Liberating Bioethics Through Agape: A Feminist Perspective from the Periphery

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To Ana, and all Others like her.
Let our stories be heard and our worlds sought playfully.
Agape is understanding, creative, redemptive, good will to all men. It is an overflowing love which seeks nothing in return.

— Martin Luther King Jr., “Love, Law, and Civil Disobedience”
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GLOSSARY

Ágape: A love for, or the capacity to love, the Other that goes beyond the totality or the sameness of your world. It is an acceptance of the Other as Other through love. This is the ultimate expression of la Alteridad (Dussel, 2013). The term ágape comes from the Christian tradition and it is usually used to refer to the ultimate or highest kind of love (Templeton, 1999). However, Dussel adapted it to this ethical understanding of unconditional love for the Other (Dussel, 2013).

Alteridad: A state of recognition of the Other, of facing the Other as Other, instead of projecting the oppressive sameness of la Totalidad (Dussel, 2013). It is coming face-to-face with the Other and recognizing them as people with equal value and interests. For the Other that has been raised from inside la Totalidad, and thus sees herself as less valuable, finding la Alteridad is that moment when she realizes that she does matter and has value as Other (Dussel, 2013).

Autonomy: The version of autonomy that I will address in the dissertation will be that of James Childress and Tom Beauchamp (2019), which has been widely adopted by mainstream bioethics. This version diverges from a strictly Kantian understanding of the term and concerns individuals and their capacity to make autonomous decisions in health care. Childress and Beauchamp argue that in order for an agent to act autonomously three conditions must be met: 1) intentionality, 2) understanding and 3) non-control (Beauchamp & Childress, 2019). While the term is disputed,
Childress and Beauchamp argue that, at a minimum, it refers to the individual’s ability to self-rule, free from external coercion or controlling influences and certain limitations (Beauchamp & Childress, 2019). These limitations include a lack of understanding and information. Therefore, in the case of clinical bioethics, the patient’s autonomy will rest partly in the physician’s ability to communicate correctly with the patient and to offer the necessary information for autonomous decision-making.

**Bioética Estadounidense:** I will be using the Spanish terminology *la bioética estadounidense* when referring to bioethics from the United States. I have chosen to use the Spanish version because the common term used when referring to bioethics done in the United States is “American bioethics.” However, this term is already an expression of the coloniality I will be criticizing. America, for individuals outside the United States, is understood as a landmass composed of multiple nations, not a sole country. Therefore, given that there is a demonym in Spanish for individuals from the United States, i.e. *estadounidense*, and I will be engaging with philosophy from the periphery via Latin American thinkers, it is more accurate to use this term when referring to so-called “American” bioethics.

**Core Countries:** Core countries, also referred to as “the center”, are those where most of the global power and wealth are concentrated, e.g. United States, France, and the United Kingdom (Wallerstein, 1974). It usually refers to what most people call the “Western” world, but without committing to a geographical area. Thus, when referring to core cultures or values throughout the dissertation, I will be referring to the cultures and systems practiced by individuals who are members of the dominant groups in core countries.
**Epistemic Injustice**: As presented by Miranda Fricker (2007), epistemic injustice occurs when we undercut an individual’s capacity as a knower. Fricker describes two common types of epistemic injustice: testimonial and hermeneutical. Testimonial injustice is when individuals are not believed or trusted because of different parts of their identity, e.g. their race and/or gender. On the other hand, hermeneutical injustice occurs when there is a deficit in the necessary tools for society to understand individuals and their distinctive experiences. Ian James Kidd and Havi Carel (2017) further explain the practice and/or experience of this phenomenon: “Since the social and epistemic practices of giving information to others and interpreting our experiences is integral to our rationality, identity, agency and dignity, it is evident that injustice which harms our testimonial and hermeneutical capacities will be a source of deep harm” (p. 175).

**Intersectionality**: It is the study, or the analytic tool used to understand the privileges and/or discriminations that come with the combination of different identities. It refers to the multiple ways in which the interaction of race, gender, disability, and other integral parts of our identity, shape and define the experiences of individuals (Crenshaw, 1991). Therefore, intersectionality exposes and studies the multidimensionality of marginalized subjects and their experiences (Crenshaw, 1989). It tries to deal with subjects who have been left in the shadows of scholarly work because they exist in the margins of different identities and “in the empty spaces in between” (Crenshaw, 1991).

**The Other**: The oppressed, the individuals or communities that are not a part of la Totalidad, nor are their values or beliefs. They are seen as external from the dominant “Us” and/or “me” and, thus, cannot be understood or given value from inside la Totalidad. This term has been used
and re-introduced in philosophy by different thinkers, from G.W.F. Hegel (1817) and Edmund Husserl (1931) to Emmanuel Levinas (1969) and Enrique Dussel (1973). However, the definition I have provided is the one given by Dussel, whose understanding of the term derives from Levinas’s writings. Levinas asserted the ethical value of the Other and criticized previous definitions which ignored its innate otherness and alterity (Levinas, 1969).

**Periphery:** Refers to countries that do not feel the benefits of globalization or which do not share in most of the world’s wealth (Wallerstein, 1974). However, the term has also been used to describe the academic work done, or the knowledge produced, in countries or by groups of people outside the cores of power and knowledge.

