

A STRUCTURED PRINCIPLIST FRAMEWORK FOR DECISION MAKING IN  
HEALTHCARE

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## ABSTRACT

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This dissertation puts forth the *structured principlist framework*, a practicable moral framework for guiding practioners' thinking in a diverse healthcare setting and grounding accepted healthcare practices and policies. This novel moral framework builds upon on the work of Tom Beauchamp and James Childress in *Principles of Biomedical Ethics*, reorganizing the four primary bioethical principles – respect for autonomy, beneficence, non-maleficence, and justice – into two necessary and jointly-sufficient conditions for the permissibility of an action: The *enabling condition*, incorporating the deontic principles of respect for autonomy and justice, requires that a proposed action be authorized by the patient or proxy and adhere to current hospital policies & procedures. The *favorability condition*, incorporating the consequentialist principles of beneficence and non-maleficence, requires that the proposed action be reasonably expected to promote the health of the patient. In normative terms, the structured principlist framework is best described as a pluralistic framework that contains consequentialist considerations yet maintains deontic constraints. This structured framework was developed in response to several criticisms leveled against Beauchamp and Childress's traditional principlist framework, ultimately capturing the benefits of bioethical principlism while providing a simplified, more guiding, and less capricious framework than the traditional framework. I argue for the structured principlist framework by demonstrating its usefulness when working through ethical conflicts at the clinical level as well as when formulating healthcare policies.

To my mentor and role-model, Barb Daly, who inspired this work and my passion for bioethics.

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## INTRODUCTION

The aim of this project is to offer a practicable moral framework that can structure and guide ethical deliberations in healthcare. I take as my starting point *bioethical principlism*, a pluralistic ethical theory focused around four *prima facie* principles: 1) Beneficence, 2) non-maleficence, 3) respect for autonomy, and 4) justice.<sup>1</sup> The most complete account of bioethical principlism comes from Tom Beauchamp and James Childress's *The Principles of Biomedical Ethics*, a work that has been monumental in shaping bioethical thought over the past 40 years.<sup>2</sup> Their work has also heavily informed my own thinking about bioethics. However, when employing their principlist framework in the assessment of clinical cases, both I and others have found it to be insufficiently guiding. In developing and arguing for my *structured principlist framework*, I have endeavored to honor the work of Beauchamp and Childress by presenting a framework that retains the importance of the four bioethical principles while clarifying the relationships between them. Clarifying these relationships will offer improved guidance when employed in a clinical or academic context, and the result is a pluralistic framework that contains consequentialist considerations while maintaining deontic constraints.

The first chapter of my dissertation is focused on presenting and critiquing Beauchamp and Childress's *traditional principlist framework*, as I will refer to their work in *Principles*. On their traditional principlist framework, ethical conflicts arise in cases where the four moral principles cannot be simultaneously satisfied. To resolve these conflicts, any of the four

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<sup>1</sup> Beneficence directs us to promote patient health and prevent harm, non-maleficence directs us to avoid causing harm, respect for autonomy directs us to respect a patient's right to make decisions involving their care, and justice directs us to provide an equitable distribution of healthcare resources. These principles are *prima facie* in that they specify moral duties but can also be overridden by competing moral duties.

<sup>2</sup> Beauchamp, Tom, and James Childress, *The Principles of Biomedical Ethics*, 6th edition (Oxford, England: Oxford University Press, 2009).

principles can be given moral priority. This means that in order to resolve moral disagreements, one must have a way of determining which principle(s) ought to be prioritized over others. In *Principles*, the mechanism for determining moral priority is a “weighing and balancing” approach in which one compares the relative weights of the competing considerations as they relate to the bioethical principles. In the first chapter I will lay out several distinct yet inter-related arguments critiquing this approach and the resulting framework.

The most general critique of the traditional principlist framework is that it relies too heavily on an individual’s intuitions, and as such fails to be sufficiently guiding in deliberations. This point has been made by several other authors.<sup>3</sup> My first unique critique charges that the framework can be used to justify both paternalistic and unnecessary interventions, which I term the *extremism criticism*. The concern here is that the traditional principlist framework allows for the justification of these two diametrically opposed positions resulting from extreme prioritizations of the principles. This criticism will also highlight another way in which the traditional principlist framework fails to be guiding, namely the fact that it can be used to justify one’s thinking *post hoc*. The next criticism focuses on the concern that the traditional framework is unable to account for the asymmetry in how patient requests and patient refusals of care are handled, and in particular noting how it fails to provide a clear and decisive reason to refuse patient requests for non-indicated care, furthering concerns about overtreatment. My final criticism is a normative critique, arguing that by allowing each of the principles to be justifiably overridden by one another the normative force of each principle is diminished.

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<sup>3</sup> Danner Clouser and Bernard Gert (1990), David Degrazia (1992), Gordon et al. (2011).

The second chapter then presents and defends my structured principlist framework. This framework consists of two conditions, the favorability condition and the enabling condition:

**Favorability Condition:** The proposed action must be reasonably expected to promote the health of the patient.

**Enabling Condition:** The proposed action must be authorized by the patient or proxy and must adhere to current hospital policies & procedures.

The favorability condition incorporates the consequentialist principles of beneficence and non-maleficence while the enabling condition incorporates the deontic principles of respect for autonomy and justice. The principles of beneficence and non-maleficence are consequentialist insofar as they aim at bringing about and avoiding certain types of ends. While these principles can be considered independently, the favorability condition understands beneficence and non-maleficence as working in concert to determine a favorable balance of benefit over harm.<sup>4</sup> The principles of respect for autonomy and justice are considered deontic insofar as they are concerned with the rights and liberties of individuals, as opposed to the promotion of the patient's health.

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<sup>4</sup> Understanding these principles as working together is sometimes referred to as “the principle of utility,” or determining the “net” good. Beauchamp and Childress, *Principles*, 149; Vaughn, Lewis, *Bioethics: Principles, Issues, and Cases*, 3<sup>rd</sup> edition (Oxford, England: Oxford University Press, 2017): 11-12; Veatch et. al., *Case Studies in Biomedical Ethics: Decision-Making, Principles, and Cases*, 2<sup>nd</sup> edition (Oxford, England: Oxford University Press, 2015): 71-72.

The resulting structured principlist framework is pluralistic in that it upholds and respects the division between deontic and consequentialist principles, allowing the enabling and favorability conditions to capture different values while imposing constraints on patients and healthcare providers alike. The enabling condition constrains healthcare professionals by prohibiting involuntary interventions, and the favorability condition constrains patients by limiting demands for non-indicated care. Chapter 2 will then see this framework applied in the context of clinical cases, and Chapter 3 will see the framework applied in the context of broader bioethical debates — focusing on the academic debates surrounding end-of-life assistance and futility declarations — as well as noting applications for healthcare policy formation. These applications will demonstrate my framework to be useful both within and outside of a clinical healthcare context.

My interest in this project and my recognition of the concerns with the traditional principlist framework arose through my involvement in clinical ethics. Early in my graduate career, I spent two summers as a clinical bioethics intern at University Hospitals Cleveland Medical Center under the supervision of Dr. Barb Daly, and since moving to Cleveland in 2017, I have been a regular member of University Hospital's full bioethics committee as well as the Patients Without Proxies (PWP) subcommittee. My experiences deliberating about ethically complex real-world cases, as well as working alongside clinical practitioners and understanding the ethical challenges they regularly face, has worked to shape my understanding of what issues are most pressing in the healthcare setting while reinforcing the inadequacies of the traditional principlist framework.

For example, during my internship there were several occasions on which I heard healthcare practitioners express feeling ill-equipped to respond to patient-requests for specific

care, even when there was agreement that abiding by the patient's request would be unfavorable or ill-advised from a health perspective. In these cases, the practitioners appeared to struggle with determining *when* they were justified in refusing a patient's request and *how* to articulate their justification to the patient. In addition, several cases brought before the full bioethics committee have involved physicians refusing to sign unilateral "Do Not Resuscitate" (DNR) orders despite acknowledging cardiopulmonary resuscitation (CPR) to be inappropriate.<sup>5</sup> This can be understood as a different version of a patient request, where instead of asking for a new intervention, the patient or proxy desires that a treatment plan continue unchanged despite a change in circumstances.<sup>6</sup>

Due to these experiences, questions of when and why providers are justified in refusing patient requests for care, and how these justifications relate to or differ from patient refusals of care, formed the basis of my research. The main conflict at the heart of these cases, and the primary source of ethical tension in many bioethical cases, is a conflict between respecting a patient's autonomy and doing what is best from a health perspective. As I will argue, the traditional principlist framework unfortunately does little to offer guidance in the face of disagreement. It is thus with an eye toward improving decision-making in a real-world healthcare context that I have engaged in this project, focusing on the ethical issues that healthcare providers most frequently face and working to provide them with a more practicable framework for ethical deliberation and justification.<sup>7</sup>

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<sup>5</sup> A unilateral do-not-resuscitate (DNR) order refers to a DNR order placed without the consent of the patient or surrogate, often justified on the grounds of medical futility. This will be discussed in Chapter 3.

<sup>6</sup> An example is a patient desiring to remain full-code despite becoming a poor candidate for CPR.

<sup>7</sup> I have had several opportunities to present my structured principlist framework to bioethics students, separating them into teams and instructing them to deliberate about six cases first using the traditional framework, and then by employing the structured framework. The results have been very promising on two fronts: The structured framework

## CHAPTER I. INSUFFICIENCIES OF THE TRADITIONAL PRINCIPLIST FRAMEWORK

*Bioethical principlism* is a pluralistic ethical theory that arose in the late 1970's, made popular by Tom Beauchamp and James Childress's *The Principles of Biomedical Ethics*.<sup>8</sup> In the healthcare setting, bioethical principlism is understood as a moral theory based around four *prima facie* principles — beneficence, non-maleficence, respect for autonomy, and justice — where each principle represents a unique moral consideration.<sup>9</sup> The “traditional principlist framework,” as I will refer to it, is Beauchamp and Childress' interpretation and implementation of bioethical principlism as presented in *Principles*. It is meant as a general guide for determining which actions may be morally permissible and which actions should be avoided, thereby assisting with ethical decision-making and justifying actions within healthcare.

In this chapter, I will provide a brief overview of bioethical principlism and the traditional principlist framework before presenting four serious criticisms of Beauchamp and Childress' work. These critiques will motivate the need for a new principlist framework that can offer clearer guidance in moral decision making, as well as more consistently render judgements that align with common practices and moral intuitions about cases. In the following chapters I will then provide a compelling alternative to the traditional principlist framework, arguing for what I refer to as the *structured principlist framework*. As with the traditional framework, my

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appears to limit both intra-team disagreements and inter-team disagreements, and it results in recommendations that the students agreed were morally permissible.

<sup>8</sup> Beauchamp, Tom, and James Childress, *The Principles of Biomedical Ethics*, 6th edition (Oxford, England: Oxford University Press, 2009).

<sup>9</sup> These four principles are the ethical core of bioethical principlism insofar as they are common to all discussions of bioethical principlism, and are the focus of Beauchamp and Childress' *Principles*. Some bioethical texts also include discussions of additional principles such as “utility,” “veracity,” and “fidelity”: However, there is no clear consensus on the inclusion of any additional principles, and each additional principle can be explained as a specification of a core principles (Beauchamp and Childress, *Principles*, 288). For example, the duty of veracity can be understood as a specific means through which we respect patient autonomy. For these reasons, I will limit my discussion to the four core principles of bioethical principlism.

structured framework appeals to the four bioethical principles previously mentioned, but differs in that it employs these principles within a novel structural framework. This structured framework consists of two conditions for the moral permissibility of an action: The *enabling condition*, incorporating the principles of respect for autonomy and justice, and the *favorability condition*, incorporating the principles of beneficence and non-maleficence. Satisfying each condition is necessary and jointly sufficient for the moral permissibility of an action.

### 1. Bioethical Principles in Healthcare Practice

The general aim of healthcare is to promote patient health and healing, meaning that healthcare providers are frequently tasked with determining which course of action is most likely to promote a patient's health.<sup>10</sup> At the same time, healthcare providers must also remain mindful of the rights of their patients. Though patient health is the central focus of healthcare, the ability of patients to make judgements about or to control the circumstances directly affecting their well-being is also a key component.<sup>11</sup> As autonomous individuals, we each have the right to direct core aspects of our lives, including decisions that directly affect our health, meaning the job of the healthcare provider involves not just caring for a patient's health needs but also striking a balance between providing a benefit while respecting the rights of their patients.<sup>12</sup>

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<sup>10</sup> Going forward I will use the term 'health' to denote the physical health of the patient. This will allow for a clearer explanation of the framework because our discussion will be indexed to a narrow set of considerations, focusing on treatment options that would clearly improve or diminish the physical aspect of a patient's health. That said, the framework can be expanded to include other aspects of patient health, including but perhaps not limited to mental health.

<sup>11</sup> This is not to take a stand on the correct theory of well-being, apart from suggesting that health is instrumental to well-being. There are several competing views of well-being that take health to be a constituent part, such as an objective list view, a preference satisfaction view, a desire satisfaction view, etc. I will remain agnostic between them.

<sup>12</sup> This is how the job of a healthcare professional is currently structured given their obligations to treat patients' health concerns while conforming to hospital guidelines regarding the obtaining of informed consent. I think this is appropriate given a provider's commitment to healing alongside the fact that patients retain the right to act autonomously within the healthcare context.

Toward this end, the four bioethical principles are intended to serve as guides for healthcare providers by making clear the parameters of their ethical obligations.

The principles of beneficence and non-maleficence represent the central aim of healthcare practice — to promote health and healing while minimizing harm — and have historically been the guiding principles in medicine.<sup>13</sup> The principle of beneficence primarily obligates healthcare providers to promote the health of their patients while its counterpart — the principle of non-maleficence — grounds a duty to refrain from causing unnecessary or unjustified harm. Taken together, the principles of beneficence and non-maleficence direct healthcare providers to promote the health of the patient while minimizing any attending, foreseeable harms.

These principles ideally guide healthcare providers in thinking about which courses of action may be more or less appropriate given the facts of a case. But while the goal of providing benefits while minimizing potential harms may seem straightforward, it is not always clear which course of action will result in the best outcome: If required to choose, should one aim to maximize potential benefits or minimize potential harms? Additionally, acting to benefit a specific patient can be limited by either a refusal of patient consent or by considering the needs of the greater community. While the former can best be described as a conflict with patient autonomy, the latter is characterized by a conflict with the principle of justice.

In contrast to beneficence and non-maleficence, the principle of respect for autonomy is centered on an individual's right to self-govern, and grounds the patient's right to make decisions based on their personal beliefs and values. This includes decisions to refuse further treatment or

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<sup>13</sup> Beauchamp and Childress, *Principles*, 149.



care. The duty to respect the rights and values of patients has become so central to healthcare that even when patients lack the capacity to decide for themselves, their values are nevertheless represented through the authority granted to decision-making proxies and living wills. In addition to these norms, it is often argued that the principle of respect for autonomy undergirds the institutional norm of obtaining a patient's informed consent, insofar as informed consent involves the patient being provided sufficient information relating to her care options and precludes the performance of actions to which she does not consent.<sup>14</sup> Yet despite the importance placed on respecting the rights of patients to make decisions regarding their care, no principle has absolute moral priority on the traditional principlist framework, and ethical tensions can still arise when the principle of respect for autonomy comes into conflict with the other bioethical principles, most commonly beneficence and non-maleficence.<sup>15</sup>

Unlike the other principles, the principle of justice is often relevant in contexts involving groups rather than individuals. This is because considerations of justice arise in relation to the distribution of benefits and burdens across a population. Broadly speaking, justice demands an equitable distribution of healthcare resources given that we think that patients experiencing similar medical issues should receive similar care. This means that the treatments a patient receives should not be unduly influenced by the patient's age, race, gender, sexual orientation, or socioeconomic circumstance. Though such factors may play a role in determining the best course of care, the quality of the care provided should not be diminished in light of such factors. This also means that healthcare resources should be appropriately distributed such that no patient is

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<sup>14</sup> Beauchamp and Childress, *Principles*, 117-129; Faden, Ruth R., and Tom L. Beauchamp, *A History and Theory of Informed Consent* (Oxford, England: Oxford University Press, 1986); 276-86.

<sup>15</sup> As will be discussed in Section 2, the traditional principlist framework considers each principle to be *prima facie*, meaning each principle can be justifiably prioritized or overridden depending on the case.

given special access, or is denied access, to healthcare resources due to any of the above listed factors.

Because considerations of justice primarily focus on macro-level issues, such as policy considerations regarding the appropriate distribution of healthcare resources, considerations of justice do not often arise in the analysis of ethical cases involving only one patient. This is not to say that concerns about justice are irrelevant in interpersonal deliberations between the healthcare provider and the patient, for it does matter how we utilize healthcare resources in particular cases. Rather, I am suggesting that thinking about the wider implications of utilizing various healthcare resources is often beyond the purview of any given practitioner. Even so, the core idea of bioethical principlism is that each of the principles is equally important and ought to be satisfied to the extent possible. Thus, determining which principles ought to take precedence in cases of conflict is the primary challenge healthcare providers face. Addressing this concern is the cornerstone of Beauchamp and Childress' traditional principlist framework.

### *1.1. Why These Principles?*

These four bioethical principles were first adopted in the latter part of the 20th century, making them a relatively recent addition to bioethical discourse. Prior to this, physicians were presumed to know best in terms of bestowing health benefits, making healthcare practice largely paternalistic in nature.<sup>16</sup> Physicians acted in line with their medical training and expert judgements, rarely consulting or informing patients about a diagnosis or possible treatment options. When making judgements regarding which courses of action to undertake, medical

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<sup>16</sup> The first code of medical ethics was published by the American Medical Association in 1847, based on the writings of physicians such as Thomas Percival and emphasized the importance of beneficence and non-maleficence. Considerations of patient autonomy were not included until the later part of the 20<sup>th</sup> century. American Medical Association, "History of the Code," (2017) <<https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/ethics/ama-code-ethics-history.pdf>>

professionals utilized the current medical science and acted in line with the general aim of healing patients and prolonging lives. As such, the principles we now refer to as beneficence and non-maleficence implicitly guided medical practice well into the 20th century. It can be said that these principles underlie the goals of medicine, both historically and presently.

However, leaving full control of medical decision making in the hands of physicians and medical researchers did not always result in optimal outcomes for patients, especially when patients doubled as research subjects. Over time numerous human rights abuses were perpetrated in the name of research and medical progress, highlighting the need for greater protection of both patients and subjects of medical research. The first document to explicitly outline the rights and protections of human subjects resulted from the 1947 Nazi Doctors' Trial at Nuremberg. Though never codified in law, *The Nuremberg Code* became the first document to outline protections for research subjects, in particular the requirement of consent and the right to refuse.<sup>17</sup> While beneficence and non-maleficence had long been implicit in medical decision-making, these guidelines helped to make them explicit and the emphasis on consent brought to light the importance of patient autonomy.

The key insight at the Nuremberg trial was that furthering medical science, a first step in furthering the goals of healthcare, sometimes means sacrificing benefits from and allowing harm to befall particular patients or research subjects in the name of progress. When this comes at the expense of denying the rights of these patients and subjects, we are treating them as a means to progress instead of ends in themselves. The principle of respect for autonomy was introduced to explicitly acknowledge the rights of patients to direct their own lives, specifically by requiring

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<sup>17</sup> "The Nuremberg Code" (1947) In: Mitscherlich A, Mielke F. *Doctors of infamy: the story of the Nazi medical crimes* (New York: Schuman, 1949): xxiii-xxv.

consent for and respecting refusals of care as it relates to the patient's interests. While introduced in 1947, the principle of respect for autonomy wasn't fully adapted to healthcare until the 1964 *Declaration of Helsinki* which extended protections from research subjects to include patients in a healthcare setting. This document also carved out provisions for medical proxies in cases where obtaining consent or refusal may not be possible.<sup>18</sup>

While the principle of respect for autonomy was first introduced as a response to human rights abuses, its significance in modern healthcare practice has grown considerably. Most notably, the strong American value of individual liberty finds its expression in respect for autonomy insofar as it gives each patient the right to make decisions about their medical care in accordance with their unique goals and values.<sup>19</sup> This is especially relevant when there are multiple methods available for diagnosing or treating a patient's condition, allowing the patient to select the method that fits best with their unique lifestyle, goals, and values. For example, there are several different treatment options available for a patient diagnosed with coronary artery disease, including medical management and coronary artery bypass graft (CABG) surgery.<sup>20</sup> Coronary artery disease occurs when plaque (comprised of cholesterol, calcium, and cell debris) builds up in the arteries, significantly narrowing the arteries and impeding blood flow

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<sup>18</sup> World Medical Association. (2018). *WMA declaration of Helsinki: Ethical principles for medical research involving human subjects*. Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>

<sup>19</sup> The understanding of respect for autonomy as being important for individual liberty overlaps with Isaiah Berlin's discussion of negative and positive liberty in a political sense. Berlin understands negative liberty as the absence of obstacles or constraints, and positive liberty as being able to act in a way that directs one's own life. Respect for autonomy can similarly be understood in a negative sense focusing on non-interference, or a positive sense focusing on the capacity to exercise and/or the ability to achieve certain ends. Sometimes the idea of positive autonomy also includes receiving assistance from others in maintaining capacity or achieving one's ends. Berlin, Isaiah, "Two Conceptions of Liberty," *Four Essays On Liberty* (Oxford, England: Oxford University Press, 1969): 118-172.

<sup>20</sup> This is not exhaustive of the possible treatment options for coronary artery disease. I am focusing on these two options because they are the least invasive and most invasive options, resulting in the largest contrasts between expected harms and benefits.

in the heart. Medical management involves non-invasive drug therapy to prevent future plaque buildup, while a CABG involves open-heart surgery to bypass the blocked artery by “grafting” a new artery around the blockage, creating a new pathway for blood to flow.

Although the CABG can provide a greater health benefit in high-risk patients by circumventing the plaque buildup, some high-risk patients may nevertheless prefer medical management because they are unable or unwilling to set aside the time necessary for post-operative recovery, because they do not see the potential benefits as being worth the risks and side-effects of surgery, or because they are concerned about tertiary issues such as post-operative pain management and the use of opioids. The principle of respect for autonomy is a formal recognition that many different considerations factor into a determination about what would be best for a given patient, and that some of these considerations may be more important to the patient than simply maximizing expected health benefits.

Granted, a consequence of this principle is that some patients will make imprudent decisions, or perhaps even decisions that fail to align with their stated values. Yet these consequences are often considered acceptable because of the significant value in allowing individuals to self-determine. This can be justified from either a consequentialist perspective on the grounds that no individual has better access to what will benefit a person all-things-considered than the individual herself, or from a deontological perspective insofar as no one has the right to make decisions of a personal nature for an autonomous individual. Hence, regardless of what benefit might be bestowed by a particular medical intervention, those who champion respect for autonomy see even more value in allowing the patient to determine what counts as a benefit.

The fourth and final principle, justice, wasn't introduced until the publication of *The Belmont Report* in 1979.<sup>21</sup> Much like the principle of respect for autonomy, the principle of justice was introduced primarily in response to the injustices committed in the United States. This time, the injustices included the long-running Radiation Experiments and Tuskegee Syphilis Study.<sup>22</sup> The Human Radiation Experiments were carried out over 30 years by the Atomic Energy Commission, the US Department of Defense, and the National Institute of Health. These experiments exposed unsuspecting citizens to radioactive fallout, injected patients with plutonium, and provided food to orphans that knowingly contained radioactive materials.

The Tuskegee study was carried out over 40 years by the United States Public Health Services, with the goal of understanding the long-term effects of untreated syphilis. The research subjects consisted of a vulnerable population of black men from the Tuskegee community. The subjects were lied to about their diagnoses and were never given the opportunity to refuse being subjects in the study. The men were simply told they had "bad blood," and when penicillin was discovered as an effective treatment for syphilis, it was withheld from this community in order to continue the study. The principle of justice is primarily aimed at a fair distribution of harms and benefits across a population, which helps to explain the wrongness of these studies: The research subjects suffered the burdens of research without receiving any of the attending benefits. Whereas respect for autonomy concerns the rights of an individual, justice concerns the rights of groups or populations and the competing claims to resources that often arise.

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<sup>21</sup> The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research" (1979).

<sup>22</sup> Cobb, W.M., "The Tuskegee Syphilis Study," *Journal of National Medical Association* 65 (1973): 345-48. The full title of the study was the "Tuskegee Study of Untreated Syphilis in the Negro Male"; Welsome, Eileen, *The Plutonium Files: American's secret medical experiments in the Cold War* (The Dial Press, 1999).

One way to further understand these principles is to consider the normative theories undergirding them. Beneficence & non-maleficence are easily understood as being consequentialist in nature given that they are aimed at bringing about and avoiding certain types of ends. Taken together, these principles help healthcare providers to think about which options they ought to present to their patients. The principles of respect for autonomy & justice can be understood as deontic in nature, given that they regard the rights of individuals and populations. Admittedly, this division is not always clear-cut, and a sufficiently complex understanding of consequentialism may be able to account for the principles of respect for autonomy and justice. Nevertheless, I think understanding these four principles through this normative divide helps us to understand the underlying importance of each of the principles.

Given that Beauchamp and Childress both helped to author *The Belmont Report*, it should come as no surprise that *Principles*, which puts forth what I will henceforth refer to as the *traditional principlist framework*, largely furthers the ideas presented in *The Belmont Report*. What may be more surprising is the fact that our current ethical principles and bioethical framework came to be through a series of committees and reports, eventually cemented in the ethical cannon by Beauchamp and Childress' *Principles*. Given that the aim of bioethics is to learn, grow, and adapt with new cases and modern insights, the goal of this project is to continue the evolution of bioethics by evaluating and improving upon the principlist framework put forth in *Principles*.

## **2. Common Critiques of the Principlist Framework**

Despite principlism being the most prominent moral theory in bioethics, the traditional principlist framework is not without its issues. Many of the criticisms leveled against this framework take aim at the framework's ability, or rather inability, to be sufficiently guiding in a

real-world context. As I will discuss, this is a result of too much indeterminacy within the framework. But before diving into these concerns it will be useful to provide some background and context, so I will begin by outlining the approach to settling disagreements between the principles as presented in Beauchamp and Childress's *Principles*.

In *Principles*, each bioethical principles is said to be *prima facie*, meaning each principle specifies a moral duty that can be overridden by a competing moral duty.<sup>23</sup> As previously mentioned, ethical concerns arise when the four principles cannot be simultaneously satisfied, and in those instances a decision procedure must be employed to determine which principle(s) ought to take precedence. Toward this end, Beauchamp and Childress propose the “weighing and balancing” approach in which the relative weights and strengths of the four principles are balanced against one another “in the process of finding reasons to support beliefs about which moral norms should prevail.”<sup>24</sup> According to *Principles*, “balancing consists of deliberation and judgement about the relative weights or strengths of the norms” where “justified acts of balancing can be supported by good reasons. They need not rest merely on intuition or feeling (although intuitive balancing is one form of balancing).”<sup>25</sup>

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<sup>23</sup> “The four clusters of principles we present in this book do not constitute a general ethical theory and provide only a framework of norms with which we can start in biomedical ethics. Our framework is sparse, because *prima facie* principles do not contain sufficient content to address the nuances of moral problems. ...The reason why directives in particular moralities often differ is that abstract starting points in the common morality can be coherently specified in more than one way to create practical guidelines and procedures.” Beauchamp and Childress, *Principles*, 16. Harkening back to WD Ross, Beauchamp and Childress describe these principles as *prima facie*, which means that the principle specifies a moral duty at first glance. However, I think this is a weaker statement than Beauchamp and Childress mean to make, given that respect for autonomy does not stop being a relevant moral duty even when it is overridden. Describing the principles as *pro tanto* more appropriately captures this in that it specifies a standing moral duty that can be overridden, but because the difference in terminology does not make a significant difference for my discussion, I will continue to use Beauchamp and Childress's original term of *prima facie*.

