disease or illness, health can be better understood as a state of complete physical, mental, and social well-being. Being in good health implies that a person has some balance between the physical, mental, emotional, and social factors that affect their lives. Additionally, good health for one individual often looks different than for others. Importantly, marginalized groups often experience greater health struggles on average due to their socioeconomic status, living conditions, and stress.

With a fuller definition of what it means to have health, it is clear that maintaining good health requires more than simply having access to medical care when necessary. Also imperative for good health is building healthy habits, like exercising regularly, having a balanced diet, sleeping enough, and utilizing effective coping mechanisms to deal with stress. Poor health can limit the opportunities available to a person, while good health is often essential to individuals being able to participate fully in daily activities and ultimately achieve their goals. Due to these significant impacts that health has on a person's life, it is important, when discussing health and

¹ Christopher Newdick, Who Should We Treat?: Rights, Rationing, and the Resources in the NHS, 8.

the provision of healthcare, that we ground ourselves by more clearly defining these terms and discussing how the debate on healthcare access has deeply ethical roots.

Importance of Ethical Guidelines in Making Health Care Decisions

In light of the gravity of the decisions and what is at stake, healthcare decisions are often guided by ethical guidelines and theories of justice. Ethics are the moral principles that help both individuals and groups determine what is right and wrong. These moral principles permeate our whole lives since they "guide or are realised in how we treat other people, in what we say and do and in the decisions and choices which we make."² These principles often involve ideas of honesty, fairness, respect, responsibility, and compassion and often guide individuals or groups in deciding what is valuable or meaningful. Justice is largely concerned with fairness and distributing benefits and burdens in society in a fair manner. Justice occurs when ethical principles are applied in a fair way. In this way, ethics serve as the foundation for justice.

Since justice is tied to ethics, justice is often understood to have a relationship with equality; however, equality has various different interpretations. For one, equality can refer to equality of input, when the same amount of resources are allocated to each person: everyone gets the same share. Another understanding of justice relies on the idea of equality of outputs. Equality of outputs helps to increase the resources allocated to underprivileged individuals or areas. For example, regions with poorer health outcomes due to poverty should be entitled to greater government investment in health care to increase the health of the underprivileged population. By doing so, the government would help to close the gap in outcomes seen between the morbidity and mortality of those living in poverty and wealthier populations.

² Øvretveit, 1997 quoted in "Rationing in health care: The theory and practice of priority setting," 129

Occurring on both micro and macro levels, justice requires that all individuals regardless of their individual characteristics, like race, gender, social status, sexual orientation, and other factors, are given equal concern from the government.³ T. M. Scanlon and Ronald Dworkin argue that any theory of justice requires equal concern for all. Using social contract theory to support his claims, Dworkin sees equal moral concern as a natural right.⁴ A government gains the power to exercise control over a political community since all of the citizens in that political community have agreed to give up some rights for the benefits that a government can provide. According to Scanlon, governments are obligated to offer their citizens benefits because they all have given up some of their freedoms.⁵ Conversely, Dworkin believes the promise of equal moral concern is a prerequisite for individuals to consent to giving up freedoms and being governed.

This requirement for equal concern exists throughout society based on a person's obligations. A person is not required to give equal concern to all individuals unless they are in a position that obligates them to give equal concern to all. In other words, a person's obligations are based on the position that they occupy. In the case of the medical professional, many believe that they should show equal concern for all their patients. Thus, to return to the question of ethics and justice in healthcare, there are three main ethical principles which are understood as central to morally practicing medicine: non-maleficence, beneficence, and autonomy.

In healthcare, non-maleficence is the ethical principle that tells medical professionals to "do no harm," as in the Hippocratic Oath. Conversely, the principle of beneficence urges healthcare professionals to always act with the goal of benefiting the patient. Lastly, doctors are

³ Karen Hegtvedt, Justice & Health Lecture, 24 July 2022

⁴ Ronald Dworkin, *Taking Rights* Seriously, 176-177

⁵ T.M. Scanlon, *Why Does Inequality Matter*?, 22

expected to work to preserve the autonomy of the patient in their care. In healthcare, the patients' autonomy refers to their ability to make informed decisions about their own medical care without being swayed by others. Following Scanlon and Dworkin, most would argue that the medical professional ought to have equal concern by practicing these three main principles of medical ethics.

The Role of Priority Setting in Health Care

Since under any theory of justice, a medical professional should have equal concern for all of their patients, health care providers and healthcare-providing governments often find themselves in a predicament. Everyone is constantly aiming for good health and more life and medical providers are supposed to help as best they can, but need tends to strain the available resources. As David Owen explains, "All the evidence there is, both national and international, suggests that if [the] need [for health care] is not infinite, it is certainly so large relative to the resources which society is able to provide now and in the foreseeable future that we can never hope to meet it completely."⁶

There are numerous reasons why this mismatch between need and available resources arises. For one, medical innovation has helped to extend the lives of the elderly, leading to an ever-increasing average in the population. More people need more care for longer periods of time. This mortality shift is in part responsible for chronic conditions, which require consistent treatment over longer periods, becoming the leading cause of illness, disability, and death.⁷ Moreover, the current medical culture– particularly in the United States, but also in other

⁶ Mason and McCall Smith, *Law and Medical Ethics*, 249, quoting D. Owen, *In Sickness and in Health: The Politics of Medicine* (1976)

⁷ Committee on the Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the* 21st Century, 3

'developed' countries– has seen a push towards increased medical intervention. The pharmaceutical industry in particular has seen a massive boom in the past few decades.⁸ As explained in *Problems of Resource Allocation*,

It is endemic to a system in which an expanding medical establishment faced with a healthier population, is driven to medicalizing normal events like menopause, converting risks into diseases, and treating trivial complaints with fancy procedures. Doctors and "consumers" are becoming locked within a fantasy that everyone has something wrong with them, everyone and everything can be cured.⁹

This tendency towards the medicalization of normal life events is paired with the issue that doctors are also more prone to investigate potential health concerns with unnecessary screening. Additionally, something that might have required a minor procedure may now also be treated more effectively by a more complicated and expensive surgery because of the scientific discoveries made in recent years. The increasing costs of medical interventions and the cultural push towards more treatment are exacerbated by the increasing average age of the population.¹⁰

Since, again, the strain on health care resources is inevitable, governments that distribute resources for health care are forced to take part in "horizontal resource allocation," which entails priority setting between various health care services. But how do we decide what services should be provided? What factors should we take into account? What values guide us as we make these kinds of decisions? This is a hotly debated topic that many have strong opinions on, but there are a few main stances on the subject.

⁸ Committee on the Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the* 21st Century, 4.

⁹ Christopher Newdick, *Who Should We Treat?: Rights, Rationing, and the Resources in the NHS*, 7

¹⁰ Mason and McCall Smith, Law and Medical Ethics, 248, Rawles, Castigating QALYs, 144

Firstly, some believe that the population would be best served if health policy aimed to increase the overall health gain in the population, rather than focusing on promoting equality. Others firmly believe that promoting equality by providing the same amount and level of care to all is the most just way to allocate resources. Still another camp believes that aiming for an equality of output by putting more resources into worse off populations is a better way to allocate healthcare resources. This strategy would help eliminate health disparities in poorer populations, which could be critical since we know that a person's zip code largely determines their health outcomes.

Some believe that public opinion in a given society should be taken into account since cultural values inform public opinion on how resources should be allocated. Following this argument, the cultural values of the society would decide if, for example, equality of access should be a priority or if a health care system should aim for the highest possible overall health gain in the population. Others even believe that the "intrinsic worth of the subject to society" should be taken into account.¹¹ Under this belief, the society would deem the lives of the elderly or less able-bodied individuals as having less worth and the care of others would be prioritized over theirs.

This debate is an inevitable one that raises many ethical questions. When the National Institute for Clinical Excellence for England and Wales was created, they described this tension: "The most important criterion is the clinical need of patients but this must be considered in relation to the severity of the disease or condition, the benefits and costs of existing treatment, and the incremental benefits and costs of the new treatment under consideration."¹² Since this

¹¹ Mason and McCall Smith, Law and Medical Ethics, 259

¹² Rationing in Health Care : The Theory and Practice of Priority Setting, 20

process of allocating resources is surely inevitable, it must follow an ethical framework following consistent principles that promote justice. However, when delving into the prevailing beliefs on resource allocation in healthcare, it seems clear that the principles that guide our decision-making have faults of their own.

Health Economics & Utilitarianism

Of the two main approaches used in deciding how health care resources should be distributed amongst a population, the prevailing technique is aiming for the greatest increase in overall population health possible. This belief is guided by a philosophical principle called utilitarianism, which is a consequentialist approach to normative ethics that considers the consequences of actions over individual rights. Its founder, John Stuart Mill, believed that the morality of any given action has no relation to the initial intent that the act is based on. Most simply put, if the consequences of an act are good overall, then the act is ethical. Thus, using his "greatest happiness principle," Mill explains that "actions are right in proportion as they tend to promote happiness, wrong in proportion as they tend to produce the reverse of happiness" with happiness referring to pleasure and the absence of pain.¹³ Another central aspect of utilitarianism is the belief that everyone's happiness matters equally. Person A's happiness always matters just as much as Person B and C and so on. As a result, what is the most good is what promotes happiness for the greatest number of people.

Following this utilitarian approach is the most widespread tactic used in health care resource allocation, aiming to promote "the greatest happiness of the greatest number" when

¹³ Utilitarianism, John Stuart Mill

resources are limited.¹⁴ As a result, the promotion of the greatest happiness tends to occur through priority setting in health care. From the perspective of the healthcare economist, the mismatch between medical need and resources can be understood as an issue of supply and demand to solve. Thus, in order to get an understanding of utilitarian techniques used in allocating health care resources, the approach of the health care economist must be explored.

Health care economists are large proponents of the utilitarian approach to resource allocation as they see promoting the "greatest happiness" in health care as improving life expectancy and quality of life. As a result, health economists measure the success of resource allocation by the "*consequences* of the decisions made, and this is measured (at least primarily) in terms of population health gain."¹⁵ As discussed previously, the strain on resources in healthcare is inevitable, so it follows that health economists would have a particular interest in achieving the maximum benefits from a particular resource and decreasing waste. Efficiency, therefore, is the main goal of health care economics, which evidently aims to get the best value for money.

There are a few different kinds of efficiency that pertain to health care: technical efficiency, allocative efficiency, and cost efficiency. The former focuses on "how well a state's health care system is able to transform health care inputs (but not costs) into health care outputs."¹⁶ Technical efficiency is often promoted in regards to giving a specific treatment. For example, in promoting technical efficiency, a health care professional may seek the most efficient means by which to screen for breast cancer. Conversely, allocative efficiency is deciding which conditions or patients should receive treatment in order to promote overall

¹⁴ Williams et al, Rationing in Health Care: The Theory and Practice of Priority Setting, 17

¹⁵ Williams et al, Rationing in Health Care: The Theory and Practice of Priority Setting, 17

¹⁶ Has the Affordable Care Act Affected Health Care Efficiency?, 197

population health as much as possible. Lastly, cost efficiency refers to the ability to provide healthcare results at the lowest possible cost.¹⁷ All three of these questions are essential to the health care economist and a health care system's ability to realize the goal of increasing efficiency overall.

Another objective of health care economics is to decrease opportunity costs, which are "the value of the consequences forgone by choosing to deploy a resource in one way rather than its best alternative use, that is, it is what you chose not to do that is the opportunity cost."¹⁸ In other words, decreasing opportunity cost means leaving as little potential benefit on the table as possible. For example, in comparing two possible treatments, the opportunity cost would be the benefit of the treatment not pursued. In attempting to measure opportunity cost, health economists seek to minimize the pain described in the utilitarian approach.

To reiterate, health care economists are largely utilitarian with their focus on efficiency in priority setting. The enduring beliefs behind health care economics is that "the interests of the community as more important than the interests of individuals."¹⁹ By finding means to promote technical and allocative efficiency and eliminate opportunity costs as much as possible, health care economists work to create the greatest increase in overall population health.