**Totalidad:** This term is used by Enrique Dussel (1973) to refer to an ontological sameness, “lo mismo”. It points to structures with an eternal return to itself, for there is no change in their sameness. It does not open to a new future, for it is guided by its own past, which in return will be its future. It is in this eternal repetition that certain structures have stated their dominance. Thus, the structures of *la Totalidad* are dominant and colonizing. They project their sameness on the Other, instead of recognizing the Other as Other. It is a violent individuality, where the other is denied, alienated, and forced to join the dominating totality as a thing or as a lesser being (Dussel, 2013).
ABSTRACT

Despite the vast number of cultures and peoples that reside in the West, ethical action in bioethics is determined through the perspective of *la Totalidad*, which does not include the Other or individuals from the periphery. In my dissertation, I argue that the universalization of U.S. clinical bioethics (*la bioética estadounidense*) and the coloniality of knowledge that extends from it are, at its core, imperialistic in nature and result in the exclusion of patients with intersectional identities. While clinical bioethics was first conceived as a critical tool for medicine, the acceptance of principlism as the central theory in the field and its moral foundation in the “common morality” has severely reduced the critical aspect of clinical bioethics. Using a case analysis, I demonstrate principlism's weaknesses in addressing the complexities that arise from marginalized identities. Instead, I propose a more comprehensive and suitable framework for clinical bioethics, a feminist and Dusselian Agapean framework, which can address patients at both the center and the periphery of bioethics.

Synthesizing the critical work of feminist bioethicists and Latin American philosophers through the ethics of liberation and Intervention Bioethics, I develop a practical approach that is more inclusive and successful than principlism. The Agapean framework holds Dusselian agape as its material principle and maintains the protection of the worst off in society and the prevention of possible harm through the centralization of relational autonomy, playful narrativity, a need for advocacy, and social justice through equal participation. Using this
approach, I address the coloniality of power and gender found in our way of producing knowledge in clinical bioethics. This dissertation fills a gap in the field by addressing the colonial aspects of mainstream bioethics and proposing a needed alternative. Moreover, by providing English translations to critical passages from Spanish and Portuguese bioethics texts, it shines a light on voices from the periphery, which have been traditionally invisibilized.
INTRODUCTION

While medicine has been upheld as one of the mighty guardians that protect human life and well-being, it is at the same time a powerful institution that can sometimes practice epistemic injustice. How physicians construe their patients and understand patients’ testimonies feeds into the care that patients receive. However, as some critics point out, the testimony of patients is often dismissed as: “irrelevant, confused, too emotional, unhelpful or time consuming” (Kidd & Carel, 2014, p. 530). Patients are often labeled as cognitively unreliable, and their testimonies may be understood as unimportant or cognitively suspect. This dismissal can negatively affect the care received by the patient, given the degree to which physicians make medical decisions based on the biases they carry into their clinical consultations. If the testimony of a patient is dismissed as unimportant or inadequate, or if a patient is not believed or is labeled as ignorant, it will change how the patient is perceived and the treatments that will be recommended. Therefore, the notion of the patient as either a competent individual or as a “confused” and “emotional” one can affect the care they receive, and consequently, their well-being.

In Chapter 1 of her book, *Undoing Gender*, Judith Butler (2004) discusses the categorization of terms like “human” and “woman”. In many cases, we use these terms in discriminatory ways, where marginalized groups of people are considered less than human and where certain women are excluded from discussions on womanhood. Butler (2004) argues that through a critical analysis of these concepts, we must find out the limits of inclusivity and translatability, and which conventional conceptions ought to be reconstructed, expanded, and
even destroyed (p. 38). This critical process necessitates a cultural translation in which we yield some of our fundamental notions to incorporate that of others. Butler (2004) states,

> The point is not to assimilate foreign or unfamiliar notions of gender or humanness into our own as if it is simply a matter of incorporation alienness into an established lexicon. Cultural translation is also a process of yielding our most fundamental categories, that is, seeing how and why they break up, require resignification when they encounter the limits of an available episteme: what is unknown or not yet known… But rather, translation will compel each language to change in order to apprehend the other, and this apprehension, at the limit of what is familiar, parochial, and already known, will be the occasion for both an ethical and social transformation. It will constitute a loss, a disorientation, but one in which the human stands a chance of coming into being anew (2004, p. 38).

This process of translating and incorporating categories across cultures requires a radical openness to change, to recognize when our established understandings promote the oppression and the invisibilization of others. As Butler recognizes, this process of changing and yielding will inevitably lead to ethical and social transformations. If we adopt more inclusive conceptions of humanity, we ought to feel morally challenged to act upon these normative changes, thus leading to deep social transformation.

This dissertation aims to partially fulfill Butler’s call for reconceptualizing our foundational notions. While Butler refers to grander terms like “human” and “woman”, I will focus on the concept of “patient”. I will argue that the conceptual idea of the patient in Western bioethics excludes marginalized identities, specifically patients with intersectional identities. A translation of the notion of the “patient” needs to be adopted if we are to overcome the injustices committed by our current, limited conception. Moral discourse surrounding medical cases and studies inevitably depends on our notion of the “patient.” How we understand this concept affects our moral deliberations and the frameworks that we propose and accept. This dissertation will argue that bioethics in the United States, or la bioética estadounidense, has been shaped by a
limited notion of the patient. This deficient notion has led to an exclusionary and restricted field of ethics. Therefore, if we are to move forward and reconstruct this limited notion, a cultural translation of the field is needed, one where the notion of the patient is able to encompass intersectional identities.