<sup>24</sup> Beauchamp and Childress, *Principles*, 20.

<sup>25</sup> Ibid.



For Beauchamp and Childress, all four principles represent values grounded in common morality, with no principle taking moral priority over the others because the strengths/weights of the principles vary in response to context-sensitive information provided by the case at hand. Because there is no fixed weight assigned to any given principle, each healthcare provider must make an individual assessment about how strongly she or he thinks a particular principle should be weighed in a given case. As David DeGrazia is quick to point out, this leads to an obvious question: “How is one to know which principle to favor when two or more of autonomy, beneficence, nonmaleficence, and justice conflict?”<sup>26</sup> In his essay “Moving Forward in Bioethical Theory,” DeGrazia raises this question before arguing that the weighing and balancing procedure put forth in *Principles* is primarily an appeal to intuition with some vague gesturing at normative theories. He astutely points out that without a clear structure for settling disagreements about which principle(s) to prioritize, it can be difficult for healthcare providers to understand how each principle ought to be brought to bear on a given case.<sup>27</sup> The indeterminacy inherent in the traditional principlist framework is the backbone for most criticisms regarding bioethical principlism.

For example, prior to DeGrazia’s critique, Danner Clouser and Bernard Gert put forth a similar argument admonishing *Principle’s* weighing and balancing approach for failing to offer any mechanism or guideline for determining the relative weights of the principles within a given context. They charge that “the principles lack any systematic relationship to each other” and that

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<sup>26</sup> Degrazia, David, “Moving Forward in Bioethical Theory,” *The Journal of Medicine and Philosophy* 17 (1992): 511-39, 521.

<sup>27</sup> I find it significant that Beauchamp and Childress themselves note that “numerous considerations must be weighed and balanced and any generalizations that could be formed might not hold even in related cases.” *Principles*, 21. This admits an inherent complexity in the weighing and balancing approach, suggesting difficulty for application in time sensitive, real-world healthcare cases.

instead of offering clear guidance about when or how to apply a given principle, the traditional framework largely leaves judgements open to the moral interpretations of healthcare providers.<sup>28</sup> Failing to provide healthcare practitioners with sufficient guidance in their ethical reasoning means “at best, ‘principles’ operate primarily as checklists naming issues worth remembering when considering a biomedical moral issue. At worst ‘principles’ obscure and confuse moral reasoning by their failure to be guidelines and by their eclectic and unsystematic use of moral theory.”<sup>29</sup> Like DeGrazia, Clouser and Gert charge the traditional principlist framework with lacking a theoretical basis for the principles, suggesting that the principles function more as reminders of ethical values than traditional principles.

Gordon et al. argue for a similar point in a slightly different way.<sup>30</sup> They begin by pointing out that specifying the principles can help us to understand how they might apply to a specific case or how to order them, a point Beauchamp and Childress raise in defense of their framework, but like the others Gordon et al. are concerned that “ranking, specification, and balancing vary greatly among different people regarding a particular case.”<sup>31</sup> If healthcare practitioners come from different perspectives and thereby specify the principles differently, this will simply result in further conflict with little room for resolution. Once again, without a clear mechanism for determining when to prioritize certain principles over others, or how the general principles ought to be applied to specific cases, bioethical principlism only serves to confuse one’s decision making or allows for idiosyncratic justifications instead of offering guidance.

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<sup>28</sup> Clouser, Danner, and Bernard Gert, “A Critique of Principlism,” *The Journal of Medicine and Philosophy* 15 (1990): 219-36, 220.

<sup>29</sup> Clouser and Gert, “A Critique of Principlism,” 220.

<sup>30</sup> Gordon et al., “Applying the Four-Principle Approach,” *Bioethics* 25 (2011); 293-301.

<sup>31</sup> Gordon et al., “Applying the Four-Principle Approach,” 293.

Yet there have also been attempts to defend principlism from these charges, such as Quante and Vieth's suggestion that Beauchamp and Childress's talk of "considered judgements" is really referring to *qualified intuitions*, meaning considered judgments are not merely matters of individual intuition but "have a history rich in moral experience that undergirds our confidence that they are credible and trustworthy."<sup>32</sup> While this pushes back on the claim that judgments rely too heavily on the intuition of individual providers, it neither precludes healthcare providers from using the principles framework to justify idiosyncratic positions *post hoc*, nor does it provide clarity for how deliberations are to actually be carried out in practice.

### 3. The Extremism Criticism

The common critiques I have discussed can be summarized as making the general claim that the traditional principlist framework suffers from too much indeterminacy, and as such fails to provide useful guidance for healthcare practitioners working in a healthcare setting. Specifically, the traditional principlist framework fails to clearly guide the moral thinking of, or to provide actionable guidance for, healthcare professionals working through complex real-world cases.<sup>33</sup>

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<sup>32</sup> Quante, Michael, and Andreas Vieth, "Defending Principlism Well Understood," *Journal of Medicine and Philosophy* 27 (2002); 621-649, 625.

<sup>33</sup> Page, Katie, "The four principles: can they be measured and do they predict ethical decision making?." *BMC medical ethics* 13 (2012). In support of my claim, a recent study sought to discover "whether these principles can be quantitatively measured on an individual level, and then subsequently if they are used in the decision making process when individuals are faced with ethical dilemmas." The author found that "people state they value these medical ethical principles but they do not actually seem to use them directly in the decision making process." However, to be fair to Beauchamp and Childress, they openly admit that their framework is a starting point for ethical evaluations and not a complete ethical theory. Yet because bioethical principlism has become the most appealed to theory in medical ethics, with most ethicists referring directly to Beauchamp and Childress's principlist framework, the shortcomings discussed remain of serious concern. Whether or not their account of principlism was intended to guide real-world ethical deliberations, it has since taken up that mantle despite its inherent lack of guidance. Thus, the nature of my project is to take the best parts of their principlism and to place them into a more structured, action-guiding framework.

There are many issues with attempting to employ an ambiguous framework, such as the lack of consistent application across cases or unclear justifications for actions.<sup>34</sup> But even more concerning is the fact that this lack of guidance can allow those employing the traditional framework to justify two diametrically opposed positions, medical paternalism and overtreatment, neither of which comport with standard medical practices or ethical thinking.<sup>35</sup> I will refer to the inability of the traditional principlist framework to clearly prohibit such actions as *the extremism criticism*.

Instances of medical paternalism and cases of overtreatment are not extreme in the sense that they are rarely found within modern healthcare; rather, my concern is that instances of paternalism and overtreatment are too prevalent despite resulting from extreme prioritizations of the principles. The concern underlying *the extremism criticism* is that at one end of the spectrum instances of paternalism appear justified when beneficence is promoted at the expense of patient autonomy, while at the opposite end of the spectrum instances of overtreatment appear justified when respect for autonomy is taken to matter most, even in the face of clear violations of beneficence and non-maleficence.

### *3.1. Justifications for Paternalism*

Paternalistic approaches to medicine were widely accepted until the end of the 20<sup>th</sup> century when *The Nuremburg Code*, *The Declaration of Helsinki*, and *The Belmont Report*

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<sup>34</sup> The ambiguity and lack of guidance inherent in the traditional principlist framework also creates issues for academic bioethical debates. This will be discussed in Chapter 3.

<sup>35</sup> Medical paternalism is when a healthcare provider ignores or overrides the clear wishes of a competent patient for the patient's own sake, insofar as doing so is expected to bestow some medical benefit. Paternalism prioritizes the principle of beneficence over the principle of respect for autonomy. Overtreatment refers to the provision of excess or unnecessary treatments, often due to the patient's request. Overtreatment typically prioritizes the principle of respect for autonomy over the principles of beneficence and non-maleficence.

introduced and then reinforced the importance of patient autonomy.<sup>36</sup> The longstanding acceptance of paternalism is understandable insofar as medical paternalism has the laudable aim of promoting patient health and healing, supported by the principles of beneficence and non-maleficence. However, as discussed in section 1, a series of human rights abuses and controversial healthcare cases illuminated the importance of patient autonomy, changing the landscape of biomedical ethics. Given the resulting shift toward respecting patient decision-making, I find it appropriate to label paternalism an extreme position insofar as it disregards the express wishes and values of the patient in favor of providing a potential benefit.<sup>37</sup>

To illustrate paternalistic reasoning as it relates to the traditional principlist framework, consider a physician who strongly believes that death is the most grievous harm that can occur, and as such preserving or prolonging a life is always seen as beneficial. Such a belief could easily guide the practitioner toward actions aimed at preserving patient lives, and taken to the extreme, such a belief could be used to justify the performance of life-preserving actions even when doing so violates a patient's stated refusal. A common example of this would be the violation of a patient's "Do Not Resuscitate" (DNR) order. Violating a patient's DNR by providing cardiopulmonary resuscitation (CPR) would prioritize the principle of beneficence over the principle of respect for patient autonomy, ultimately violating the patient's autonomy in favor of attempting to confer a health benefit on the patient.

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<sup>36</sup> The first code of medical ethics was published by the American Medical Association in 1847 and emphasized the principles of beneficence and non-maleficence based on writings and practices of physicians such as Thomas Percival. This "doctor knows best" view of medicine remained unchanged until the Nuremburg Trials of 1946 and The Belmont Report in 1979.

<sup>37</sup> Medical paternalism is often described as a healthcare provider overriding the wishes of a patient for the patient's own sake. Casarett, D J et al. "Would physicians override a do-not-resuscitate order when a cardiac arrest is iatrogenic?." *Journal of general internal medicine* 14 (1999): 35-8. This study examines the conditions under which physicians would be willing to override a patient's DNR.

While paternalistic attitudes still exist in healthcare, the 1973 case of Dax Cowart marked a change in common thinking about medical paternalism. Dax was only 25 years old when he was caught in an unfortunate explosion that resulted in second and third degree burns to over 65% of his body. When first responders arrived on the scene, Dax quickly and firmly stated that he did not want any medical treatment and that he wanted to be let to die. His wishes were respected while en route to the hospital, but as soon as he arrived the doctors and nurses in the burn unit began administering treatments in an attempt to save his life. These treatments continued for 10 months despite Dax's clear and continual refusal of any medical treatment, and despite two psychiatric evaluations that each affirmed his capacity to make decisions regarding his medical care.<sup>38</sup>

In this case, healthcare professionals prioritized the principle of beneficence over the principle of respect for autonomy, ultimately saving Dax's life at the expense of violating his right to make determinations about the course of his care. Following his ordeal, Dax never wavered in his conviction that the doctors were wrong for subjecting him to life-saving interventions against his expressed wishes.<sup>39</sup> According to a 1983 interview with Dax:

The [doctor's] motives weren't wrong. What was wrong was the actual forcing of me to undertake the treatment. I had full use of my mind. I demonstrated that I could think. That I could reason. That I had given it some thought. I knew I was burned bad enough, I didn't want to live... Why is it right to be subjected to

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<sup>38</sup> Kliever, Lonnie, *Dax's Case: Cases in Medical Ethics and Human Meaning* (Southern Methodist University Press, 1989).

<sup>39</sup> After a decade of difficult recovery, Dax eventually enrolled in a law program and became an attorney and a prominent patients' rights activist. Specifically, he advocated for patients' rights to make decisions for themselves.

painful treatment against someone's wishes, especially if he's demonstrated an ability to reason?... My contention is that I should have been the one to make that choice at that time.<sup>40</sup>

In large part due to the public backlash in light of Dax's case, instances of medical paternalism are no longer common place or generally accepted within healthcare, especially given policies such as the requirement of informed consent. However, the actions of these doctors can nevertheless be justified by appeal to the traditional principlist framework.

As previously discussed, the four bioethical principles are *prima facie*, meaning that any prioritization of the principles can be argued for on the traditional framework. As such, if a physician believes that death is the greatest possible harm, she could reasonably argue that violating her patient's autonomy is the lesser of the possible ethical violations. To illustrate, consider a case in which this physician is caring for a patient who goes into cardiac arrest, yet this patient has a DNR order in place. Given the DNR order, performing CPR would be to act paternalistically, as this would go against the patient's stated wishes and violate the right of the patient to self-determine. Yet respecting this patient's autonomy would require that the physician allow her patient to die, thereby violating the duty of beneficence. Because that the traditional principlist framework allows for either principle to be given more priority, this physician's belief that death is the greatest harm gives her reason to argue that her duty of beneficence should take moral priority over her duty to respect patient autonomy.

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<sup>40</sup> Engel, Margaret, "A Happy Life Afterward Doesn't Make Up for Torture," *Washington Post* (June 26, 1983).

In further support of her claim, this physician could also argue that respecting her patient's decision and allowing him to die is worse than intervening insofar as allowing him to die would remove the possibility of any future benefit to, or autonomous actions by, the patient. The claim here is that acting paternalistically would not only prioritize the health of the patient, but it could potentially promote the future autonomy of the patient as well. This argument values the preservation of autonomy over the exercise of autonomy by claiming that preserving the patient's ability to make future decisions could justify violating the patient's autonomous directive at present.<sup>41</sup>

In many ways this physician's argument sounds reasonable, and given that the aim of healthcare is to promote health and healing, this is likely indicative of what some actual healthcare practitioners think. Despite medical paternalism being discouraged in practice and getting curbed by policies such as informed consent, which gives priority to the exercise of autonomy over the preservation of autonomy, it nevertheless remains troubling that the traditional principlist framework allows for the justification of extreme measures that are no longer morally condoned in our healthcare system. This demonstrates a problematic disconnect between our moral framework and moral norms.

### *3.2. Justifications for Overtreatment*

While paternalistic attitudes are still prevalent within healthcare, instances of medical paternalism have been substantially decreasing over the decades. However, the shift away from

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<sup>41</sup> Libertarian views of self-ownership support the common view that the exercise of autonomy is more important than the preservation of autonomy, often harkening back to the arguments presented in John Stuart Mill's *Utilitarianism*. While some may disagree with this view, the principle of respect for autonomy is often understood within bioethics to ground the patient's right to *make* autonomous choices, meaning that the principle more clearly supports the exercise of autonomy insofar as it directs us to abide by the patient's present decision-making.



paternalism has given rise to new concerns, namely that the pendulum has swung too far to the opposite end of the spectrum by placing too much emphasis on patient autonomy. Given mounting concerns about overriding patient wishes and the increased emphasis on respecting patient autonomy, it now appears that some practitioners may be too responsive when it comes to appeasing patient preferences, sometimes resulting in instances of overtreatment. On the traditional principlist framework, providing non-indicated care can appear justified when respect for autonomy is taken to the extreme, essentially prioritizing the patient's autonomy even when doing so foreseeably fails to provide a benefit or when it results in harm. Cases involving overtreatment, the continuation of futile treatments, and the providing of non-indicated diagnostic and therapeutic interventions all stem from this shift away from medical paternalism and toward an increased focus on respect for patient autonomy.

Understanding potential justifications for this extreme focus on respect for autonomy starts with examining hospital policies requiring informed patient consent. Informed consent policies are largely couched in the principle of respect for autonomy, requiring that healthcare providers gain authorization from the patient, or a healthcare proxy, before moving forward with any diagnostics, interventions, or research. Though these policies are meant to ensure that patients are allowed to decide and direct the course of their care, what it means to “gain authorization” can be understood in at least two different ways. One sense of authorization can refer to *autonomous authorization*, meaning a patient with substantial understanding of all pertinent information intentionally authorizes a specific action free from coercion or undue

influence.<sup>42</sup> On this understanding, the authorizing of the action denotes the autonomous will of the patient.

Despite claims that autonomous authorization “ought to serve as the benchmark for the moral adequacy of institutional rules,” ethicists including Beauchamp and Childress admit that this standard “may turn out to be excessively difficult or even impossible to implement.”<sup>43</sup> As such, authorization in the clinical setting often refers to a second sense of authorization, known as *effective authorization*. Effective authorization refers to legally effective authorization provided by the patient, as determined by the policies of the institution. Though effective authorization must be free from coercion or undue influence, this standard of consent does not guarantee that the patient has ‘substantial understanding’ of all pertinent information, nor that the authorization necessarily represents the will of the patient.<sup>44</sup>

To ensure that effective authorization is not too divorced from autonomous authorization, informed consent is often thought to require some set of the following elements: Competence in understanding, voluntariness in deciding, disclosure of relevant material information, recommendation of a plan, understanding of this information, a decision in favor of a plan, and authorization of the chosen plan.<sup>45</sup> However, even if satisfying these elements edges a policy of effective authorization closer to meeting the standards of autonomous authorization, there still remains the difficulty of knowing to what extent the patient has actually understood and reasoned

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<sup>42</sup> Faden, Ruth, and Tom Beauchamp, “The Concept of Informed Consent,” from *A History and Theory of Informed Consent*, (Oxford, England: Oxford University Press, 1986), 276-286.

<sup>43</sup> *Principles*, 120.

<sup>44</sup> Just as it is possible to have effective authorization without autonomous authorization, it is similarly possible to have autonomous authorization without effective authorization. For example, a mature minor may come to a reasoned decision about her medical care, yet fail to have the legal authorization to consent. Cases such as these will be addressed in Chapter 3.

<sup>45</sup> *Principles*, 120-121.

through the relevant information. The closer an informed consent policy gets to reflecting the will of the patient, the better the policy is thought to be, because standard justifications for informed consent appeal to the principle of respect for autonomy.

The connection between informed consent and respect for autonomy is readily apparent. Informed consent policies are meant to allow individuals the right to self-determine, to the extent they are capable, by being afforded an opportunity to play an active role in determining the course of their care. From *The Nuremberg Code* to *The Belmont Report*, the importance of respecting persons has been a guiding principle in developing hospital policies as they relate to research subjects and patients. For example, *The Belmont Report* states:

Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided when adequate standards for informed consent are satisfied.<sup>46</sup>

Some authors, such as Onora O'Neill, argue that informed consent is grounded in something more narrow than respect for autonomy, such as preventing deception and coercion.<sup>47</sup> Yet most authors, including Beauchamp and Childress, continue to hold that “respect for autonomy does provide the primary justification of rules, policies, and practices of informed consent.”<sup>48</sup>

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<sup>46</sup> The National Commission, “The Belmont Report.”

<sup>47</sup> O'Neill, Onora, “Some Limits of Informed Consent,” *Journal of Medical Ethics* 29 (2003): 4-7.

<sup>48</sup> *Principles*, 118.

Beauchamp and Childress agree with O'Neill in that informed consent procedures are important for providing assurance that the patient has been neither deceived nor coerced, but unlike O'Neill, they assert that informed consent also includes positive entailments such as instilling the patient with relevant understanding and actively avoiding various forms of manipulation.<sup>49</sup> They claim that informed consent procedures ought to afford patients the opportunity to make substantially autonomous choices — choices that are intentional, that are based on the patient's understanding, and which are free from controlling influences — given that these get us closer to the moral benchmark of autonomous authorization.<sup>50</sup> As such, they see requirements of informed consent as a way for the autonomy of patients to be respected by providing assurances that patients are able to make decisions “free from both controlling interference by others and from certain limitations such as an inadequate understanding that prevents meaningful choice.”<sup>51</sup>

While none of this seems particularly troubling, grounding the justification for informed consent in the principle of respect for autonomy in essence requires that healthcare providers treat the principle of respect for autonomy as though it is preeminent in relation to the other bioethical principles. For informed consent policies affirm a patient's right to refuse care, including life-sustaining care, and as such these policies appear to prioritize the principle of respect for autonomy over the principles of beneficence and non-maleficence. And while the traditional principlist framework does not take a stand on the comparative weights of the principles, having an institutional policy that treats one principle as preeminent is an issue

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<sup>49</sup> *Ibid.*

<sup>50</sup> *Principles*, 100-101.

<sup>51</sup> *Principles*, 99.

insofar as it creates confusion as to how practitioners ought to prioritize the principles in practice. If a healthcare professional is required to prioritize patient autonomy over the other principles in some contexts, such as when a patient refuses care, it is reasonable to think this will spur her to give added weight to patient autonomy in seemingly similar contexts, such as when a patient requests specific care.

To illustrate, requirements of informed consent most straightforwardly ground a patient's right to refuse care even when such care is deemed medically beneficial, and while this can be narrowly understood as safeguarding a patient's right to control what happens to her or his body, it also sends a broader message that a patient's right to control the course of her or his care is so important that it can outweigh even the provision of life-saving measures. The patient's "right to refuse" is grounded in a patient's right not to be interfered with, while the patient's "right to control the course of her or his care" focuses on the relative importance of patient autonomy within healthcare. More specifically, the former understanding interprets autonomy as a negative right while the latter understanding fails to distinguish between respect for autonomy as a negative or positive right. Instead, the latter understanding simply recognizes the importance of respecting patient autonomy in comparison to other moral duties and healthcare goods.

Because debates regarding how the principle of respect for autonomy ought to be interpreted — whether as strictly negative or as containing some positive component — have yet to be settled within the sphere of moral philosophy, the average medical practitioner cannot be expected to have a considered and nuanced view on the matter.<sup>52</sup> As such, the latter

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<sup>52</sup> Christman, John, "Autonomy in Moral and Political Philosophy," *The Stanford Encyclopedia of Philosophy* (Spring 2018 Edition), Edward N. Zalta (ed.), <<https://plato.stanford.edu/archives/spr2018/entries/autonomy-moral/>>; Dworkin, Gerald, *The Theory and Practice of Autonomy* (Cambridge: Cambridge University Press, 1988): 3–7.

understanding of autonomy would not be unreasonable for someone working in the healthcare field to surmise, given the numerous policies and norms related to protecting patient rights. However, failing to distinguish between autonomy as a negative or positive right opens the door for patient requests of care to potentially be considered as equally authoritative as patient refusals of care. For when a patient requests a specific diagnostic procedure or medication, that request can readily be understood as an expression of the patient's wishes and an attempt for that patient to direct her or his own medical care. Moreover, practitioners may feel pressured to abide by such patient requests even when there is no foreseeable benefit, given that patient autonomy is respected regardless of the potential medical benefit when it comes to refusals of care.<sup>53</sup>

This means that just as the traditional principlist framework can be used to justify paternalistic intuitions when beneficence is prioritized to the extreme, it can also justify overtreatment stemming from patient requests for care when patient autonomy is prioritized to the extreme. For if a healthcare practitioner is led to believe that respect for patient autonomy is preeminent given the institutional importance of informed consent and a patient's right to refuse life-sustaining care, she may reason that respect for patient autonomy should also take precedence with regard to a patient's request for care, even when that care isn't medically beneficial.

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<sup>53</sup> Even for those trained in moral theory and bioethical theory, there is an ongoing debate about how exactly the principle of respect for autonomy should be interpreted. It can be understood as entailing both negative and positive rights, and though the assumption of positive autonomy is a controversial interpretation of the principle of respect for autonomy, it nevertheless occurs in actual medical practice. A survey found that 36% of physicians would provide an unnecessary MRI for a patient complaining of lower back pain solely on the grounds that the patient requested the MRI. Campbell, E. G., et. al., "Professionalism in Medicine, Results of a National Survey of Physicians," *Annals of Internal Medicine* 147 (2007): 795-802.

This is especially true when the expected harms are minimal, such as a patient requesting an unnecessary MRI.<sup>54</sup> In cases where the risk of harm clearly outweighs the benefit, healthcare providers might be more reluctant to abide by the patient's request given that their actions would be the direct cause of the harm. For example, it is highly unlikely that a surgeon would agree to remove a generally healthy patient's arm simply because the patient requests the amputation. Yet as the risk of harm decreases, so does the barrier to abiding by the patient's request. When asked to prescribe antibiotics to treat a common cold virus, healthcare providers are sometimes willing to comply, in part because the risk of harm to the patient is minimal, even though the collective public harm is significant.<sup>55</sup> This makes sense given that refusals of care not only prioritize respect for autonomy over beneficence, but also satisfy the principle of non-maleficence insofar as the healthcare provider is withholding an action. From a healthcare provider's perspective, there may appear to be some symmetry between refusals and requests when both are expressions of the patient's wishes and neither causes significant harm to the patient.

This is not to suggest that practicing healthcare professionals do not have justified reasons for refusing patient requests for unnecessary care, but rather that the traditional principlist framework does not readily supply healthcare professionals with such a justification. The traditional framework thus fails to appropriately guide the deliberative process for healthcare providers, and it is precisely in the face of mounting patient pressure and patient requests that

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<sup>54</sup> Ibid.

<sup>55</sup> "Antibiotic use--whether appropriate or not--has been linked to rising rates of antimicrobial resistance, disruption of the gut microbiome leading to *Clostridium difficile* infections, allergic reactions, and increased health care costs. And yet, physicians continue to overprescribe this class of medication. A 2016 Centers for Disease Control and Prevention report estimates that at least 30% of antibiotics prescribed in US outpatient settings are unnecessary. Another report cites a slightly higher figure across a variety of health care settings." Fiore et al., "Antibiotic overprescribing: Still a major concern," *Journal of Family Practice* 12 (2017): 730-736.

healthcare practitioners should be able to appeal to bioethical principlism for guidance, especially as overtreatment becomes increasingly prevalent.<sup>56</sup>

### 3.3. *Post Hoc Justifications*

Not only is it troubling that the traditional principlist framework can be used to justify two diametrically opposed extreme positions, but these examples also highlight a further issue regarding the framework's openness to *post hoc* justifications, meaning the framework can simply be used to support a pre-reflective conclusion as opposed to the physician being guided to a conclusion via the framework. This is another way in which the traditional framework fails to guide decision-making within healthcare, and it is concerning that healthcare providers are able to *appeal* to the traditional principlist framework in order to justify their reasoning without first employing the framework to *guide* their reasoning. So long as the healthcare provider can provide reasons in support of her prioritization of the principles, reasons that she could have formed prior to and independently of considering the case at hand, then she is able to utilize the framework after the fact in order to provide a justification for her pre-formed conclusion regarding what should be done.

The fact that the traditional framework is susceptible to being used to justify decisions *post hoc* is a further consequence of the framework's insufficient structure and guidance; instead of guiding one's initial thinking, the traditional principlist framework simply allows one to create a justification for the action that already aligns with their pre-reflective thinking. If the traditional framework could only be used to justify a range of actions that fit within the accepted norms of

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<sup>56</sup> A 2017 survey estimated that 20% of all medical care is unnecessary and found that physicians reported 'patient pressure/request' as a reason for overtreatment 59% of the time. Lyu, Heather et al., "Overtreatment in the United States," Ed. Imelda K. Moise. *PLoS ONE* 12.9 (2017): e0181970. PMC. Web. <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5587107/>>



healthcare, perhaps this would not be of significant concern and the framework could be used as a check on the permissibility of proposed actions. However, given that the traditional principlist framework can be used to justify a large range of actions including those that fall outside of the accepted norms, it seems fair to say that this framework not only fails to offer appropriate guidance but also fails to act as a check on those who need it most.