In order to promote efficiency, health care economists use economic evaluations to explore the cost effectiveness of interventions by taking into account both the costs and consequences of an intervention.²⁰ There are numerous different kinds of economic evaluations used by health care economists, including cost-benefit analyses, cost-effectiveness analyses,

¹⁷ Has the Affordable Care Act Affected Health Care Efficiency?, 197

¹⁸ Williams et al, Rationing in Health Care: The Theory and Practice of Priority Setting, 50

¹⁹ Williams et al, Rationing in Health Care: The Theory and Practice of Priority Setting, 53

²⁰ Williams et al, Rationing in Health Care: The Theory and Practice of Priority Setting, 49-51

cost-minimisation analyses, and cost-utility analyses.²¹ A cost-benefit analysis measures the consequences of an action in monetary terms, whereas the cost-effectiveness analysis measures costs in monetary terms and consequences are measured in the most appropriate physical unit (i.e results are reported in cost per unit). A specific kind of cost-effectiveness analysis known as a cost-utility analysis is particularly differentiated by "the adoption of summary outcome measures."²² The healthcare industry largely uses cost-utility analyses, such as Quality Adjusted Life Years and Disability Adjusted Life Years, in order to make decisions with the goal of promoting efficiency.

Quality-Adjusted Life Years

The cost utility analyses called Quality Adjusted Life Years, or QALYs, have the most widespread implementation in health care and health care policy. Since QALYs follow a utilitarian approach to health care decision-making, it follows that "the imperative to maximise the benefits to society from health care spending – and as such the preferred or recommended course of action is to allocate resources to the intervention that will maximise health gain per pound [or dollar] spent."²³ As a composite measure the Quality Adjusted Life Year attempts to quantify and take into account exactly what one would think: quality of life and life years. It assumes that both the quality of life and the length of life are central to assessing utility.

Using the QALY approach, 'quality of life' is measured with the goal of objectively calculating disease burden and an individual's health outcomes. Thus, the QALY can be used for individual patients to decide between treatments for their specific condition in an attempt to help

²¹ Williams et al, Rationing in Health Care: The Theory and Practice of Priority Setting, 49-51

²² Williams et al, Rationing in Health Care: The Theory and Practice of Priority Setting, 49-51

²³ Williams et al, Rationing in Health Care: The Theory and Practice of Priority Setting, 50

them quantify the pain and pleasure that the treatment would result in. More often, the QALY used to quantify the cost-effectiveness of providing treatment and health care economists, policymakers and providers try to quantify the worth, or utility, gained from providing treatments. As explained in *Rationing in Health Care : The Theory and Practice of Priority Setting,* "Health economics adopts a normative framework to evaluate the cost-effectiveness of health care services and offers a 'technical' solution to the problem of scarcity of resources by providing decision-makers with recommendations that will help in informing resource allocation decisions."²⁴ By assigning worth to a person's life in terms of quality and life left, the health care economist makes a recommendation that aims to increase utility in the population.

Importantly, the process by which QALYs are calculated poses various ethical questions. How does one quantify the quality of one's life? Is it fair to decide the worth or utility of someone's life? What would make one person's life worth more than another? What constitutes a good life to begin with? 'Quality of life' implies worth or goodness for something that is extremely subjective. Similarly, the calculation of life years remaining suggests that years gained necessarily correlates with worth.

There is some disagreement on the best way to measure quality of life when calculating QALYs Often when using rating scales, subjects must simply place different health outcomes on a linear scale from most to least preferred. The place on the line as well as the distances between the health outcomes allow researchers to determine a utility score. Another rating scale, known as visual analog scales, similarly asks respondents to rate health outcomes on a scale of 0 to 1 with 0 being death and 1 being perfect health. Rating scales often produce biased results, whereas other utility measures prevent this by including risk.

²⁴ Williams et al, Rationing in Health Care : The Theory and Practice of Priority Setting, 49

Some of the most highly regarded quality of life measures that include risk are the standard gamble (SG) and the time trade-off (TTO). The time trade-off approach asks individuals to decide if they would rather trade off a shorter life in good health for a longer life with a lesser health state. For example, the question might be posed if one would prefer to live 10 years in good health or live 20 years with blindness in one eye. Based on the respondents' answer, the researchers keep adjusting the years until the respondent is indifferent and believes that 10 years in good health is equal to a certain amount of years with blindness in one eye.

When using the standard gamble approach to measuring health utilities, people are asked to rank a list of health outcomes from best to worst. Next, the researchers begin "setting up the gamble" by asking the respondents to consider a hypothetical, such as the following: "You have only three months to live. You can either choose to live them as an inpatient with significant side effects (the poorest health state listed—admission with comorbidities) or you can choose to gamble. In the gamble, your choices are: live the three months in perfect health or instant death."²⁵ The respondents are then asked if they would take the gamble or live with the side effects. By repeating similar hypothetical questions repeatedly and then comparing their answers with their inherent risk-taking behavior, researchers can produce a utility score that is regarded as reliable.

Another common way of calculating quality of life is Rosser's Classification of Illness States. Rosser's classification uses two variables to determine quality of life: disability and distress.²⁶ Disability is measured on a scale from I-VIII and distress is quantified as none (A), mild (B), moderate (C), or severe (D). Respondents are presented with a matrix of 32 cells that

²⁵ Garza and Wyrwich, "Health Utility Measures and the Standard Gamble," 361

²⁶ John Rawles, "Castigating QALYs," 144

represents every possible combination of these variables and then asked to rate the health state in each cell on a scale of -1 to +1, where +1 represents perfect health, 0 represents death, and -1 represents a health state worse than death. Using a large group of peoples' answers, researchers can attempt to quantify quality of life in this way.

Once a person's health is quantified in terms of quality of life, the QALY approach then assigns a quality of life weight to a given time period with a weight of 1 indicating perfect health and a weight of 0 signifying a health state that is largely considered to be equivalent to or worse than death. This weight is then multiplied by the amount of life remaining. The results of a QALY analysis are reported in "cost per additional QALY gained". To illustrate the calculation, if a treatment will extend a person's life by 10 years with a quality-of-life weight of 0.5, then the treatment will result in a QALY gain of 5.

The Problems with Quantifying Life Using QALYs

Efficiency is largely increased in health care by creating the cost-utility analyses, such as Quality-Adjusted Life Years. In aiming for improved efficiency and quantifying measures of health and health care, the health care economist aims to reduce waste and help make decisions that will often ultimately improve productivity from a numerical standpoint. In his work *Taking Rights Seriously*, Ronald Dworkin discusses the philosophical approach on which the health care economist bases their work, utilitarianism. Dworkin explains, "though [forms of utilitarianism] count up the impact of political decisions on distinct individuals, and are in this way concerned with individual welfare, they merge these impacts into overall totals or averages and take the improvement of these totals or averages as desirable quite apart from the decision of any

individual that it is."²⁷ Since health care economists focus on increasing metrics of utility, the people that the numbers represent are often forgotten. Health care becomes about improving numbers more than about providing quality care to real people.

More specifically, the utilitarian approach taken to increase efficiency in health care forces assumptions to be made that are ethically questionable. The utilitarian unit of the QALY, for example, is based on ethical assumptions that somewhat arbitrarily assign worth to people's lives. How would we even quantify quality of life objectively? What counts as quality of life depends on what one wants out of life on an individual level. Each person can only judge for themselves what counts as success when it comes to quality of life since this is based on a person's goals and what they want out of life. The notion of *overall* quality of life is not necessarily tied to a singular goal since, like the notion of health, it often varies from person to person. Since overall quality of life and thus the perceived value of life is difficult to pin down for a given patient, the notion of waste in health care specifically poses critical ethical questions about who should be determining the value of life– the patient, the doctor, or the healthcare system as a whole.

In an attempt to quantify 'utility' or quality of life using rating scales, SG, TTO, or Rosser's Classification, the QALY metric makes assumptions about health and well-being that are deeply flawed. Intuitively, one might be uncomfortable with the previously discussed processes used to quantify quality of life. Most quality-of-life measures ask respondents to put themselves in hypothetical situations that they themselves have never actually experienced and ask them to approximate their intuitions. These kinds of questions tend to reveal more about the person responding and what they value in life rather than the answer to the question. The worth

²⁷ Ronald Dworkin, *Taking Rights Seriously*, 172

of a life cannot be accurately determined in these ways, so applying the equal concern discussed by Dworkin based on these 'utility' measures is unjust.

Additionally, quantifying the 'utility' of a person makes claims about health and wellbeing that disadvantages certain groups. In the article "Qualms About QALYs," Alwyn Smith explains, "A difficulty about the use of any measure which allocates resources by assigning different values to similar durations of lives of different quality is that it imposes a judgment about the value of life with which affected individuals might not concur."²⁸ For example, 'utility' will be drastically lower for someone who is disabled than for someone who is able-bodied. Still, some disabled people likely believe their quality of life to be better than some of their ablebodied counterparts. Even if a disabled person does have a lower quality of life than an ablebodied person, it does not mean that their life (or the years that can be saved due to medical intervention) is worth any less. In fact, most patients would value their life somewhat equally, so how do you accurately measure utility or worth using these metrics?

Similarly, in the calculation of life years gained, groups may be unable to gain more than a certain amount of life from a treatment and may, therefore, be excluded from receiving lifesaving treatment when QALYs are used to make health care decisions. Among these groups are the elderly or those with fatal health conditions that would typically gain less life years from a given treatment. Following QALY approach, some of the most vulnerable patients in the population receive care that is not guided by beneficence and non-maleficence, and their autonomy is not protected. By simply following the numbers in decision-making, those that most need to rely on the rest of society become neglected, including the elderly, disabled, and those with fatal health conditions.

²⁸ Smith, "Qualms about QALYs," 1135

Conclusion

As discussed, a fuller definition of health recognizes it as a state of complete physical, mental, and social well-being that is constantly changing as the individual seeks balance between all of these aspects of life. Having poor health can put an exorbitant amount of physical, mental, and social stress on the individual and prevent them from participating fully in the daily activities of life that most take for granted. With poor health, opportunities may ultimately become limited and one's goals may become quickly out of reach. Since health is so central to a person's ability to flourish, health care decisions are extremely weighty and should be guided by strong ethical principles and a commitment to justice. Significantly, a commitment to justice necessitates equal concern for all individuals regardless of their individual characteristics, like race, gender, social status, sexual orientation, and other factors. This requirement for equal concern relies on the position one takes in society and the obligations that fall under that title. In the health sphere, the government has this duty to all of its citizens and medical professionals have this duty to all of their patients.

These duties that the government and the healthcare industry have are tested regularly due to one simple fact: need tends to strain the available resources. Thanks to the increasing age of population, the increasing costs of technological advances, and the cultural push towards more treatment, health care resources cannot possibly meet the ever-increasing needs fully. This strain on resources creates an ethical dilemma: if everyone in a society deserves equal concern from the government and health care professionals, what is the best way to allocate the limited resources that we have?

The approach of the health economist, which is also often used in policy-making, is a utilitarian one that aims to increase the 'greatest happiness of the greatest number.' Consequently, the focus of the health economist is increasing the overall health of the population as much as possible, concentrating on improving people's life expectancy and the quality of their life. This consequence-based approach to solving the issue of immense resource demands aims to enhance allocative efficiency and decrease opportunity costs. Economic evaluations, such as cost-utility analyses, are an essential tool for increasing efficiency in health care decision-making. The most widely used cost-utility analysis is the Quality-Adjusted Life Year, which assesses utility using quality of life and life years.

In the calculation of QALYs, 'quality of life' implies worth or goodness for something that is extremely subjective. Utility measures, such as rating scales, standard gamble (SG), the time trade-off (TTO), and Rosser's Classification of Illnesses, attempt to quantify quality of life, but the methods by which they do so cannot result in an accurate evaluation of quality of life since the notion of a good life varies from person to person. Moreover, the calculation of life years remaining suggests that years gained necessarily correlates with worth. However, elderly or those with fatal health conditions are then neglected since they could gain less in life years than other patients. When we get too bogged down in the numbers, we lose sight of the individual and we devalue life, resulting in discrimination against certain groups of people. Ultimately, with the purely utilitarian approach to the allocation of healthcare resources, health care becomes about improving numbers more than about providing quality care to real people.

Chapter 2: Deontological Ethics Prioritizing the Duty to the Individual Patient

Introduction

With the downfalls of the utilitarian approach being explored in the context of healthcare decision-making, I now turn to Kantian deontology. I begin this chapter with a case study called 'the Case of Child B' to further illustrate the importance of recognizing individual patients before delving into a discussion of morality and deontological ethics. With duties and rights being central to the Kantian approach, I then provide a fuller discussion of how central duties are to the provision of healthcare. The relationship between duties and rights is then explored, as rights are central to reaffirming duties in a healthcare system. I then discuss the centrality of trust in the doctor-patient relationship and how a lack of trust compromises not only the doctor-patient relationship but also the patients' relationship with the entire healthcare system. With trust at the center of quality care, there is necessarily a focus on the individual patient that I explore in the next section. Though the deontological approach importantly focuses on the individual, it is unrealistic to believe that everyone can always receive all the care they could ever need. However, duties are absolute in deontology. As a result, I ultimately argue that the deontological approach is insufficient for guiding resource allocation as it does not offer any guidance when duties conflict.