The effects of limited frameworks and notions in bioethics can be largely felt in practice, as healthcare practitioners adopt these imperfect notions as their moral guides. It is not unknown to us that the well-being of patients is tested when the actions and judgements of healthcare professionals are morally lacking. For example, testimonial injustices are exacerbated when healthcare professionals carry their biases to the workplace. As an institution, healthcare tends to import the same stereotypes and assumptions about marginalized groups that we see in broader culture, given that physicians are subject to the same problematic biases that are at work in broader society. Therefore, vulnerable groups that tend to be marginalized or negatively impacted by stereotyping disproportionately experience the effects of these epistemic injustices (Fricker, 2007). Women, non-whites, individuals with disabilities, and sick people tend to be vulnerable to stereotypes that undermine their epistemic capacities and confidence (Kidd & Carel, 2017). When the testimonies of individuals from these marginalized groups are dismissed in the clinical setting, in addition to harming their capacities as a knower, healthcare

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1 Throughout the dissertation, when discussing bioethics produced in the United States, I will refer to it as la bioética estadounidense. I have chosen the Spanish translation given that in the literature, bioethics done in the United States is usually called “American Bioethics”. However, this name already shows the type of coloniality that I am trying to avoid. Outside the United States, America is understood to be the landmass in which North, Central, and South America are found. Therefore, to avoid confusion, and to decenter the idea of the United States as “America”, I will be using the Spanish etymology for people from the United States, estadounidense. I have committed to this terminology all throughout the dissertation as it serves two purposes: it shines a light on the coloniality behind the term “American bioethics”, and it supports the cultural translation being done in the project, which focuses on the work being done in Latin America.
professionals are also undercutting the patient’s health and well-being. For example, it has been shown that women tend to be less believed in medicine when claiming to be experiencing pain. Consequently, they are more likely to be given a sedative than actual pain medication (Hoffmann & Tarzian, 2001). There is an unfair treatment of patients with marginalized identities that result from the biases found in society and, which in turn, are reflected in the medical field.

Given the medical system’s perpetration of systemic injustices and the resulting harm experienced by patients, a normative branch had to be introduced to the field of medicine. Clinical bioethics presents itself as an intermediary intended to protect ethics in medicine, and consequently, to protect patients. However, I will argue that this supposed guardian fails to appropriately care for certain patients. Catherine Myser (2003) argues that our current approach to bioethics establishes the normativity of whiteness in America, and others argue that while the problems that we encounter in clinical bioethics are global, our approach to bioethics is completely Western-centered (Carrese & Rhodes, 1995; Ryan, 2004; Chattopadhyay & De Vries, 2008; Garrafa et al., 2016). For example, the centering of autonomy has been understood as integral to moral behavior in the United States. Principlism, the framework defended by Tom L. Beauchamp and James F. Childress (1979; 2019), and championed by la bioética estadounidense, presents autonomy as one of its four central principles and claims its foundation on a universally shared common morality. However, this emphasis on autonomy is not shared within cultures with more community-based values around the globe. Therefore, we have been employing an ethical model specific to the United States that has been imposed globally. More specifically, we have created and defended accounts and frameworks to protect the patient using this limited model. The notion of the patient used under la bioética estadounidense is too limited,
as it fails to encompass all other people who do not fit the mold. When presented with patients whose values differ from those favored in the United States, mainstream bioethics falters.

I will argue that *la bioética estadounidense* compromises the ability of patients who do not share the core values present in Western culture to share their knowledge and make sense of their own experiences. We have implicitly established the Western way of producing knowledge, which traditionally excludes women and non-whites, as the correct way. This foments and perpetuates a coloniality of power and knowledge that results in epistemic injustices (Garrafa et al., 2016). I argue that because our mainstream accounts of bioethics are incapable of making sense of the intersectional identity of patients and of their differing values, their ethical dissemination of cases is often incomplete and insufficient. The narrow approach taken by *la bioética estadounidense* does not consider the complexity of persons and the normative challenges that arise from intersectional and marginalized identities. Throughout the history of the field, different ethicists have attempted to address this issue through the development of a multiplicity of theories, usually referred to as “critical bioethics.” Some of these approaches include feminist approaches to bioethics, disability ethics, and critical race theory. However, the focus of these critical theories on specific issues has limited their approach to the effects that combined marginalizations have on the patient, i.e., the effect of intersectional identities. Additionally, many of the proponents of these critical approaches have been individuals from the West, writing from and for core countries. This is not to say that thinkers from the periphery have not engaged with these topics, but that it is the ideas from thinkers from the West that tend to become popularized and studied in mainstream bioethics.

However, bioethicists beyond the United States have engaged with critical bioethics and have tried to implement new ways of addressing clinical problems in bioethics from the
periphery while decentering the mainstream, “American” way of thinking (Wong, 2020; Garrafa et al., 2018; Fayemi & Macaulay-Adeyelure, 2016; Frontera, 2009). Throughout this dissertation, I will specifically focus on the work being done in Latin America. While there are many marginalized and oppressed groups in the United States that are affected by the exclusion of their identities in the creation of ethical frameworks, I have chosen to focus on the Latin American community. Studies show that there is a large health disparity between Latinos and white individuals in the United States, which results in higher mortality rates and lower life expectancy for Latinos (Vega et al., 2009). The reasons behind this health disparity are vast, ranging from mistrust, differing cultural beliefs, and the language barrier (Juckett, 2013). Consequently, Latinos tend to visit healthcare professionals less than other patients, and when they do go to the doctor, they report lower levels of satisfaction (O’Brien & Shea, 2009; Fiscella et al., 2002). Dissatisfaction can lead to health disparities, for there is a correlation between satisfaction, trust, and following through on the advice of physicians.