#### **4. The Refusal/Request Asymmetry**

Thus far I have argued that the traditional principlist framework lacks a clear decision procedure for weighing and balancing the principles, and that this lack of structure combined with the *prima facie* nature of the principles results in the *extremism criticism*. I have also argued that the traditional framework is additionally problematic in that it allows for *post hoc* justifications on the part of healthcare professionals. I will next argue that even the policies and protocols enacted to safeguard against the practices of medical paternalism and overtreatment cannot be justified by appeal to the traditional principlist framework. While the previous two sections criticized the traditional framework on the grounds that it fails to offer sufficient moral guidance for those engaged in healthcare practice, this argument criticizes the framework on grounds that it fails to offer support for common healthcare policies and moral intuitions.

As mentioned, although the traditional principlist framework allows for the justification of medical paternalism and overtreatment, standard hospital policies do not. Policies of informed consent allow patients to refuse any unwanted care, thereby stopping practitioners from being overtly paternalistic, and policies aimed at limiting instances of overtreatment or the provision of futile care support practitioners in refusing patient requests for unnecessary care. As a result of these policies, patient refusals of care are almost always abided by in practice while patient requests for care are not. Honoring patient refusals of care while limiting patient requests for care

is best described as an asymmetry with regard to patient refusals and requests, and while these policies may seem intuitively correct, I will argue that traditional principlist framework has trouble accounting for the justification of this request/refusal asymmetry in practice.

As discussed in section 3.2, when determining how to respond to a patient, healthcare providers must consider how much weight to give the principle of respect for autonomy as well as how the principle ought to be interpreted. Interpreting the principle of respect for autonomy as a strictly negative duty means that one satisfies this duty by adhering to a policy of non-interference; that in order to respect the autonomy of a patient, one ought to refrain from interfering in the affairs of that individual.<sup>57</sup> This interpretation makes sense of a patient's right to refuse care, even when treating the patient would be medically beneficial. For example, in the case of Dax Cowart, an interpretation of respect for autonomy focused on negative rights or non-interference means that Dax's medical team acted inappropriately by treating him without his consent and in spite of his explicit and continued refusals, regardless of the fact that the interventions were necessary to sustain Dax's life.

When it comes to patient requests for care, the American Medical Association (AMA) is clear that requests for care need only be abided by when determined to be medically beneficial.<sup>58</sup> This suggests that unlike refusals of care, when it comes to patient requests for care the principles of beneficence, non-maleficence, and justice are given priority over the principle of respect for autonomy. This seems right insofar as a patient's right to direct her or his medical

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<sup>57</sup> Childress, James, "The Place of Autonomy in Bioethics," *Hastings Center Report* 20 (1990):12-17. "The principle of respect for autonomy can be stated negatively as 'it is [prima facie] wrong to subject the actions (including choices) of others to controlling influence.'...This negative formulation focuses on avoidance of controlling influences, including coercion and lying."

<sup>58</sup> *AMA Principles of Medical Ethics: I, IV, V*; Code of Medical Ethics Opinion 5.5: Medically Ineffective Interventions (2018). <<https://www.ama-assn.org/delivering-care/medically-ineffective-interventions>>

care should not include access to any and all services the patient thinks would be beneficial. For doing so would be to reduce healthcare to nothing more than a consumer-based product, and it would no longer be complying with the general goal of promoting health and healing. This also fits with a strictly negative interpretation of respect for autonomy, for a strict right not to be interfered with cannot obligate positive assistance from others. In terms of moral theory, we can thus make sense of the asymmetry between refusals and requests by appealing to a strictly negative interpretation of respect for autonomy: A right to non-interference can stop a provider's action via refusal but cannot initiate a provider's action via request. However, as discussed previously, this negative formulation of respect for autonomy is not the only formulation to be had.

Despite this negative formulation of respect for autonomy being the most natural and common interpretation of the principle, Childress notes that “the principle of respect for autonomy also has clear positive implications in the context of certain relationships, including health care relationships... it engenders a positive or affirmative obligation to disclose information and foster autonomous decisionmaking.”<sup>59</sup> As a positive duty, respect for autonomy “requires both respectful treatment in disclosing information and actions that foster autonomous decision making... that we assist them in achieving their ends and fostering their capacities as agents, not merely that we avoid treating them solely as means to our ends.”<sup>60</sup> While Beauchamp and Childress do not go so far as to say that respect for autonomy requires assisting patients to achieve specific ends, they make it clear that respect for autonomy amounts to more than simply non-interference. On their view, respect for autonomy requires that healthcare providers

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<sup>59</sup> Childress, “The Place of Autonomy in Bioethics,” 13.

<sup>60</sup> *Principles*, 104.

sometimes take active steps to help maintain or increase a patient's capacity for autonomous decision-making, though what specific actions this may justify remains unclear.

Regardless of what precisely Beauchamp and Childress had in mind when suggesting healthcare providers may sometimes take positive steps to enable patients to act autonomously, by suggesting that respect for autonomy may require more than non-interference they open the door to the idea that healthcare providers may sometimes be required to take positive steps as a part of respecting a patient's autonomy. In the clinical setting, it matters less what Beauchamp and Childress intended by raising the idea of these positive duties, than how healthcare providers interpret their obligations with regard to respecting patient autonomy. For although we can make sense of the refusal/request asymmetry in theory by appealing to a strictly negative interpretation of the principle of respect for autonomy, the distinction between negative and positive autonomy can easily become blurred in practice: Negative autonomy can slide into positive autonomy given this suggestion of positive duties, as well as policies such as informed consent which treat respect for autonomy as preeminent among the principles.

In practice, given that respect for autonomy grounds a patient's right to refuse medical care even when it doing so runs counter to the principles of beneficence and non-maleficence, a healthcare provider could understandably infer that respect for autonomy similarly grounds a patient's right to request medical care even when that care runs counter to the principles of beneficence and non-maleficence. Such an inference is especially likely if most healthcare providers understand "respect for patient autonomy" to mean something general such as "respect the patient's right to self-direct." Noting that a particular option fails to benefit the patient seems like the most straightforward means of justifying a denial of a patient request, but this is the issue with having an open framework and treating one principle, respect for autonomy, as preeminent

in practice: If the principle of respect for autonomy is given significant weight over the other beneficence and non-maleficence in one context (refusals), it not unreasonable to think the principle of respect for autonomy should also be given significant weight in adjacent cases (requests).<sup>61</sup>

While I cannot account for the actual thinking of every healthcare provider who provides non-indicated care at the patient's request, what I can say is that the apparent preeminence of respect for autonomy within healthcare can reasonably be appealed to as justifying such an action, and the traditional principlist framework fails to clarify why requests for care should be treated differently from refusals of care. This inability of the traditional framework to provide a clear and decisive reason to refuse patient requests for care is concerning because overtreatment is a real issue and healthcare practitioners cite patient requests as the primary reason for providing non-indicated care.<sup>62</sup>

Perhaps concerns about the seeming justification of overtreatment can be resolved by further exploring the concept of patient autonomy, by examining what is fully entailed in the idea of respecting autonomy, through grounding the requirement of informed consent in some other principle such as non-maleficence, or by diving into the philosophical nuances regarding acts and omissions. Unfortunately, those actively engaged in healthcare practice have neither the time nor the training to defend their actions through these means. What these providers need is a strong

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<sup>61</sup> Another way to justify denying a patient's request could be by prioritizing the principle of justice. However, the same issue regarding the apparent preeminence of respect for autonomy still stands meaning that healthcare providers may not see it as outweighing autonomy, and if the request is for a generally non-scare resource, such as access to an MRI machine, justice seems to hold even less weight.

<sup>62</sup> As mentioned in footnotes 35 & 36, a 2017 survey estimated that 20% of all medical care is unnecessary and found that physicians reported 'patient pressure/request' as a reason for overtreatment 59% of the time, and a 2007 survey found that 36% of physicians would provide an unnecessary MRI for a patient complaining of lower back pain solely on the grounds that the patient requested the MRI.

reason for refusing patient requests of non-indicated care and a clear way of justifying and communicating this to patients. This is precisely what the traditional principlist framework fails to provide.

## **5. The Normative Underpinnings of Bioethical Principlism**

I have spent much of this chapter problematizing the leading bioethical theory in healthcare, but this is not to say that bioethical principlism is without merit. In contrast to some of the earlier criticisms, I will next argue that bioethical principlism has a strong moral foundation and is especially fitting for healthcare given its pluralistic nature. My specific concern has been that the leading principlist framework is insufficiently guiding for those regularly engaged in healthcare practice, but this criticism is not inherent to bioethical principlism itself. To understand how bioethical principlism can best be implemented in healthcare, I will now step back and consider the normative foundation of bioethical principlism as well as competing bioethical views.

In considering how the bioethical principles relate to normative ethical theories, I think the four principles can generally be grouped into those that are consequentialist and those that are deontic in nature. Though this division is not always clear-cut, in most instances it is fair to classify the principles of beneficence and non-maleficence as consequentialist in nature, and the principles of respect for autonomy and justice as being deontic in nature.<sup>63</sup> The principles of

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<sup>63</sup> Some may argue that a sufficiently complex understanding of consequentialism may be able to make sense of the importance of respecting people's rights, meaning the principles of respect for autonomy and justice could be understood as being grounded in a consequentialist theory. I find this approach philosophically interesting and I do not think such an interpretation would undermine my overall argument, given that what is important is to understand these principles to function as binaries indicating whether a patient's rights have been respected or violated. My designation of respect for autonomy and justice as deontic is simply meant to reflect this binary nature of these principles, and to contrast these with the principles of beneficence and non-maleficence which function on a continuum and regard the promotion of patient health.

beneficence and non-maleficence are consequentialist insofar as they aim at bringing about and avoiding certain types of ends, and these distinct principles are sometimes referred to as “the principle of utility” when understood as working in concert. The principle of utility directs one to produce the most favorable balance of benefit over harm, meaning that one should act to maintain or promote a patient’s health while minimizing any potential risks.

The principles of respect for autonomy and justice, on the other hand, differ in that they concern not the promotion of a person’s health but rather the rights and liberties of individuals. It is commonly accepted that in a liberal society such as ours, all individuals are free and equal: All persons are free insofar as they are not naturally subject to the will of another, and each is equally capable of formulating an individual life plan and directing her or his life in accordance with that plan. In order to adhere to the principle of respect for autonomy, healthcare providers must respect their patients by acknowledging the right of each individual to direct core aspects of her or his life, including which courses of medical care she or he is willing to undergo. The principle of respect for autonomy does not make exceptions for the potential benefit that may be provided or inhibited by the patient’s decision, and this often results in an ethical tension with the principle of beneficence. Like the principle of respect for autonomy, the principle of justice is also concerned with the rights and liberties of persons but applies to groups as opposed to individuals. More specifically, justice demands that we ensure a fair distribution of benefits and burdens across a relevant population, though what a fair distribution looks like is sometimes spelled out in different ways.

Because the bioethical principles relate to differing prominent normative ethical theories, a resulting pluralistic framework can avoid engaging in a debate over which moral theory is correct. Instead, principlism can take each moral theory to be saying something meaningful

about right actions while remaining ecumenical between them. In a pluralistic society such as ours, an approach that offers room for individuals to freely prioritize their values is important, especially given that healthcare depends in part on recognizing and respecting the values and goals both between individuals and within individuals. For within each individual there are distinct lines of reasoning, and ethical frameworks function to provide us with guidance in deciding between one line of reasoning or another without dictating which outcomes one ought to privilege.

A pluralistic approach to healthcare recognizes that each normative theory contributes toward our understanding of how to engage with others, and a pluralistic ethical framework allows an individual to act on her or his values while still being able to respect the differing values of other individuals. Moreover, many individuals are themselves pluralists, and bioethical principlism captures the competing moral values from which most people reason, exemplified by the four bioethical principles.<sup>64</sup> This is important because although the expected consequences of healthcare interventions can help providers assess whether or not it would be beneficial to proceed with a proposed action, the promise of good consequences should not undermine or remove the patient's right to accept or refuse those consequences for themselves. Given all this, I think the pluralism inherent in bioethical principlism makes it a well-suited ethical theory for the healthcare setting.<sup>65</sup>

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<sup>64</sup> Beauchamp and Childress, *Principles*, 12-13. "The set of moral principles defended in this book functions as an analytical framework intended to express general norms of the common morality that are a suitable starting point for biomedical ethics... We treat principles as the most general and comprehensive norms, but we draw only a loose distinction between rules and principles. Both are general norms of obligation."

<sup>65</sup> For further defences of pluralism, see Slote, Michael A., *Common-Sense Morality and Consequentialism* (Routledge & Kegan, 1985) and Scheffler, Samuel, *The Rejection of Consequentialism: A Philosophical Investigation of the Considerations Underlying Rival Moral Conceptions* (Oxford University Press, 1994).



Though no other ethical theory has gained more traction in healthcare than bioethical principlism, other bioethical approaches have also been argued for over the years: Casuistry, monism/deductivism, specified principlism, moral particularism, and anti-theoretical approaches such as narrative ethics. Casuistry is a bioethical approach employing case-based reasoning and works by discerning key rules or principles in an exemplar case in order to apply those same rules or principles to a relevantly similar case. Though this can be useful to deploy in certain instances, as an overarching theory it is often criticized for lacking any moral force given that it provides no clear or consistent moral norms or goals.<sup>66</sup> Moreover, there may be substantial disagreement about which principles or rules to draw from an exemplar case, as well as how they ought to be applied to a new case. This renders casuistry largely unhelpful in a practical setting.

At the other end of the spectrum, deductivism is a monist theory focusing on a single foundational principle for providing ethical justification. The foundational principle could be consequentialist or deontological in nature, and ethical judgments are derived from considering this foundational principle given relevant information about the case.<sup>67</sup> Though each normative theory may have its appeal, expecting care providers to commit to and act on a singular normative theory is impractical and unhelpful given the prior discussion of ethical pluralism. Promoting this in a clinical setting could result in health care providers adhering to differing ethical norms, leading to inconsistent or contentious care both between providers and between providers and their patients. Moreover, such thinking is what undergirds practices like medical paternalism, which has been denounced by bioethics groups and medical associations alike.

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<sup>66</sup> Strong, Carson, "Critiques of casuistry and why they are mistaken," *Theoretical Medicine and Bioethics* 20 (1999): 395-411.

<sup>67</sup> For more on deductivism, see David DeGrazia, "Moving Forward in Bioethical Theory: Theories, Cases, and Specified Principlism," *Journal of Medicine and Philosophy* 17 (1992): 512.

Apart from deductivism, most alternatives to bioethical principlism are anti-theoretical approaches. This includes casuistry, specified principlism, moral particularism, and narrative ethics. *Specified principlism*, put forth by David DeGrazia, attempts to combine these different approaches; like traditional principlism it begins with foundational principles, but differs in that it employs casuistry in drawing relationships between norms of differing levels and allows for discursive justification throughout the system. *Moral particularism* denies that the moral valence of any particular element must remain consistent across cases, while *narrative ethics* looks to specific narrative cases to help discern moral problems and consider resolutions. As with casuistry, these various approaches may be useful as supplemental means of working through cases, but each lacks the foundational moral grounding of bioethical principlism, making them far less practicable for guiding moral thinking in a diverse healthcare setting.

## **6. Normative Critique of Bioethical Principlism**

The main criticisms of bioethical principlism discussed in section 2 were put forth by many of the authors arguing for the alternative theories mentioned in section 5: DeGrazia was pointing out the flaws in order to argue in favor of Richardson's specified principlism; Clouser and Gert used their critique to bolster an argument for deductivism; Gordon et al. thought they could resolve the issues with an organizing meta-principle of common morality. While this to be expected and in no way invalidates the criticisms they present, it may have stopped these authors from considering a deeper issue with the traditional principlist framework and way in which this issue might be resolved. Specifically, I think the main issue with bioethical principlism, as presented in the traditional principlist framework, is the idea that all four principles ought to be weighed against one another and that the reasons pertaining to one principle can justifiably override the reasons pertaining to the others.

Thus far the main concerns raised have been regarding the usefulness of the traditional framework in a healthcare setting, as well the types of actions it could be used to justify. I will now argue that these concerns stem from a more fundamental criticism, namely that it is unclear, as DeGrazia notes, what grounds or justifies the principles in the first place:

[Beauchamp and Childress] go on to develop an account of *prima facie* principles, which they refer to as their 'theory.' So why are the 'higher' theories necessary? They appear to play no significant justificatory role in their system, yet invite seemingly pointless disputes between rule-utilitarians and deontologists. What is important is the convergence of the two theories, and the convergence occurs at the level of principles and at 'lower' levels.<sup>68</sup>

Though DeGrazia suggests that the normative theories have little role to play in actually grounding the bioethical principles, Clouser and Gert seemingly acknowledge that there is a clear relationship between the principles and certain normative theories, given that when we prioritize some principles over others we appear to be acting in line with certain normative values:

The four main theories are reduced to four principles from which agents are told to pick and choose as they see fit, as if one could sometimes be a Kantian and sometimes a Utilitarian and sometimes something else, without worrying whether the theory one is using is adequate or not.<sup>69</sup>

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<sup>68</sup> Degrazia, "Moving Forward in Bioethical Theory," 519.

<sup>69</sup> Clouser and Gert, "A Critique of Principlism," 223.

Even though it remains unclear exactly to what extent the principles are meant to draw on these normative theories, I think it is right to draw this connection between the principles and normative theories. No one denies that beneficence and non-maleficence are both consequentialist in nature, and as previously mentioned they are sometimes referred to as the “principle of utility” when considered collectively. Similarly, it is readily apparent that the principles of respect for autonomy and justice draw on deontic values insofar as they are concerned with the rights of individuals and groups.

While Clouser and Gert criticize the traditional principlist framework on the grounds that one may pick and choose when to be a utilitarian or when to be a Kantian in order to justify the outcome most desired, pointing to a weak relationship between the principles and normative theories, I contend that the issue lies in the fact that Beauchamp and Childress have rather failed to fully draw out the necessary relationships between these principles and theories. The fundamental issue with the traditional principlist framework is not a weak connection between the principles and the normative theories, but rather the idea that principles grounded in competing normative theories can easily and justifiably override one another.

Specifically, I take issue with the claim that the principles can be weighed and balanced against each other as a means of determining which moral norms ought to prevail. Though some may object that it is not incoherent to imagine weighing consequentialist reasons against deontic considerations, my claim is not that doing so would be incoherent. Rather, allowing such a trade-off fails to acknowledge the core value underlying each principle, resulting in an ethical framework with too much indeterminacy and the ability to justify wrong actions. By treating all four principles as though they can be weighed and balanced against one another, Beauchamp and

Childress allow for a consequentialist reason to outweigh a deontic reason in one case and a deontic reason to justifiably outweigh a consequentialist reason in another. This is what opens the door for the justification of extremist positions, as discussed in section 3, and fails to recognize that a deontic reason is not the sort of reason that holds weight only when the consequences permit, or that may be overridden by a good consequence. This is to misunderstand the nature of a deontic principle and the sort of reasons it supplies, just as it is to misunderstand the nature of a consequentialist principle to suggest that it may be overridden by deontic concerns.

Deontic reasons are binary insofar as they either permit or restrict an action, given the duties of the moral agent and the natures of those with whom she or he is engaging. Failing to treat a deontic reason in this manner is to fail to act appropriately given the reasons one has available. Conversely, consequentialist reasons take into consideration the harms and benefits that may result from some action, largely ignoring concerns about the rights of any given individual. Unlike deontic reasons, consequentialist reasons can be assessed on a sliding scale of better to worse, with the most compelling reasons being those that justify the best state of affairs comparatively.<sup>70</sup> Allowing consequentialist considerations to be weighed against deontic considerations not only allows for the justification of paternalistic actions, but can also allow for healthcare providers to perform actions that would be detrimental to the health of their patients in the name of respecting a patient's right to autonomy, as is sometimes the case with

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<sup>70</sup> For some contemporary characterizations of consequentialist positions, see Peter Singer, Peter Railton, and Henry Sidgwick.

overtreatment.<sup>71</sup> This cuts against the goal of healthcare and a healthcare provider's duty to benefit her or his patients.

As argued for in the previous section, the appeal of bioethical principlism is the pluralistic nature of the principles in that they can capture numerous competing values, yet the primary issue has been the lack of systematic deliberation when those values compete. I think the solution is to recognize the role these values actually play in the practice of healthcare. If the primary goal of healthcare is to promote or maintain health and healing by pursuing courses of action that have favorable balances of benefits over harms, this suggests that a healthcare provider's recommendations should include consequentialist considerations, guided by the principles of beneficence and non-maleficence. Yet pursuing this goal should not come at the cost of violating a patient's rights, meaning a healthcare provider's actions should at the same time be constrained by the patient's willingness to accept the recommendation, drawing on the importance of respect for autonomy. As such, I think healthcare practice is best guided by a pluralistic framework that contains consequentialist considerations yet maintains deontic constraints. The advantage of this view is that it can take from both consequentialism and deontology, capturing an element of the consequentialist view by assigning great significance to the consequences of therapeutic interventions yet still allowing room for patients to self-determine given the deontological constraints.

This is additionally supported when we consider the history of healthcare, as discussed in section 1. Healthcare was largely paternalistic until the late 1970's, when public outcry following

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<sup>71</sup> Note that this would only be true given a view where the healthcare professional is seen as having an obligation to support or assist with a patient's autonomous wishes, requiring that respect for autonomy be understood as a positive right. This is a controversial view, but not outside the realm of consideration, especially as a practical matter.

Dax's case and legal decisions such as *Bouvia v. The Superior Court* finally forced healthcare practitioners to respect patient refusals of beneficial care. Court cases finally put into law what *The Nuremberg Code*, *The Declaration of Helsinki*, and *The Belmont Report* had all been suggesting, namely that respect for autonomy and justice place constraints on what healthcare providers can and cannot do in the pursuit of benefitting patients. This means that while the principles of beneficence and non-maleficence guide healthcare, the principles of respect for autonomy and justice act as constraints on what may be done.

## 7. Concluding Remarks

Given the above understanding of how the normative theories relate within healthcare, it becomes clear why a framework that allows one to freely 'weigh and balance' each of the four principles against the others is unsuccessful in guiding deliberation and resolving conflicts. Understanding each of the principles to be *prima facie* allows consequentialist reasons to be outweighed by deontic reasons, and deontic reasons to be outweighed by consequentialist reasons, therein diminishing the normative force of each. Moreover, to claim that the principles can be weighed against one another is to suggest that it is the job of healthcare providers to determine the trade-off between a patient's health and a patient's rights. Yet healthcare providers have neither the resources nor the right, legally or morally, to make such a decision regarding their patients.<sup>72</sup>

In the next chapter I will put forth a structured framework that acknowledges how the principles are grounded in these normative values and organizes the principles such that these

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<sup>72</sup> From a consequentialist perspective it can be argued that no individual has better access to what will benefit a person all-things-considered than the individual herself, and from a deontological perspective that no one has the right to make decisions of this nature for an autonomous individual.

values are appropriately respected. This framework will be centered around two conditions, one consequentialist and the other deontic in nature. By respecting the division between the deontic and consequentialist principles, these conditions will imbue different values while imposing checks on each other. Specifically, the deontic condition will constrain healthcare providers such that medical paternalism cannot be justified, and the consequentialist condition will constrain patients such that demands for non-indicated treatments will have no force. The decision procedure laid out in this structured principlist framework will also cut back on the ability of healthcare professionals to bend the principles such that they fit with their pre-formed judgements, will provide clear guidance on how to evaluate the moral permissibility of a given action, and will more accurately capture how the principles are employed in real-world healthcare practice.



## CHAPTER II. A STRUCTURED PRINCIPLIST FRAMEWORK FOR DECISION MAKING IN HEALTHCARE

The previous chapter raised several distinct, yet interrelated criticisms of Beauchamp and Childress's traditional principlist framework that follow from the central concern that the traditional framework fails to recognize the different types of reasons stemming from the differing bioethical principles. The traditional principlist framework utilizes a weighing and balancing approach to decision-making that allows for each principle to justifiably override the others, therein allowing for consequentialist reasons to override deontic reasons and vice versa.<sup>73</sup> As discussed, allowing the principles to trade off in this manner fails to acknowledge the core value underlying each principle, results in too much indeterminacy, and allows for the justification of extreme positions that run counter to the core values of healthcare. Given this, I concluded by suggesting that a successful principlist framework is one that acknowledges the normative foundation of the bioethical principles and orders them such that the value of each principle is respected. The aim of this chapter is to put forth such a framework, which I have termed the *structured principlist framework*, or *structured principlism* when being employed.

The structured principlist framework groups the four bioethical principles into two distinct sets, based on the fundamental normative theory in which each principle is grounded. Beneficence and non-maleficence are grouped along consequentialist lines to form what I have termed the *favorability condition*, and given their deontic similarities, respect for autonomy and justice are grouped together to form the *enabling condition*.<sup>74</sup> My argument for separating the

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<sup>73</sup> For my full discussion of these criticisms, see Ch. 1, sec 2.

<sup>74</sup> Some may argue that a sufficiently complex understanding of consequentialism may be able to make sense of all four bioethical principles, or that justice isn't always understood as a deontic principle. While I find these debates to be philosophically interesting, they do not challenge or change our understanding the structured principlist

principles in this manner is that doing so appropriately constrains the ways in which the principles interact, as such limiting the concerns about indeterminacy and extremism. The resulting framework will be a structured principlist approach to ethical decision making without the need for weighing or balancing.<sup>75</sup>

After explaining the structure and functioning of the structured principlist framework, I will demonstrate its ability to appropriately guide deliberations by applying it to cases involving patient refusals and patient requests of care, the two types of cases that presented the most difficulty for the traditional principlist framework in Chapter 1. When working through these cases, I will contrast the structured principlist framework with the traditional principlist framework to demonstrate how assessing the moral permissibility of a proposed action in terms of two conditions provides a simplified, more guiding, and less capricious framework than the traditional principlist framework.

### **1. The Favorability Condition**

Healthcare has traditionally been guided by the principles of beneficence and non-maleficence, emphasizing the professional's obligation to heal while minimizing harm. The principle of beneficence grounds a healthcare provider's duty to promote the health of her patients while its counterpart — the principle of non-maleficence — grounds a duty to refrain from causing unnecessary or unjustified harm.<sup>76</sup> Taken together, the principles of beneficence

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framework. My designation of the principles as deontic or consequentialist is simply meant to reflect the ways in which these principles are generally understood and whether they function along a continuum or as a binary constraint within the framework.

<sup>75</sup> There may still be the need for some weighing insofar as healthcare professionals must assess the benefits of some procedure relative to the risks in order to determine if that procedure would be beneficial, but this weighing is empirical assessment of known risks and benefits stemming from medical expertise and does not involve the weighing or balancing of moral principles that is at issue with the traditional principlist framework.

<sup>76</sup> Beauchamp, Tom, and James Childress, *The Principles of Biomedical Ethics*, 6th edition (Oxford, England: Oxford University Press, 2009): 149. "The principle of nonmaleficence imposes an obligation not to inflict harm on

and non-maleficence point to considerations that favor certain actions over others, helping to guide practitioners' thinking in assessing how beneficial various actions would be on the whole. My proposal is to combine these principles into a single condition termed the *favorability condition*.<sup>77</sup> To satisfy the favorability condition, an action must be favorable in terms of promoting the health of the patient, meaning the foreseeable risks must be outweighed by the foreseen likely benefits.<sup>78</sup>

Although the goal of healthcare is to promote patient health, satisfying the favorability condition requires neither recommending nor performing the action that is expected to *maximize* the health benefits for the patient.<sup>79</sup> Rather, there is a minimum threshold of favorability that actions must reach in order to be considered beneficial and satisfy the favorability condition. This is because requiring healthcare providers to offer or perform only those options that would maximize health benefits may frequently result in the exclusion of reasonable alternatives, significantly limiting the set of options from which patients may select. This is problematic for several reasons. One issue is that there is often a positive correlation between the expected harms and benefits associated with an intervention, meaning interventions expected to yield significant

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others.” On page 197 they go on to claim that “principles of beneficence potentially demand much more than the principles of nonmaleficence, because agents must take positive steps to help others, not merely refrain from harmful acts.”