The Problem of Supply & Demand for Individuals: The Case of Child B

Although resource allocation is inevitable, the public often becomes enthralled in cases of rationing in health care. One prevalent example of a case of resource allocation in England that

took the media and thus the public by a storm is known as the Case of Child B.²⁹ Having recovered from acute lymphoblastic leukemia when she was just five years old, Jaymee Bowen was 10 years old when she received a second cancer diagnosis of acute myeloid leukemia.³⁰ Her pediatric oncologists told her father, David Bowen, that Jaymee had only eight weeks to live and that they would only recommend palliative care at that point since the only possible treatment had little chance at success and had high costs.

David Bowen refused to accept the prognosis and the recommendation of palliative care, seeking out medical advice from doctors across the United States and Britain. Eventually, he found the medical support he needed to seek out the treatment; however, the health authority, the Cambridge and Huntingdon Health Commission, refused to cover the costs of the treatment. David Bowen then took this decision to the High Court in Britain, but the results did not end up as he had hoped. On March 10, 1995, the High Court ruled that the Cambridge and Huntingdon Health Commission should reconsider funding Jaymee's treatment, but later that same day Appeal Court judges overturned the High Court's ruling. Jaymee's chemotherapy and bone marrow transplant would not be paid for by the NHS.

Although the details of the case were sometimes obscured or skewed by the media to stir public interest, the Case of Child B shows how members of the public grow deeply emotional about issues of resource allocation in health care. Rationing in health care is a deeply polarizing issue and, in the case of Jaymee Bowen, the public often felt that the NHS, unwilling to pay the cost of the treatment, had sentenced her to death. In fact, the *Sun* published a newspaper editorial titled "Condemned by bank balance" the day after the Appeal Courts' ruling that posed the

²⁹ John Carrier Lecture, SOC 390

³⁰ Ham, "Tragic choices in health care: Lessons from the Child B Case," 1258

question "What state is this country in when a girl's right to life hinges on the size of a hospital bank balance?"³¹ That same day the *Daily Mirror* wrote, "Money is everything in health care today... A child's life now is worth only what a health authority's accountants are willing to pay for it."³² Editorials like these stirred public interest so much that an anonymous donor stepped forward to pay for Jaymee Bowen's treatment, which allowed her to live longer than any of the doctors had predicted.

After Jaymee's doctors declared that she was in remission from the acute myeloid leukemia, her father sought to publicize the case even more to continue to fundraise for more treatment and lifted the identification ban. The world then learned the girl called Child B was really Jaymee Bowen and a face was also put to the newly learned name. Many that followed the Case of Child B could not help but feel for the 10-year-old girl in the picture, but were they right? Was the NHS really putting a price on the life of a child? Should the needs of an individual really outweigh those of an entire population? This case provoked such emotional responses from the public because many believed that the 10-year-old girl in their newspapers was betrayed by their government, who had a duty to provide her quality care. The public feared that Jaymee's case had shown that the NHS had lost sight of the individual and was devaluing life unfairly thanks to its utilitarian approach.

Deontological Ethics & Morality

Arguments concerning resource allocation rely on a deontological approach as they make claims about a person's rights. Opposite of utilitarianism, deontology is a philosophical approach

³¹ Entwistle et al, "Media Coverage of the Child B Case," 1588

³² Entwistle et al, "Media Coverage of the Child B Case," 1588

that focuses on the intentions of an action more so than the consequences of that action. Kantian ethics rely on the idea that human reason serves as the source for the laws of nature and the moral law and it guides all humans in the way that they interact with one another. In fact, Kant believed that, through logical deduction, humans can discern the rational duties that they have to one another. These duties are universal since all people are inherently worthy of respect, and dignity in his view. Thus, the morality of an action lies entirely in whether or not it fulfills these duties. As a result, an action can be morally right even if there are poor outcomes: as long as the action that caused the poor outcomes was based on a moral duty, then the action is right. Conversely, no matter how morally good the consequences of an action, some choices are forbidden by these duties. Regardless of the circumstances, we are all duty-bound to one another under this view.

Kant's view of deontological ethics is sometimes specified as agent-centered deontology, focusing on the duties of the agent rather than rights of the victim or patient.³³ Central to agent-centered theories of deontology is the idea of agency. An important distinction to help emphasize the importance of agency is the difference between ethics and morality. Though they are often used interchangeably, morality is determined personally, while ethics tends to refer to a set of standards for right and wrong that guide groups, like communities or social settings. This distinction is essential to understanding agency: since morality is more personal than ethics, the individual is inclined to maintain their moral integrity. As a result, categorical imperatives force us to concentrate on having good morals in our own agency, rather than focusing on how our actions lead to others doing morally wrong. Under an agent-centered deontological theory, both

³³ Alexander and Moore, "Deontological Ethics."

sides of a relationship have both permissions and obligations that provide agent-relative reasons for action.

Duties in Healthcare

In healthcare, duties are central to provision of quality care. Since health is incredibly personal and central to a person's ability to engage in everyday activities and achieve their goals, patients are approaching health care providers from a place of vulnerability. The patient *needs* the help of the doctor in medical situations and trusts the doctor to treat them to the best of their ability. Thus, obligations arise from the trust being placed in the doctor that has been recognized throughout history in various ways to assure the patient that their trust is not misplaced. For example, the Hippocratic Oath, or a similar version, has been taken by medical professionals for centuries as a vow that they will fulfill their duty to "do no harm."³⁴ The American Medical Association published a Declaration of Professional Responsibility outlining the duties that a healthcare professional has to their patients and society as a whole. The Preamble asserts that physicians must come together across differences and reaffirm their commitment to the duties of a physician with "humanity as [their] patient."³⁵ Additionally, the language of 'duties' repeatedly appears in health care legislation, especially within the NHS, as seen through the Duties of Care and Candour and the Health and Social Care Act of 2012.

The duty of care requires that healthcare professionals provide the care their patients need to prevent unreasonable harm or loss. For example, a case is currently being made by the relatives of two men who died from COVID after being moved from hospital to care homes.³⁶

³⁴ Encyclopædia Britannica, "Hippocractic Oath."

³⁵ American Medical Association, "Declaration of Professional Responsibility."

³⁶ John Carrier, NHS Services Lecture

They argue that the healthcare providers that transferred their relatives violated the duty of care.³⁷ The duty of candour promotes openness and honesty in health care. It states that healthcare professionals *must* be open and honest with their colleagues, patients, and regulators and encourage their peers to be open and honest.³⁸ They must participate in investigations and reviews, promote learning and improvement, inform the patient of any incidents, apologize for them, and offer a remedy for the problem.³⁹

In 2012, the UK passed the Health and Social Care Act of 2012, which outlined eight duties related to the goals of the duties of candour and care. This act required the secretary of state to provide a comprehensive, quality service per the NHS constitution.⁴⁰ The secretary of health must reduce inequalities, promote research, review training, and report/review treatment given.⁴¹ This act ensures that patients have more input in their care as it promotes openness and quality of care. These duties serve as ethical guides for healthcare professionals and government officials that are in positions where they have to make decisions about health care resources. They have an obligation to the people that they are supposed to be serving or caring for.

The Right to Healthcare

Duties in healthcare are further upheld by the language of rights. The agent-centered duties have a flipside in the rights of the patient. The obligation of the healthcare professional and policymaker to the individual flows from more than just the trust of the patient when a healthcare system recognizes healthcare as an unalienable right. When duties to health and health

³⁷ John Carrier, NHS Services Lecture

³⁸ John Carrier, NHS Services Lecture

³⁹ John Carrier, Quality Assessment and Clinical Governance Lecture

⁴⁰ Carrier and Kendall, 247-258

⁴¹ Carrier and Kendall, 247-258
care are reaffirmed by rights language, these duties are undeniably absolute. Many political philosophers recognize equal concern as a right more generally; however, based on Scanlon's equal concern the right to equal concern creates duties contingent on the role of the agent– in this case, medical professionals and policymakers must show equal concern to the patients they are responsible for assuring quality care. Rights language has also been used more explicitly by various governments and healthcare organizations to reassert the obligation to the patient.

As previously discussed, T.M. Scanlon discusses the duties that people have to one another in his work *Why Does Equality Matter*? To Scanlon and Ronald Dworkin, equal concern is a natural right. Following social contract theory, governments are able to exercise their power because the citizens in their political community have agreed that they will give up some rights for the benefits that a government can provide. Through this tacit agreement, the citizens agree to be ruled. However, Scanlon also believes that governments take on an obligation to provide benefits for all of its citizens: the government must show equal concern for all of its citizens. He believes that this duty of equal concern exists throughout society on smaller scales based on the position a person occupies: it would be impossible for all individuals to have equal concern for everyone, so it must be based on the role a person occupies with the role creating particular obligations. For example, parents should show equal concern for all of their children. In the case of government officials and healthcare professionals, Scanlon would argue that they are obligated to show equal concern for all that they serve or care for.

Beyond the natural right of equal concern, rights have been outlined in line with ethical principles commonly understood as central to providing effective care. At the International Health Conference in New York in 1946, the idea of the World Health Organization was conceived along with a constitution governing the organization.⁴² 26 governments came together under the World Health Organization recognizing the benefits that the organization would have in stabilizing their own nations. Without a standard of health, care, and access to care, governments could easily face destabilization, but, by coming together and establishing the language of the right to health, would help these 26 nations avoid it. The founding of the World Health Organization in 1948 then coincided with the creation of the Universal Declaration of Human Rights, which was proclaimed by the United Nations General Assembly. These two documents created a web of rights language that did not allow for the violation of human rights in the health sphere.

In the preamble of the Constitution of the World Health Organization, the committee states that principles on which the constitution and the WHO is built on. They begin the constitution by stating that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."⁴³ The preamble delves into various principles on the promotion of health, ultimately declaring that its member states have an obligation to support and contribute to the health of its people through health care because of this right.

Similarly, in the American Medical Association Code of Medical Ethics, a section is devoted to defining health care, noting how it "affects our opportunity to pursue life goals, reduces our pain and suffering, helps prevent premature loss of life, and provides information needed to plan for our lives."⁴⁴ The Code goes on to explain that providing an "adequate level" health care to all its members is an obligation of the society regardless of the individual's ability

⁴² "The Preamble of the Constitution of the World Health Organization," Frank P. Grad, 981

⁴³ Constitution of the World Health Organization, 1

⁴⁴ American Medical Association Code of Medical Ethics

to pay. As a result, the AMA's Principles of Medical Ethics (2001) begins by declaring that "a physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights."⁴⁵ Interestingly, the government of the United States, unlike the United Kingdom and all other industrialized nations, does not recognize the right to health and health care as a human right or even as a goal of universal coverage. However, governing bodies within the medical profession, such as the AMA, have recognized health care as a right.

Alternatively, the United Kingdom's National Health Service was founded on the ideas outlined in William Beveridge's 1942 report titled "Social Insurance and Allied Services." Central to the creation of the NHS is the idea that health and health care is a human right. Now referred to as the Beveridge Report, "Social Insurance and Allied Services" detailing his plan for social services in post-war Britain. Following the Second World War, the government should focus its efforts on eliminating what Beveridge calls the 'Five Great Evils': Want, Disease, Ignorance, Squalor and Idleness. In more modern terms, Beveridge means the government should focus on the provision of education, social insurance, increasing employment, and creating a national health service. Ultimately, these 'Five Great Evils'– and not just the national health service– are all weighty factors in a society's health. In other words, the United Kingdom's post-war push for Beveridge's proposed social services recognized the fuller definitions of health and health care outlined in the Constitution of the World Health Organization.

By using right languages to describe health and health care, the WHO, the AMA, and the NHS reaffirm the duty to patients. Rights create relational duties. If every individual patient has a right to receive quality health care, health care professionals and policymakers have a duty to

⁴⁵ "The Code of Medical Ethics of the American Medical Association," Frank A. Riddick, Jr, MD, 9

care for every patient and help fulfill their rights based on their position in the healthcare system. Importantly, the United States government itself does not recognize the right to health and health care in any of its governing documents. However, various governments and health care organizations have used rights language surrounding health and healthcare to maintain the health care systems' obligation to the individual.