Additionally, while the United States harbors more than 44 million immigrants, approximately 51% come from Latin American countries (Gelatt et al., 2022). The whiteness and coloniality of mainstream bioethics are thus not only felt by individuals outside the United States, but also by the millions of LatinX immigrants who pass through the U.S. medical system. Consequently, this study of Latin American bioethics should prove helpful even inside the United States, where members of these cultures also reside. It should be both a medical and ethical priority to ensure that Latino patients are receiving adequate care, which requires the use of comprehensive and inclusive ethical frameworks to identify their voices and experiences so they can be incorporated in the discussion.
While the discussion of this dissertation will center around philosophies and cases from Latin America, the main focus will be the inclusion of intersectional identities to the conception of the patient and the development of ethical frameworks. This will mean that I will focus on cases that portray LatinX patients with intersectional identities. The discussion of the intersectional patient will be mainly delivered through multiple discussions of Ana’s case (presented below). Ana’s case is a case study of a Latina born in the United States, who serves as her mother’s primary caregiver. The case shines light on issues that would not need to be considered in cases where the patient does not hold an intersectional identity. This case presents various important aspects, like the fact that Ana is a woman and caregiving has been seen traditionally as a woman’s job. It also deals with Ana’s intersectional identity and the conflicting cultural values that leave her incapable of knowing what is right.

Ana’s Case: Ana is a 52-year-old with a full-time job. She is also a second-generation Mexican American woman living in the United States. Since her father died, her mother, Mrs. C, has been living with her. Given that she is unmarried and childless, the family decided that Ana should be the one to care for their mother. Lately, Ana has noted some increasing changes in Mrs. C. She has grown forgetful and violent. Following a visit to her physician, Mrs. C is diagnosed with dementia. The physician recommends that Ana institutionalize Mrs. C in a home, where she will get the needed care. However, Ana feels guilty even thinking about it. She was raised to believe that it is her duty as a daughter to care for her mother. Indeed, within her cultural background it would be unforgivable for a daughter to place her mother in a nursing home rather than providing the care herself at home. She also wants to respect her mother, who would not want to be institutionalized, and uphold what is left of Mrs. C’s autonomy. On the other hand, she has a job, and her
mother’s violent outbursts seem to be affecting Ana’s mental health. Ana feels trapped in two worlds, given that her Hispanic values dictate that she should be the one to care for her mother while her U.S. culture deems it morally acceptable to send her mother to a home. Healthcare professionals advise her to institutionalize Mrs. C and her siblings believe that it would be wrong. Ana does not know what to do.\textsuperscript{2}

Ana’s case will be a touchpoint in every chapter, for it will serve as a basis for considering the strengths and shortcomings of previous theoretical frameworks. Through Ana’s case, I will show that our current ethical frameworks are not able to provide the adequate, cross-cultural examination that people like Ana deserve. While mainstream ethical approaches may be able to provide some help, they would inevitably flatten out the cultural importance of the decision Ana has to make. Ana and all people like her deserve an ethical framework capable of considering the complexities associated with intersectional identities; a framework capable of appropriately weighing differing values.

A study of Ana’s case will also help show the health disparity experienced by members of marginalized groups, and by those that are the \textit{worst off}, who experience even more seclusion. Through an exploration of this case, we will see how the layers of marginalized identities pile on and create an invisibilization of already oppressed Others, e.g., the elderly, women, and Spanish-speaking individuals. One of my main arguments throughout the dissertation is that these specific groups of individuals are not considered in the creation and development of mainstream frameworks. We usually don’t get a proper representation (or any representation!) of their

\textsuperscript{2} A different version of Ana’s case was initially introduced in Flores et al. (2009). While I have changed some details about the case and added emphasis on others, the struggles of Ana are fundamentally the same.
position because of the invisibilization that occurs when marginalized identities mix. Consequently, the ethical tools at our disposal are not qualified to deal with the worst off.

Instead of using mainstream bioethics as a mold that “fits all”, we need to critically analyze and highlight the knowledge being produced in the periphery and by groups that have been historically left out of the epistemic pool. Because I will be centering on cases that deal with intersectional and marginalized identities, I will be looking at the ethical frameworks being developed from the periphery and those presented by feminists. I will specifically be discussing Intervention Bioethics and the ethics of liberation as philosophies and frameworks from the periphery, and care ethics and narrative ethics as representatives of feminist approaches. Out of necessity, feminists and philosophers from the periphery have had to find ways to adapt and create frameworks that reflect their experiences. Thus, a critical analysis of the work they have done individually and an assessment of how to bring those ideas together should prove helpful.

Several discussions of Ana’s case will serve to highlight how other theories fail to consider what is necessary in cases of intersectionality, making way for a new framework. Principlism will be shown to be incapable of dealing with intersectional identities in clinical bioethics and the conflicting values that emerge when considering gender and culture. Moreover, the discussions of this case will showcase not only the shortcomings of principlism but also the failings of applying the ethics of liberation and feminist approaches separately. While the ethics of liberation and feminist approaches may address certain aspects of Ana’s case that principlism is incapable of addressing, they will still be shown to be lacking. Instead, I will combine approaches to present the patient as a complex individual with intersectional identities, and which as a result, will be able to cover more of the important issues and values in the case. Therefore, the discussion of Ana’s case will showcase the harm of creating and adopting theories
that take the patient to exist ‘outside of a social context’ or that center patients whose identities belong to the oppressive majority. Theories that adopt a simplistic notion of the patient are incapable of helping people like Ana.

This dissertation adds two necessary developments to the current literature in bioethics: 1) it adds to the fairly new and underdeveloped accounts of clinical bioethics being done from/for the periphery, and 2) it combines the arguments in the ethics of liberation with those proposed by feminist theory in clinical bioethics to generate a more robust and inclusive framework. The discussions and analysis provided throughout the chapters will lead to the development of the Agapean framework, a more cohesive and inclusive approach to clinical bioethics. My proposed account, the Agapean framework, will address the complexities of intersectional identities better than alternative accounts. I will demonstrate the applicability and flexibility of the Agapean framework through case studies and comparisons against mainstream accounts of la bioética estadounidense. The aim of this project is to provide a foundation for addressing patients and individuals whose identities have made them victims of exclusion in clinical bioethics and, consequently, the medical system by developing an accessible framework that considers the Other as Other. The discussions and arguments defended throughout this body of work will benefit the field through the development of a needed framework which addresses shortcomings in bioethics, speaks to underserved communities, and helps in the introduction and translation of peripheral knowledge to mainstream bioethics.