<sup>77</sup> Beauchamp and Childress, *Principles*, 149. Beauchamp and Childress note that “some philosophers combine nonmaleficence with beneficence to form a single principle.” However, the traditional principlist framework put forth by Beauchamp and Childress allows for these principles to function independently given the *prima facie* nature of each. My view differs in that it treats these two principles as different aspects of a single duty, the duty to act for the benefit of the patient by aiming to promote the health of the patient through morally acceptable means.

<sup>78</sup> Healthcare providers may also have to account for “known unknowns” and the potential for “unknown unknowns” depending on the situation and available evidence. Chapter 2, section 1.3. will examine the assessment of, and minimum requirements for, satisfying the favorability condition.

<sup>79</sup> By “maximize the health benefits” I mean the option that provides the most net benefit for the patient. Because the maximization of benefits is being discussed within the context of the favorability condition, this should not be understood to exclude the consideration of relevant risks.

benefits often come with higher risks, such as performing invasive surgery or providing chemotherapy. When necessary, these interventions can save patients' lives, yet they also pose serious risks to patients. Some risk-averse patients may prefer to try mid-range, lower-risk/lower-benefit alternatives first, and failing to offer those alternatives verges on being paternalistic toward the patient.<sup>80</sup>

Additionally, there may be non-health related considerations that push a patient toward preferring a mid-range option, such as the amount of time the patient can take off from work, issues with transportation to and from appointments, the out-of-pocket expenses the patient would incur, particular moral or religious beliefs such as eschewing blood products or animal products, etc. Real patients have real lives that complicate their willingness or ability to accept certain treatment options, and healthcare providers should work with patients to determine which interventions best fit with each patient's unique situation.<sup>81</sup> Moreover, if a patient is only told about the intervention expected to maximize health benefits and the patient refuses that intervention, the healthcare provider is faced with a dilemma: They must either provide the patient with an alternative option or fail to treat the patient altogether.

Failing to treat the patient when there is a reasonably beneficial, albeit less beneficial, alternative available violates the healthcare provider's duty of beneficence because it would be to knowingly withholding care that could help the patient. Such an ultimatum — “accept the one

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<sup>80</sup> An example of this was discussed in Chapter 1, section 1.1. In that example, I discussed two possible treatment options for patients with congestive heart failure, undergoing a CABG or receiving medical management, noting why some patients may prefer the lower-risk option of medical management.

<sup>81</sup> An alternative suggestion might be that healthcare providers should recommend the option that maximizes benefit for the patient all-things-considered, but I find this highly impractical for it would require the healthcare professional to have a deep and intimate knowledge of the patient's life circumstances, goals, and values prior to offering a recommendation. While such a relationship may be the moral ideal, it fails to recognize the realities of modern healthcare. Moreover, it is unrealistic to expect a highly specialized professional to know such intimate details about a patient who has recently been referred to them, yet this professional may need to quickly offer a recommendation regarding the patient's care.

treatment plan I am offering or receive no care” — would cut against the goals and practice of healthcare. This suggests that the better route would be offering an alternative should the patient refuse the option with expected maximal benefit, yet offering a reasonable alternative only *after* the patient refuses the care initially offered threatens to undermine the trust relationship between the patient and provider. Some patients may feel coerced or deceived having not been given a range of options from the beginning, and patients could justifiably wonder what other relevant information is being kept from them.

One final consideration is the practical challenge inherent in determining which option would maximize the expected health benefits. In this section, I will go on to argue that the assessment of favorability relies on a healthcare provider’s epistemic competency, practical experience, and knowledge of the patient’s unique situation. Given the various considerations that go into assessments of favorability, it would be overly demanding — perhaps even unreasonable — to require that healthcare professionals not only assess the favorability of each alternative but also make definitive assessments about how the options stack up against one another. While in some cases there may be one option that clearly stands out as maximizing health benefits, in many cases there is likely to be reasonable disagreement about which option maximizes benefits. Because there is less likely to be reasonable disagreement about the range of options that would likely provide a benefit, this adds support for the idea that healthcare providers can best fulfill their obligations by determining the eligible set of favorable options.

This suggests that the best practice would be to provide patients with an eligible set of options at the outset, with the eligible set being those options that satisfy the favorability

condition in that they are reasonably expected to promote the health of the patient.<sup>82</sup> This would allow the patient to exercise some control over their healthcare by selecting the option that best fits with their unique goals of care, their current lifestyle, and any particular values that may be relevant to their decision. While this may allow room for patients to make imprudent decisions by selecting the least favorable of the options presented, constraining the patient's choice by only offering the most beneficial options would be paternalistic.<sup>83</sup> Unfortunately, allowing room for the possibility of imprudence is an unavoidable part of respecting patients' rights to make autonomous decisions. However, by requiring a minimum threshold of favorability, what we can do is ensure that each of the options contained in the eligible set will be medically appropriate for the patient in that each is reasonably expected to result in more benefit than harm.

Actions that fail to satisfy the favorability condition are those that are reasonably foreseen to result in more harm than benefit, or those that result in no foreseeable benefit and might be considered futile.<sup>84</sup> On the structured principlist framework, satisfying the favorability condition is necessary for the moral permissibility of an action within healthcare, meaning actions that fail to meet this threshold of favorability are morally impermissible for a healthcare professional to perform.<sup>85</sup> Assessing whether a proposed action would meet this threshold

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<sup>82</sup> Chapter 2, section 1.3., will discuss the criteria for the creation of an eligible set.

<sup>83</sup> This does not imply that any time a patient selects the least favorable option that they are being imprudent, for some patients may have good reason for selecting the least favorable alternative. Rather, I am acknowledging that my view does allow for a patient to select the least favorable option without a convincing reason for doing so. So long as the patient does not lack decision-making capacity, it is the patient's right to determine which option they prefer to pursue, even if others think they are making an unwise decision. Issues related to patient consent and autonomy will be further discussed in the context of the enabling condition, Chapter 2 section 2.

<sup>84</sup> Chapter 3, Section 2, discusses the philosophical literature on how to best understand and employ the concept of futility before examining futility in light of the structured principlist framework.

<sup>85</sup> Almost all potential therapies poses at least a minor risk, and if there is no attending benefit the action would fail to meet the minimum requirement for the favorability condition. This means that the provision of futile care and non-indicated care are morally impermissible given that they fail to bestow a health benefit. Considerations related to policies prohibiting futile care will be discussed in Chapter 3, section 2.

requires a utility calculation, which is fitting given that the principles of beneficence and non-maleficence are consequentialist in nature. A proposed action's favorability should be calculated based on the expected health outcomes for the patient, requiring that the healthcare provider be epistemically competent and adhere to professional norms. Given that this condition is informed by and grounded in the normative and epistemic obligations of healthcare professionals, I will next examine the basis for these professional obligations including what is unique about the nature of the healthcare profession.<sup>86</sup>

### *1.1. Normative Obligations*

When thinking about the normative obligations of healthcare professionals, we must begin by considering what characterizes a professional and what being a member of a profession entails morally. According to Michael Bayles, there are three necessary features of all professions:

- 1) That they require extensive training to practice,
- 2) that the training involves a significant intellectual component, and
- 3) that the trained ability provides an important service to society.<sup>87</sup>

More robustly, this means that a professional is understood to refer to an individual with a unique or specialized skillset beyond what the average person is expected to have, has the ability to analyze problems and advise others within their area of expertise, and who provides a service

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<sup>86</sup> Some may object to my classifying epistemic obligations as distinct from normative obligations, given that epistemology is a normative field. One could therefore understand my discussion of epistemic obligations as focusing on a subset of the broader normative obligations of the healthcare profession.

<sup>87</sup> Bayles, Micheal, *Professional Ethics* (Belmont, CA: Wadsworth Publishing Co., 1981): 7-11, 7.

that is vital to the good of society or the members of society. Given these criteria, lawyers, engineers, architects, accountants, and healthcare practitioners are all examples of professionals. In addition to these necessary criteria, Bayles also notes some common features of professions such as certification or licensing, organizations for members, and professional autonomy.

I would argue that in addition to these, another commonality among professionals is that they have moral commitments beyond what the law requires, as evidenced by the fact that each profession has its own code of ethics. These codes arise out of the fact that it is hard for members outside of the profession to judge whether someone is behaving appropriately within the confines of that profession, and because actions such as deceiving a patient or client are seen as morally wrong even when they do not cross the boundary into being illegal. Andrew Alexandra and Seumas Miller make the case that we can best understand and assess the moral norms unique to each profession by looking at the *telos* definitive of the professional role.<sup>88</sup>

Turning to the idea of healthcare as a profession and healthcare practitioners as professionals, we must then understand what is unique about the practice of healthcare, in particular what important service is being provided to society, in order to more fully understand the normative obligations of the healthcare professional. In *Just Health Care*, Norman Daniels examines the nature of healthcare by asking what kind of a good healthcare is and how healthcare differs from other goods.<sup>89</sup> For example, should healthcare be “assimilated to other commodities, like cars or personal computers,” and if not, what makes healthcare unique?<sup>90</sup> Daniels’s suggestion is that health is unique insofar as “impairments of normal functioning

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<sup>88</sup> Alexandra, Andrew, and Seumas Miller, “Needs, Moral Self-Consciousness, and Professional Roles,” *Professional Ethics* 5 (1996): 43-61, 43.

<sup>89</sup> Daniels, Norman, *Just Health Care* (Cambridge: Cambridge University Press, 1985).

<sup>90</sup> Daniels, *Just Health Care*, 10-11.



through disease and disability restricts an individual's opportunity *relative to that portion of the normal range his skills and talents would have made available to him were he healthy*" and thereby "reduce[s] the range of opportunity open to the individual in which he may construct his 'plan of life' or 'conception of the good'." <sup>91</sup> Daniels's suggestion is that having the opportunity to form a life plan according to one's own conception of the good is a significant part of what constitutes an individual's well-being in society, and impairments to one's health significantly reduce and limit individual well-being in a way that a deprivation of other types of goods do not. <sup>92</sup>

All this is to say that healthcare as a profession provides a service that is vital to the members of society insofar as each individuals' health is central to their well-being within society. If patients are significantly injured or diseased, they have a fundamental need for medical aid, and the *telos* of healthcare is to provide such aid. <sup>93</sup> From this, we can now begin to understand the particular moral duties of healthcare professionals. One of the first things to note is that while healthcare fills a fundamental role within society, the duties of healthcare professionals are aimed toward individual patients. Unlike an engineer who aims at benefitting society through developing new technologies and who has little direct contact with the individual members of society, physicians are trained to directly engage with and benefit the members of society set before them, namely their patients.

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<sup>91</sup> Daniels, *Just Health Care*, 27-28 & 32-35. Emphasis is original, and I will assume that Daniel's claim applies to women as well as men.

<sup>92</sup> In *Justice as Fairness*, John Rawls explains the "conception of the good" as "an ordered family of final ends and aims which specifies a person's conception of what is of value in human life or, alternatively, of what is regarded as a fully worthwhile life." Rawls, John, *Justice as Fairness: A Restatement* (Cambridge, Mass: Belknap Press, 2001): 19.

<sup>93</sup> Alexandra and Miller, "Needs, Moral Self-Consciousness, and Professional Roles," 49.

This means that most of a physician's moral obligations arise in the context of interpersonal interactions. In common with other professionals who work directly with clients, such as lawyers and accountants, physicians become subject to trust relationships and fiduciary relationships with their patients.<sup>94</sup> These relationships and attending moral duties arise out of the fact that physicians, like lawyers and accountants, have such specialized knowledge and skill sets that patients must often place their confidence in physicians and expect that their physician will not deceive or mislead them. Given that nurses and physicians are entrusted to act for their patients benefit, they have a further obligation to only offer or act on those options that are reasonably expected to promote the health of their patient.<sup>95</sup> To act in a way that would foreseeably diminish the health of a patient, or that would knowingly cause harm to the patient without an overriding health benefit, would be to violate the trust placed in the healthcare professional.<sup>96</sup>

The duty not to harm one's patients is expressed by the moral principle of non-maleficence, but because we recognize that each intervention brings with it some risk of harm, this principle is often considered alongside the principle of beneficence: Any expected harms must be offset by the expected benefits of the procedure. This duty to avoid non-beneficial

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<sup>94</sup> The trust relationship should be distinguished from the fiduciary relationship given that fulfilling the obligations of the fiduciary relationship could involve a degree of deception or paternalism, if such actions are seen as being in the best interest of the patient. The trust relationship primarily pertains to the exchange of information between a patient and provider, while the fiduciary relationship primarily involves beneficial actions to promote the patient's health.

<sup>95</sup> "Health" is being understood as normal functioning for a typical member of a species, as argued for by Daniels. Daniels, *Just Health Care*, 28-32. For example, it would be wrong for a healthcare professional to prescribe something because they get a monetary kickback, especially if it is not as efficacious as an alternative. Healthcare providers are supposed to consider the interests of their patients, not their own interests. It would similarly be wrong to intentionally diminish the health of the patient, even upon the patient's request, insofar as doing so would significantly limit that individual's opportunities to pursue various life paths.

<sup>96</sup> Given the nature of a fiduciary relationship, it is reasonable to think that this holds true even if the patient states that they would be willing to accept the harm.

actions places a restriction on the types of actions healthcare providers may engage in, and is captured by the favorability condition in that it would be impermissible to offer or engage in any action that would foreseeably result in more harm than benefit. Because this obligation arises out of the unique nature of the healthcare profession, the favorability condition's restriction on non-beneficial care holds even if the patient would be willing to consent to unfavorable care.<sup>97</sup> The favorability condition restricts the actions of the healthcare professional regardless of the patient's willingness to consent, and this also places a constraint on the patient insofar as they are limited in the set of therapeutic options from which they may select. It is the obligation of the healthcare professional to determine the set of options that satisfy the favorability condition and patients may then accept or refuse the options presented in this set; patients cannot require their healthcare providers to move forward with unfavorable options that fall outside the set. In this way, the favorability condition places a reasonable constraint on patient requests for care and offers a definitive stance on the wrongness of overtreatment or the provision of non-beneficial medical care.

### *1.2. Epistemic Obligations*

In order to identify those options which can be reasonably expected to benefit the patient, healthcare providers must be appropriately knowledgeable in their field of expertise. This is important because the favorability condition cannot stipulate which particular actions or action

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<sup>97</sup> One may wonder whether these moral duties also pertain to those practicing medicine outside of a standard healthcare setting, such as a plastic surgeon performing cosmetic surgery. Although some instance of cosmetic surgery are accepted as having a place within healthcare, such as reconstructive surgery following an accident or a post-mastectomy, elective cosmetic surgery for purely enhancement purposes appears to fall outside the scope of healthcare insofar as it is not a fundamental good contributing to society or its members. Given the definition of a profession, plastic surgeons do not clearly fit and could be thought of as tradespeople as opposed to professionals. This would mean that while plastic surgeons must function within some moral code, it is not necessarily the same moral code as a healthcare professional. For example, plastic surgeons knowingly expose their clients to health-related harms without any attending or justifying health-related benefits, something that would be inappropriate for a healthcare professional.

types may be favorable; it is the responsibility of the healthcare professional(s) who will be engaging in the action to determine the favorability of the action, and this requires epistemic competency on the part of the healthcare professional.

Assessing the favorability of a proposed action should take into account current medical knowledge and the guidance of the larger medical community, but healthcare professionals may also act based on their individual medical training, knowledge, and professional experience. In some cases, a practitioner's professional opinion may conflict with others in the healthcare profession. To satisfy the favorability condition it is not necessary that all healthcare professionals would arrive at the same conclusion regarding the favorability of some action; what matters is that the healthcare professional bases their reasoning on the standards for belief set forth by the medical community. Alida Liberman describes this as the professional duty of epistemic competency:

In health care, understanding and responding appropriately to empirical evidence is essential. Medical practice involves understanding how the body and mind work, diagnosing the ways in which they fail to function well, and helping them function better. These goals cannot be achieved if one's professional decisions are grounded in empirically false beliefs; for example, a doctor who falsely believes that vaccines cause autism will be unable to adequately care for public health.<sup>98</sup>

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<sup>98</sup> Liberman, Alida, "Wrongness, Responsibility, and Conscientious Refusals in Health Care," *Bioethics* 31 (2017): 495-504, 499.

This is to say that while the favorability condition permits healthcare providers to make determinations of benefits and risks based on their professional experience and features unique to the case, it also requires a sufficient level of epistemic competency. The obligation of epistemic competency requires that healthcare professionals stay informed as to the empirical research being done in their field of expertise, including staying alert to new training programs being offered or new techniques being implemented, as well as being attuned to the norms set forth by their colleagues and the larger medical community.

The requirement of epistemic competency is what allows for determinations of favorability to be left open to the professional judgements of healthcare providers. Leaving room for professional judgement is important because there are justifiable reasons a healthcare provider's recommendation may deviate from the empirical evidence, such as being more or less familiar with certain techniques/medications or modifying determinations of favorability in light of a patient's unique goal of care. For example, while a healthcare provider cannot assume to know what would promote a patient's well-being in a robust sense, she may recognize that recommending a minimally invasive therapy would be most in line with a specific patient's expressed goals and preferences despite data supporting the recommendation of a more invasive therapy. While the norms of practice can provide invaluable information regarding expected health outcomes, what will in fact be the best option for a patient will depend on that patient's unique circumstances. This supports the earlier claim that healthcare provider should offer a set of favorable options, not just the option that is expected to maximize health outcomes.

Although the favorability condition leaves room for professional judgements to differ regarding assessments of favorability, the more those judgements diverge from the empirical evidence the more important it becomes to alert the patient to the disagreement. If it happens that

a practitioner's assessment of favorability *significantly* differs from her colleagues, the norms of their sub discipline, the larger medical community, or the empirical evidence then she is obligated to alert her patient to the professional disagreement and clearly explain her reasons for offering or recommending the action in question. Doing so allows the patient to make a more informed decision and to consider recommendations from other healthcare professionals if desired.

Allowing for variability in determinations of favorability also means that there will often be more than one course of action that is judged to meet the threshold for favorability, creating a set of options that would each satisfy the favorability condition. While a healthcare provider is not required to act on the most favorable option within the set, she does have a professional duty to provide her patient with the full set of options she assesses to be favorable; leaving out a favorable option because she thinks it would be too time intensive or too costly would be to violate her fiduciary duty toward the patient. In the interest of the patient, she should also explain which option(s) she assesses to be the most favorable, and her recommendations should reflect the varying degrees of favorability while taking into account situational information relevant to that patient. Just as it would be wrong to omit an option on non-medical grounds, it would similarly be wrong for a healthcare provider to strongly recommend one of the least favorable options simply because she thinks performing that action would be less time intensive or less burdensome for her to perform.

Outlining the normative and epistemic obligations of healthcare professionals helps to both support and explain the favorability condition. These obligations help to support and make sense of the favorability condition by justifying why actions that fall outside of the eligible set would be inappropriate to perform, as well as outlining what is expected of any given healthcare

professional. As I will next explain, these professional obligations are also what grounds a healthcare professional in determining the eligible set of favorable options by setting the standard for the threshold of favorability.

### *1.3. Assessing Favorability*

Given that satisfying the favorability condition requires meeting a minimum threshold of favorability — specifically, the proposed action must be *reasonably* expected to promote the health of the patient — it is important to outline what constitutes reasonability in order to understand where this threshold lies. Again, I cannot specify exactly what constitutes a minimally beneficial action, for favorability is context-specific, but I can speak to what ought to go into making such a determination given the normative and epistemic obligations of the healthcare professional.

Given what I have said thus far, there may be a concern that an action with an expected 1% or even 0.001% net benefit would technically qualify as favorable and must therefore be presented as part of the eligible set. This would set the threshold for favorability extremely low taking away the moral force of the condition, seemingly justifying options that most people would consider overtreatment or unnecessary care, and would result in an eligible set of options so large that it threatens to overwhelm the average patient by causing decision paralysis. While it would be convenient to be able to say something like “an option must be expected to have a net benefit of 10% in order to be considered favorable,” this is also unrealistic because reasonability is context-specific and involves various types of considerations, making it difficult to provide a clear numerical estimate of “net” benefit.

“Reasonability” is context-specific in that determining the degree to which we think of something as providing a benefit depends not only on the patient’s unique health needs, but also

on what alternative interventions may be available as well as the likely outcome without treatment. For example, according to the National Cancer Institute, a patient diagnosed with pancreatic cancer has an expected 5-year survival rate of 12.4% when diagnosed at the regional stage, meaning the cancer has spread to but not beyond the regional lymph nodes.<sup>99</sup> Given that chemotherapy carries significant risks and side-effects, the fact that chemotherapy has a 5-year survival rate of only 12.4% in these cases may make it seem like it fails to be reasonably beneficial. But when viewed within the larger context, specifically the fact that there is no alternative to chemotherapy and that the patient is certain to die without chemotherapy, it begins to seem more reasonable to say that trying chemotherapy would be a beneficial course of action. Despite the low survival rate, the lack of meaningful alternatives makes chemotherapy more reasonable because it is the only course of action that presents the possibility of a benefit, however slim.<sup>100</sup>

Alternatively, we can consider a case in which a patient is diagnosed with early-stage prostate cancer which has much higher long-term survival rates. A 20-year study found that in cases of early-stage prostate cancer, performing surgery to remove the cancerous tissue did not prolong the life of the patient and often led to serious complications including infections, erectile dysfunction, and urinary incontinence.<sup>101</sup> The authors of the study suggest that in cases of early detection, healthcare providers should consider radiation therapy without surgery, or even

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<sup>99</sup> National Cancer Institute: Surveillance, Epidemiology, and End Results Program, “Cancer Stat Facts: Pancreatic Cancer,” <<https://seer.cancer.gov/statfacts/html/pancreas.html>>

<sup>100</sup> This may also justify the use of experimental therapies when there are no other alternatives. In such cases, it is up to the patient to decide whether the known, or perhaps even unknown, risks are worth such a small chance at benefit. That said, if there is no meaningful indication that the experimental therapy has a chance at providing a benefit, then the healthcare professional would be justified in excluding it from the eligible set, even if that would leave the set empty.

<sup>101</sup> Wilt, Timothy, and Michael K. Brawer, “The Prostate Cancer Intervention Versus Observation Trial: A Randomized Trial Comparing Radical Prostatectomy Versus Expectant Management for the Treatment of Clinically Localized Prostate Cancer,” *Journal of Urology* 152 (1994): 1910-1914.



observation without intervention, as the preferred courses of action. This alone may seem sufficient to suggest that surgery does not fall into the set of favorable options for men diagnosed with early-stage prostate cancer, although “many doctors determine a man’s possible treatment options based not just on the stage, but on the risk of cancer coming back (recurrence) after the initial treatment and on the man’s life expectancy.”<sup>102</sup> However, should the patient also suffer from a complicating health issue, for example a clotting factor disorder such as hemophilia A or B, this would render surgery exponentially high risk for the patient and further decrease the assessment of favorability. Even if the expected survival rate of surgery for a man with a clotting factor disorder would still be significantly higher than the expected survival rate for a patient undergoing chemotherapy for pancreatic cancer, the fact that there are lower-risk alternatives to surgery in the case of prostate cancer but no meaningful alternatives in the case of pancreatic cancer makes an important difference.

The presence of meaningful alternatives changes the baseline for how we assess the favorability of a given intervention. A baseline of death without the intervention, as is true in the case of pancreatic cancer, makes the intervention of chemotherapy appear beneficial despite the significant risks and low success rate. On the other hand, a baseline of a lower-risk alternative with expected similar or improved health outcomes, such as radiation or observation in the case of early-detected prostate cancer, makes the option of surgery appear less beneficial or even non-beneficial given the risks. This highlights the importance of epistemic competency on the part of the healthcare professional, given that their judgement ought to be based in an assessment of the empirical data and knowledge of meaningful alternatives. It is also important that the healthcare

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<sup>102</sup> The American Cancer Society, “Initial Treatment of Prostate Cancer, by Stage,” <<https://www.cancer.org/cancer/prostate-cancer/treating/by-stage.html>>.

professional is familiar with the norms of the profession and sub-discipline. This is because knowing what constitutes “standard practice” can provide additional evidence for determining favorability; for if physicians in general do not recommend an option as being favorable, then no particular physician should think that it is reasonable without very specific and compelling reasons related to the unique situation of the patient.<sup>103</sup>

This works to show that determinations of what options would be “reasonably beneficial” are highly context specific; they are specific to healthcare, specific to the particular sub-discipline in which one is trained, and particular to the patient including their diagnosis, prognosis, and situational factors beyond their health. Reasonability is therefore best determined by standard healthcare practices as well as the informed judgement of the healthcare professional making the assessment, with said judgement being informed by evidence from research as well as their own professional experience. Outlining these contours of reasonability leaves it open that any given professional might on occasion get an assessment wrong, much like a referee might get a call wrong in the midst of a fast-paced soccer match. This does not mean that the call or the assessment was necessarily unreasonable if best evidence initially appeared to support it, but it does mean that the more time, resources, and evidence one has available for making the assessment, the higher our standard of reasonability should be.<sup>104</sup>

In summary, the favorability condition is one of two necessary and jointly sufficient conditions for the moral permissibility of an action within healthcare, capturing the

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<sup>103</sup> Such a reason could relate to the patient’s refusal of or inability to undergo the alternatives, such as a Jehovah’s Witness refusing to undergo surgery if doing so requires the use of blood products, or a patient with a severe carbolic acid allergy rendering surgery highly unfavorable. In such cases, alternatives such as bloodless surgery may be recommended despite not being a part of standard practice.

<sup>104</sup> The sports analogy and attending claim about increased standards of reasonability are drawn from Gaus, Gerald, *The Order of Public Reason: A Theory of Freedom and Morality in a Diverse and Bounded World* (Cambridge: Cambridge University Press, 2011): 244-258.

consequentialist values expressed in the principles of beneficence and non-maleficence.<sup>105</sup> To satisfy this condition, actions performed must meet the minimum threshold of favorability as determined by the normative and epistemic obligations of the healthcare profession. This condition captures the consequentialist elements of healthcare, namely the overarching goal of promoting patient health and healing by directing healthcare practitioners to offer only those options that fall into the eligible set, as determined by the reasonable expectation that they will promote the health of the patient. As a consequence, this constrains patients' requests for unnecessary or non-beneficial care by providing practitioners with a clear justification for refusing such requests: Non-indicated care necessarily falls outside of the eligible set by failing to meet the threshold of favorability, and performing an unfavorable action is morally impermissible given the professional norms and obligations of healthcare practice.

## **2. The Enabling Condition**

In contrast to our previous discussion, the principles of respect for autonomy and justice concern not the promotion of a person's health but rather the rights and liberties of individuals. As previously mentioned, it is commonly accepted that in a liberal society such as ours, all individuals are free and equal. All persons are free insofar as they are not naturally subject to the will of another, and each is equally capable of formulating an individual life plan and directing her or his life in accordance with that plan. Because these principles are about the duties owed to individuals in light of their natures, both of these principles can be considered deontic in nature.