The Doctor-Patient Relationship

The doctor-patient relationship is a fragile one that must have mutual trust.⁴⁶ The doctor undertakes an obligation to the patient because of the law or simply by the function of being a doctor. The patient exposes themselves to risk at the hands of the doctor and must therefore trust the doctor with their lives. With the health and wellbeing of the patient at stake, the trust required for this relationship is unique from other professional relationships. Moreover, even if a patient has trust in their particular doctor, they may lack confidence in the overall system of which the doctor is a part. This lack of trust in the system is common; in fact, as of July 2000, "only four in ten Americans surveyed for one poll reported having a lot or a great deal of confidence in 'the medical system.'"⁴⁷ As a result, there are many factors that could hinder a successful doctor-patient relationship or more generally a patient's experience with the healthcare system as a whole.

The economic context in which the relationship occurs may affect the trust that the doctor will fulfill their duty to the patient.⁴⁸ In a highly capitalistic society with for-profit health care, the doctor may have ulterior motives for choosing particular interventions, or the patient may be

⁴⁶ Hoppe, 'Medical Ethics and Patient Safety', 59.

⁴⁷ Committee on Quality of Health Care in America, Crossing the Quality Chasm, 46

⁴⁸ Hoppe, Nils, Medical Law and Medical Ethics, 70

concerned that the doctor has ulterior motives. For instance, some American doctors have been known to over-investigate problems, provide unnecessary referrals, and push patients towards surgical interventions over less profitable treatment options to increase profit. In an analysis of patients' trust in health care providers and patient satisfaction with the quality of care, it was shown that "the rising cost of medical care threatens a vital aspect of the effective delivery of medical care– patient trust in their physician and continuity of care."⁴⁹ With high costs for care, not only the patients trust in their specific provider, but also the healthcare system as a whole can be compromised.

The legal context of the relationship may have similar repercussions as the doctor may fear legal consequences and act out of an abundance of caution to protect themselves rather than provide the best care for the patient.⁵⁰ In fact, Mason and McCall Smith discuss the effects of defining the doctor-patient relationship in legal terms:

There is no doubt, too, that the defining of a relationship, such as that of doctor and patient, in legalistic terms leads to a subtle but important change in the nature of the relationship. Trust and respect are more likely to flourish in one which is governed by morality rather than by legal rules and, no matter how appropriate the law may be for the regulation of many of the other ordinary transactions of life, the injection of formality and excessive caution into the relationship between doctor and patient cannot be in the patient's interest if it means that each sees the other as a potential adversary.⁵¹

⁴⁹ Cunningham, "High Medical Cost Burdens, Patient Trust, and Perceived Quality of Care," 415

⁵⁰ Hoppe, Nils, Medical Law and Medical Ethics, 70

⁵¹ Mason and McCall Smith, *Law and Medical Ethics*, 16

To maintain the duty-based relationship between the patient and the doctor, trust must be established and maintained. The patient must feel as though they can speak openly with the doctor and truly believe that their doctor has their best interest in mind as the doctor makes decisions about their care. For the doctor-patient relationship to result in the effective care that is deserved by the patient, medical professionals must fulfill the duties that they have to their patients as individuals, building trust with the patient. Thus, if the government or economic system within which a doctor practices will not provide the resources needed for an individual to have the care they want, the doctor-patient relationship can easily be compromised.

Individualism & Autonomy

When actions and decisions are guided by duties, the individual is often prioritized over the 'common good.' As medical professionals work to build trust in the relationship, there is necessarily this focus on the individual that is central to providing effective care. When a health care professional recognizes the patient's individuality, the patient's personality is understood as important to who they are and the care they should receive. Additionally, the patient's past, present, and future are imperative to the patient and should also be seen as critical by the medical professionals. Recognizing individuality in health care allows the patient to become more than just a number as with approaches to health economics.

A charity known as 'Alive' based out of Bristol works to make sure that patients' individuality is acknowledged as they receive end of life care. Alive encourages residents in end of life care to engage in meaningful activities in which they share their life histories with one another. Their vision is "a world where older people live lives full of joy, meaning and connection.³⁵² Their hope is that by working "to prioritise health and wellbeing into later life," they can help prevent care homes from sticking residents in front of a television to sit there depressed in silence.⁵³ Alive recognizes that health is more than just about receiving basic medical care since a person's health relies on finding a balance between their physical, mental, and social well-being. Without recognizing a person's individuality in their medical treatment, healthcare providers cannot attend to the needs of the patient– particularly their mental and social needs. Initiatives like those taken by Alive that work to recognize the individuality of the patient are therefore critical to the pursuit of patients' health.

Having established that it is essential to treat patients as individuals, I return to one of the central tenets of the medical profession's guiding ethics: autonomy.⁵⁴ A patient has autonomy when they are able to make informed decisions about their care. Autonomy aligns with individualism as autonomy recognizes the worth and dignity of every individual as well as their right to make decisions about their own care with ample information on their health and their health care options.

The doctor-patient relationship and the health care system as a whole should respect the individuality of the patient. In respecting the individual, the health care system can help preserve the autonomy of the patient in making health care decisions. As previously mentioned, the individual's experience of health and well-being is different from person to person. Everyone also all has different understandings of what 'quality of life' entails. When the individual is recognized and given more autonomy in the provision of their care, their personal experiences and understanding of health and quality of life are able to inform the decisions that are made

⁵² Alive Activities, "About Alive."

⁵³ Alive Activities, "Our History."

⁵⁴ Karen Hegtvedt, Justice & Health, July 24 2022

regarding their care. When a patient feels as though they are being respected as an individual and has autonomy in their care, they are receiving patient-centered care.

Quality Care for All Costs

As we have established, the medical profession is founded on a commitment to the individual patient. Trust is established in the doctor-patient relationship through the obligations of medicine. However, the commitment to the individual in medicine is often "at odds with the egalitarian codes of the broader system."⁵⁵ While dealing with limited resources, how can we realistically always expect every patient to always be considered individually by the health care system? How can the health care provider fulfill their duty to each one? Although Kant himself declared that "a conflict of duties is inconceivable," the strain on resources evidently possesses an issue for fulfilling all duties in health care.⁵⁶ As the individualist perspective affords the patient with more agency, "the rise of consumerism has given birth to a new, more demanding and more articulate patient with greater awareness of their rights and entitlements."⁵⁷ With increased patient demands and the cost of healthcare and health care innovation, it is unrealistic to believe that we can always fulfill everyone's health care needs regardless of cost or resources required.

To illustrate, I turn to the struggles and backlog experienced by the United Kingdom, which was exacerbated by the COVID-19 pandemic but continues to this day. The British Medical Association published an "NHS backlog data analysis" in January 2023 that highlights the growing backlogs across the National Health Service in the U.K. The NHS, more than many

⁵⁵ William et al, Rationing in Health Care : The Theory and Practice of Priority Setting, 16

⁵⁶ Kant 1780, p. 25

⁵⁷ William et al, Rationing in Health Care : The Theory and Practice of Priority Setting, 16-17

healthcare systems, is built on duty-based language, which I will return to in the following chapter. Despite the fact that the NHS Constitution stipulates a duty to provide patients with services within maximum waiting times, the backlog situation has become especially dire since the start of the pandemic.

Figure 1⁵⁸



Source: BMA analysis of NHS England Consultant-led Referral to Treatment Waiting Times statistics • The data includes estimates for missing data.

According to the BMA, there is a record amount of patients awaiting treatment and clearing the backlog will take years.⁵⁹ In February 2020 prior to the pandemic, there were already 4.43 million patients waiting to receive care. As of December 2022, the waiting list had grown to about 7.2 million people (Figure 1). Not only are there more people on the waiting lists,

⁵⁸ The BMA. "NHS Backlog Data Analysis."

⁵⁹ The BMA. "NHS Backlog Data Analysis."

but also waiting times have increased exponentially as a result. In December 2022, 3.1 million of the 7.2 million patients waiting for care had to wait over 18 weeks, which is also a record high (Figure 2). Additionally, 406,035 patients were waiting over a year for treatment – "which is around 239 times the number of people waiting over a year pre-pandemic in December 2019."⁶⁰ These astounding numbers do not include the hidden backlog of patients that have slipped through the cracks that have not sought care, canceled appointments, or have not been able to schedule appointments due to the pandemic. All of the statistics overwhelmingly show the same thing: a health care system cannot always fulfill all of its duties to all of its patients equally.

Figure 2⁶¹



Percentage of patients waiting over 18 and 52 weeks for consultant-led elective care August 2007 to December 2022

Source: <u>BMA analysis of NHS England Consultant-led Referral to Treatment Waiting Times statistics</u> • The data includes estimates for missing data.

BMA

⁶⁰ The BMA. "NHS Backlog Data Analysis."

⁶¹ The BMA. "NHS Backlog Data Analysis."

Therein lies the issue with solely using the deontological approach in the allocation of healthcare resources. Importantly, the obligation to every patient is recognized, but what happens when a choice must be made between various obligations? Kantian ethics "cannot tell me which duties I should prioritise over others, as all my duties are absolute."⁶² Since all humans are inherently worthy of respect and dignity, all of our rational duties between humans are universal under Kant's view: to be morally right, you must fulfill these duties no matter what regardless of the circumstances. Kantian deontology therefore cannot be a reliable means of determining how resources should be allocated in a healthcare system.

Conclusion

The Case of Child B presents an uncomfortable ethical dilemma that implies to some that the government can decide the worth of a child's life. The utilitarian approach can easily elicit these feelings since the person and the worth of life must be quantified with the main goal of efficiency. The individual patient is quickly lost under this view. However, using deontological ethics that focus on the intent of the agent– in this case the doctor but also society as a whole– rather than the result of the action combats this issue. In fact, the consequences of the action are irrelevant to the moral goodness of the action: if the action was based on moral duties, the action itself must be morally good. Since Kant regards all humans as deserving of dignity and respect, the moral duties that people have to one another are universal and absolute. As a result, if a person does not fulfill their duties to others, their actions are wrong regardless of the circumstances– even when forced to pick between multiple duties.

⁶² David Misselbrook, Duty, Kant, and Deontology.

Duties are central to the running of a health care system as patients seek out care from a place of vulnerability. The patient *needs* help from a medical professional and by seeing a doctor they are placing their trust in that doctor. The obligation to the patient derives from the trust that the patient puts in the medical professional. Various oaths and declarations of obligations to the patient have been used throughout history to affirm the responsibility to the patient, including the Hippocratic Oath, the American Medical Association's Declaration of Professional Responsibility, and, within the U.K.'s NHS, the Duties of Care and Candour and the Health and Social Care Act of 2012. These oaths and declarations attempt to help maintain the duty to the patient as central to the provision of health care. Similarly, rights language, as with declarations of obligations, can help to reassert the duties owed to an individual. Duties in a healthcare system can flow from the rights of a patient when the right to health and health care are recognized.

The relationship between the patient and their healthcare provider is unique as it requires so much trust. Economic and legal contexts may prevent trust from being established, leaving the doctor-patient relationship compromised. Nonetheless, when a health care system works to maintain the trust between a patient and their providers, the individual is much harder to disregard. The focus on the individual and the relationship with that individual forces the health care system to see the patient as more than just a number as with utilitarian approaches used in health economics. Organizations like the charity 'Alive' recognize the importance of acknowledging the individuality of the patient in providing care by focusing on more than just the physical well-being of their patients. Health care systems should work to include more initiatives like those taken by 'Alive' so that the duty to the individual is fulfilled. Recognizing the individual should also be taken one step further with the principle of autonomy as autonomy does not just the worth and dignity of every individual but also respects the individual's right to make decisions about their own care.

With the cost of providing high quality care to all, it is unrealistic to believe that everyone's health care needs can be fulfilled all the time regardless of cost or resources required. However, agent-centered deontology is absolute: it does not allow for picking between responsibilities when all of them cannot be fulfilled simultaneously. To illustrate, I described the strain on resources during the COVID-19 pandemic experienced by the largely duty-based National Health Service of the United Kingdom. Agent-centered deontology cannot help decision-makers in the NHS decide how to allocate resources, because the only right course of action occurs when everyone satisfies all their obligations which is impossible with such an immense strain on healthcare resources. To maintain this commitment to the individual patient while realistically being able to make decisions between different duties, agent-centered deontology cannot suffice. Rather a different ethical approach must be taken to making decisions of health care resources allocation that relies on something other than absolute duties.