I start the discussion in Chapter 1 by presenting the state of the field of bioethics and the problem I want to combat through the rest of the dissertation. Through an analysis of the history of the field and the critiques that have been brought against it, I will show the deficient nature of la bioética estadounidense in its current state. The exclusion of peripheral knowledge and the
centralization of principles from the West have led to a normativity of whiteness in the field and the prolongation of a hidden colonization. Mainstream frameworks constructed under this exclusionary account of the field understand the patient as a Western white man who always shares the ideologies and morality of the West. I will argue that the champion of la bioética estadounidense, principlism, has served as the conductor of this limited view of the patient through their arguments on common morality.

Chapter 2 will begin the work of cultural translation by presenting an alternative account of bioethics constructed from the periphery. If Butler is right, then we ought to consider how other cultural interpretations of our accepted notions might challenge ours. Through this comparison, we might be able to understand what needs yielding and reconstruction versus what needs to be broken down and eliminated. Given the centrality of Western thought and preferences from core countries inherent in la bioética estadounidense, I will present an alternative born in Latin America. Intervention Bioethics, which philosophically roots itself in the ethics of liberation, offers us an alternative to principlism. While principlism surrounds itself with the common morality of the West, Intervention Bioethics focuses on the protection of the Other through arguments on liberation and emancipation.

Chapter 3 will formally introduce the need for accounts in the field to include an intersectional view of the patient. La bioética estadounidense fails to include marginalized and often invisibilized identities in its ethical considerations. Therefore, in Chapter 3, I present three amendments that all frameworks ought to adopt if they intend to correct this issue. After an analysis of the literature, I argue that an intersectional account of bioethics ought to include a relational account of autonomy, rely on playful narrativity, and promote activism and advocacy. I
will argue that through the implementation of care ethics and Lugones’ account of world traveling, we can more easily accomplish the introduction of these amendments.

Finally, Chapter 4 will present my proposed interpretation of a cultural translation of the field of bioethics. This translation will take the form of a new framework, which I will refer to as the Agapean framework. This interpretation does not attempt to eliminate the notions and conceptions that were ‘translated’ from different accounts, be it Intervention Bioethics, principlism, care ethics, narrative ethics, or the ethics of liberation. Instead, it serves as an alternative, an attempt to show how our current notions fail and to provide a new translation that more appropriately deals with marginalized identities.

Throughout Chapter 4, I will attempt to combine the ideas of Intervention Bioethics, feminist approaches, and principlism, not through a careless ‘mix and match’ of concepts but by critically engaging with the process proposed by Butler. I will examine which notions and concepts from these theories need yielding and which ones are better suited to care for the intersectional patient. The concept of Dusselian agape will be at the center of this new framework, as I argue that love for the Other ought to be the fundamental force upon which we build more intersectional accounts. Through an analysis of three historical case studies, I will show the benefits of adopting the Agapean framework and its suitability to address patients with marginalized identities that have been ignored in mainstream accounts of la bioética estadounidense. I will argue that the Agapean framework, which should be classified as part of the critical bioethics branch, will be superior to principlism in practice - not because it is “universal,” but because it recognizes the value and importance of context.
CHAPTER ONE

‘LA BIOÉTICA ESTADOUNIDENSE’: A CRITIQUE OF IMPERIALISTIC ETHICS

This chapter will introduce the concept of *la bioética estadounidense* as a critique of the cultural bias inherent in the field and the consequences of prolonging the primacy of principlism in U.S. bioethics. I will first provide a brief history of bioethics as a discipline by discussing the origins of the field in the United States and the prevalent values that have reigned since its early days. After introducing the history of bioethics and its main framework, principlism, I will then address critical responses to it. As we will see, these critiques have been raised against both *la bioética estadounidense* as a field, and against principlism as its champion. This chapter will offer the background for my argument that bioethics requires a more inclusive and diverse framework that can lead the field away from its imperialistic origins and tendencies. I will propose the introduction of coloniality scholarship to bioethics so that we may decentralize the conversation from a mostly western approach to one that includes those on the “periphery.”

1.1 History of the Field

Bioethics was first conceived as a critical intermediary between philosophy and medicine at a moment in time when innovative technologies and treatments were being developed, bringing with them new ethical dilemmas. As Stephen Scher & Kasia Kozlowska note, unprecedented advances brought with them unprecedented ethical problems. The advances in science made during World War II (e.g., sulfa drugs, penicillin, the polio vaccine) marked some
of the biggest challenges to an under-prepared field (2018, p. 32). For the first time, public and private funding sources became available to promote medical advances. However, absent established rules and limitations, many decisions were being made without ethical supervision or oversight. For example, Albert Jonsen (1997) offers examples such as the National Institute of Health-funded scientists who were keeping alive newly aborted fetuses to use for experimentations and studies, patients that were fighting for their right to deny treatment, and the expansion of women’s reproductive rights that were all occurring at this time.¹

After World War II, the pursuit of medical advancements led to viewing diseases as another “war” to be fought; but this approach came at significant cost to the patient. Patients were no longer seen as persons, but as a locus for disease (Scher & Kozlowska, 2018, p. 34). Their needs were reduced to those defined by medicine and they were expected to be passive observers in the “war” taking place in their bodies and being fought by doctors. Their role as patients was simply to trust the physician and submit to their “battle plans.” Physician paternalism reigned supreme.