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<sup>105</sup> The favorability condition is very reminiscent of how "the principle of beneficence" is understood in "The Belmont Report," incorporating both considerations of maximizing benefit (beneficence) and minimizing harm (non-maleficence). Combining these considerations, as opposed to taking the principles separately, is also sometimes referred to as "maximizing utility" or determining "the net good.;" The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research" (1979).

In order to adhere to the principle of respect for autonomy, healthcare providers must respect their patients by acknowledging the right of each patient to direct core aspects of her or his life, including which courses of medical care she or he is willing to undergo. Similarly, justice is about respecting the rights of individuals within specific populations and ensuring that the rights of some do not unfairly outweigh or infringe on the rights of others.

As with the favorability condition, I similarly propose that autonomy and justice be combined into a single condition for the moral permissibility of an action termed the *enabling condition*.<sup>106</sup> To satisfy the enabling condition, an action must:

- 1) Be authorized by the individual(s) directly concerned, and
- 2) adhere to current hospital policies & procedures.

The requirement that the action be authorized by the individual(s) directly concerned follows from the principle of respect for autonomy, and the requirement that the action adhere to current hospital policies and procedures follows from the principle of justice. The former requirement is important because a patient's consent signals that the healthcare provider is enabled to move forward with a specific course of action, and only that course of action, thereby providing the patient with some control over the course of her or his care. The latter requirement regarding hospital policies and procedures helps to ensure that each patient is provided fair access to

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<sup>106</sup> Though this condition is largely about gaining authorization from the patient to move forward with some proposed course of care, considerations about the rights of other parties captures more than merely the requirement to gain authorization. Simply stated, an action is only permitted if it is both authorized and just, meaning both parts must be met for a healthcare professional to be enabled to act. This is why I have termed this condition the 'enabling condition,' rather than something along the lines of an 'authorization condition.'

healthcare resources by requiring healthcare providers to comply with policies that contribute toward the optimization of resource allocation. These requirements will be explained in sections 2.1. and 2.2., respectively. Failing to meet either of these requirements means that the enabling condition fails to be satisfied.

### *2.1. Patient Autonomy*

What the enabling condition adds to the structured principlist framework is the idea that whether to go forward with an action does not just depend on the expected benefits of the act, but also the circumstances under which the action would be performed. Actions that would violate the rights of patients are morally wrong to perform, even if the expected benefit would be significant. This claim is supported by the principle of respect for autonomy which grounds a healthcare provider's duty to respect a patient's right to self-direct and to act in accord with her or his values, even when doing so fails to maximize the potential benefit for the patient.<sup>107</sup>

As previously discussed, hospital policies such as the requirement to obtain informed consent aim to recognize the principle of respect for autonomy by acknowledging the rights of individuals to make decisions about the course of their medical care: Patients have the right to accept or refuse any proposed course of medical care, including refusals of life-sustaining care.<sup>108</sup> This entails that patients are free to select options that may be considered imprudent insofar as they fail to maximize the potential medical benefits, so long as the option has been deemed at least minimally favorable by the healthcare professional who will be performing the action in question. This is further supported by the normative obligations of the healthcare

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<sup>107</sup> This assumes the patient has the capacity to consent, has been provided all relevant information, and has in no way been coerced or manipulated into providing consent.

<sup>108</sup> For a detailed discussion of informed consent and a patient's right to refuse life-sustaining care, see Ch. 1, Sec. 3.

professional, insofar as we think that a moral norm stemming from being a professional is respecting the members of society, and especially those members reliant on the professional's specialized skills and knowledge.

A patient's right to choose among the eligible set of favorable options is important in healthcare because there are myriad reasons a patient may prefer to consent to an option considered sub-optimal from a healthcare perspective, such as considerations related to follow-up care or the risks associated with a procedure may dissuade a patient from consenting to an option that offers greater potential benefits. For example, we can again consider a patient with coronary artery disease.<sup>109</sup> There are three standard care options for treating such patients:

- 1) Medical management which involves non-invasive drug therapy,
- 2) angioplasty which is a minimally-invasive surgery to open the artery and often includes the placement of a stent, or
- 3) an open-heart coronary artery bypass graft (CABG) surgery.<sup>110</sup>

A patient who medically qualifies for a CABG may instead prefer to try medical management because they are uncomfortable with the idea of being put under anesthesia, because they do not see the potential benefits of a minimally-invasive surgery such as an angioplasty as being worth the surgical risks, or even because the patient does not have the necessary support system or time off from work to ensure a successful recovery post-surgery.

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<sup>109</sup> This example was first discussed in Chapter 1, section 1.1.

<sup>110</sup> Reenan, Jennifer, "Indications for Bypass Surgery," *AMA Journal of Ethics* 6 (2004): 78-81.

As seen in section 1.3. of this chapter, there are several different ways in which a risk-benefit analyses can be performed, and as the above example illustrates, there are many situational factors that guide patient decision-making beyond considerations of expected medical benefit. Respecting patient autonomy means allowing the patient to take these varying factors into account when making a decision about her or his medical care, and not presuming that maximizing potential medical benefit will be the patient's overriding consideration. Just as the favorability condition expresses the healthcare professional's obligations in formulating a recommendation, the enabling condition expresses the healthcare professional's obligations with regard to respecting patients' rights to self-determine.

When a patient consents to a treatment option, the patient is authorizing her or his healthcare provider to perform a narrow and specific set of actions. These actions include all measures necessary to complete the agreed upon care, and do not extend to future actions that may be foreseeable and favorable but which are independent of the current care. For example, even though it is common practice to perform postoperative testing on a patient following a heart valve replacement, the patient's consent to the surgery does not extend to consent for the postoperative testing. Despite the follow up testing being foreseeable and favorable given the surgery, the information relevant to acquiring consent for the surgery will be different from the information relevant to the postoperative testing, meaning the patient's informed consent must be provided for each step prior to that action being performed. However, this also entails that a patient's unwillingness or inability to consent to related future care, absent some unexpected change in circumstances, may be grounds to determine the care in question unfavorable.

For example, if a patient with kidney disease has an unstable living situation, is unable to commit to a long-term care plan, or has been shown to be unreliable in taking necessary

medications, then the option of a kidney transplant becomes significantly less favorable.<sup>111</sup> This means that if a healthcare provider has good reason to think that a patient would not be willing to consent to, or would not follow through with specific future care necessary in order to provide a substantial health benefit, then that healthcare provider would be justified in removing that option from the eligible set. The enabling condition grounds the patient's right to self-direct their care, but only applies to care that falls within the eligible set of favorability. Some options may fall outside of that set either because they would be medically inappropriate given the patient's health condition, or because they fail to meet the threshold of favorability due to circumstances pertaining to the patient's actions or circumstances.

## 2.2. *Justice*

Although the principles of beneficence, non-maleficence, and respect for autonomy all provide different reasons for action, they are similar insofar as they are each concerned with micro-level interpersonal decisions, such as how the healthcare provider or care team ought to interact with a specified patient. Justice differs from these principles in that it is relational and concerns macro-level decisions, such as how we ought to distribute healthcare resources across a population, how we ought to structure our healthcare system to meet the needs of the patient population, or what specific policies a hospital ought to adopt. Shifting our inquiry from case-specific questions such as “what ought I to do when my patient wants to be full code?,” to policy level questions such as “what ought we to do when cases of potential futility arise?” means that

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<sup>111</sup> When considering candidates for transplants, transplant care teams assess the patient's support system and living situation in addition to their health needs. This is primarily because organs are scarce resources and providing one to a patient who cannot or will not properly care for it is arguably a misuse of a scarce resource. However, the argument I have presented does not depend on the scarcity of the resource. Even if a kidney were not a scarce resource, performing surgery on a patient who is unable or unwilling to commit to after care, such as taking anti-rejection meds, taking antibiotics, and keeping the wound clean would still be inappropriate given that the surgery would foreseeably cause more harm than benefit.



we are no longer asking about the authorization of specific patients. Instead, these macro-level questions force us to think about what we owe to certain groups, how we ought to respond to conflicts between patients or groups of patients, and how we ought to distribute and utilize our resources among various potential patients. These concerns are best addressed through thoughtful policy formation.<sup>112</sup>

Given that we have different moral considerations for interpersonal and policy level decisions, it is important that the structured principlist framework offers guidance at both levels of inquiry. The structured framework accomplishes this by incorporating both respect for autonomy and justice into the enabling condition; at the interpersonal level, the enabling condition requires healthcare providers to respect patient autonomy by gaining authorization for proposed procedures, while at the policy level the enabling condition requires healthcare providers involved in policy deliberations to consider what constitutes a fair distribution of healthcare resources within a given population. However, understanding the enabling condition to be functioning at both the levels of decision-making does not mean that physicians can simply ignore considerations of justice during interpersonal interactions with patients. Despite justice being primarily a policy level principle, its application is still relevant at the interpersonal level and can impose obligations on individual healthcare providers via the enabling condition alongside the principle of respect for autonomy.

A complication for thinking about justice in interpersonal deliberations is that individual healthcare providers rarely have the opportunity or ability to assess how their decisions in interpersonal cases affect large-scale issues such as the pattern of distribution of healthcare

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<sup>112</sup> Chapter 3 will apply the structured principlist framework to issues of policy formation.

resources. However, what healthcare providers can assess is whether they are compliant with relevant hospital policies aimed at ensuring appropriate resource distribution. Insofar as healthcare providers adhere to hospital policies when engaging with their patients, they have done enough to satisfy the justice component of the enabling condition. This is not to say that each policy enacted within a hospital is perfect insofar as it actually leads to an appropriate distribution of resources, or that some cases would not result in better resource allocation if a particular provider violated some hospital policy. Rather, insofar as individual providers are epistemically limited in knowing the downstream consequences of their specific choices, providers ought to adhere to the policies set in place in order to optimize resource allocation, especially given that such policies are formed based on an assumption of compliance by relevant healthcare professionals.<sup>113</sup>

As a component of the enabling condition, justice is therefore met at the interpersonal level when a healthcare provider acts in line with current policies and procedures, and justice is violated when a provider makes themselves an exception by violating set policies and procedures. Justice is in this sense deontological and reminiscent of Immanuel Kant's *Categorical Imperative* insofar as making oneself the exception to the rule is considered morally wrong.<sup>114</sup> Given the epistemic limitations of practicing healthcare professionals, considering

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<sup>113</sup> This implies that even if a healthcare provider thinks a given policy will fail to optimize healthcare resources, the provider should still abide by the policy. If the issue is that the policy will fail to optimize resources in a particular case, the provider should discuss the case with their colleagues and superiors instead of breaking with the policy. If the issue is that the policy is ill-formed and always fails to optimize resource allocation, then the provider should flag this as a reason for the policy to be reconsidered. While these are not ideal solutions, because of the epistemic limitations of any given healthcare provider, considerations of justice are more likely to be satisfied by adherence to the norms than by allowing each provider to make their own determinations when they disagree with the norm.

<sup>114</sup> For a brief overview of Kant's writings on the *Categorical Imperative*, see Johnson, Robert and Cureton, Adam, "Kant's Moral Philosophy", The Stanford Encyclopedia of Philosophy (Spring 2019 Edition), Edward N. Zalta (ed.), <<https://plato.stanford.edu/archives/spr2019/entries/kant-moral/>>.

whether the justice component of the enabling condition has been met is thus a matter of checking whether one is in compliance with current hospital policies. For our present purposes, this is how justice will be understood as it relates to the enabling condition. This is because our discussion has thus far been indexed to issues of interpersonal decision-making in order to demonstrate how the structured principlist framework guides decision-making for practicing healthcare professionals, and I think it best to complete our discussion at this level of inquiry before expanding the discussion to include applications of structured principlism at the policy level.

Although the discussions in this chapter are indexed to understanding the favoring and enabling conditions at the interpersonal level, justice as a substantive principle is only really satisfied if hospital policies are successfully aimed at appropriate distributions of healthcare resources. This means that it is at the level of policy creation that justice has significant moral force. Chapter 3 will therefore consider how some of the leading theories of justice would function within the structured principlist framework as it relates to policy creation. Without taking a stand on a particular substantive account of justice, I will show the structured principlist framework to be applicable for policy deliberations as well as interpersonal deliberations, with the former being especially important given that satisfying the justice component of the enabling condition at the interpersonal level assumes hospital policies are aimed at fair distribution of healthcare resources.

### **3. Principlism Without the Weighing**

Unlike the traditional principlist framework, the structured principlist framework does not involve any weighing or balancing of the four principles when determining the moral permissibility of an action. Instead, the structured principlist framework requires assessing

whether the two conditions, favorability condition and enabling condition, have been satisfied.

These two conditions are necessary and jointly sufficient for determining the moral permissibility of an action, meaning both conditions must be satisfied for the action to be morally permissible within healthcare practice:

**Favorability Condition:** The proposed action must be reasonably expected to promote the health of the patient.

**Enabling Condition:** The proposed action must be authorized by the patient or proxy and must adhere to current hospital policies & procedures.

Taken together, these conditions mean that no matter how favorable a given action is expected to be, if that proposed action fails to satisfy the enabling condition it is morally impermissible to perform. Conversely, even if action satisfies the enabling condition, it is nevertheless impermissible to perform if that action is reasonably expected to be unfavorable as determined by the relevant healthcare professional(s). In normative terms, this is best described as a pluralistic framework that contains consequentialist considerations yet maintains deontic constraints.

The enabling condition differs from the favorability condition insofar as respecting the rights of individuals does not come in degrees the same way that an action can be more or less favorable. When applying the favorability condition, one action may be assessed to be less favorable than another, yet the less favorable action may still meet the minimum standard of favorability all things considered. There is no obligation for healthcare providers to perform only

the most favorable action; rather, the favorability condition recognizes a sliding scale with regard to the favorability of varying actions and requires only that each action performed be above the minimum threshold of favorability. This allows for a set of treatment options to be presented to the patient, so long as each would satisfy the favorability condition. In this way, patients may be presented with multiple treatment options to choose from, thus allowing patients to choose the option that best fits with their unique goals and values.

While the favorability condition assesses options along a continuum of better to worse, the enabling condition functions as binary insofar as it is either met or fails to be met. Failing to respect even a portion of a patient's decision is failing to respect that patient as an autonomous individual, as it is inappropriate for a healthcare provider to decide which of the patient's myriad values ought to be upheld. Also unlike the favorability condition, there is no set of options that might satisfy the enabling condition; either a favorable action is enabled insofar as it is authorized by the patient and is in accord with hospital policies, or it fails to satisfy one or both of these components and is therefore impermissible to perform.

By separating the four principles into two conditions it remains possible to refer directly to each of the principles by breaking down the relevant condition, while at the same time removing the problematic process of weighing and balancing. Without a clear decision procedure for settling conflicts the structured principlist framework may seem overly simplistic; however, I contend that restructuring the principles in this manner actually avoids the conflicts Beauchamp and Childress aim to address through the process of weighing and balancing. This is because the conflicts between the principles are not inherent in the principles themselves but arise as a function of the traditional principlist framework allowing significant trade-offs between the principles. Treating each independent principle as *prima facie* fails to acknowledge the core

values underlying each principle insofar as consequentialist reasons can override deontic reasons and vice versa, resulting in an ethical framework with too much indeterminacy and the ability to justify wrong actions.<sup>115</sup> By separating the principles into two distinct conditions based on their normative underpinnings, the structured principlist framework acknowledges the core values underlying each principle and thereby avoids the pitfalls of the traditional principlist framework.

Unlike traditional principlism, structured principlism also avoids criticisms of indeterminacy because it becomes clear how each principle relates to the others, and this in turn avoids the extremism criticisms discussed in Ch. 1, sec 3. For example, on the structured framework the enabling condition ensures that the principle of respect for autonomy is always abided by, yet respecting a patient's autonomy cannot require healthcare providers to perform actions that would be deleterious given that the action must also satisfy the favorability condition. The favorability condition removes any force a positive interpretation of respect for autonomy might have, and thus avoids even the semblance of a justification for the provision of non-indicated care, overtreatment, or futile care. At the other end of the spectrum, although the principle of beneficence must always be abided by given the favorability condition, a favorable action would nevertheless be impermissible to perform when it does not respect the patient's autonomy, given that the enabling condition must also be met. This then allows the structured framework to avoid any potential justifications for paternalistic actions.

Some might worry that the structured framework is overly limiting given that instances of conflict are minimized by one condition constraining another, meaning that what patients and healthcare professionals may permissibly do is constrained by members of the opposite group.

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<sup>115</sup> See Ch. 1, section 6, for my full argument related to the normative critique of the traditional principlist framework.

For example, the favorability condition constrains the set of actions for which patients may provide consent by requiring that healthcare providers only offer treatment options that meet a minimum standard of favorability.<sup>116</sup> The enabling condition likewise constrains the healthcare provider insofar as she may only move forward with a favorable action when it has been consented to and so long as it complies with accepted hospital policies and procedures. While I accept that this is more limiting than the traditional framework, I would argue that these constraints are a feature insofar as they permit only actions that promote patient health and respect the rights of individuals. It is precisely the limitations imposed by the enabling condition and the role-specific constraints of the favorability condition that allow structured principlism to justify only those action that align with our common intuitions and current healthcare practices, in contrast to the more extreme actions that could be justified using the traditional principlist framework.

#### **4. Applying the Structured Principlist Framework**

Thus far I have argued for two conditions, the favorability condition and the enabling condition, which form the basis of the structured principlist framework. On the structured principlist framework, the traditional weighing and balancing approach is replaced with a determination about whether each of these two conditions have been satisfied; instead of weighing each principle against the others, morally permissible actions are those that satisfy both conditions and any action that fails to satisfy either condition is morally impermissible for a healthcare professional to perform.<sup>117</sup> By restructuring the four bioethical principles into two

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<sup>116</sup> As discussed in Chapter 2, section 1.3., determinations of favorability are context specific, so it is the role of physician is to create an eligible set of recommendations from which the patient may select.

<sup>117</sup> One might be concerned that this is overly strong, but given that healthcare workers have an obligation to promote the welfare of their patients, I do not find it unreasonable to say that it would be morally wrong for a healthcare professional to perform a non-favorable action even if he or she were enabled to do so by the patient. In

conditions for moral permissibility, structured principlism remains grounded in the bioethical principles while simplifying the decision procedure.

When employed in order to reason through a non-controversial case, both conditions of the structured framework are easily satisfied insofar as only favorable courses of action are presented to the patient as treatment options, those options are in accord with current hospital policies and procedures, and the patient is willing to consent to one of the options presented. While the framework need not be explicitly consulted in these cases, it is nonetheless ever present as a check on moral permissibility when concerns happen to arise.

When the structured framework is employed in ethically contentious or controversial cases, such as those involving patient refusals or requests of care, structured principlism clearly rules out certain options as being morally impermissible. The elimination of certain options provides clear guidance for healthcare providers insofar as it stops extremist positions from ever being justified, unlike the traditional framework. To demonstrate, I will discuss two such cases, examining the way in which the structured framework can help healthcare providers reason through the decision and contrasting this with the traditional principlist framework.

#### *4.1. Patient Refusals of Consent*

**Mary the Jehovah's Witness:** Mary has just given birth to her second child. The child is in good health, but Mary suffered complications during delivery resulting in significant obstetric hemorrhage. Unable to control the postpartum bleeding through other measures, Mary's healthcare team determines that a postpartum

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some cases the action may be neutral in terms of risks and benefits, but those actions would still fail to meet the enabling condition with regard to justice insofar as performing a futile or unnecessary medical test or treatment would waste medical resources, potentially denying quality healthcare for others.



hysterectomy is required to stop the bleeding and potentially save Mary's life.

Due to the significant amount of blood Mary has lost, as well as the risk of increased blood loss during and post surgery, a transfusion of blood products and clotting factors would significantly increase the chance of a good health outcome following a postpartum hysterectomy. Without a transfusion of blood products, the surgery is significantly less likely to save Mary's life. However, as a practicing Jehovah's Witness, Mary is willing to consent to the surgery but not to a transfusion of the blood products.

#### 4.1.1. Structured Principlism

On the structured principlist framework, there are only two dimensions on which we can evaluate the permissibility of an action: The favorability condition and the enabling condition. Starting with the favorability condition, it would appear that there are several possible actions that would likely be at least minimally favorable with regard to Mary's health:

- 1) Performing a postpartum hysterectomy while utilizing blood products as needed,
- 2) performing a postpartum hysterectomy without utilizing any blood products, or
- 3) providing Mary with comfort care (this involves the provision of IV fluids and pain medication to ease any discomfort while Mary declines).

The first option, performing the surgery while providing Mary with the necessary blood products is clearly the most favorable option insofar as it offers the highest likelihood of Mary's survival. However, assuming that Mary is very likely to die without a postpartum hysterectomy, the second option of performing the surgery without the use of blood products would also be

favorable in comparison to the baseline of no treatment, though only so long as the surgical team assesses there to be the possibility of surgical success without the use of blood products. For example, in some cases blood alternatives can provide sufficient volume and carry enough oxygen to sustain a patient until their bodies are able to compensate for the blood loss. This option would be less favorable than providing a blood transfusion if the artificial blood products cannot replicate all the functions of blood or lead to a slower recovery, but the use such products would still satisfy the favorability condition if they are expected to keep Mary alive in this circumstance. The last option, providing only comfort care, would be favorable in terms of symptom management but would be the least favorable from a health perspective insofar as it would not attempt to sustain Mary's life.

Given that all three options would be at least minimally favorable for Mary, each should be explained as a possible courses of action, leaving it to Mary to accept or refuse them based on her specific goals and values.<sup>118</sup> The enabling condition is only satisfied if Mary consents to one of the options presented and that option comports with hospital policies and procedures.<sup>119</sup> If

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<sup>118</sup> While offering Mary the possibility of using blood alternatives arises with regard to her particular beliefs as a Jehovah's Witness, it is not unreasonable to think that the use blood alternatives should be offered even to those who do not have clear religious objections. There may be non-religious reasons a person would not want to consent to a blood transfusion and so long as there is a favorable alternative that does not require them, that option should be provided as well. The larger point is that, when possible, patients should be provided with information regarding the various treatment options available, even when some of the options would be less favorable than others.

<sup>119</sup> Time permitting, Mary's healthcare team should have a serious and detailed conversation with her about the possibility of performing a hysterectomy with a blood transfusion, given that it would be the most favorable option. Healthcare professionals should not coerce their patients, but they should engage in discourse about the varying favorability of the options. Through this discourse the healthcare team may achieve greater understanding of the goals and values driving their patient's convictions, and may offer the patient further reasons for thinking one options may be more preferable than another. If the healthcare team can successfully explain how a medically preferred option might align with the patient's goals or values, then that patient may become willing to enable a more favorable option for which they previously refused to consent.

Mary refuses to consent to all of the options provided, then no further action should be taken and Mary's decision to refuse any further treatment should be respected.

#### 4.1.2. Traditional Principlism

Thinking about this case using the traditional principlist framework may result in a similar outcome when compared with the structured principlist framework, such as Mary consenting to the postpartum hysterectomy with the use of blood alternatives. However, unlike structured principlism, traditional principlism does not rule out the possibility of medical paternalism. If the healthcare provider in charge of Mary's care is greatly concerned about Mary's health and thinks that a religious conviction is not a sufficient reason rule out the most beneficial course of action, that provider would favor performing a blood transfusion alongside the hysterectomy even when Mary refuses to consent to the blood products. This can be justified on the traditional framework by weighing the principle of beneficence as more important than respect for autonomy, with the reasoning being that performing the action with the highest likelihood of saving a patient's life is of greater importance than abiding by a patient's non-health related beliefs.

While acting paternalistically would certainly violate hospital policy, the healthcare provider could nonetheless think she is morally justified to act paternalistically toward Mary given her professional aim to promote health and healing. Applying the traditional framework does not clearly direct healthcare providers toward medical paternalism in cases such as these, nor does it direct one away from such a view if they share the attitudes of our imagined healthcare professional. Instead, it allows healthcare providers to be the final arbiter when deciding which aspects of the case are most important — the patient's values or the patient's health — and can be used to seemingly justify the intuitions unique to that healthcare

professional. Given the traditional framework, Mary must simply hope to receive a physician willing to acknowledge her religious commitments, or trust that the hospital's policies will safeguard her right to refuse blood products in spite of the moral framework being employed by her care provider.<sup>120</sup>

#### *4.2. Patient Requests for Care*

**Dimitri the Demanding Patient:** Dimitri is 68 years old and recently strained his back while helping a friend move. After a week of experiencing lower back pain, he makes an appointment to get his back assessed by a physician. Upon examination, his physician explains that there are no signs of a serious condition such as disk compression or nerve damage, and without a history of cancer Dimitri need not be concerned. She recommends that Dimitri take pain medication until the pain dissipates, usually within 2-4 weeks. However, Dimitri is skeptical that a physical examination is sufficient to rule out any serious underlying damage and adamantly demands that he undergo an MRI for more definitive results.

##### *4.2.1. Structured Principlism*

When applying the structured principlist framework to the case of Dimitri, it is readily apparent that performing the MRI would satisfy the authorization portion of the enabling condition insofar as assisting with Dimitri's request would respect his right to self-govern. Providing the MRI could also satisfy the justice component of the enabling condition so long as

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<sup>120</sup> While policies of informed consent are meant to safeguard patients' rights, in reality physicians sometimes fail to follow policies and it is disturbing that the traditional principlist framework can be used to justify such an action instead of clearly telling us what is morally problematic about violating a patient's refusal. And while such instances of paternalism are rarely openly discussed, I in fact know of a recent local case in which an adult Jehovah's Witness's written refusal was ignored (the patient was under anesthesia and could not communicate at the time).

MRIs are considered appropriate diagnostic tools for individuals with lower back pain. However, as stated previously, one cannot definitively determine whether the justice component has been satisfied without knowing the specific policies and regulations of the healthcare institution.

For example, “Hospital A” may have a blanket policy outlining the importance of diagnostic testing, “Hospital B” may have a more narrow policy outlining best practices as they relate to the use of certain diagnostic tests, and “Hospital C” may not take a clear stand on the appropriate use of diagnostic testing apart from leaving such decisions to qualified healthcare practitioners. In the case of Dimitri, the justice component would likely be satisfied at “Hospital A” insofar as MRIs can sometimes be useful tools when diagnosing back pain, but the justice component may not be satisfied at “Hospital B” if the policy guidelines recommend physical examinations as the best practice for diagnosing lower back pain.<sup>121</sup> For our present purposes, I will stipulate a broad policy as found in “Hospital A,” such that both the authorization and justice components of the enabling conditions are met with regard to Dimitri’s request. This is to demonstrate that even with the enabling condition satisfied the favorability condition must still be assessed, given that the enabling and favorability conditions function independently of one another and must both be satisfied in order to justify the performance of an action.

Assessing the favorability condition requires making an assessment about the likelihood that the MRI will be a useful diagnostic tool for diagnosing Dimitri. This assessment should be based on both the healthcare provider’s clinical experience as well as relevant empirical data.<sup>122</sup> With regard Dimitri’s particular circumstances and request, a 2015 study found that “among

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<sup>121</sup> Chapter 3 will discuss justice at the macro level of policy creation.

<sup>122</sup> See Chapter 2, sections 1.2. and 1.3. for discussions regarding the epistemic requirements of healthcare professionals and assessments of favorability.

older adults with a new primary care visit for back pain, early imaging was not associated with better 1-year outcomes.”<sup>123</sup> If this research data aligns with our healthcare provider’s clinical experience, then she has good reason to think that providing the MRI would constitute medically unnecessary care insofar as it is unlikely to be a useful diagnostic tool or provide a reasonably meaningful benefit for the patient. Insofar as the MRI is not reasonably expected to promote Dimitri’s health, abiding by Dimitri’s request would fail to meet the minimum requirement for satisfying the favorability condition.