Chapter 3: The Ethics of Compassion

Introduction

In light of the shortcomings of both ethical approaches taken in the first two chapters, in this chapter I seek a different means for determining how healthcare resources should be allocated. Instead of deontology and utilitarianism, I argue for the Dalai Lama's ethics of compassion which blends aspects of consequentialism, deontology, and Aristotelian virtue ethics into an ethical theory of its own kind. I describe two facets of this ethical approach, its reliance on practical wisdom and gradualism, which make it best suited for deciding how resources should be ethically allocated. Next, I outline the value of compassion and patient-centered care, describing the importance of compassion in the doctor-patient relationship and the provision of high-quality care. Though many argue that providing compassionate and patient-centered care can be too costly, I show that it can increase efficiency and help to limit waste. The next section of this chapter focuses on the effects of compassion on the practitioner- in this case the healthcare provider. Using the Dalai Lama's discussion of the interdependence of all humans, I describe how the health outcomes of the patient correlate with the well-being of the medical professional. As a result, I describe the possible positive effects that instating compassion training in medical settings could have both on the quality of care and the well-being of medical professionals. Lastly, I discuss how compassion can and should be implemented on a large scale, using the work of Dr. David Addiss of the Focus Area for Compassion and Ethics at the Task Force for Global Health. Ultimately, I show that on both the micro and macro levels, the ethics of compassion should guide healthcare decision-making, especially in decisions of resource allocation.

The Ethics of Compassion

Since utilitarianism and deontological ethics are too rigid to effectively assist in making healthcare decisions, I now turn to a different ethical approach that is far more fluid. Through his Buddhist teachings, the Dalai Lama has created a secular ethical approach that has been labeled by different scholars as deontological, consequentialist (like utilitarianism), and similar to virtue ethics. However, as discussed by Abraham Velez de Cea in "The Dalai Lama and the Nature of Buddhist Ethics," the ethical theory presented by the Dalai Lama is "irreducible to clear-cut versions of consequentialism, deontological, or Aristotelian virtue ethics."⁶³ As a result, the Dalai Lama's ethical theory is of its own kind, entirely separate from the previously discussed ethical approaches.

The Dalai Lama's ethical theory consists of three kinds of ethics: the ethics of compassion, the ethics of restraint, and the ethics of virtue. When an action is undertaken with the goal of avoiding harm to others, this is called an ethical action. Conversely, when an action is motivated by spiritual qualities, like love compassion, patience, tolerance, etc., this is referred to as a spiritual act. Importantly, spiritual acts are what give our lives meaning, according to the Dalai Lama. The ethics of restraint occurs when ethical actions are performed, while the ethics of virtue involves the development of spiritual acts. Ethical acts and spiritual acts work together to produce lasting and genuine happiness. Lastly, ethics of compassion are developed by the ethics of restraint and the ethics of virtue and serve as "the necessary foundation and motivation for both restraint and cultivation of virtue."

The Dalai Lama discusses the importance of 'great compassion,' which is an unconditional form of compassion that applies to all individuals. To the Dalai Lama, everyone

⁶³ Velez de Cea, "The Dalai Lama and the Nature of Buddhist Ethics," 535.

should aim to achieve great compassion; however, great compassion serves as an ideal and is not a requirement for leading an ethical life. In order to develop ordinary compassion into great compassion, the practitioner must undergo a long process of practicing ethics of restraint and ethics of virtue in the form of ethical and spiritual acts.

The strength in this theory lies in its reliance on practical wisdom rather than absolute precepts. Similar to the consequentialist, the Dalai Lama argues that in most cases we can rely on precepts and the goal of limiting harm to others. However, this ethical system rejects the strong codifiability thesis. In the Dalai Lama's words, "there can be no general rule in respect to this [ethical dilemmas]. Rather, there is likely to be a multiplicity of competing considerations, which we must assess in the light of reason and compassion."⁶⁴ When applying practical wisdom to determine whether an act is ethical or not, the Dalai Lama takes into account various other factors, including "the intent or end of the act, the nature of the act itself, its time, circumstances, the extent to which the act is free or voluntary, and whether it is an isolated act or the expression of a pattern."⁶⁵ Since this ethical theory takes into account various factors, unlike the deontological and utilitarian approaches, it can far more effectively apply to hard cases, which often occur in issues of healthcare.

Additionally, the Dalai Lama's ethical approach can be applied effectively to resource allocation because it only asks of the practitioner to do what they can according to their limitations and circumstances. Because finite resources are such a limiting factor in deciding what care individuals should receive, this gradualism based on the means of the practitioner makes this ethical theory apply better to the issue of resource allocation far better than deontology and utilitarianism.

⁶⁴ The 14th Dalai Lama, Ethics for the New Millenium, 154

⁶⁵ Velez de Cea, "The Dalai Lama and the Nature of Buddhist Ethics," 507.

Some argue that this ethical theory created by the Dalai Lama is too ambiguous— that it is far too unclear the actions that should be taken in any given circumstances. However, other ethical approaches that provide hard and fast rules to complex moral questions are unable to account for the multiplicity of competing factors that should be taken into account. As Velez de Cea explains, the Dalai Lama's ethical theory is "subtle and defies simplistic dilemmas such as the dilemma between absolutism and relativism, or between agent-relative and agent-neutral ethical theories." With its reliance on practical wisdom, this theory is best suited to help make ethical decisions on healthcare resource allocation thanks to its ability to take into account individual circumstances and the limitations of the practitioner.

Compassion & Patient-Centered Care

Compassion should be one of the main values that guides the provision of healthcare. Often incorrectly used interchangeably with empathy, compassion has three main elements. Firstly, compassion requires awareness both of the patient and the self. The healthcare provider should be aware of the patients' suffering, regardless of whether it is physical, mental, social, and spiritual. They should also be honest with themselves about their motives, biases, and other internal factors that might affect the care they give. The second aspect of compassion is empathy: the physician should work to imagine the suffering of the patient and be able to resonate with them. Lastly, having compassion requires a commitment to take the action required to alleviate the patient's pain, whether that be physical, mental, social, etc. David G. Addiss explains that "compassion arises from a sense of shared humanity, from solidarity, respect and a profound awareness of interconnectedness."⁶⁶ When compassion is central to healthcare, the patient receives the dignity and respect they deserve as individuals.

⁶⁶ Addiss, "Compassion in Disasters."

To show how patient's experience compassion from their healthcare providers, Sinclair et al. empirically investigate compassion in healthcare from the patient's perspective. In their study "Compassion in Health Care: An Empirical Model," patients describe the ways they have experienced compassion in their palliative care with several noting that compassion is more than their physical, emotional, and spiritual needs being met.⁶⁷ Providers also showed compassion for their patients by expressing interest in understanding them and their needs and attempting to build relationships with them. The patient's responses outlining their experiences of compassion were separated into seven categories: virtues, relational space, virtuous response, seeking to understand, relational communicating, attending to needs, and patient-reported outcomes.

Compassion in healthcare is paramount because, when compassion is the focal point of all aspects of healthcare, patient-centered care can be achieved in which the patient is positioned at the center of their healthcare decisions. With the patient driving their own healthcare decisions, their values, preferences, and needs can better influence their care, resulting in increased quality of care and patient satisfaction. Patient-centered care also emphasizes a fuller definition of health, promoting physical health and the emotional, social, and spiritual dimensions of health. Evidently, central to achieving patient-centered care is the relationship between the patient and their providers so the patient's needs can be understood and they can comfortably make well-informed healthcare decisions. Thus, patient-centered care acknowledges the significance of both the patient as a multi-faceted individual and the relationships that are cultivated between the patient and the provider.

For a fuller picture of patient-centered care, I turn to Picker's Eight Principles of Patient-Centered Care.⁶⁸ In these eight principles, researchers from Harvard Medical School have

⁶⁷ Sinclair et al, "Compassion in Health Care: An Empirical Model."

⁶⁸ Picker Institute, "The Picker Principles of Person Centred Care."

outlined what they deemed to be the eight criteria for patient-centered criteria that provide a framework for delivering quality care that is patient-focused:

- 1. All patients should have access to quick and dependable healthcare.
- 2. All treatment should be effective and clinically appropriate and interactions with physicians, promoting a sense of confidence and trust.
- 3. When patients require numerous healthcare providers, the transitions between healthcare professionals should be smooth and coordinated, ensuring continuity of care.
- 4. Healthcare providers should acknowledge the importance of the patients' support network, including friends, family, and caregivers, and work to make them feel supported.
- 5. Physicians should clearly communicate with patients to ensure that they have accurate information to inform their decision-making and manage their care.
- 6. The patient's autonomy must be preserved, allowing them to make well-informed decisions about their own care.
- 7. The healthcare provider must recognize patients' emotional needs, treating them with empathy and respect.
- The patients' physical and environmental needs should also be met by the healthcare professional.

Evidently, central to these eight principles are relationships. Healthcare providers must prioritize the well-being of their patients and provide care that meets their needs holistically. In order to do so, healthcare providers must understand their patients' emotional, social, and physical needs and tailor their care accordingly. The healthcare provider must work to cultivate a relationship based on compassion to create trust and a sense of understanding between the provider and patient. When healthcare providers demonstrate empathy, patients feel heard, respected, and valued, which can create positive relationships that are essential for effective communication and better treatment outcomes. As a result, the World Health Organization has begun to emphasize the importance of providing people-centered health care, considering " compassion as essential for quality universal health coverage." To accomplish this, healthcare providers must be trained to develop empathy towards their patients, by practicing active listening, effective communication, and understanding their patients' perspectives. Healthcare providers to be self-aware, reflective, and open-minded to build empathy with patients, particularly as they aim to recognize their biases and work to overcome them.

As demonstrated, healthcare providers must be able to prioritize compassion in their practice to effectively care for patients; however, the provision of patient-centered care requires substantial resources. Building relationships with patients requires far more time and energy on the part of the physician, which is costly. However, since rationing is inevitable, economic efficiency is inarguably a crucial consideration in healthcare decision-making. By following the Picker Principles of Person Centred care, healthcare providers can build trust, foster effective communication, and ultimately provide better care to their patients. As a result, a focus on economic efficiency, though essential to running a healthcare system, cannot compromise compassion and trust in doctor-patient relationships. Thus, the key to finding the best way to allocate resources is creating a decision-making process that is able to reconcile patient-centered care with economic efficiency as much as possible, as the National Institute for Health and Care Excellence has tried to do.

Efficiency & Patient-Centered Care

Some argue that patient-centered care can be overly costly as it requires medical providers to invest more time and effort into the relationships they have with their patients. However, patient-centered care is not only ethical and compassionate, but when put into practice it also has economic advantages that make it a sound business strategy. Research shows that patients who are actively engaged in their healthcare experience better health outcomes and lower costs. In "The Value and Values of Patient-Centered Care," some of the demonstrated economic advantages of patient-centered care are listed. Various studies show that patients confident enough to actively engaged in their care:

- Are less likely to require an emergency room visit or hospital stay (Greene and Hibbard, 2012)
- Are more likely to adhere to treatment plans and manage their illness (Greene and Hibbard, 2012; Hibbard, Greene, and Overton, 2013; Remmers and others, 2009)
- Adopt healthy behavior changes (Harvey and others, 2012; Hibbard and others, 2007)
- Are associated with better health outcomes (Greene and Hibbard, 2012; Remmers and others, 2009; Skolasky, Mackenzie, Wegener, and Riley, 2011)
- Incur lower costs (Hibbard, Greene, and Overton, 2013)⁶⁹

Additionally, it has been shown that patient-centered care increases the effectiveness of healthcare, which helps patients avoid costly readmissions and further care. In these ways, patient-centered care improves cost-effectiveness as well as overall quality of care.

⁶⁹ Epstein and Street, "The Value and Values of Patient-Centered Care," 27.

Placing the patient at the center of their healthcare decisions also improves patient satisfaction, which has its own advantages from an economic perspective. When healthcare providers have increased patient satisfaction, they are likely to retain their patients and have a better reputation that encourages prospective patients to seek them out for care. For example, in the United States hospitals can become certified for providing patient-centered care, which could attract more prospective patients. Thus, in the competitive healthcare marketplace of the United States, patient-centered care can help providers set themselves apart from their competitors.

Overall, patient-centered care offers both ethical *and* economic advantages. As demonstrated, patient-centered care rightly prioritizes the needs and values of the patient, allowing them to have greater autonomy in their care. Providers must also show compassion and build trust in patient-centered care, improving the doctor-patient relationship. Patient-centered care often results in better health outcomes, lower costs, and greater overall patient satisfaction. Moreover, as healthcare organizations are striving to distinguish themselves from their competitors and maximize their market share, patient-centered care can be a powerful differentiating tool. As a result, patient-centered care is not only the most ethical approach to healthcare, but it can also serve as the foundation of a successful business strategy.