In 1953 the United States established the NIH's Clinical Center, a hospital devoted to research, and their accompanying Clinical Research Committee (CRC) came into being. It was the CRC’s early efforts that opened the door for bioethics as a field (Fletcher, 1995). However, more than 10 years passed before policies toward change started being implemented. The first traces of bioethical policies and laws can be seen in 1957 with the Martin Salgo case (Salgo v. Leland Stanford Jr. Univ. Bd. Trustees, 1957). In Salgo, the plaintiff sued his physicians for

¹ While the NIH released a statement at the time denying their support of work related to newly aborted fetuses, there were many reports of similar NIH-funded research being done outside the United States. These reports were in addition to the released recommendation of the NIH advisory panel, where they recommended the use of fetuses in this manner in the United States.
making a medical decision without his input, a choice that resulted in Salgo’s paraplegia. Moreover, Salgo argued that the physicians had neglected to warn him of all the possible side effects of the procedure. This led the court to establish informed consent as a necessity, giving patients the sole right to make risk/benefit decisions regarding medical interventions. Such lack of ethical oversight and patient protection led to the rise of bioethics.

Daniel Callahan identifies three “streams” that brought about the field of bioethics. He describes the first stream as the political and cultural upheavals that marked the 1960s, a time period where institutions came under increasing scrutiny (2012, p. 7). The second stream was the public’s reaction to the fast-approaching advances being made both in technology and medicine. There was confusion concerning what these medical and technological changes would mean to our understanding of a good life. Lastly, Callahan's third stream concerned the attempt to make academia more relevant, to abandon a strictly academic, ivory tower stance, in favor of an engaged, applied approach that took up important issues of the day (2012, p. 8).

Callahan speaks of the disillusionment with analytic philosophy of the time, a field dominated by metaethics, the uses of language and concepts, and the struggle between deontology and utilitarianism. The ethics being studied was far from a normative approach and focused instead on analytic ethics. It was this disillusionment that drove Callahan himself towards the creation of what would be later known as the Hastings Center, the first research center for bioethics (2012).

Moreover, it was such discontent with academia that led Callahan and his co-founder, psychiatrist Willard Gaylin, to ensure that the Hastings Center would be a freestanding institution, separate from any university. One of their first tasks, besides research, was education
through the introduction of ethics into the medical curriculum, an enterprise that met with mixed success. Medical students began to identify deficits within their units and curricula, which was seen as an attack on their institutions, and which marked bioethics as a critical enterprise that targeted physicians' failures (Callahan, 2012, p. 14). Yet while there was some skepticism surrounding the field, this did not stop it from spreading. Following a conference on the teaching of ethics in medical schools, medical ethics education had begun to take shape and spread roots at other universities (2012, p. 14).

Bioethics, as an interdisciplinary tool of normative decision-making, grew in popularity through the establishment of four principles (justice, autonomy, beneficence, and nonmaleficence) that could guide those that wished to incorporate a bioethical framework. Tom L. Beauchamp writes:

In the early history of modern bioethics, principles were invoked to provide frameworks of general guidelines that condensed morality to its central elements and gave people from diverse fields an easily grasped set of moral standards. Principles gave an anchor to a youthful bioethics in the 1970s and early 1980s and contributed a sense that the field rests on something firmer than disciplinary bias or subjective judgment (1995, p. 181). Instituting a set of standard principles meant that anyone could engage with the field, in addition to providing the philosophical background needed to validate bioethics as a discipline.

While there have been several principles-focused frameworks, none have gained the popularity of principlism. The *Principles of Biomedical Ethics* was first introduced in 1979 by James Childress and Tom L. Beauchamp. In their text Childress and Beauchamp present their principles as the most general normative standards of conduct in biomedical ethics (Beauchamp, 1995, p. 182; Beauchamp & Childress 1979).² These four principles are supposed to address

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² Childress and Beauchamp have since then revised their book and have implemented changes to the original argument. However, it is worth noticing that out of 24 critics (John Arras, Edmund Pellegrino,
basic moral obligations that pervade the medical tradition, and which have been expressed through ideas of beneficence and nonmaleficence. However, as presented by Beauchamp and Childress, the four principles go beyond the traditional practices of medicine by introducing respect for autonomy and the primacy of justice (Beauchamp, 1995, p. 182). Together, these four principles intend to offer a comprehensive normative framework for biomedical ethics.

These authors have been careful to specify that even though their framework consists of four principles, there is no hierarchy amongst them (2019, p. 3); they are intended to be treated as having equal normative weight. None of the four principles should take precedence over any of the others. Moral deliberation thus requires one to determine when one principle might need to override a competing one. For example, an individual’s autonomy may have to be undermined if her autonomous decisions might endanger public health (e.g., wearing masks during the COVID pandemic). In some instances, autonomy will override beneficence, with healthcare professionals respecting the patient’s right to autonomous decision-making, even in cases where such decisions will lead to the death of the patient, as in a case when a patient refuses life-saving medical treatment. The four principles are intended to be taken as basic, universal normative principles shared and defended by common morality upon which a solid framework can be built.