At best, an unnecessary MRI would be medically neutral by posing no risk but offering no benefit, and in a worst-case scenario an unnecessary MRI could result in further unnecessary procedures related to incidental findings or false positives.<sup>124</sup> Even when the provision of non-indicated care is not foreseen to harm the patient, acting in a way that is not foreseen to provide a medical benefit is failing to act in line with the aims and obligations of the healthcare profession.<sup>125</sup> So long as the favorability condition fails to be satisfied insofar as a particular course of care is determined to be non-beneficial or unnecessary, the fact that the patient requests or even demands such care gives the healthcare professional no additional reason to act. Hence,

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<sup>123</sup> Jarvik JG, Gold LS, Comstock BA, et al. “Association of Early Imaging for Back Pain With Clinical Outcomes in Older Adults,” *JAMA* 313 (2015):1143-1153.

<sup>124</sup> According to Jarvik et al, “we had hypothesized that patients undergoing early imaging would have worse outcomes, due to incidental findings leading to unnecessary and potentially harmful interventions. This was not the case.” While this suggests that such cases are not common with regard to MRIs for back pain, this does not rule out the possibility of unnecessary imaging leading to unnecessary care in this or other instances.

<sup>125</sup> Refer back to section 1.1. of this chapter for a discussion of the normative obligations of healthcare professionals. Additionally, placebos raise an interesting issue insofar as they offer no physiological benefit yet can result in patient reporting of benefits. Some studies have found that outcomes for certain types of arthroscopic surgery are no better than sham surgeries. However, placebos are only permitted when the physician is in clinical equipoise with regard to the relative benefits of the placebo compared to the standard course of care, meaning the physician has no justification for thinking that the placebo would be more or less beneficial than the standard course of care. So long as both the standard procedure and the placebo are foreseeably beneficial, the physician does not fail in her duty with regard to the favorability condition. Nyrhinen J., et al, “Arthroscopic partial meniscectomy versus sham surgery for a degenerative meniscal tear,” *New England Journal of Medicine* 366 (2013): 2515-2524.

regardless of whether Dimitri's request satisfies the enabling condition, his healthcare provider would be justified in refusing to provide an MRI on the grounds that it would fail to satisfy the favorability condition. The structured principlist framework thereby places a constraint on patients such that they cannot demand access to non-beneficial care, just as it places a constraint on healthcare providers such that they are not justified in acting paternalistically toward their patients.

#### 4.2.2. Traditional Principlism

When working through this case using the traditional principlist framework, the extent to which patients requests for care should be abided by becomes less clear. While the principle of non-maleficence urges one to avoid doing harm, especially when there is no attending benefit, it does not clearly prohibit the performance of actions that are medically unnecessary so long as they are not foreseeably harmful. As such, turning to the principle of non-maleficence fails to provide much guidance with regard to Dimitri's requested MRI. Similarly, turning to the principle of beneficence also fails to provide clear guidance because considerations of beneficence help to guide healthcare providers toward actions that benefit their patients, yet is silent on what to do when an action is medically neutral. When an action is foreseen to produce more harm than benefit, these principles are useful insofar as they guide the healthcare professional away from performing the action in question, but they are seemingly silent when it comes to the provision of non-harmful, non-indicated care such as unnecessary diagnostic tests. Even when we generously interpret these principles similarly to how they are understood on the structured principlist framework, requiring some minimal benefit to justify assistance, the

traditional principlist framework would nevertheless allow these principles to be justifiably outweighed by considerations of patient autonomy.<sup>126</sup>

The ability of respect for autonomy to outweigh considerations of medical need matters because when physicians were polled on a national survey, just over a third reported that they would comply with Dimitri's request for the MRI despite acknowledging it to be unnecessary.<sup>127</sup> This means that these physicians would comply simply on the grounds that doing so would satisfy Dimitri's request, even though Dimitri's right to autonomy does not clearly entail a right to positive assistance from third parties. The claim that physicians would assist patients in accessing non-indicated care, simply due to patients requesting such care, has been supported by other studies as well.<sup>128</sup> For example, a 2017 study that gathered responses from 2,106 physicians, all of whom were members of the American Medical Association, found that roughly 20.6% of overall medical care was thought to be unnecessary and that 59% of physicians indicated "patient pressure/request" as a reason for the provision of unnecessary care.<sup>129</sup>

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<sup>126</sup> Refer back to Chapter 1, section 3.2.

<sup>127</sup> A 2007 survey found that 36% of physicians would provide an unnecessary MRI for a patient complaining of lower back pain solely on the grounds that the patient requested the MRI. Campbell, E. G., et. al., "Professionalism in Medicine, Results of a National Survey of Physicians." *Annals of Internal Medicine* 147 (2007): 795-802.

<sup>128</sup> See Lyu, Heather et al. "Overtreatment in the United States." Ed. Imelda K. Moise. *PLoS ONE* 12.9 (2017): e0181970. PMC. Web. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5587107/>; Campbell, E. G., et. al., "Professionalism in Medicine, Results of a National Survey of Physicians," *Annals of Internal Medicine* 147 (2007): 795-802; Schwartz AL, Jena AB, Zaslavsky AM, McWilliams JM. "Analysis of Physician Variation in Provision of Low-Value Services," *JAMA Intern Med* 179 (2019):16–25; Bogdanich, Walt, and Jo Craven, "Medicare Claims Show Overuse for CT Scanning," *The New York Times* (2011) <<https://www.nytimes.com/2011/06/18/health/18radiation.html>>; Emanuel, Ezekiel, and Victor Fuchs, "The Perfect Storm of Overutilization," *JAMA* 299 (2008):2789–2791.

<sup>129</sup> Lyu, Heather et al. "Overtreatment in the United States." Ed. Imelda K. Moise. *PLoS ONE* 12.9 (2017): e0181970. PMC. Web. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5587107/>



Similarly, a meta-study found that roughly 25% of healthcare spending, roughly \$800 billion, goes toward the provision of unnecessary care.<sup>130</sup>

Although the physicians polled in these studies did not have the opportunity to elaborate on their overall reasoning for providing unnecessary care based on patient requests, one way to make sense of this is to recall that the principle of respect for autonomy can be viewed as both a negative right and as a positive right, with the former requiring non-interference and the latter involving some degree of assistance by others.<sup>131</sup> Although the extent to which patients have a right to assistance is not a settled matter, the apparent preeminence of patient autonomy within the healthcare system may understandably lead some healthcare providers to think that acting in line with a patient's stated wishes is more important than acting based on medical need. As discussed in Chapter 1, the traditional principlist framework allows for considerations of autonomy to trump considerations stemming from the other principles, so even if physicians are not explicitly appealing to this framework as a means of justifying their decisions, the traditional framework offers little help or guidance in combating the pervasive issue of overtreatment.<sup>132</sup>

Contributing to this issue is the fact that in recent years, healthcare has come to be seen as somewhat akin to a consumer product to which patients are entitled to purchase it if they want.

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<sup>130</sup> Shrank, William, et al., "Waste in the US Health Care System: Estimated Costs and Potential for Savings," *JAMA* 322 (2019): 1501-1509.

<sup>131</sup> Beauchamp and Childress expressly deny that respect for autonomy is a strictly negative duty, claiming that "respect involves respectful *action*, not merely a respectful *attitude*. It requires more than noninterference in others' personal affairs. It includes, in some contexts, building up or maintaining others' capacities for autonomous choice while helping to allay fears and other conditions that destroy or disrupt autonomous action." Beauchamp and Childress, *Principles*, 103. Admittedly the way I am employing this principle may not entirely capture all that these authors hoped for, but this is because the broadness of their interpretation is problematic insofar as it leaves open avenues for paternalistic interventions. In "Why Doctors Should Intervene," Terrence Ackerman argues for medical paternalism by starting with the claim that respect for autonomy entails more than merely noninterference. Ackerman, Terrence, "Why Doctors Should Intervene," *Hastings Center Report* 12 (1982): 14-17.

<sup>132</sup> Refer to Chapter 1, section 4.

This shift is sometimes attributed to anti-paternalistic sentiments as well as rising out-of-pocket costs for patients.<sup>133</sup> Consumeristic attitudes can lead to patients feeling as though they have a right to demand care they believe will be beneficial, regardless of what practitioners advise and despite objections. Attitudes such as these combined with an emphasis on patient satisfaction may lead practitioners to feel as though they should relent and perform actions they deem to be non-beneficial and relatively harmless, and these actions can be justified on the traditional framework by giving increased weight to respect for patient autonomy. Even accepting that the traditional framework can in theory be used to deny such requests by emphasizing the negative or non-interference formulation of respect for autonomy, the distinction between negative and positive autonomy is hard to maintain in practice. Whether or not these practitioners actually think they should abide by such requests, studies have clearly indicated that instances of unnecessary or non-beneficial care have become an issue in the past decade, and the traditional framework appears to justify instances of overtreatment more than it deters them.

## **5. Concluding Remarks**

The cases of Mary and Dimitri demonstrate the enabling and favorability conditions to act as direct, substantive constraints on both patients and healthcare providers: By requiring patient authorization the enabling condition places a constraint on healthcare professionals in that it prohibits paternalistic actions, and by requiring a minimum standard of benefit the favorability condition places a constraint on patients in that it prohibits the provision of non-indicated care.

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<sup>133</sup> Emanuel, Ezekiel, and Victor Fuchs, "The Perfect Storm of Overutilization," *JAMA* 299 (2008):2789–2791.

These constraints are the result of separating the four bioethical principles into two necessary and jointly sufficient conditions based on their normative underpinnings, and that this separation prohibits trade-offs between the core values underlying each principle.

Unlike the traditional framework which was criticized in Chapter 1, section 6, for allowing such trade-offs, the unique organization of the structured principlist framework makes it the case that deontic reasons can no longer be used to justify the overriding of consequentialist reasons, and appeals to consequentialist reasons can no longer be used as a justification for overriding deontic reasons. Not only does this set the structured framework apart from the traditional framework by avoiding the normative critique, but these constraints also bring my framework more closely in line with currently accepted healthcare norms, practices, and policies.<sup>134</sup>

The structured principlist framework is an improvement on the traditional principlist framework in that it formalizes the notion that patients do not have a right to demand treatments that will not be beneficial, and it prohibits physicians from treating patients without their consent. While both of these ideas are commonly reflected in hospital policies, they should also be reflected in the moral framework healthcare providers employ when working through complex and difficult cases. I have thus far argued that the structured principlist framework better aligns with the policies and procedures common to healthcare, follows from a common understanding of the bioethical principles and the values they represent, and most importantly

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<sup>134</sup> For example, The American Medical Association (AMA) Code of Medical Ethics Opinion 1.1.3 states that patients have the right “to make decisions about the care the physician recommends and to have those decisions respected. A patient who has decision-making capacity may accept or refuse any recommended medical intervention.” The patient’s right to refuse care is enforced by the enabling condition, and the specification that patients may accept or refuse *recommended* care is enforced by the favorability condition.  
<<https://www.ama-assn.org/delivering-care/ethics/patient-rights>>

provides a structured method for decision-making by integrating the medical knowledge of the physician with the values of the patient. In making these arguments I have been focusing on issues of interpersonal decision-making within healthcare. To demonstrate the wider applicability of my framework, the next chapter will apply the structured principlist framework to larger bioethical debates and issues of policy formation.

## CHAPTER III. FURTHER APPLICATIONS OF THE STRUCTURED PRINCIPLIST FRAMEWORK

In the previous chapter the structured principlist framework was applied to two clinical cases, demonstrating it to be practicable in guiding healthcare practitioners through complex ethical decision-making. The aim of this chapter will be to demonstrate the broader applications of the structured principlist framework. Not only is structured principlism useful in a clinical context, but it can also be used to clarify and guide the robust bioethical debates that ultimately inform our thinking, especially as that thinking informs healthcare practices and policies.

In this chapter I will not take a definitive stand on the moral permissibility of specific controversial practices, such as active euthanasia, but will rather demonstrate how structured principlism disentangles complex debates, such as the debate surrounding end-of-life assistance, by clarifying the source of the ethical tension. Through clarifying the core disagreements in philosophical debates, structured principlism can then help to provide guidance for thinking about the creation of relevant policies. This broader application of the structured principlist framework is important because the justice component of the enabling condition requires that healthcare providers adhere to current hospital policies and procedures, but this requirement is only meaningful if those policies are themselves morally supported.

### **1. Summarizing the Structured Principlist Framework**

Before moving into the broader applications of the structured principlist framework, it will be helpful to briefly summarize the key components of the structured framework. After leveling three distinct yet interrelated criticisms against Beauchamp and Childress's traditional principlist framework in Chapter 1, I set out to argue in favor of a more practicable framework that retains the usefulness of the core bioethical principles while providing much needed

scaffolding. The resulting *structured principlist framework*, laid out in Chapter 2, organized the four bioethical principles into two necessary and jointly sufficient conditions for moral permissibility:

**Favorability Condition:** The proposed action must be reasonably expected to promote the health of the patient.

**Enabling Condition:** The proposed action must be authorized by the patient or proxy and must adhere to current hospital policies & procedures.

The favorability condition incorporates the principles of beneficence and non-maleficence, while the enabling condition incorporates the principles of respect for autonomy and justice. After applying the structured framework to cases involving patient requests and refusals of care, it became clear that the enabling and favorability conditions act as direct, substantive constraints on both patients and healthcare providers. The enabling condition places a constraint on healthcare professionals by requiring the authorization of the patient before acting, thereby prohibiting paternalistic actions, and the favorability condition places a constraint on patients by requiring a minimum standard of benefit, prohibiting the provision of non-indicated care.

Given that a moral framework is only useful insofar as it can offer guidance on which actions are morally justified and which actions ought to be avoided, the structured framework's ability to appropriately constrain deliberations is one of its primary features. Chapter 1 saw the traditional principlist framework criticized on the grounds that the open weighing structure

allowed for the justification of morally dubious actions, and the structured framework avoids this by denying that consequentialist and deontic reasons can override one another. I have thus far argued that structuring the four principles in terms of these two conditions better captures the moral importance of each principle while simultaneously making sense of our current healthcare practices and policies, resulting in a pluralistic framework that contains consequentialist considerations while maintaining deontic constraints. In arguing for this, I have primarily focused on healthcare deliberations at the clinical level to demonstrate the framework's ability to guide the moral deliberations of healthcare practitioners in their interpersonal interactions with patients.

In order to next demonstrate the broader applications of the structured principlist framework, this chapter will focus around two bioethical debates: The permissibility of end-of-life assistance and determining declarations of futility. I will take each of these debates in turn, first summarizing the major arguments and then attempting to locate the key moral disagreements. By mapping these debates onto both the traditional and structured principlist frameworks, I will demonstrate the superior clarity and guidance provided by the structured principlist framework. I will then also point to ways in which this guidance is helpful for policy formation, allowing healthcare providers to be confident that they are acting rightly when abiding by healthcare policies and procedures at the clinical level.

## **2. The End-of-Life Debate**

Contemporary end-of-life debates center around questions of when, how, and if it is ever appropriate to assist patients in dying. The three end-of-life options most frequently discussed are passive euthanasia, physician-assisted suicide, and active euthanasia. Passive euthanasia refers to the withholding or withdrawing of treatments, knowing that the patient will die as a

result. This practice is commonly justified by appeal to the patient's right to refuse treatment, and is therefore often described as allowing, rather than causing, the patient's death. In contrast, active euthanasia refers to a physician actively bringing about the death of a patient for the patient's own sake, usually by means of directly administering an overdose of barbiturates. Physician assisted suicide (PAS) differs in that a physician provides the means through which a patient may end her or his own life, but stops short of physically assisting the patient in ending their life.

Passive euthanasia is the only end-of-life option legalized throughout the entirety of the United States and has become standard practice in the modern American healthcare system. Physician-assisted suicide has been legalized in only eight US states as well as the District of Columbia, while active euthanasia is currently illegal throughout the United States. While the moral justification for passive euthanasia will be discussed, the core of this discussion will focus on the moral permissibility of the controversial practices involving end-of-life assistance, with the phrase "end-of-life assistance" referring to both physician-assisted suicide and active euthanasia.

Without taking a stand on the moral permissibility of end-of-life assistance or endorsing any particular arguments for or against such practices, the aim of this section is to examine the common arguments that make up the end-of-life debate in light of both the traditional and structured principlist frameworks. Section 2.1. will map the main arguments in favor of end-of-life assistance onto the traditional principlist framework, paying special attention to how the relevant bioethical principles are being interpreted by the various authors. Section 2.2. will do the same for arguments opposing end-of-life assistance. After framing the end-of-life debate in terms of the traditional principlist framework, the debate will be re-framed in terms of the



structured principlist framework. Doing so will demonstrate that in contrast to the traditional framework, the structured framework more clearly identifies which bioethical principles are centrally at issue, allowing for more clarity and guidance with regard to these practices and the attending policies governing them.

### *2.1. Arguments in Favor of Assistance*

Many of the arguments in favor of assistance-in-dying rely on explicit appeals to the principles of respect for autonomy. However, as we begin evaluating the arguments it will quickly become clear that for the principle of respect for autonomy to do the work in supporting these claims, autonomy must be interpreted in a positive sense that is ultimately problematic. After examining the issues with a positive conception of autonomy, I will argue that the stronger argument in favor of end-of-life assistance is one that appeals to a negative conception of respect for autonomy coupled with an appeal to beneficence. While this stronger line of argumentation exists within the end-of-life debate, it is not readily apparent when mapping the debate in terms of the traditional principlist framework.

Dan Brock is one of the original proponents of assistance at the end of life. He argues that the values of “individual self-determination or autonomy and individual well-being... the very same two fundamental ethical values supporting the consensus on patient’s rights to decide about life-sustaining treatment also support the ethical permissibility of euthanasia” insofar as we recognize “a central aspect of human dignity lies in people’s capacity to direct their own lives in this way.”<sup>135</sup> His claim is that so long as people have a vested interest in determining how and when they die, and we think it is at least sometimes appropriate to respect that interest above

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<sup>135</sup> Brock, Dan, “Voluntary Active Euthanasia,” *Hastings Center Report* 22 (1992): 10-22, 11.

keeping the patient alive, then respect for autonomy should allow the patient to “control the manner, circumstances, and timing of their dying and death.”<sup>136</sup>

In “The Philosophers’ Brief,” Ronald Dworkin and others similarly argue that individuals have the right to make their own decisions about death and dying, but these authors do so by appealing to the US constitution and prior court decisions.<sup>137</sup> They argue that the US constitution forbids the government from imposing specific religious or moral convictions on its citizens, and court decisions such as *Planned Parenthood v. Casey* ground a person’s right to make decisions “involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy.”<sup>138</sup> While admitting that states have an interest in protecting individuals from irrational, coerced, or ill-formed decisions that may hasten their deaths, Dworkin et. al argue that this does not entail that states may deny patients the right to demonstrate their reasons for requesting assistance in dying are “rational, informed, stable, and uncoerced.” Given this, they conclude that it would be impermissible for the state to impose a blanket prohibition on end-of-life assistance. For a blanket prohibition would be imposing a particular conception of meaning and value on individuals, thereby violating the liberty interest established by the courts, meaning cases should be considered on an individual basis given the very personal nature of a terminal illness and the variability in people’s value sets and beliefs.

More recent advocates for end-of-life assistance, such as Brittany Maynard, similarly appeal to the importance of being able to control the dying process. In her essay “My Right to Death With Dignity at 29,” Maynard discusses facing her impending and inevitable death after

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<sup>136</sup> Ibid.

<sup>137</sup> Dworkin R, Nagel T, Nozick R, Rawls J, Scanlon T, Thomson JJ, “Assisted Suicide: The Philosophers’ Brief,” *New York Review of Books* 44 (1997): 41-47.

<sup>138</sup> *Planned Parenthood v. Casey*, 505 U.S. 833, 851 (1992).

being diagnosed with terminal brain cancer, and uses her unique perspective to argue for the moral permissibility of physician-assisted suicide.<sup>139</sup> Echoing Brock, Maynard explains that “having this choice at the end of my life has become incredibly important. It has given me a sense of peace during a tumultuous time that otherwise would be dominated by fear, uncertainty and pain.”<sup>140</sup> The importance of self-determination is common to many arguments for end-of-life assistance, given the deeply personal nature of death and dying.

These arguments all appear to be grounded in the principle of respect for autonomy, the idea that individuals should be afforded the opportunity to self-determine and to make decisions in line with their values. However, as discussed in the previous two chapters, the principle of respect for autonomy can be interpreted in two very different ways: 1) Respecting a patient’s autonomy may be understood to include the positive duty of assisting the patient in achieving their ends, or 2) respecting a patient’s autonomy may be understood as a strictly negative duty of non-interference. Given that these arguments aren’t simply about a patient being allowed to refuse treatment, but rather claim that it may sometimes be permissible for healthcare providers to take active measures to assist these patients in dying, for example by providing an excess of barbiturates, these arguments appear to be relying on the positive interpretation of the principle.

Unfortunately, employing the positive interpretation of the principle of respect for autonomy is not without its drawbacks. Recall that in Chapter 1, section 3, I criticized the traditional principlist framework based on what I termed the *extremism criticism*: The indeterminacy inherent in the traditional principlist framework allows for the justification of two

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<sup>139</sup> Maynard, Brittany, “My Right to Death with Dignity at 29,” CNN, Nov 2014.

<<http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html>

<sup>140</sup> Ibid

diametrically opposed positions that are each at odds with the accepted norms of healthcare. In this discussion, section 3.1. focused on paternalism as one possible extreme measure, and section 3.2. focused on overtreatment as the other possible extreme measure. The concern regarding overtreatment arises when the principle of respect for autonomy is thought to entail positive duties to assist patients in achieving certain ends, as well as when respect for autonomy is treated as preeminent among the other principles. These are the same two conditions that are being appealed to in the above arguments for end-of-life assistance.<sup>141</sup>

A further concern is that not only does accepting a positive conception of autonomy raise issues insofar as it can justify overtreatment, but it could also be used to justify end-of-life assistance even in cases where there is no medical indication for such assistance. Specifically, there is nothing in the above arguments to limit end-of-life assistance to only terminal cases or cases involving significant physical or psychological suffering. While the arguments presented have all centered around patient requests at the end-of-life, we can also imagine end-of-life assistance being requested by patients suffering from chronic depression, non-terminal neurodegenerative diseases such as Multiple Sclerosis, patients experiencing sudden life changes due to acute paralysis or amputation, or even patients experiencing significant hardship due to socioeconomic difficulties as opposed to physical ailments. If we take respect for autonomy to both have moral priority and to entail a positive duty, it becomes difficult to justify allowing end-of-life assistance in some cases yet denying end-of-life assistance to patients such as these.

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<sup>141</sup> Chapter 1, section 3.2., first argued that policies such as informed consent require healthcare providers to act as though the principle of respect for autonomy is preeminent and provided evidence that physicians in fact feel compelled to comply with patient requests for care supporting the idea that physicians sometimes act as though respect for autonomy entails a positive component.

On the traditional principlist framework, in order to avoid these concerns while simultaneously retaining the moral force of respect for autonomy, one would have to deny that respect for autonomy entails positive duties. However, denying this positive conception of respect for autonomy would also seemingly undercut the arguments in favor of assistance at the end-of-life. This is because a negative right of non-interference supports the withholding or withdraw of care, allowing for voluntary passive euthanasia, but fails to provide healthcare professionals with a clear reason to take positive steps toward actively assisting patients, such as providing them with life-ending medications.

One of the most straightforward ways to argue for assistance while relying on a negative conception of autonomy is to couple the appeal to respect for autonomy with an appeal to beneficence, the moral duty to promote the good of the patient. The appeal to beneficence is necessary in order to provide healthcare professionals with a decisive reason to actively assist the patient, independently from mere patient preference. Such a reason might be construed as bestowing a benefit upon the patient or preventing harm to the patient. This means that although a strictly negative conception of autonomy fails to engage the healthcare provider in assistance, an appeal to autonomy, understood as non-interference, coupled with an appeal to beneficence could provide the healthcare professional with a positive reason to act while also prohibiting involuntary end-of-life interventions. Brock in fact appears to recognize the need for both principles, for although his argument appears to focus primarily on considerations of autonomy, it is actually supported by two values, the second value being “patient well-being” which can be understood as “patient benefit.”

This value of individual well-being can be understood as relating to the principle of beneficence. While the “good of the patient” is often narrowly understood as what promotes the

physical well-functioning of the patient, it can also be understood more broadly to include what the patient views as a benefit or burden. Brock appears to understand individual well-being in latter sense, given his claim that both passive and active euthanasia are justified when “life is no longer considered a benefit by the patient, but has now become a burden.”<sup>142</sup> While this may appear to be conflating patient autonomy and beneficence, Brock’s focus on patient well-being, or non-health related benefits, is understandable given that end-of-life cases differ from most in that there are few, if any, physiological benefits to bestow upon an actively dying patient. This is because even though the primary aim of healthcare is to impart health-related benefits on patients by “treating the patient’s disease” or “saving the patient’s life,” such goals become infeasible when the patient is terminally ill. In cases where a patient’s physiological functioning cannot be improved such that their life will be saved or even meaningfully extended, the only benefits still to be had are the relief of pain and suffering. As such, end-of-life cases appear to require healthcare providers to reevaluate their goals and what can be understood as a “benefit” for the patient, turning away from a focus on physiological improvement and toward a focus on non-health related benefits such as patient well-being.

Importantly, non-health benefits should only factor into a healthcare professionals’ assessment of favorability when the eligible set of favorable options is empty. When the eligible set is not empty, which is true in the vast majority of cases, considerations of non-health benefits and harms are captured by the enabling condition in that they are a part of what leads the patient to accept or refuse the option(s) provided. Non-health benefits are typically captured by the enabling condition rather than the favorability condition because the epistemic obligations of

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<sup>142</sup> Ibid.

healthcare professionals cannot reasonably be expected to include an assessment of non-health benefits for each patient, given that this would require having intimate knowledge of each patient's goals, values, and life circumstances.<sup>143</sup> Moreover, the healthcare professional cannot have a normative obligation to include considerations of non-health benefits because non-health benefits are about what the *patient values* apart from their health, as such a determination can only be meaningfully made by the patient or proxy. Thus, where there is a set of favorable options for promoting the patient's health, non-health benefits are appropriately captured by the enabling condition: Non-health considerations are what factor into a patient's acceptance or refusal of the options presented, a determination that can only be made by the patient and which works to modify the patient's assessment of the favorable options.<sup>144</sup>

However, in cases of terminal illness the eligible set of options can no longer be about what will reasonably improve the patient's health, meaning healthcare professionals must act on other considerations, such as what will make the patient comfortable during the dying process. Hospice care and palliative care, or comfort care, are often where healthcare providers turn when patients are dying, providing us with insights as to what we think count as benefits in such cases; these may include relieving the patient's pain, helping the patient to accept or come to terms with their inevitable death, and generally providing comfort during what is often the most frightening portion of a patient's life. Helping the patient to feel in control during the dying process or offering relief for intractable suffering may be reasonable extensions of these aims, and in cases

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<sup>143</sup> The structure of the American Healthcare System precludes most healthcare professionals from being able to gain intimate knowledge of, or form lasting relationships with, patients. For example, most specialists first meet patients when they are referred, yet the specialist may quickly have to make a diagnosis and offer recommendations.