The Effects of Compassion on Healthcare Providers

The Dalai Lama discusses the interdependence of all humans in his work, *Ethics for the New Millennium*. Everyone is deeply connected and, therefore, what we put out into the world comes back and affects us. He argues that this interdependence is what serves as the ultimate rationale for compassion:

Because self and others can only really be understood in terms of relationship, we see that self-interest and others' interest are closely interrelated. Indeed, within this pic- ture of

dependently originated reality, we see that there is no self-interest completely unrelated to others' interests. Due to the fundamental interconnectedness which lies at the heart of reality, your interest is also my interest . . . It is in everybody's interest to do what leads to happiness and avoid that which leads to suffering.

Although many describe compassion as something that is given from one person to another, compassion is actually an interpersonal process. As previously discussed, the relationship between the patient and provider is central to the quality of care received by the patient. However, the well-being of the healthcare provider also directly correlates to the health and well-being of the patient. Thus, when the relationship between provider and the patient is characterized by compassion, the patient's health outcomes improve as well as the well-being of the provider.

Compassion Training

Often people discuss the human's innate sense of empathy for others. Thomas Jefferson, for example, declared, "Nature hath implanted in our breasts a love of others, a sense of duty to them, a moral instinct, in short, which prompts us irresistibly to feel and to succor their distresses...." To some extent, humans tend to naturally have and develop a sense of empathy throughout life without really working to develop it. However, as previously described, empathy is simply emotional resonance, whereas compassion is one step forward: empathy in action.

In emotionally intense settings, like healthcare, people can become paralyzed by their emotional resonance, and empathy sometimes falls short of compassion. At this point, healthcare professionals often experience compassion fatigue, burnout, and mental health issues, leading them to question their professions. Throughout the pandemic, healthcare professionals experienced these feelings at record highs, leading to a mass exodus from the healthcare system. As a result, there has been immense shortages of healthcare professionals both in the United States and the United Kingdom.

Mascaro et al describe this emotional weight that the medical profession can have on providers. Ironically, despite empathy and compassion being fundamentally important to establishing an effective doctor-patient relationship, "empathy declines precipitously during medical training and residency." In fact, medical students tend to experience higher rates of burnout, loneliness, depression, and suicidality than the rest of the population. Psychological struggles are associated with interpersonal deficits, which then further affects the quality of care provided to patients. Mascaro et al performed a controlled study on the Cognitively-Based Compassion Training (CBCT) in second year medical students to examine the effects of compassion training on healthcare professionals and quality of care. The students who took part in CBCT experienced "a decrease in loneliness and depression and increased compassion." As a result, the promotion of compassion throughout a healthcare system can lead to both increased health outcomes and well-being of all members of the system.

Implementing Compassion on a Large Scale

The importance of compassion has been emphasized in the practice of healthcare on a small scale– in the interactions between patients and providers. However, by implementing compassionate approaches to decide how resources should be allocated, compassion can occur on a larger scale. Dr. David Addiss serves as director of the Focus Area for Compassion and Ethics (FACE) at the Task Force for Global Health. FACE's mission is to "refocus our attention on the people behind health statistics by bringing compassion and ethics to the center of our work." Addiss aims to highlight the importance of using *both* compassion and ethics to improve

global health to avoid taking unsustainable action or losing sight of the whole person or the communities they are serving.

Many argue that decisions regarding public policy should be guided strictly by evidence and absent of emotions, like compassion, that could sway the decision-makers. Compassion, they say, "privileges the few whom we can see," so compassion should not play a role in public policy. However, Addiss proposes a different fix: "The answer to identified person bias is not to banish compassion from decision-making in resource-limited settings, but, rather, to expand the scope of compassion to include all persons..." That is, instead of allowing compassion to unjustly tilt policymakers in favor of one group over another, they should show compassion for all as best as possible.

As previously discussed, Dworkin and Scanlon's 'equal concern' requires that a person or organization have equal consideration for all of the people to which they are duty-bound based on their position. To take the idea of equal concern one step further, this equal consideration should involve equal *compassion* for all. Under this view, global health policy makers ought to have equal compassion for everyone that their policies govern. As described by Liz Grant at the Epidemiology of Compassion & Love conference in 2020, "Global health is a shared movement you have to have a shared heart and again compassion drives that shared heart."

Conclusion

The Dalai Lama's secular ethics effectively blends the valuable aspects of utilitarianism, deontology, and virtue ethics into an ethical theory of its own. Thanks to its reliance on practical wisdom and dependence on the limitations of the practitioner, the Dalai Lama's ethics are most suitable for determining how healthcare resources should be allocated. This ethics of compassion does not rely on hard and fast rules, like utilitarianism and deontology. Instead, the Dalai Lama

has shown "psychological depth and awareness of the complexity of the moral landscape" by creating an ethical theory that takes into account various relevant factors. This ethical theory should be used throughout the healthcare system, particularly in resource allocation.

Additionally, compassion is paramount to the functioning of the healthcare system on both macro and micro levels. I have shown that, when compassion permeates on the level of care, patient-centered care can occur, leading to improved patient outcomes and efficiency. Due to its status as an interpersonal process, compassion is not only central to the health and wellbeing of the patient but also that of the healthcare providers. As seen through the work of Dr. David Addiss, this extends to public health. As a result, compassion training throughout the healthcare system can help to improve various aspects of the healthcare system.

Chapter 4: Applying the Ethics of Compassion with NICE Towards Solving the Inconsistent Triad of Healthcare

Introduction

Following the introduction of the Dalai Lama's ethics of compassion, I begin by discussing the logician's "inconsistent triad," which has been used to describe the tension between access, quality, and cost. The question at hand is whether cost, quality, and access can all be achieved simultaneously following an existing clear cut ethical approach. To illustrate the difficulty of balancing these three aspects of care, I then delve into how the United States' healthcare system and the United Kingdom's National Health Service have sought a balance between access, quality, and cost. Following Albert Weale, I acknowledge that there is no clear cut solution to what many call the inconsistent triad of healthcare since we inevitably live in "a world of conflicting values."⁷⁰ I argue that, in deciding how healthcare resources should be distributed, absolute principles should be replaced by a hierarchy of social and cultural values, namely affordability, access, quality, and compassion. Using the National Institute for Health and Care Excellence as a model, I propose that healthcare systems should use decision-making processes that effectively follow the ethics of compassion, taking into account not only quality of care and cost-effectiveness, but also social values. Ultimately, I argue that NICE effectively replaces principles with process by accounting for cost, access, quality, and social values, while promoting transparency and compassion to preserve patient autonomy and the doctor-patient relationship.

⁷⁰ Weale, "Rationing health care: A logical solution to an inconsistent triad," 410

Access, Quality, and Cost: An Inconsistent Triad

The provision of high-quality comprehensive healthcare is a fundamental objective of any healthcare system. However, the challenge is how to achieve this goal while balancing the competing demands of access, cost, and quality. Providing comprehensive, high quality health care amidst ever-increasing costs is believed to present "an inconsistent triad; a collection of propositions, any two of which are compatible with each another but which, when viewed together in a threesome, form a contradiction."⁷¹ If cost, quality, and access are truly an inconsistent triad, then no more than two of the three objectives can be achieved simultaneously, but not all three at once.

As we have seen in the first two chapters, the trouble with balancing these aims in healthcare is not just a matter of balancing access, quality, and cost. Since the balancing of these aims has important ethical implications, ethical principles play a significant role in guiding how these are balanced in resource allocation. A purely utilitarian approach, as we have seen, can help to increase access in its mission to increase overall societal welfare; however, this comes at the cost of providing health care that affords the patient dignity as an individual in a care setting. Conversely, deontological ethics promote this sense of individualized care as it relies on the rights of the patient and the duties that flow from the physician to the patient. However, duties are absolute from the strictly Kantian approach, but resource allocation is inevitable. As a result, this approach is entirely at odds with the ideas of rationing and priority setting. Thus, the challenge for healthcare systems is to balance these competing ethical considerations while also addressing cost concerns.

⁷¹ Weale, "Rationing health care: A logical solution to an inconsistent triad," 410

Healthcare systems around the world struggle with creating a sense of balance between cost, quality, and access. The cultural values of a country impact decisions made in balancing these three aspects of care and, consequently, "every nation's healthcare system reflects its history, politics, economy, and national values."⁷² The United States and the United Kingdom have adopted approaches to creating a balance between cost, quality, and access in healthcare that are nearly polar opposite.

US Healthcare vs National Health Service

The US healthcare approach has several shortcomings, particularly in its complexity. Patients find the US healthcare system difficult to navigate, expensive, unreliable, and often impersonal. Care delivery processes are often overly complex, requiring steps and handoffs that slow down the care process and decrease rather than improve safety. The US healthcare system has three main features.⁷³ Firstly, the system is accidental. In fact, it is hardly a system at all since it was created over time without a comprehensive vision, leading to disorganization and inefficiencies in the system as a whole. Secondly, in the US healthcare is market-based, so the profit motive has a significant influence over the entire healthcare system. Lastly, the US government does not recognize health care as a human right, unlike all other industrialized nations.

As an example of how these factors have affected the evolution of American healthcare consider the creation of sickness funds for railroad workers and other dangerous professions in the 1800s. During WWII, FDR's National War Labor Board enforced wage controls but ruled that health insurance and other fringe benefits were not subject to these wage controls. As a

⁷² T.R. Reid, 2010

⁷³ Ellen Idler, SOC 390

result, employers could use benefits to compete for workers. Thus, from the beginning, access to healthcare has been somewhat tied to the individuals' occupation, which continues today. The market-based model is largely to blame for the lack of access. This model primarily allows access based on financial resources, and families of lower socioeconomic status can easily be left behind. Consequently, in the United States health care has become more of a privilege than a right.

Importantly, many still argue that the US healthcare system is the envy of the world, seeing it as incredibly innovative. The profit motive has fostered incredible medical discoveries and inventions with the help of specialists at academic centers. However, "what most people need is not the latest and greatest."⁷⁴ The incredible technology created by and for the US healthcare system, though life-changing for many people, has not proven to have a substantial impact on the population's health. The US spends an extremely excessive amount of money on health care, which does not correlate with the quality of care or an increase in the health of the population. After the Affordable Care Act passed, the number of uninsured Americans decreased dramatically, but as of 2020 30 million Americans remained uninsured, according to the National Health Interview Survey.⁷⁵ Ultimately, health care is not a human right in the United States as there are far too many issues with access, coverage, and care. Instead, the market-based model limits access, making health care a privilege shaped by the ability to pay.

Conversely, as mentioned in the previous chapter, the United Kingdom established its National Health Service in 1948 with the goal of providing all of its citizens high-quality comprehensive care in an attempt to overcome the 'inconsistent triad' of quality, cost, and access. To achieve this goal, the government-run NHS was founded with three main features: it

⁷⁴ Emanuel, *Reinventing American Healthcare*, 110.

⁷⁵ Finegold et al, "Trends in the U.S. Uninsured Population, 2010-2020."

is universal, free at the point of service, and financed through taxes. These elements have made the health service highly successful at times, though at other times it still struggles to balance the systems' needs for quality, access, and cost.

When Aneurin Bevan proposed a National Health Service, he understood the central mission of this new healthcare system as increasing access. As a result, the NHS provides care to all regardless of an individual's ability to pay for the services provided. In order to increase access, individuals pay little if at all for many health services. Instead, the government funds the healthcare system, through taxation and National Health insurance, which some argue cannot possibly provide enough resources.





The red line on the bar graph represents health spending per capita in the United Kingdom and the blue line represents health spending per capita in the United States.

⁷⁶ OECD (2023), Health spending (indicator).

As one might expect based on the NHS' government funding, health spending in the United Kingdom is in fact lower than the United States. The Organization for Economic Cooperation and Development (OECD) regularly publishes new data on the health spending of member countries that shows the discrepancy in spending between the two countries. As of 2021 the United Kingdom spent \$5,387 per capita, which is less than half that the United States was spending at \$12,318 per capita (Figure 1). Additionally, the United Kingdom's healthcare spending accounted for 5.9% less of their Gross Domestic Product than that of the United States (Figure 2). As seen through the OECD data, the government-funded NHS inarguably spends far less on healthcare than the United States.