Raanan Gillon, Al Jonsen, Stephen Toulmin, Michael Yesley, Franklin Miller, David DeGrazia, Ronald Lindsay, Carson Strong, John-Stewart Gordon, Oliver Rauprich, Jochen Vollmann, Quill Kukla, Henry Richardson, Peter Herissone-Kelly, Robert Baker, Robert Veatch, Tris Engelhardt, Robert “Skip” Nelson, Neal W. Dickert, Dan Clouser, Bernard Gert, and John Rawls) mentioned in the last edition by the authors, as those whose written and published critiques were considered in the development of the book, the overwhelming majority were white men, with no self-identifying women being mentioned (Beauchamp and Childress 2019, p.3). This is worth mentioning given that, as I will discuss later in the chapter, important critiques brought against the theory have been from people of color and women who argue that principlism does not encapsulate the diverse human experience.
By common morality, Beauchamp and Childress refer to a moral force that establishes moral standards for everyone alike. According to them, common morality establishes vital norms that are established pre-theoretically (2019, p. 321). Any framework derived from common morality will share three features: they will be pluralistic, they will rely on ordinary and shared beliefs, and they will treat as normatively suspect any theory that does not consistently hold these shared, pre-theoretically established beliefs (2019, p. 321). In other words, frameworks derived from common morality should maintain a plurality of normative theories, instead of adhering to a single ethical theory. Additionally, the principles held by common morality are, to some degree, intuitive and shared by a plurality of people, for they are presented as pre-theoretical.

Moreover, Beauchamp and Childress argue that “all persons committed to morality accept the standards in common morality” (2019, p. 7). What makes a common morality such is that it holds values shared by all persons who value morality. They assert that the four principles are drawn from this common morality, universally shared by moral individuals. As such, principlism is presented as being applicable in the global context. The authors claim,

Our common-morality theory does not view customary moralities as part of the common morality even though they may embody elements of the common morality. Our theory is committed to a global bioethics in the sense that the principles are universally applicable, not merely local, customary, or cultural rules (2019, p. 321).

Before engaging in a discussion of the parts of principlism that make it so appealing to the public and the critiques that have arisen from it, one must understand what each of these principles entails. Firstly, the authors define an autonomous being as someone who is able to “act freely in accordance with a self-chosen plan”, while an individual of diminished autonomy is one who is “substantially controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans” (2019, p. 77). Thus, the first principle introduced is a respect for that
state of being, a need to respect an individual’s ability to act in accordance with a plan they chose without external influences. Respect for autonomy will require noninterference in the affairs of others in addition to, in some cases, helping maintain their autonomy by maintaining their capacity to act in such a way. Helping maintain and build up the autonomous capacity of others might include certain actions like alleviating their fears (2019, p. 80).

The next two principles are beneficence and maleficence. In the past, it was suggested that these principles are one and the same, making it redundant to include them both. However, Beauchamp and Childress assert the necessity to keep them separate, thus distinguishing the two (2019, p. 116). Nonmaleficence refers to the moral obligation to “do no harm” or as it has been presented in the literature, "do no evil". Beneficence, on the other hand, is the active obligation to help others, to promote good, and to remove or prevent evil (2019, p. 116). The authors separate the two principles by arguing that:

Obligations not to harm others, such as those prohibiting theft, disabling, and killing, are distinct from obligations to help others, such as those prescribing the provision of benefits, protection of interests, and promotion of welfare… Each of the three principles of beneficence requires taking action by helping—preventing harm, removing harm, and promoting good—whereas nonmaleficence requires only intentional avoidance of actions that cause harm. Rules of nonmaleficence, therefore, take the form "Do not do X" (2019, p. 116-117).

While beneficence argues for positive actions that promote moral behavior and practices, nonmaleficence relies on the idea of avoiding actions that might lead to immoral acts or the harming of others. In medicine, however, sometimes harming others will come as a necessity in order to achieve a greater good, e.g., causing you pain through treatments and procedures to

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3 While they do focus on external influences, referencing the influence of one or more individuals, they also make mention of internal influences. By internal influences that can undermine a person's autonomy, they refer to things like mental illness (2019, p. 79).
remove a malignant tumor. Therefore, there is once again no hierarchy among the principles. There will be cases where not harming someone will take precedence over helping them, while in others, we will need to cause pain in order to remove harm.

The last of the principles, justice, is the most complicated to present in the context of principlism. While the principle of justice is introduced as one of the four basic principles that should drive moral decision-making, Beauchamp and Childress never clearly explain what they mean by it or how one should approach it. In their chapter dedicated to the principle of justice, specifically distributive justice, they address certain problems concerning justice in the medical field, but the reader is never provided with a definition or a framework for identifying an injustice. Instead, they present six frameworks used to define and signal cases of injustice but do not argue in favor or against any of these: “We do not suggest that these theories are of equal importance, and we make no attempt to rank one over the others” (2019, p. 199). The six frameworks they present are 1) utilitarianism, 2) libertarian theories, 3) communitarianism, 4) egalitarianism, 5) the capability approach, and 6) well-being theories (2019, p. 198).

Each theory above presents a different approach to the just distribution of resources and provides different definitions of the concept. For example, well-being theories stress social justice as concerned with human well-being, specifically with six core elements, i.e., health, personal security, knowledge and understanding, equal respect, personal attachments, and self-determination (2019, p. 204). On the other hand, libertarian theories focus on the unfettered operation of fair procedures and transactions under the law, with a government’s actions being just if they affirm individual liberty and property rights (2019, p. 200). Therefore, while some of the six frameworks can complement each other and an individual can maintain some of them
cohesively at the same time, others will be in constant competition. Childress and Beauchamp don’t provide an argument in favor of any of the six theories, but instead seem to argue that we could apply different frameworks of justice, depending on the case. These authors focus on issues of justice that need to be addressed in medicine, like providing fair opportunities, rejecting unfair discrimination, and avoiding exploitation in research.