<sup>144</sup> Excluding non-health benefits from favorability assessments is what helps constrain the eligible set of favorable options such that it excludes non-indicated care. If non-health benefits were included in the favorability assessment, the fact that the patient desires some course of action could place it over the threshold of favorability despite the option offering no meaningful health benefit.

where palliative care is insufficient for achieving such ends one could make a case for end-of-life assistance.<sup>145</sup>

As previously mentioned, addressing concerns regarding dependency, fear, and even pain can be understood as a focusing on non-health related benefits, and although these are rooted in patient values, we can nevertheless understand our reasons for acting as relating to beneficence or favorability. As opposed to being grounded in the patient's right to autonomy, end-of-life assistance is best understood as a final means of benefitting the patient when no other avenues remain. This is what allows us to take the value of individual well-being, as Brock does, as a reason to assist patients in dying without appealing to a positive conception of autonomy. It is not simply because the patient requests such assistance, but because assisting the patient would remove the burden of life and bestow the benefit of death.<sup>146</sup>

Rosamond Rhodes takes this view when arguing that assistance in dying can sometimes be part of a healthcare provider's duty.<sup>147</sup> She begins her argument by examining what a right to life, or right to death, entails on the part of the healthcare professional. While she thinks "someone with a right to life would have the liberty to live and also the liberty not to live," this analysis "tells us nothing about what we must actively do. It merely explains "negative rights,"

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<sup>145</sup> My analysis will remain agnostic as to which method of providing benefit, palliative services or end-of-life assistance, ought to be preferred. The goal here is simply to determine the strongest arguments in favor of end-of-life assistance in order to then examine how they relate to the arguments rejecting the moral permissibility of end-of-life assistance.

<sup>146</sup> This understanding of non-health related benefits seems to suggest that end-of-life assistance can most readily be understood as a benefit in cases of terminal illness. While I acknowledge that cases of terminal illness would be the simplest for justifying end-of-life assistance, it remains an open question as to whether some non-terminal cases involving assistance may also be justified on the grounds of either health or non-health related benefits, such as patients diagnosed with neurodegenerative disorders like ALS.

<sup>147</sup> Rhodes, Rosamond, "Physicians, Assisted Suicide, and the Right To Live or Die," *Physician Assisted Suicide: Expanding the Debate* (New York: Routledge, 1998): 165-176.



the choices we must allow others to make for themselves.”<sup>148</sup> The most a right to life, or a right to death, can ensure is that healthcare providers should not interfere with the patient’s choice, meaning “a duty to try to help another save or end a life would have to come from another source.”<sup>149</sup> That source is the duty of beneficence, as Rhodes explains:

The duty to get involved, the duty to do good for another. ... If alleviation of suffering (both mental and physical) is a need, or if preservation of dignity is a need, or if respect for self-determination (autonomy) is a need, then there certainly may be times when beneficence requires assisting others in meeting their needs... If a person needs to alleviate suffering, preserve dignity, or continue to act from his own choices, and if he also requests the assistance of another in doing what he cannot do for himself, then beneficence binds the one who can to aid the one who cannot.<sup>150</sup>

As noted by Rhodes, the end-of-life debate is not merely about what patients are permitted to do at the end of life, it is also about what justifies healthcare providers in assisting patients in achieving those ends. When we turn to this latter issue of *assistance*, it becomes clear that the principle of beneficence, or the duty to promote the good of the patient, is required to do the moral lifting.

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<sup>148</sup> Rhodes, “Physicians, Assisted Suicide,... Die,” 167-169.

<sup>149</sup> Rhodes, “Physicians, Assisted Suicide,... Die,” 169.

<sup>150</sup> Rhodes, “Physicians, Assisted Suicide,... Die,” 169-171.

It should now be clear that although arguments for end-of-life assistance often explicitly appeal to the principle of respect for autonomy by noting the importance of respecting a patient's right to choose the time and manner of their death, absent an explicit appeal to positive autonomy and acceptance of the attending consequences, these arguments fail to explain why a healthcare provider should *actively assist* patients in dying. It is instead the principle of beneficence that most directly justifies assistance at the end-of-life, insofar as death may sometimes be considered a benefit.<sup>151</sup> The principle of respect for autonomy is then perhaps most helpful in that it prohibits such actions from being done involuntarily, meaning it prohibits the possibility of things like death panels even in cases where doing so could be considered a benefit.

Just as the principle of beneficence justifies providing pain-relieving medications to patients who are suffering, it can be argued that we are also justified in taking active steps to relieve pain in extreme cases by providing physician-assisted suicide or voluntary active euthanasia, especially when the patient is terminally ill and suffering. Understanding these as the strongest arguments in favor of end-of-life assistance shifts the end-of-life debate from questions of whether patients are entitled to make personal decisions about the time and manner of their deaths, to questions of whether the death of the patient may ever be considered beneficial such that healthcare professionals are justified in bestowing that benefit through end-of-life assistance.

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<sup>151</sup> In her essay, Rhodes also argues that healthcare professionals are the most fitting people to assist patients with end-of-life decisions, given that they can assess the patient's capacity, discuss relevant alternatives, and is likely to have a long-term relationship with the patient including understanding how the patient's long-held beliefs fit with the patient's decision to end their life. Rhodes, "Physicians, Assisted Suicide, and the Right To Live or Die," 172.

## 2.2. *Arguments Against Assistance*

Just as with the previous examination looking at the arguments in favor of end-of-life assistance, I will again refrain from endorsing any of the arguments presented here. Instead my aim is to present the strongest version of each view while remaining agnostic about the moral permissibility of end-of-life assistance. This is because the primary goal is to charitably understand the end-of-life debate as it has been taking place in the context of the traditional principlist framework. Through analyzing both positions I will demonstrate that the arguments for and against end-of-life assistance fail to directly engage with one another, and that this in large part due to the unstructured nature of traditional bioethical principlism.

In taking a stand against end-of-life assistance, Daniel Callahan critiques arguments from respect for autonomy along the same lines as previously discussed, noting that “the moral move from my right of self-determination to some doctor’s right to kill me” does not follow.<sup>152</sup> He points out that when arguments for assistance are grounded in respect for autonomy, they aren’t simply about the patient waiving their right to life, for assistance may also involve bestowing “the power to take that life” upon the healthcare practioners. Callahan is concerned that not only does respect for autonomy fail to justify a move from “my right” to “the doctor’s right,” meaning the justification for the doctor to become involved and assist, but that it also opens the door to slippery social consequences such as complicity in, and acceptability of, killings.

While his argument rightly cuts against the claims made by Maynard and Dworkin et al., this line of argumentation fails to directly engage with what I have suggested are the stronger

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<sup>152</sup> Callahan, Daniel, “When Self-Determination Runs Amok,” *Hastings Center Report* 22 (1992): 52-55, 52.

arguments for end-of-life assistance, namely arguments from beneficence. Only at the very end of the essay does Callahan consider arguments relating to well-being, claiming that those who advocate for end-of-life assistance on grounds of promoting patient well-being are moving “beyond the promotion and preservation of health into the boundless realm of general human happiness and well-being.”<sup>153</sup> This, he argues, is moving beyond the proper role of healthcare.

The American Medical Association (AMA) takes a similar stance to Callahan, arguing that end-of-life assistance is morally unacceptable on the grounds that such practices are “fundamentally incompatible with the physician’s role as healer.”<sup>154</sup> However, like Brock and Rhodes, the AMA acknowledges that death may be considered a benefit for certain people by noting that “some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life.”<sup>155</sup> Yet despite acknowledging that end-of-life assistance may be viewed as beneficial by some patients, the AMA maintains that assisting those patients would run counter to the professional goals and duties of healthcare practitioners. So while the AMA acknowledges that death may be viewed as a benefit by some patients, and in some cases may even be the only reprieve for terminally ill patients suffering from a painful and debilitating illnesses, the AMA nevertheless argues against providing this particular benefit on the grounds that doing so would be antithetical to the professional duties of a healthcare provider.<sup>156</sup>

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<sup>153</sup> Callahan, “When Self-Determination Runs Amok,” 55.

<sup>154</sup> American Medical Association, “Euthanasia: Code of Medical Ethics Opinion 5.8,” <<https://www.ama-assn.org/delivering-care/ethics/euthanasia>>; “Physician-assisted Suicide: Code of Medical Ethics Opinion 5.7,” <<https://www.ama-assn.org/delivering-care/ethics/physician-assisted-suicide>>.

<sup>155</sup> Ibid.

<sup>156</sup> Admittedly, the AMA’s understanding of the physician’s role as a healer is quite narrow, and my earlier discussion of non-health related benefits suggests a possible re-thinking or broadening of the physician’s role. Determining the limits and scope of the healthcare profession will help to further inform assessments of favorability by specifying the normative obligations of the healthcare professional. It is not the function of the structured

There are two ways in which we can interpret the AMA's claim: The first interpretation is in line with Callahan's suggestion that healthcare is properly understood as narrowly promoting patient health, making the promotion of patient well-being beyond the scope of healthcare, and the second interpretation is that we should understand violations of non-maleficence as unacceptable when they result in the loss of life. This latter interpretation does not suggest that euthanasia would fail provide a benefit, but rather that the healthcare provider would be violating the duty of non-maleficence by causing significant harm to the patient, specifically the harm of death.<sup>157</sup> This interpretation is further supported by the AMA's warning that "the physician who performs [active] euthanasia assumes unique responsibility for the act of ending the patient's life."<sup>158</sup> As mentioned in Chapter 1, section 5, the principles of beneficence and non-maleficence can either be understood as providing unique and independent directives — beneficence is the duty to do good while non-maleficence is the duty to refrain from causing harm — or they can be understood as working together in determining the "net" good. To make sense of this "death as a significant harm" interpretation of the AMA's claim, the principles of beneficence and non-maleficence must be understood as working independently given that the core claim is that non-maleficence should be given moral priority over beneficence when the violation of non-maleficence will result in the death of the patient.

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principlist framework to determine or inform the core professional responsibilities within healthcare, but rather to guide healthcare providers in decision-making *given* the normative and epistemic obligations entailed by the healthcare profession.

<sup>157</sup> Views arguing for death as a significant harm include comparativism or deprivation accounts as argued for by Nagel 1970, Quinn 1984, Marquis 1989, and Feldman 1991.

<sup>158</sup> American Medical Association, "Euthanasia: Code of Medical Ethics Opinion 5.8," <<https://www.ama-assn.org/delivering-care/ethics/euthanasia>>; "Physician-assisted Suicide: Code of Medical Ethics Opinion 5.7," <<https://www.ama-assn.org/delivering-care/ethics/physician-assisted-suicide>>

The main idea supporting this line of argumentation is that despite the general aim of healthcare being to benefit patients, we should not pursue a benefit when doing so would require inflicting significant harm on the patient, such as the harm of death. Death is sometimes considered the ultimate harm because it precludes the possibility of any future benefits or any future exercise of autonomy.<sup>159</sup> Given such a view, it is the *prima facie* nature of the principles on the traditional principlist framework that allows for the AMA or others to separate considerations of beneficence from considerations of non-maleficence and to argue that one of these principles ought to be promoted at the expense of the other.

Interestingly, those who argue against end-of-life assistance are often accepting of passive euthanasia. For example, Callahan denies that it is the appropriate role of the healthcare provider to relieve suffering brought on by “anguish or despair at the human condition,” or presumably the existential angst and fear inherent in being diagnosed with a terminal illness, yet “the doctor who, at the patient’s request, omits or terminates unwanted treatment does not kill at all” and may be morally justified in that omission.<sup>160</sup> This is a common theme among those arguing against end-of-life assistance, including the AMA; while they argue that it is impermissible to be the proximate cause of the patient’s death, they agree that it is permissible to stand back and allow the patient to die even when doing so prolongs or increases the patient’s suffering.

Callahan, Brock, and James Rachels are some of the philosophers who attempt to explain this stance by casting the differences between passive and active euthanasia in terms of the

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<sup>159</sup> This account of the harm of death stems from Nagel’s deprivation account, which has been argued to be the most plausible account of the wrongness of death within healthcare. Solberg, Tollef, and Espen Gamlund, “The badness of death and priorities in health,” *BMC medical ethics* 17 (2016), doi:10.1186/s12910-016-0104-6.

<sup>160</sup> Callahan, “When Self-Determination Runs Amok,” 53.

act/omission distinction. Those in favor of assistance, such as Brock and Rachels, argue that the proximate cause of the patient's death is not important; rather, what matters is whether one is morally culpable for the death. Those arguing against assistance claim that causality matters as well as culpability, and that being the cause of the patient's death is significantly worse than simply standing back and allowing the patient's death. While those engaged in this debate often turn to examples that pull at intuitions regarding causality and culpability, when the act/omission debate is couched in terms of the bioethical principles it quickly becomes apparent that the principles of beneficence and non-maleficence are actually at issue.

As discussed, the best arguments in favor of assistance appeal to beneficence to justify bringing about the death of the patient, and those arguing against assistance are appealing to the significant violation of non-maleficence. However, when it comes to the justification for omissions, thereby allowing for passive euthanasia, the justification is grounded in respect for autonomy. Turning back to Callahan's claim, it is "at the patient's request" that we are justified in omitting treatment, citing the importance of respect for autonomy understood as non-interference. The AMA similarly condones passive euthanasia when the patient refuses further treatment insofar as treating the patient would violate respect for autonomy. Passive euthanasia also satisfies non-maleficence insofar as one isn't bringing about the death of the patient, and it may satisfy beneficence insofar as the patient considers life more burden than benefit.<sup>161</sup> Still, it

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<sup>161</sup> There may be some debate in the metaphysics about whether omissions can count as causes, but in healthcare there is a practical distinction between acts and omissions as captured by the principles of beneficence and non-maleficence. The principle of beneficence is violated when providers fail to act and thereby allow harm to come to a patient or allow some harm to continue. The principle of non-maleficence is violated when providers act in such a manner that they are the proximate cause of the harm.

is an appeal to respect for autonomy that clearly justifies omissions insofar as the patient has refused further treatment.

Thus far we have seen that although some proponents of end-of-life assistance argue for assistance on the grounds that doing so respects patient autonomy by allowing them to control the time and manner of their dying, such arguments fail to motivate healthcare providers to act save for a positive interpretation of the principle. Because such an interpretation is contentious and open to significant consequences, a stronger argument for assistance can be grounded in an appeal to beneficence. Those opposed to assistance then counter that non-maleficence holds more weight than beneficence when the benefit would require actively ending the life of the patient, and all parties can agree that passive euthanasia is permissible due to respect for patient autonomy understood as non-interference. The depth of analysis required to map these arguments onto the traditional principlist framework and suggests that while the traditional framework is able to make sense of the debate surrounding end-of-life assistance, it does little to guide or untangle the debate, instead often allowing for the various positions to talk past one another. Moreover, the ability to prioritize one principle at the expense of the others can lead to troubling consequences, such as justifying end-of-life assistance per the patient's request even when such assistance would fail to be medically indicated or otherwise beneficial.

### *2.3. Evaluating End-of-Life Assistance Using Structured Principlism*

In order to figure out whether end-of-life assistance can ever be justified, one must first determine the core of the ethical conflict and how this conflict relates to one's moral duties. As seen above, a brief survey of the literature could easily lead healthcare providers to think that the debate is about the appropriate limits of respect for autonomy and that those who oppose such assistance are attempting to be paternalistic. Or another reading might lead one to think that the



core of the debate is between the principles of respect for autonomy and non-maleficence, leaving it unclear exactly how the relative weights of each principle are to be compared. Yet another reading of the debate could center around the act/omission distinction, leading one to think that the debate turns on issues of causality and culpability. However, our extended analysis has elucidated the core issue as a disagreement as to whether end-of-life assistance can reasonably be considered a benefit such that healthcare providers have a duty to provide it. This is not only the best version of the debate, but also a debate that healthcare professionals are readily equipped to engage in.

All this is to say that while the bioethical principles are useful in understanding the contours of the end-of-life debate, the traditional principlist framework is largely unhelpful in clarifying where the crux of the debate is located. For example, because this debate involves three competing principles and the traditional framework allows for any prioritization of these principles, it would not be unreasonable to read the debate as being predominately between respect for autonomy and non-maleficence. It was only through an extended analysis and without clear guidance from the traditional framework that we were finally able to locate the core disagreement as being between beneficence and non-maleficence. I will next demonstrate the structured principlist framework to be an improvement in that it readily elucidates where core disagreements arise and provides a clear pathway for thinking through the permissibility of end-of-life assistance.<sup>162</sup>

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<sup>162</sup> You will recall that the structured principlist framework is comprised of two necessary and sufficient conditions for the moral permissibility of an action: The enabling condition and the favorability condition. The *favorability condition* requires that the proposed action is favorable insofar as it is reasonably expected to promote the health of the patient, while the *enabling condition* requires that the proposed action is authorized by the patient or proxy and adheres to current hospital policies and procedures.

When evaluating end-of-life issues using the structured principlist framework it makes sense to begin with the enabling condition because it acts as a gatekeeper: If the patient refuses life-sustaining care, there is no further debate to be had.<sup>163</sup> The structured principlist framework requires that both the enabling and favorability conditions be met in order to justify an action, so when a patient refuses care the enabling condition fails to be met and healthcare providers must step back in order to respect the refusal.<sup>164</sup> The enabling condition thus ensures that no end-of-life assistance is performed involuntarily, and also helps to make sense of the wide-spread acceptability of voluntary passive euthanasia: When a patient or surrogate decision-maker refuses care, even life-extending or life-saving care, healthcare professionals must respect that decision by refraining from interfering with the patient (physically or otherwise). All cases of voluntary passive euthanasia can thus be understood as cases in which the enabling condition fails to be satisfied. It is only in cases where the enabling condition *is* satisfied that debates about benefits and harms become relevant.<sup>165</sup>

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<sup>163</sup> This is not to suggest that a reasonable debate cannot be had about the benefits or harms of continuing such treatment, but rather that the outcome of any such debate will have no bearing on what should be done. So long as the enabling condition fails to be satisfied, acting on the basis of benefitting the patient against the patient's expressed refusal would be inappropriate according to the structured principlist framework. Additionally, because the enabling and favorability conditions function independently and both must be satisfied for the moral permissibility of an action, it does not make a substantive difference which condition is evaluated first. While in our discussion it makes sense to begin with the enabling condition, in practice it would often make sense to begin with the favorability condition insofar as a healthcare provider will want to determine the set of options they are comfortable with presenting to the patient prior to asking the patient for consent.

<sup>164</sup> This assumes that the patient has the capacity to make such a decision. If the patient is determined to lack capacity, a surrogate decision-maker should be appointed, and the enabling condition should be assessed in terms of the surrogate's consent or refusal of further care on the patient's behalf.

<sup>165</sup> As noted in footnote 26, in practice it will often be useful for healthcare providers to assess the favorability condition first, in order to determine which options should be offered to the patient. Moreover, a patient will want to know the benefits and drawbacks of various life-extending measures or assistance-in-dying before deciding whether to consent or refuse those measures. However, once a patient provides an informed refusal of a treatment option, that refusal should be respected regardless of the expected benefits of performing the action.

Although the enabling condition is useful for grounding the moral justification of voluntary passive euthanasia, it is unable to help us assess the moral justifications for end-of-life assistance apart from ensuring such assistance would not be involuntary. This is because the fundamental disagreement regarding end-of-life assistance relates to how one assesses the benefits and harms associated with bringing about the death of a patient. To understand whether end-of-life assistance could ever be justified we must turn to the favorability condition. By allowing the principles of beneficence and non-maleficence to come apart, the traditional framework allows for those arguing in favor of assistance to focus on the foreseen benefits while those in opposition primarily focus on the harms. Unlike the traditional framework which allows for an assessment of benefits and harms to be carried out independently from one another, the structured framework requires that one consider whether, on balance, the benefits outweigh the harms in each case. So long as the patient would be willing to consent to end-of-life assistance, it falls on the healthcare provider to assess the favorability of carrying out such an action.

As previously discussed, arguments in favor of assistance suggest that actively helping a patient to die may satisfy the favorability condition by relieving the patient's suffering and removing the burden of life. In cases where the patient is terminally ill and intractably suffering, this non-health benefit may be the only benefit that remains. Opposing this, some could argue that intentionally ending the life of a patient fails to satisfy the favorability condition insofar as the harm of death significantly outweighs any attending benefits, including relief from pain. There is also a debate to be had about the proper role of the healthcare professional: Is the role of a healthcare professional limited to improving patient health, or should it also be extended to incorporate patient well-being (non-health benefits) in some circumstances? These are deep disagreements and debates about the fundamental nature of death, suffering, and the proper role

of the healthcare professional. Unfortunately the favorability condition is unable to help settle these types of philosophical disagreements; rather, the role of the favorability condition is to help pinpoint the core of the disagreement between those arguing for and against end-of-life assistance, to separate that discussion from other tertiary considerations such as patient autonomy, and to guide assessments of favorability given the normative and epistemic obligations of the healthcare professional.<sup>166</sup>

For example, when discussing arguments for assistance and noting that some non-health related benefits may be thought to justify end-of-life assistance, such as control over one's own dying process or relief from intractable suffering, it is tempting to take the patient's wishes as indicative of, or even constructive of, what would be good for them. Yet this admittedly begins to blur the line between autonomy and beneficence despite my arguments against a positive conception of respect for autonomy. By separating considerations into the enabling and favorability conditions, the structured principlist framework helps to keep considerations related to beneficence and autonomy distinct: The enabling condition directs us to determine whether the patient has capacity and would consent to the action given their goals and values, thus prohibiting involuntary actions, while the favorability condition directs us to judge whether the action is reasonably expected to benefit the patient. Not only does this division protect patients by prohibiting end-of-life assistance when the action would be involuntary, but it also provides

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<sup>166</sup> The normative and epistemic obligations of the healthcare professional are what guide and constrain assessments of favorability, meaning debates regarding the proper role of the healthcare professional are important for informing the favorability condition and that the favorability condition cannot be employed in settling such a debate. As such, I will refrain from taking a stand on whether non-health benefits can ever in fact be used to justify end-of-life assistance, though I can and have outlined the narrow conditions under which non-health benefits could factor into favorability assessments should we think that physicians ought to promote patient well-being and not just patient health.

healthcare providers with a justified reason for refusing to assist patients in cases where the assistance would fail to be medically indicated or otherwise considered beneficial.<sup>167</sup>

When the structured principlist framework is applied within a healthcare setting, it provides healthcare practitioners with two main questions to consider: 1) What specific treatments/actions are reasonably favorable for this patient and 2) will the patient or proxy consent to any of the treatments/actions deemed favorable? When thinking about cases of terminal illness, answering the first question will likely include considerations of hospice care, palliative services, continuing life-sustaining measures, as well as the possibility of assistance in dying.<sup>168</sup> Unfortunately, as seen in Chapter 2, section 1.3., assessments of favorability are quite complex even when the goal of the healthcare provider is clear, so determining whether the option of palliative care is sufficient to close the door to the possibility of end-of-life is not something I will take a stand on here. This is for healthcare professionals to continue debating, and what the favorability condition adds is a clear focus and structure to that debate. Once the eligible set of favorable options has been determined, if the patient is willing to consent to one or more of the options presented then both the favorability and enabling conditions will have been met and the healthcare professional is morally permitted to proceed with any of the actions that satisfy both conditions. Conversely, if the patient refuses to consent to, or withdraws consent

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<sup>167</sup> Chapter 2, section 3, argued that a primary feature of the structured principlist framework is the way in which it appropriately constrains both healthcare professionals as well as patients. The enabling condition constrains healthcare providers from acting contrary to the patient's wishes, while the favorability condition constrains the set of actions for which a patient may provide their consent. The way in which these conditions have now been shown constrain patients and providers in the context of end-of-life assistance is yet another example of this feature in action.

<sup>168</sup> "Life-sustaining measures" may include things such as artificial hydration/nutrition, dialysis, artificial ventilation, artificial pumps such as an LVAD, and aggressive treatments including chemotherapy and radiation. In cases of terminal illness these measures are not expected to significantly improve the patient's health outcomes, but rather may be used to slow the rate of the patient's decline.

from, life-sustaining measures or assistance in dying, then the enabling condition fails to be met and passive euthanasia becomes the default as the only remaining morally appropriate course of action.<sup>169</sup>

#### *2.4. Forming End-of-Life Policies*

The purpose of the structured principlist framework is not to definitively indicate which actions are morally permissible and which are impermissible, for then it would be akin to an objective list view which I do not endorse.<sup>170</sup> Rather, the purpose of the structured framework is to offer guidance to healthcare practitioners by better organizing how they think through the possible options and outlining which features would make an action morally impermissible. As such, the structured principlist framework intentionally leaves it open as to whether active euthanasia or physician-assistance suicide are in fact morally permissible, instead clarifying the ethical tension and encouraging debate while remaining ecumenical between the different positions regarding the favorability of assistance.

By organizing and clarifying the moral debate surrounding end-of-life assistance, structured principlism can be useful in guiding policy formation. For example, it should now be clear that for end-of-life assistance to be justified on the structured principlist framework it must satisfy not only the enabling condition but also the favorability condition, meaning that healthcare professionals must have good reason to think that the hastened death of the patient could be considered a benefit. Thus, when considering the creation of a policy that would permit

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<sup>169</sup> It would not be incompatible for a patient to consent to comfort care/palliative services but refuse life-sustaining care such as continued use of artificial hydration/nutrition. Each action should be evaluated independently, and a patient may still receive comfort treatments while being let to die via passive euthanasia.

<sup>170</sup> For a brief explanation of objective list theories, see the Stanford Encyclopedia of Philosophy entry on Well-Being, section 4.3. Crisp, Roger, "Well-Being," *Stanford Encyclopedia of Philosophy* (2017) <<https://plato.stanford.edu/entries/well-being/>>

some forms of end-of-life assistance, structured principlism requires clarification regarding the circumstances under which a patient's hastened death could be considered a benefit. This might limit such policies such that they apply only to the terminally ill, as is currently the case with regard to physician-assisted suicide in the United States, or this might be thought to include patients who are experiencing intractable pain and suffering as is the case with end-of-life assistance in The Netherlands. This could even justify instances of active euthanasia when the patient meets the criteria for physician-assisted suicide yet is unable to physically end her or his own life.

While the favorability condition helps us to consider the circumstances under which a hastened death would be a benefit, the enabling condition helps us to consider the means through which patients can request and providers can administer assistance. For example, the enabling condition requires that the assistance is in line with the wishes of the patient, meaning policies must be written to safeguard against the possibility of involuntary assistance in dying. The structured principlist framework would therefore support something along the lines of physician-assisted suicide, given that it requires that the patient takes the final step in ending her own life and thereby safeguards against any involuntary killings. Prohibiting surrogates to request end-of-life assistance could be another way of safeguarding against abuse of such a policy. Without taking a stand on the details of the policy, we can see how the structured principlist framework helps to guide policy deliberations by requiring us to think about the specific circumstances under which the enabling and favorability conditions would be satisfied.