The red line on the bar graph represents health spending as a total percent of GDP in the United Kingdom and the blue line represents health spending as a total percent of GDP in the United States.

⁷⁷ OECD (2023), Health spending (indicator).

Despite the substantial difference in spending, the United States' high spending does not translate to comparable improvements in health outcomes. For one, the morbidity and mortality rates between the two countries are similar. Additionally, as of 2020 the average life expectancy at birth in the United Kingdom was 80.4 years, which is actually 3.4 years higher than the United States' 77 years (Figure 3). As seen through the data on health spending and outcomes in the two countries, the overall efficiency of the NHS cannot be ignored.





The red dot represents life expectancy at birth for the United Kingdom, while the light blue dot represents life expectancy at birth for the United States.

⁷⁸ OECD (2023), Life expectancy at birth (indicator)

As seen through this efficiency, the NHS is relatively successful at balancing quality, cost and care. However, increasing access remains central to the mission of the NHS, so access is often prioritized over quality. As a result, cost containment has been a key issue for the NHS since its inception. Since it is largely government funded, the NHS only has access to fairly limited resources. To keep costs low, the government has employed various cost-containment efforts, including underfunding the system and rationing services. Rationing often occurs through waitlists for services, which can affect access to care. While cost containment is important, as we saw in chapter two it can also have unintended consequences such as limited access to certain services and longer wait times. Rationing and waitlists are often noted as the greatest shortcomings of the NHS.

A World of Conflicting Values

As evidenced by the healthcare systems of the US and the UK, the inconsistent triad in healthcare poses a significant challenge to healthcare systems around the world. In "Rationing health care: A logical solution to an inconsistent triad," Albert Weale discusses the tension between cost, quality, and access in healthcare, arguing that the best approach does not necessarily simply choose two of the three:

There is no single approach to addressing the inconsistent triad in healthcare. Instead, each healthcare system must find a balance that works for its unique set of circumstances... As Sir Isaiah Berlin said, 30 years ago, we live in a world of conflicting values where clearcut solutions cannot in principle be found. To suppose that we can escape this conflict of values by retreating

to an ideologically and organisationally simpler world casts a veil of deceit over the choices that must be made.⁷⁹

There is no single ethical approach that can fully address this 'inconsistent triad' in healthcare, but we cannot simply choose and focus on two of the three aims. It is important to recognize that following singular ethical approaches will always leave something to be desired in healthcare. Instead, the values that guide decision-making need to be prioritized and help to inform decisionmaking, but not as hard and fast rules. By acknowledging the importance of certain values, healthcare systems can blend positive aspects of the deontological and utilitarian approaches in decision-making to work towards achieving their fundamental objective of providing highquality comprehensive care for all.

A NICE Solution: The National Institute for Health and Care Excellence

At the end of 1997 the newly-elected Blair government in the UK announced the establishment of a 'National Institute for Clinical Excellence' that would be expected "to give a strong lead on clinical and cost effectiveness – drawing up new guidelines – and ensuring they reach all parts of the health service."⁸⁰ Despite being established by the government, NICE is an independent body that provides guidance on the use of health technologies and interventions in the NHS. Central to this mission was creating a transparent process by which recommendations could be made on treatments based on scientific evidence and cost-effectiveness. Transparency in the process helps to hold the decision-making body responsible for their conclusions and open

⁷⁹ "Rationing health care: A logical solution to an inconsistent triad," 410.

⁸⁰ Rawlins, "National Institute for Clinical Excellence: NICE works."

up the process up to critique, ultimately helping to affirm the validity of the final recommendations being made.

NICE recognizes the need for both high quality and efficient treatments, so clinical effectiveness is a key consideration in their decision-making, however, it is not the only criterion. In fact, on the NICE website, there is page outlining the guiding principles of NICE that provides two principles that are taken into account in their decision-making process: they aim to "use evidence that is relevant, reliable and robust" and "base [their] recommendations on an assessment of population benefits and value for money."81

Initially, the British Medical Journal editor Richard Smith left a scathing review of the institution, titled "The failings of NICE," that declared NICE was "living a double lie."82 For one, Smith argues that NICE refused to admit that they had anything to do with rationing. The other lie Smith cites is that initially NICE seemed to treat that the decisions being made were solely technical problems. Whether or not a treatment was made available seemed to rely entirely on whether or not there was sufficient evidence. As Smith eloquently put it, "the evidence supports decision making, but the evidence can't make the decision. The values of the patient or the community must be part of the decision.... Deciding where cost effectiveness ends is not a technical but an ethical judgement."⁸³

As expressed by Smith, social values are a critical factor relevant to these decisions that were initially absent from the decision-making process. How can one determine the benefit of a treatment without determining the social values that inform what benefit means? Realizing this fundamental shortcoming in their initial approach, NICE sought out a means of incorporating

⁸¹ NICE, "Who We Are: Our Principles."
⁸² Smith, "The Failings of NICE."

⁸³ Smith, "The Failings of NICE."
social values in their process.⁸⁴ Their solution was the Citizens Council, a demographically representative group of 30 people selected randomly tasked with determining social values that would "resonate broadly with the public."⁸⁵ For example, the Citizens Council helped to determine that "an additional adjusted life year is of equal value for each person," regardless of individual characteristics, like age.⁸⁶ By determining the social values of the public and attempting to incorporate them into their decision-making process, NICE takes an important step towards bridging the gap between the utilitarian and deontological approaches.

Over ten years after the founding of the National Institute for Clinical Excellence, the government passed The Health and Social Care Act of 2012 into law, which created the 'new' NICE. With the passing of this act, the National Institute for Clinical Excellence became responsible for the quality standards of the NHS as well as public health and social care in England. To reflect its new responsibilities, the institute was renamed the National Institute for Health and Care Excellence, though it is still referred to as NICE. Its new responsibilities placed NICE "at the heart of the government's plans to improve health and social care."⁸⁷ The Health and Social Care Act of 2012, thus, took an important step towards recognizing a fuller definition of health that also acknowledges the importance of mental and social well-being. By providing care that promotes physical, mental, and social well-being, the British government recognizes the importance of each of its citizens as a whole person not just a patient.

⁸⁴ Rawlins, "National Institute for Clinical Excellence: NICE works," 215.

⁸⁵ Smith, "The Triumph of NICE."

⁸⁶ Smith, "The Triumph of NICE."

⁸⁷ "A 'new' NICE for health and social care," 523.

Concerns about NICE

Particularly in its early years, NICE experienced backlash for what many believed to be a fundamental flaw. As Toby Lipman, a general practitioner from Newcastle, wrote to the BMJ, many claim that NICE "imposes a 'one size fits all' population view" that detracts from the proper functioning of both the doctor-patient relationship and the patient's ability to exercise autonomy. Lipman points out that the NICE guidelines prevent individualized care as they apply to patient populations and diseases rather than individual patients. Instead, he argues that these decisions should be made between clinicians and patients and "informed both by evidence and by patients' values and expectations, a process that follows from the "[application of] epidemiological principles . . . to the beliefs, judgements and intuitions that comprise the art of medicine," which is the basis of evidence-based medicine."⁸⁸ If a decision-making body is unable to successfully deal with these shortcomings, truly person-centered care may be out of reach since it is essential for a healthcare system to recognize differences between patients and ensure patient autonomy.

Though the inability to account for individual differences between patients could be detrimental to patient-centered care, this shortcoming can be solved with compassionate care. NICE recognizes this by putting the responsibility on the physician to bridge the gap to providing care responsive to individual circumstances. In fact, in a section titled 'Your Responsibility' in their guidelines they explain the physician's responsibility in regards to the guidelines:

When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their

⁸⁸ Smith, "The Triumph of NICE."

patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.⁸⁹

NICE argues that the role of the physician is to use both the guidelines, as well as their medical knowledge to help their patients in making decisions about their healthcare. The physician's duty to the patient would imply that the responsibility of applying the guidelines to individual circumstances falls on the doctor and doctor's ability to build trust in their relationships with patients. Additionally, the physician is in the best position to apply these guidelines with compassion and, as a result, a deeper understanding of the patient and their circumstances. By placing the duty on the physician and monitoring the physician's ability to take both individual circumstances and NICE guidelines into account, this shortcoming is solved.

The second objection regarding NICE guidelines relies on the idea that patient autonomy is compromised when NICE influences treatment decisions. For example, when NICE does not recommend certain treatments, providers are less likely to suggest those treatments to their patients. However, a central tenet in NICE's decision-making processes is transparency. NICE publishes all of their guidelines, technology appraisal guidance, diagnostics guidance, interventional procedures guidance, and medical technologies guidance on their website for all to see. Although they are unlikely to have the same understanding of the recommendations and evidence as a medical professional, patients can easily access all of the same information that their doctors read. Thus, transparency can help maintain the patient's autonomy to some degree,

⁸⁹ NICE, "Suspected Cancer: Recognition and Referral."

but patients will likely struggle to comprehend the complex medical information on the NICE website as well as their providers.

Conclusion

The United States and the United Kingdom take very different approaches when it comes to quality, cost, and access. The US system is guided largely by three factors. First, the US 'system' is not really a system at all: rather, it developed piece by piece over time without a comprehensive vision. It is also market-based and the profit-motive drives everything. Additionally, in the U.S. healthcare is not recognized as a right. Lastly, the US healthcare system prioritizes having the highest quality care possible over being easily accessible to all and having reasonable cost for care. Conversely, the UK's NHS was founded largely with the goal of solving the problem of access, so it is government-run, universal, and free at the point of service. Since the government funds the NHS, the UK does not spend near as much on healthcare as the US, but experiences similar health outcomes— in part due to the efficiency of the system. However, the resulting cost containment measures have negatively affected access and quality in the form of waitlists. Thus, though they have extremely different values, neither the US nor the UK have been able to find a sustainable balance between cost, quality, and care.

The difficulty to solve the issue of the 'inconsistent triad' largely lies in the tendency to rely on simple principles in a world of conflicting values. The struggle between cost, quality, and access cannot be fulfilled by a singular clearcut ethical approach, like utilitarianism or deontology. Instead, principles should be replaced by processes in which values guide decisionmaking rather than unbreakable rules. Thus, the path to ethical decision-making in allocating healthcare resources lies in creating processes for determining important values that should guide decisions and finding a balance between them. I have argued that compassion should be one such value as it enables the implementation of patient-centered care that recognizes the individual as multifaceted, while promoting patient autonomy. When compassion is central to the provision of healthcare, the relationships between patients and practitioners are rightly placed at the heart of quality care.

The UK's National Institute for Clinical Excellence took important steps towards improving decision-making practices in resource allocation. In its production of NHS treatment guidelines, NICE takes into account clinical effectiveness, cost-effectiveness, *and* social values. Some argue that the guideline approach prevents individualized care since it applies to patient populations rather than individuals. However, compassionate care from individual doctors solves the issue of the rigidity of guidelines. Afterall, individual physicians practicing compassion are in a far better place to deal with the nuances of individual cases since they have a deeper understanding of the patient and their circumstances. It has also been argued that, when NICE does not recommend certain treatments, the treatment options available to patients are limited, inhibiting full patient autonomy, but the transparency of NICE works to combat this issue. In fact, patients have access to all of the same information as their doctors via the NICE website. Lastly, as evidenced patient-centered care improves cost-effectiveness as well as overall quality of care. Thus, decisions about priority setting in healthcare should be made with four goals in mind: lowering costs, increasing access, improving quality, and promoting compassion.

Conclusion

Introduction

In the first two chapters, I have shown where the two prevailing ethical approaches to decision-making in healthcare fall short. Though the utilitarian approach is able to increase efficiency, it falls into the trap of seeing patients' lives simply as numbers in equations. Conversely, the deontological approach solves this problem recognizing the individual patient and the healthcare system's duties to each individual patient. However, the absolute duties of Kantian ethics put it at odds with the whole goal of rationing in the first place. In the third chapter I sought a different means for resource allocation decision-making in healthcare that could overcome both the shortcomings of the utilitarian and deontological approaches. I argue that the Dalai Lama's ethics of compassion account for these shortcomings as it does not depend on strict rules. In hard cases, a multiplicity of factors can be accounted for with the application of practical wisdom. I have argued that the NICE model largely follows these ethics of compassion since the decision-making process appropriately takes into account not only clinical and costeffectiveness but also social values. Nevertheless, the NICE guidelines are blanket guidelines for entire populations and thus have an inability to account for individual patient differences, like comorbidities. I have ultimately argued that the best means for decision-making in healthcare priority setting aligns largely with the NICE model but solves this problem of accounting for differences between patients, restoring more agency to the patient, so that patient-centered care can be implemented. In this chapter, I describe what putting compassionate care in practice with a modified NICE model could look like. I then show that this change cannot occur in a vacuum: there must be other fundamental changes to healthcare and healthcare systems to fix the problems of cost, quality, and access.

The New Models' Incompatibility with American Healthcare

The privatization of healthcare often results in a culture of healthcare being viewed as a commodity to be bought and sold in the market. In the face of a market-based healthcare system, there is intense competition for consumers between private healthcare providers, including hospitals, pharmaceutical companies, insurance companies, medical technology companies, etc. Unfortunately, the United States' healthcare system is driven by the profit-motive and, as a result, the National Health Expenditure hitting a whopping \$4.3 trillion, making healthcare the largest industry in the country.⁹⁰ This kind of spending in a privatized healthcare system is often accompanied by a tendency to treat healthcare as a commodity rather than a public good.

In the context of the provision of care, this capitalist approach to healthcare can promote almost factory-like healthcare. The doctor's time is thought of in terms of money and patients are pushed in and out the door as a result with little time to build relationships with their providers. Since specialists tend to make more, Americans are pushed around from one specialist to the next. As previously discussed, hospital executives try to raise the bottom line by encouraging expensive surgical procedures instead of less invasive interventions regardless of the patients' circumstances. When healthcare is market-driven, not only does care become absurdly expensive and extremely inaccessible, the quality of care can also be compromised in some ways because private healthcare is driven by self-interest. Currently American healthcare is, therefore, at odds with the goal of providing compassionate care that is accessible and affordable.

The UK's NHS was supposed to address these issues; however, since 2010, the conservative Prime Ministers of the United Kingdom have stressed the system. As a result, health care has been underfunded and increasingly privatized, and is now on the verge of a

⁹⁰ Centers for Medicare and Medicaid, "National Health Expenditure Fact Sheet."

collapse. In January 2023, an NHS Wales physician named Peter Neville took to social media to shed light on the changes in healthcare he has seen since the conservative party took over last.⁹¹ Neville begins by noting that the demand has risen exponentially in recent decades as the elderly begin to account for more and more of the population. Simultaneously, funding for care has not increased and in some areas, it is even being cut. For example, Neville explains that social care funding has been cut so, when elderly patients who need care packages are ready to be discharged, they often must wait in the hospital until they are able to receive a care package. Consequently, "about 33% of hospital beds are filled with 'fit for discharge' patients. UK hospitals can do nothing about this. We are effectively working on 66% capacity. Which is one of the key reasons why A&E is rammed."92 Neville also notes that pension and pay has worsened in recent years, which- combined with the low morale due to overrun hospitals- has led to a max exodus of healthcare workers. The amalgamation of all these factors has led to the current conditions of the NHS where it stands on the brink of collapse, but Neville claims the NHS was at its best in 2008 before the conservative government's dominance in Parliament. Thus, the NICE model had been sustainable until it became overrun with increased privatization and underfunding that is characteristic of the United States.

The Larger Solution: Changing the System

The inconsistent triad and healthcare rationing have long been concerns for healthcare systems worldwide. Governments and policymakers have sought to fix this problem by increasing efficiency or sometimes finding more funding. However, rationing is not exacerbated only by poor funding and waste, but also disorganization in healthcare systems. Quality, access,

⁹¹ Gibson, "Consultant explains why NHS is on verge of collapse."

⁹² Peter Neville Twitter Feed

and cost cannot be fully reconciled with the current systems as they are. The structure of the US healthcare system, for example, is not conducive to improving access and cost. Thus, it is necessary to change the healthcare systems themselves, as there are fundamental shortcomings in the ways care is organized.

This sentiment was shared by the Committee on the Quality of Health Care in America in their report, "Crossing the Quality Chasm: A New Health System for the 21st Century." In the United States, "quality problems are everywhere, affecting many patients. Between the health care we have and the care we could have lies not just a gap, but a chasm."⁹³ The committee was assembled in 1998 with the goal of finding solutions for closing this chasm.

The committee emphasized that Americans deserve a healthcare system of the quality they need and want. However, they recognized that this higher level of quality cannot be achieved by further stressing current systems of care. Instead, they argued that changing the systems of care is necessary, as the current care systems cannot do the job. Simply trying harder will not work. To find a solution, they embarked on an extensive review of the literature and a communications workshop with the goals of identifying impactful environmental factors that affect care, creating strategies designed to increase accountability, and proposing further areas of research. As a result, they propose changing the American healthcare system, following six aims for healthcare improvement: safe, effective, patient-centered, timely, efficient, and equitable. According to the committee, these six aims are the foundation for a high-quality healthcare system.

The first aim is to provide safe care: providers should avoid injuries to patients that are seeking care from a place of vulnerability. The committee also declares that care should be

⁹³ Crossing the Quality Chasm: A New Health System, 1

effective and based on scientific knowledge. Medical practitioners should use this scientific knowledge to provide services to patients that would benefit and know when not to provide treatments when the patient would not benefit. Thirdly, healthcare professionals should provide patient-centered care that respects the individual patient's preferences and values. The fourth aim is to provide timely care by reducing waiting times that could worsen patient outcomes. The committee similarly highlights the importance of efficiency, particularly by avoiding waste of equipment, supplies, ideas, and energy. The committee's last aim outlined in the report highlights the importance of providing equitable care that does not vary in quality because of personal characteristics, like race, ethnicity, gender, and socioeconomic status.

As argued by the Committee on Quality of Health Care in America, healthcare *systems* must change to provide the high-quality care that Americans need and deserve. The six aims for healthcare improvement outlined by the Committee provide one possible framework for achieving this goal. Although it has been over two decades since they published this report, American healthcare still has a long way to go in most, if not all, of these categories. In the US, healthcare reform is extremely difficult since health care has not been declared a right by the government and healthcare has become an intense subject of debate between Republicans and Democrats. Nonetheless, the United States needs to continue to promote the provision of care that is safe, effective, patient-centered, timely, efficient, and equitable by promoting healthcare reforms, such as the Obama administration's Patient Protection and Affordable Care Act.

An Attempt at Changing the System: The Affordable Care Act

The Patient Protection and Affordable Care Act (ACA), also known as Obamacare, is a comprehensive health care reform law that was enacted in the United States in 2010. As previously discussed, American healthcare is insurance-based and various issues arise when

patients are uninsured. For example, "a lack of insurance may generate inefficiencies if individuals avoid high-value and low-cost preventative care, only to later rely on high-cost emergency care that may deliver worse outcomes."⁹⁴ By incentivizing the purchasing of insurance, individuals are more likely to attend regular check-ups and partake in preventative care measures that increase the effectiveness and affordability of care. Thus, one of the key elements of the ACA is what some call the "three legged stool" approach, which includes improving the non-group insurance market, implementing the individual mandate for insurance, and increasing insurance affordability through subsidies and Medicaid expansions.

The first prong of the three-pronged approach seeks to improve the non-group insurance market for individuals and small businesses. Until the ACA, many Americans did not have insurance through their employer and did not qualify for public coverage, so they had to purchase insurance on the individual market, often characterized by high costs and limited options. As a result, the groups needing to use the individual insurance market tended to lack health insurance entirely. To address these issues, the ACA established a Health Insurance Marketplace, commonly known as the "Federal Exchange," to facilitate insurance purchases and stimulate competition among insurance plans. With the introduction of the Federal Exchange, there was a substantial increase in the number of Americans with health insurance.

The second aspect of the ACAs approach was the individual mandate, which required most Americans to have health insurance or face a penalty. When individuals are uninsured, there is a greater strain on the system as a whole. According to a study published in the Journal of Health Economics, "large swaths of Americans simply chose not to participate in the insurance market leading to poor health outcomes, cost shifting, and in many cases higher costs

⁹⁴ "Has the Affordable Care Act Affected Health Care Efficiency?," 196.

than when individuals are insured."⁹⁵ Thus, like the Federal Exchanges, the individual mandate helped to significantly increase the number of insured Americans. The idea behind the individual mandate lies in increasing risk pooling: the more people with insurance, the more affordable insurance can be for all. When insurance companies decrease their insurance rates, individuals are further motivated to purchase health insurance.

The last of the three-prong approach of the ACA is increasing affordability through subsidies and Medicaid expansions. The ACA subsidies were tax credits that aimed to assist people with lower incomes afford health insurance. Specifically, these tax credits helped lower the cost of monthly premiums for people that enrolled in health insurance plans through the Federal Exchange. The Medicaid expansions similarly sought to increase affordability by increasing the number of people eligible for Medicaid, a government health insurance program for people with low incomes. Until the ACA, Medicaid could only cover certain groups, namely pregnant women, children, and those with disabilities. However, after the ACA, Medicaid covered all individuals with an income up to 138% of the Federal Poverty Level.

Since the ACA's reforms were proposed, healthcare has increasingly become a polarizing topic of debate between the Republican and Democratic parties. Republican politicians took issue with the ACA for three main reasons: they believed it interfered with personal freedoms and free-market principles; they criticized the ACA's implementation, arguing that the government has no business managing healthcare; and lastly they argued that the ACA does not control costs and took issue with the taxes. Some aspects of these claims are fully justified. For example, the Federal Exchange website was regularly down, making it more difficult to use.⁹⁶

⁹⁵ "Has the Affordable Care Act Affected Health Care Efficiency?," 196.

⁹⁶ Emanuel, *Reinventing American Healthcare*.

However, the ACA– one of the largest health care reforms in US history– was undeniably succeeding at enhancing the American healthcare system in certain ways.

As seen through the Affordable Care Act, large scale healthcare policies are required to upgrade the cost, quality, and access of healthcare while maintaining patient-centered care. In order to promote justice in healthcare, changes to the *system* are essential. Improving the means by which decisions about healthcare resources are made can only do so much to enhance the care provided. Conversely, enhancing healthcare systems so that care is better organized can boost efficiency and better health outcomes on the whole. Thus, in the quest for improving cost, quality, and access, better decision-making processes must be supported by changes in the system that serve to promote justice and equity on larger scales while recognizing healthcare as a right.

Systems Affect Individuals

Although greater systemic change is paramount in improving healthcare, the individual patients must be remembered in the face of change. My sister, Sophie, was lucky. My family was fortunate that we could afford Sophie's care and that she was selected as a member of a clinical trial. However, through my mother's work fundraising for GLA research, I have seen that some in need fall through the cracks. Most of NIH funding goes towards a handful of common diseases. This affects those children I had seen at children's hospitals and all the families I had met at patient conferences. With the problem of resource allocation, someone always must lose out, but by using an ethics of compassion that allows medical professionals to take into account individual circumstances, less patients like Sophie fall through the cracks.

Conclusion

Compassion prevents healthcare from becoming bureaucratic and impersonal. As the Dalai Lama rightly declared in 1992, "Love and compassion are necessities, not luxuries. Without them, humanity cannot survive." Given the importance of compassion in affording dignity to individuals, it should occur in healthcare in more than just the individual relationships between healthcare providers and their patients. Through compassionate decision-making processes that govern how healthcare resources are distributed, compassion can occur on a much larger scale. Thus, decisions in healthcare should be guided by an equal concern and equal compassion for all. With compassion at the center of both doctor-patient relations and public health policies more broadly, global health initiatives and health care services are far more effective in promoting well-being.

In the United States, market-based healthcare has led to the commodification of health. When healthcare providers– and the industry as a whole– is obsessed with 'raising the bottom line,' self-interest begins to drive care rather than the needs of the patient, leading to care that is factory-like, impersonal, more costly, and at times dangerous. Evidently, the structure of the healthcare system has immense implications for the quality, access, and cost of care. A disorganized system leads to disorganized care. Thus, like the Committee on the Quality of Health Care in America, I have proposed that the issues resulting from 'the inconsistent triad' cannot really be solved without healthcare reforms that affect the system as a whole, like Obama's ACA.

Ultimately, policy makers and providers alike cannot simply work to improve efficiency to try to solve the issues of cost, quality, and access. With efficiency as the prime focus, individual patients can easily be lost within a healthcare system. Compassion prevents individuals from slipping through the cracks both in the provision of healthcare and the creation of healthcare policies. When compassion, high quality, easy access, and affordability are the goals of healthcare policies and resource allocation, justice can best be upheld. Thus, supported by structural changes to the American healthcare system, pairing the NICE model with compassion would help take sizable steps towards providing comprehensive, high-quality care to all.

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