### **3. Resource Allocation and Futile Interventions**

In *Just Health Care*, Norman Daniels suggests that there are two basic assumptions that shape our thinking regarding resource allocation: 1) There is always a scarcity of healthcare

resources and 2) we “cannot or should not rely on just market mechanisms to allocate these resources.”<sup>171</sup> While I acknowledge that there may be reasonable disagreement as to whether we ought to rely on just market mechanisms for allocation, I will refrain taking a stand on the normative claim and simply point out that the US healthcare system does not in fact rely on just market mechanisms.<sup>172</sup> As to Daniel’s first assumption about the scarcity of resources, it is important to recognize that healthcare resources can be scarce in a number of ways including, but not limited to, the sheer number of physical resources available.<sup>173</sup>

For example, although the everyday physical resources necessary to sustain and treat patients (IVs, catheters, pharmaceuticals, syringes, etc.) are often ubiquitous in the US, the personnel required to administer and maintain these common items may be limited. In the midst of a nursing shortage, the amount of time each nurse is be allotted to spend with a patient becomes exceedingly limited. Access to diagnostic testing can also be a limited resource depending on the number of patients requiring MRIs, CT scans, or X-Rays in a given period of time. Even the number of inpatient hospital beds, Intensive Care Unit (ICU) beds, and Emergency Room stretchers available to patients are ultimately limited. While these more common resources rarely need to be rationed, mismanagement of any of these resources, such as

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<sup>171</sup> Daniels, Norman, *Just Health Care* (Cambridge: Cambridge University Press, 1985): 19.

<sup>172</sup> Regardless of whether or not we ought to rely on just market mechanisms, we simply cannot rely on solely market mechanisms for resource allocation given the current state of the US healthcare system. Market mechanisms depend on competition and free choice among consumers, and neither of these are fully or properly present in the United States healthcare system. For example, in the case of an emergency, a patient is unable to freely choose which hospital to go to or to compare hospital prices in advance. This is in part because of the nature of being in acute distress and the requirement of immediate attention, but it is also because the process for discovering and comparing hospital prices is notoriously opaque.<sup>172</sup> Moreover, the US healthcare system’s reliance on insurance providers limits competition between hospitals and artificially inflates hospital pricing, making it even more difficult for patients to find out, in advance, what they would be required to pay out of pocket.

<sup>173</sup> While economists are often quick to point out that everything is scarce in an economic sense, I find it worth mentioning the ways that things can be scarce in a non-material sense given that some scarcity is due to limited accessibility as opposed to a finite number of objects.



failing to discharge patients in a timely fashion, can lead to problematic scenarios in that both material and non-material resources become increasingly scarce.

Healthcare institutions thus require policies aimed at efficiency and limiting the provision of nonindicated care. This is the role of distributive justice at the macro level: Determining a fair distribution of healthcare resources, and therein guiding policy decisions aimed at prioritizing various healthcare needs. Admittedly, questions of distributive justice are not limited solely to discussions of healthcare resources, and may include issues of fairness in the context of employment, taxation, public services, etc. However, given that the role of justice within the structured principlist framework is to guide the development of and adherence to hospital policies and practices, this discussion will remain focused on healthcare resource allocation. Of the various healthcare policies and protocols aimed at appropriate resource allocation, those regarding determinations of medical futility are among the most controversial.

Cases involving determinations of medical futility can pose problems on two different fronts. The first issue involves the creation of futility policies: Given that it can be difficult to clearly define what counts as futile or excess treatment, forming a policy aimed at justifying the limitation of care can be challenging. For example, is a treatment futile only if it is entirely ineffective and offers no chance for improvement of the patient's condition, or can a treatment be considered futile when it is acutely effective but will not provide a substantial medical benefit such that the patient's overall condition is expected to improve?<sup>174</sup> The second issue involves carrying out futility protocols in a real-world context: Once an intervention is determined to be

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<sup>174</sup> Successfully performing CPR on a patient diagnosed with terminal cancer would be an example of an acutely effective treatment that does not improve the patient's overall condition. While re-starting the patient's heart is beneficial in the short-term, it cannot stop the progression of the terminal disease.

futile, should the patient's care be terminated despite the patient's refusal, or does the patient have a right to demand (continued) access to those resources? As with the previous section, I will begin by surveying the futility debate as it appears in the literature, mapping the discussion onto the traditional principlist framework, and will thereafter examine the debate in terms of the structured principlist framework.

### *3.1. Challenges to Creating Futility Policies*

To understand how futility has been discussed in the literature, it will be helpful to begin with Brody and Halevy's "Is Futility a Futile Concept?"<sup>175</sup> This is because Brody and Halevy begin by surveying the literature on futility, and from this extrapolate four major types of futility. Interestingly, their stated motivation in undertaking this project is reminiscent of the overtreatment concerns raised in chapters 1 and 2, with Brody and Halevy expressing concern that physicians feel significant pressure to provide excess treatments at the end-of-life due insistence by patients and surrogates.<sup>176</sup> In response to these concerns, Brody and Halevy suggest that a clear concept of futility could help to push back against this norm of overtreatment.<sup>177</sup> While I agree that defining futility is critical for the formation of a justifiable futility policy, the previous criticisms of the traditional principlist framework as laid out in Chapter 1 suggest that clear understanding of futility may not be enough to resolve issues of

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<sup>175</sup> Brody, Baruch, and Amir Halevy, "Is Futility a Futile Concept?" *Journal of Medicine and Philosophy* 20 (1995): 123-144.

<sup>176</sup> In motivating their project, Brody and Halevy note that physicians of the time (1995) felt significant pressure to provide excess treatments, or overtreatment, due insistence by patients and surrogates. As will be discussed in section 3.2., the issues posed by patient pressure are still relevant today.

<sup>177</sup> "The function of invoking futility is to authorize physicians to unilaterally limit life prolonging interventions in certain cases, while preserving the rights of patients and surrogates to decide about the provision of such interventions in other cases." Brody and Halevy, "Is Futility a Futile Concept?" 124.

patient pressure. Given this, my aim is to demonstrate how the structured principlist framework can help not only assist with thinking about policy formation but also real-world implementation.

According to Brody and Halevy, the four categories of medical futility are: Quantitative/physiological, imminent-demise, lethal-condition, and qualitative. *Quantitative or physiological futility* is used to describe cases in which the proposed action will not result in the intended physiological effect.<sup>178</sup> An example of this is CPR “when it cannot lead to spontaneous heartbeat.”<sup>179</sup> CPR might be a surprising yet poignant example as Barbara Daly illuminates in her article “An Indecent Proposal: Withholding Cardiopulmonary Resuscitation.” Despite the way CPR is portrayed in the media, Daly cites data showing only an 18.1% survival rate for hospitalized patients receiving CPR. This number drops down to 13.9% when considering “favorable neurological outcomes,” and drops even lower still when looking at survival outcomes in high-risk groups.<sup>180</sup> In making her argument that most attempts at CPR will not result in the intended physiological effect and should therefore be considered futile, Daly is thus appealing to the concept of physiological futility.

The second type of futility, *imminent-demise*, refers to cases in which a patient is actively dying and the proposed treatment is unable to halt this process. For example, performing CPR in a patient with advanced cirrhosis would be considered futile even when it leads to spontaneous heartbeat, so long as the patient’s terminal prognosis remains unchanged. However, interventions that delay the disease progression such that they prolong the dying process are not considered

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<sup>178</sup> They clarify that measures such as CPR may produce some effect, such as continued temporary perfusion of the body, but still fail to produce the *intended* physiological effect such as spontaneous heartbeat. When a measure will not produce the intended physiological effect, it should be considered futile.

<sup>179</sup> Brody and Halevy, “Is Futility a Futile Concept?” 127.

<sup>180</sup> Daly, Barbara, “An Indecent Proposal: Withholding Cardiopulmonary Resuscitation,” *American Journal of Critical Care* 17 (2008): 377-380.

futile on this understanding. The third type of futility, *lethal condition futility*, is similar to the idea of imminent-demise except in that all interventions are considered futile for terminally ill patients regardless of whether they extend the dying process.

The fourth type of futility is *qualitative futility*, and assessing this turns on whether the patient is expected to have an acceptable quality of life post-intervention. Going back to the data cited by Daly, when considering whether to provide CPR to a patient we must take into account the fact that only 13.9% of patients receiving CPR have favorable neurological outcomes. This suggests that for the roughly 86% of patients, performing CPR is not expected to result in an acceptable quality of life by most people's standards. Or in the case of terminally ill patients such as Brittany Maynard, this suggests that any interventions, including life-extending interventions, would be considered futile when they fail provide an acceptable quality of life. Maynard herself appears to endorse this view when explaining that "after months of research, my family and I reached a heartbreaking conclusion: There is no treatment that would save my life, and the recommended treatments would have destroyed the time I had left."<sup>181</sup> As this example further illustrates, the same intervention may be considered futile according to one criteria but not another; if the treatments recommended to Maynard were successful in extending her life, they could be considered futile according to the *lethal condition* and *qualitative* criteria but not according to the *physiological* or *imminent-demise* criteria.

In a more recent essay, Eric Chwang suggests that in searching for a definition of futility, Brody and Halvey's four conceptions of futility "are not different ways of resolving an

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<sup>181</sup> Maynard, "My Right to Death with Dignity at 29." Although she does not go so far as to describe these treatments are futile, she clearly supports the idea that the treatments, including potentially life-extending treatments, can fail to be beneficial when they heavily impinge on the patient's quality of life.

ambiguity in ‘futility’; they are merely different reasons a treatment might be futile.”<sup>182</sup> On this view, what determines whether a particular treatment will be useful or futile depends on the goal or aim of the treatment, and the four categories suggested by Body and Halevy can best be understood as pointing to various reasons we may describe an intervention as futile given the particular goals of care. This understanding appears to align with the formulation of current futility policies, such as the futility policy at University Hospitals Cleveland Medical Center. The policy at University Hospitals designates an intervention as futile when 1) there is no meaningful chance of achieving the intended medical outcome, 2) it would cause harm and suffering which significantly outweigh the benefit to the patient, 3) it would offer little, if any, hope of survival outside of an intensive care unit, and/or 4) the intervention would be inconsistent with recognized professional standards of care.<sup>183</sup>

### *3.2. Challenges to Carrying Out Futility Protocols*

Even when accepting that futility primarily denotes a lack of medical benefit or an inability to satisfy the goals of care, there remains a tension between these considerations and the principle of respect for autonomy. In “Medical Futility: Legal and Ethical Analysis,” Peter Clark claims that “what has fueled the fires of the current multifaceted [futility] debate is the patients' rights movement and the perception that the right of self-determination extends not only to the refusal of medical treatments but to demands for overtreatment.”<sup>184</sup> This should sound familiar because it is the same criticism leveled against the traditional framework in Chapter 1 Sec. 3

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<sup>182</sup> Chwang, Eric, “Futility Clarified,” *Journal of Law, Medicine, and Ethics* 37 (2009): 487-495, 490.

<sup>183</sup> This policy is not available to the public. It was made available to me as an active member of their monthly ethics committee.

<sup>184</sup> Clark, Peter, “Medical Futility: Legal and Ethical Analysis,” *AMA Journal of Ethics* (2007)  
<<https://journalofethics.ama-assn.org/article/medical-futility-legal-and-ethical-analysis/2007-05>>

regarding patient requests for non-indicated care. In applying this concern to the futility debate, Clark helps to explain the primary challenge hospitals face when creating and justifying futility policies: Even when there is consensus among physicians that a specific treatment offers no meaningful chance of achieving the intended medical outcome, those same physicians often feel hesitation at the idea of taking the decision out of the patient's hands. This is most apparent in the context of unilateral do-not-resuscitate (DNR) orders, which refers to a DNR orders placed without the consent of the patient or surrogate.

Under ideal circumstances, a DNR order would be placed following a comprehensive code status discussion wherein the patient or surrogate acknowledges that attempting cardiopulmonary resuscitation (CPR) would be medically inappropriate. However, in actuality, most DNR orders are placed only a few days prior to the patient's death, "thus serving as a surrogate marker for impending death rather than the result of a planned decision," and some portion of these DNR orders are even placed in opposition to the patient's expressed wishes.<sup>185</sup> When there is clinical judgement that CPR would cause more harm than benefit but the patient or family is in support of doing everything, "there is generally no legal guidance... as to the form or content of such a DNR order or the process by which it is executed."<sup>186</sup> As such, it is largely up to the medical institution to create a policy defining futility and outlining procedures for implementing unilateral DNR orders. Commonly, these procedures call for a 2-physician signoff

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<sup>185</sup> Loertscher, Laura, et al., "Cardiopulmonary Resuscitation and Do-Not-Resuscitate Orders: A Guide for Clinicians," *The American Journal of Medicine* 123 (2009): 4-9, 5.

<sup>186</sup> Miceli, Meredith, "Unilateral Do-Not-Resuscitate Orders," *Ochsner Journal* 16 (2016): 111-112.

process in order to “confirm the medical decision-making surrounding the DNR order and help protect the attending physician from claims of unsoundness or arbitrariness of decision.”<sup>187</sup>

Yet even when there is medical consensus that CPR would be futile or even foreseeably harmful, some physicians nevertheless fail to comply with hospital procedures in that they refuse to sign a unilateral DNR order.<sup>188</sup> The concern here is that even when there are clear policies and procedures for placing a unilateral DNR order, many physicians nevertheless feel uncomfortable overriding the patient’s wishes or taking code status decisions out of the patient’s hands. As seen in the cases of overtreatment and non-indicated care, when given various moral considerations physicians tend to weigh respect for autonomy as being more important than the other principles, even when doing so would foreseeably harm the patient or waste precious healthcare resources. This is true even when the physicians would be acting in line with hospital policies, suggesting that additional moral guidance or justification is needed in cases of justified refusals of care.

### *3.3. Futility and the Structured Principlist Framework*

Thus far we have seen the difficulty inherent in trying to define futility and create policies limiting care, namely the fact that it can be unclear what counts as a benefit and how concerns about resource allocation help to inform policy considerations. Unfortunately, even when clear futility policies and protocols are enacted, physicians may nevertheless be apprehensive to abide by those protocols when doing so would conflict with patient autonomy.

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<sup>187</sup> Ibid. University Hospitals Cleveland Medical Center is an example of a healthcare institution with a two-physician sign-off procedure for the placement of unilateral DNR orders.

<sup>188</sup> Issues of physician resistance to complying with unilateral DNR policy procedures were first brought to my attention through University Hospital ethics committee meetings. Several cases have been discussed in which all relevant healthcare professionals have agreed that CPR would be inappropriate and that a unilateral DNR order ought to be placed, yet the DNR was not ultimately placed due to the physicians’ reluctance to sign the order. While part of this reluctance may be due to fear of litigation for going against the wishes of the patient and/or family, the fear of litigation most directly stems from a fear of violating patient autonomy even in cases of futile care.

The traditional principlist framework is largely unhelpful in that it separates out each of these considerations without offering much guidance on how to relate or balance them. On the traditional framework, considerations of patient benefits are distinct from considerations of resource allocation, and each of these is again distinct from considerations of patient autonomy. Yet when it comes to issues of futility and resource allocation, all of these considerations are in fact intertwined. Determinations of futility in part relate to the goals of care which can take into account patient values, and determinations of effective resource allocation require accurate assessments of expected medical benefit. This is not to say that one cannot relate these considerations when appealing to the traditional principlist framework, but rather that the traditional framework does not offer clear guidance or have an obvious mechanism for doing so.

When turning to the structured principlist framework, these distinct considerations are all captured by the two conditions for moral permissibility, the favorability condition and the enabling condition. Much like the previous cases of non-indicated care, the favorability condition fails to be satisfied when there is insufficient medical benefit, thereby prohibiting healthcare providers from moving forward with the intervention. Granted, our previous discussion of end-of-life care complicates matters slightly, insofar as non-health benefits may be relevant to considerations of favorability when there are no health benefits to be had. For example, if a terminally ill patient will no longer benefit from continued life-support insofar as she will only continue to deteriorate, the continuation of those life-support measures may reasonably be considered futile. But perhaps this patient has a unique goal, such as being transported back to her home state so that she can die and be buried amongst her family.<sup>189</sup>

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<sup>189</sup> This example is based on a real case where an international patient requested the continuation of what appeared to be futile interventions, until the point that she could reach her home country. Her goal was to die and be immediately buried amongst her family members.



In this context, even though the life-support measures offer no clear medical benefit, so long as they are not clearly harming the patient they may be considered favorable in light of this secondary goal. Once this goal of care has been realized, then the life-support measures would no longer constitute an ongoing benefit and may at that time be considered futile. Admittedly, allowing some non-health benefits to be calculated into the favorability assessment complicates matters to a degree, but I see this is a feature as opposed to a flaw. Healthcare decisions are exceedingly complex and more goes into making decisions about a patient's course of care than merely whether an intervention is likely to benefit the patient in narrow health terms; the patient's goals and values also help to determine which intervention, if any, is right for them.

Allowing non-health benefits to factor into decisions at the end-of-life is a way to incorporate patient goals and values without relying on a positive conception of patient autonomy. Instead of moving forward with an intervention simply because the patient asks, the healthcare professional must have reason to agree that the abiding by the request could be considered beneficial from a healthcare perspective. This reason could be to lessen the pain and suffering of the patient, as discussed previously, or the reason could be to sustain the patient long enough for friends and families to say their farewells. But sustaining a patient indefinitely, without a clear goal or objective for the continued care, would not clearly constitute a benefit from a healthcare perspective especially if doing so prolonged the suffering of the patient.

One might be concerned that this opens the door too far, such that abiding by any patient request at the end-of-life could be considered a benefit. This is the importance of having clear and well-constructed policies on matters such as futility. While benefits can extend to more than simply physiological improvement, there is also a point at which continued interventions may produce more harm than good, and issues of resource scarcity also need to be taken into account.

The policy created by University Hospitals, discussed in section 3.1., is an example of imposing limitations on futile care while allowing for some flexibility in these precarious situations.<sup>190</sup> For example, in stipulating that an intervention is futile when “there is no meaningful chance of achieving the intended medical outcome,” this policy requires that there be an identifiable goal related to the proposed or continuing intervention and indexes the determination of futility to the likelihood of achieving that goal. This is not to say that a thorough policy can predict and forestall all potential complications with regard to determinations of futility, but it can offer necessary guidance for those tasked with making the determinations.

Creating a sound hospital policy is important not only in that it provides clear guidance to practitioners faced with difficult situations, but it is also an essential component to upholding the principle of justice. For example, the conditions set out in the University Hospitals futility policy, or similar conditions other hospitals might adopt, can serve the purpose of identifying situations in which the time expenditure of essential medical personnel qualifies as a wasted resource, and thus constitutes an unfair use of resources. By identifying the types of actions that constitute unfair or unnecessary uses of resources, a well-constructed policy becomes a route to upholding the principle of justice as a key component of the enabling condition.

It can now be seen how the enabling and favorability conditions work together in the context of futility. At a macro level, the justice component of the enabling condition requires that healthcare institutions enact clear and well considered policies and procedures that take into account, among other things, a fair distribution of healthcare resources. In a clinical context,

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<sup>190</sup> According to University Hospitals Cleveland Medical Center, an intervention is considered futile when 1) there is no meaningful chance of achieving the intended medical outcome, 2) it would cause harm and suffering which significantly outweigh the benefit to the patient, 3) it would offer little, if any, hope of survival outside of an intensive care unit, and/or 4) the intervention would be inconsistent with recognized professional standards of care.

justice directs healthcare providers to abide by those policies and procedures, some of which can offer guidance for understanding how and when the favorability condition is satisfied. While some healthcare providers may still feel conflicted when abiding by a policy that takes the decision out of the hands of the patient or goes against the patient's expressed wishes, the structured principlist framework makes it clear that providing futile care violates both conditions and as such is not morally justified.

While determinations of futility can be context dependent to a degree, once there is consensus among the relevant healthcare providers that the intervention qualifies as futile, providing or continuing that intervention violates both the favorability condition and the enabling condition with regard to the justice criterion. Even if the patient would consent to the intervention, thereby satisfying the authorization component of the enabling condition, the justice component fails to be satisfied so long as procedures dictating the withdrawal of futile care or implementation of a unilateral DNR order are ignored. While failing to satisfy the favorability condition is sufficient for precluding an action insofar as both conditions must be satisfied for the moral permissibility of an action, the justice component of the enabling condition adds an extra layer of assurance. For when a patient request a futile or non-indicated intervention, providing that intervention would not only fail to act in a way that benefits the patient, violating the favorability condition, but would also fail to be in accord with hospital policies and procedures, violating the enabling condition despite the patient giving consent for the intervention. Because the enabling condition may fail to be satisfied even when the patient explicitly requests a procedure, it takes the force out of patient requests when fulfilling the request would fail to comport with the healthcare provider's professional duties.

#### **4. Concluding Remarks**

The structured principlist framework has now been shown to be clear and straightforward in application, offering guidance to healthcare professionals in morally complex clinical situations. When asked about their justification for acting or withholding care, healthcare professionals can utilize the structured framework to confidently explain their decision in terms of the two conditions. When adopted by multiple healthcare providers, this can help to structure a robust discussion by allowing for easily identifiable points of contention, such as whether the action is favorable. In addition to being useful in clinical situations, I have thus also demonstrated structured principlism to be helpful in organizing and clarifying academic debates as well as formulating important hospital policies. While the traditional principlist framework has helped to capture and solidify important ethical considerations in moral thought, the structured principlist framework helps to move our thinking forward another step by clarifying the relationship between the bioethical principles and ensuring that one type of consideration does not get overshadowed by another.

The initial aim of this project was to offer a practicable moral framework that can structure and guide ethical deliberations in healthcare. The arguments I have laid out over three chapters work together to support the structured principlist framework as an improvement on the traditional principlist framework when employed in both clinical and academic settings. In the clinical context, the enabling and favorability conditions seamlessly integrate medical knowledge with patient values while appropriately constraining both patients and providers, can be used to ground important policies such as requirements of informed consent, and frequently result in recommendations that comport with accepted healthcare policies and procedures. In an academic context, the framework's clear structure helps to untangle complex debates by clarifying the

source of ethical disagreement and assists with the important task of healthcare policy formation. Beauchamp and Childress's traditional principlist framework was monumental for progressing ethical decision-making within healthcare, bringing us to where we are today, and it has long formed the basis for my own thinking about bioethics. In arguing for a more structured version of bioethical principlism, I have endeavored to honor their work by continuing the progression of bioethical thought.

## CONCLUSION

The focus of this project has been first to consider the benefits and drawbacks of Beauchamp and Childress's traditional principlist framework and then to argue for an improved version of bioethical principlism. In particular, my aim was to provide a practicable moral framework that can structure and guide ethical deliberations in healthcare. This resulted in the structured principlist framework, a pluralistic framework comprised of two necessary and jointly sufficient conditions for the moral permissibility of acting within a healthcare setting:

**Favorability Condition:** The proposed action must be reasonably expected to promote the health of the patient.

**Enabling Condition:** The proposed action must be authorized by the patient or proxy and must adhere to current hospital policies & procedures.

These two conditions incorporate the four bioethical principles found in of Beauchamp and Childress's traditional principlist framework but presents them in a structured format that more clearly guides decision-making within healthcare. These conditions are grounded in the normative and epistemic obligations of the healthcare professional, and assessments of favorability are left open to the informed judgement of the healthcare provider who ought to be guided by the aims and norms of the healthcare profession. The enabling condition then allows the patient to select from the eligible set of favorable options, allowing the patient to choose the option they prefer given their unique goals, values, and life-circumstances. In normative terms,

the structured principlist framework is best described as a pluralistic framework that contains consequentialist considerations yet maintains deontic constraints.

While I have argued that the advantage of my framework is that it provides clear guidance for healthcare professionals, some may still be concerned that providing clear guidance is not an intrinsically good feature of a moral framework. For example, we can imagine a framework that offers clear guidance but is based on a false assumption, making it the case that the framework always guides one toward morally wrong actions. If forced to choose between employing such a framework or a less guiding framework, it seems the framework offering less guidance would actually be preferable given that it would not consistently direct one toward performing wrong actions. This works to show that providing clear guidance is only a virtue to the degree that the guidance helps one to arrive at the best or correct answer. Fortunately, enough has already been said to defend the structured principlist framework against this final concern.

As argued for in Chapter 2, sections 1 and 2, the structured principlist framework's enabling and favorability conditions are grounded in the professional obligations of the healthcare provider, specifically the normative and epistemic obligations that arise from the nature of the healthcare profession. This ensures that the two conditions are informed by and closely align with the moral requirements of the healthcare professional, as determined by those within the healthcare profession and which have been formalized in ethical codes and hospital policies. These ethical codes and policies are themselves informed by the four bioethical principles, which are in turn captured in the enabling and favorability conditions. All this is to say that satisfying these two conditions helps to ensure that healthcare providers are abiding by professional norms and obligations. For example, a healthcare provider must be epistemically

competent to properly assess an option as being reasonably beneficial, and allowing the patient to choose from the eligible set of favorable options respects the patient's right to self-determine.

Additionally, Chapters 2 and 3 explained how these two conditions help to make sense of accepted healthcare practices and policies such as the requirement of informed consent, the refusal of medically futile interventions, and the widely accepted permissibility of passive euthanasia. Even more importantly, these conditions also work to constrain both healthcare providers and patients in order to exclude morally wrong actions, such as medical paternalism and overtreatment. While these practices are prohibited by the norms of the healthcare profession, individual providers do sometimes feel justified in acting paternalistically or feel pressured to assist patients when they demand specific care. Addressing these concerns was the initial motivation for my research. Unlike the traditional principlist framework which not only fails explain the wrongness of these actions but can even be used by providers to justify such actions, I have argued that the structured principlist framework takes a clear stand in prohibiting both types of actions as well as providing healthcare professional with the necessary tools to explain their decision.<sup>191</sup>

Lastly, Chapter 3 demonstrated how the structured principlist framework can assist with complex bioethical debates by clarifying the source of the ethical tension, while at the same time remaining ecumenical between the different positions. The purpose of the structured framework is not to determine what types of interventions are right or wrong, for an intervention may be appropriate in one context but not in another. Rather, the purpose of the structured principlist framework is to make clear the reasons one has for acting in a given context by guiding the

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<sup>191</sup> The enabling condition prohibits healthcare providers from acting paternalistically given that the patient is permitted to select from the eligible set of favorable options, and the favorability condition prohibits patients from receiving non-indicated care given that they are only permitted to select from the eligible set of favorable options.



deliberative process and ensuring that the action falls within the limits of moral acceptability, all the while still allowing for reasonable debate and disagreement. This is important because these bioethical debates are a part of what guide new policy formation and help us to evaluate the policies currently in place.

One final thing to note is that because this project has been focused on moral decision-making within healthcare, an area for future examination could be a parallel rethinking of research standards. For example, the Belmont Report allows for exposing populations of people, including children, to risks “even when individual research subjects are not the direct beneficiaries,” given that doing so is sometimes required to provide a benefit to broader society.<sup>192</sup> The moral permissibility of such a trade-off is not obvious and deserves further consideration. While the structured principlist framework may go part way toward re-thinking research ethics, its narrow focus on interpersonal healthcare practice does not say enough about the rights and relationships of certain groups, such as the competing interests of future patients who would benefit from research and the research subjects who are being put at risk, sometimes without any benefit to themselves. Though intimately connected to healthcare practice, healthcare research has its own set of ethical norms, practices, and challenges that would benefit from critical consideration and perhaps something similar to the structured principlist framework.

In summary, the structured principlist framework is an improvement on the traditional principlist framework not simply in that it helps to guide decision-making within healthcare practice, but also because it justifies those actions, and only those actions, that align with the

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<sup>192</sup> The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, “The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research” (1979).

current policies, practices, and accepted moral norms within the healthcare setting while leaving open room for reasonable debate and moral progress. Many of the ethical challenges within healthcare arise from moral uncertainty regarding how to prioritize the bioethical principles when moral duties conflict, so providing a structured decision-procedure for working through this uncertainty is the primary feature of the structured principlist framework. It is for the reason outlined in these chapters that I think adoption of the structured principlist framework could improve not only healthcare practice but also the ethical debates surrounding complex topics in healthcare and bioethics.

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