While principlism has been the central theory in bioethics it has nevertheless met with some criticism. Even though it is by far the most used and well-known framework in bioethics, it has been criticized since its beginning, by some of the very same individuals who pioneered the field. For example, Daniel Callahan has expressed his discontent with and fears concerning the theory:

It is not that the principles are necessarily the wrong ones, or that there is no good method for reconciling conflicts among them (the standard objections). Instead, it is that they have served most effectively as a kind of blocking function. By providing a relatively easy method to solve many ethical problems, and by being only too well adapted to Anglo-American culture, principlism has in practice (if not necessarily in its theory) short-circuited the opening of larger, more important issues. Principlism, for instance, surely leads to a robust, dominating moral role for autonomy in bioethics, but it offers no guidance whatever about how to use our freedom or what counts as a good exercise of autonomy. The right to make a choice is regularly confused with the goodness of a choice, two utterly separate matters (2012, p.19)

If it is true that principlism misses the mark, then why is it so popular? John H. Evans (2000) argues that the acceptance and popularity of principlism has less to do with its correctness and is instead connected to our understanding of coherent ideas and the championing of certain types of knowledge over others in the Western tradition. Evans argues that principlism satisfies the social conditions for knowledge that have been historically established in the United States. When assigning authority in epistemic matters we have given preferential treatment to formally rational decision-making systems (2000, p. 36). Max Weber called the formally rational logic
surrounding decision-making the inescapable fate of the modern world, transforming all areas of social life and institutionalizing rationalization (Brubaker, 1984, p. 44). Principlism, unlike other more abstract theories, offers calculability and predictability, the champions of formal rationality. This ability to be commensurable simplifies bioethical decision-making and ensures its popularity among members of non-philosophical groups. Healthcare professionals who may lack both formal training in philosophy and prior experience engaging in "high-risk" normative decision-making can be taught these four pre-established principles more comfortably and be expected to apply them more easily than alternative theories.⁴

Moreover, critiques of principlism arguably say more about the critics than the theory. B. Andrew Lustig (1992) admits that while principlism has its flaws, it might be as close as one can get to a normative theory in bioethics, and to ask anything more is to have unrealistic expectations about ethics in general. Lustig claims: "One might view certain criticisms of principlism as indicative of the predilections of those who require more of ethics than it is ever likely to deliver" (1992, p. 498). Given how disparate people's beliefs seem to be, especially when combined with their personal agendas and their theoretical commitments, maybe the best we can do is get them to agree on a particular set of principles.

1.2. Critiques of La Bioética Estadounidense

In what follows, I will divide the different critiques brought against la bioética estadounidense as a field and against principlism into three separate discussions. I will begin

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⁴ By high-risk normative decision-making, I refer to moral decisions that might have unusual consequences. We are used to making moral decisions on a daily basis, e.g., "I will not lie to my boss", "I will keep my promise and not divulge this secret", but it is less usual for us to make decisions that may lead to someone's death or to the creation of policies that might impact the well-being of large groups of people. In the case of medicine, healthcare professionals are often making high-risk choices.
with Carl Elliott’s argument that the field of bioethics has lost its critical edge; that in its ties to private corporations and clinical practice, bioethics has lost the ability to be critical. I will then move on to consider the discipline’s inadvertent establishment of the normativity of whiteness. These first two critiques will encompass bioethics as a discipline: what I will call (in a critical vein) la bioética estadounidense. However, the third subsection will specifically address principlism’s shortcomings. Given that principlism has reigned as the champion of la bioética estadounidense, it is important to discuss how the framework fails, so we can later discuss what needs to change.

1.2.1 Carl Elliott and The Loss of Bioethics’ Critical Edge

There are a variety of critiques against la bioética estadounidense that I could address in this chapter. Yet many of them can trace their roots to Carl Elliott’s foundational critique. Elliot argues that clinical bioethics has sold out to medicine; rather than acting as the gadfly or the external moral perspective to clinical medicine, it has instead become part of the healthcare system’s bureaucracy. The external perspective that bioethicists intended to offer has been usurped with the expansion of the field and with bioethicists being hired and retained as consultants by medical institutions (Elliot, 2005). This bureaucratic turn ensures the loss of the field’s critical edge.

Elliott argues that due to the large number of bioethicists being funded by corporations and who work for hospitals and other institutions, clinical bioethicists have become spokespersons for the interests of these institutions instead of maintaining the critical focus they were intended to have (2005, p. 381). This widespread “sellout” results in the failure of clinical bioethics to bring an external critical lens to clinical practice. As he argues:
An ethicist employed to do clinical ethics consultation by a hospital or to give advice on regulatory policy for a pharmaceutical company is probably unlikely to write a book about, say, the intersection of bioethics case studies and literary criticism. It will also shape the stance of the field. Bioethicists will probably produce even fewer critiques of the biomedical enterprise as a whole. They will be more likely to produce arguments about how to make the system better, rather than to challenge the system itself (2002, p. 5).

The topics being addressed, and the arguments bioethicists defend, will be impacted by the reality of who is paying their salary. In recent years, we have seen a number of ethicists being fired from companies like Google for pushing back on policies and research they deemed problematic or unscholarly. It should thus come as no surprise that, given the bureaucratic turn of the field, bioethicists are less and less likely to criticize the institutions that employ them and their policies or practices. For example, we have already seen many professional bioethicists shift from questioning certain questionable technologies to accepting them, not just for therapeutic purposes but for enhancement (Elliott, 2005, p. 382).

Elliott argued elsewhere that bioethical expertise has shifted from scholars investigating the morality of issues to one of professional advice-giving.

It is possible to spend your days with like-minded colleagues from all manner of academic and clinical backgrounds, trying to make sense of some of the most intractable human problems, from illness and mortality to injustice and insanity. At its best, the work can be intellectually thrilling, and many of the people doing it are generous and welcoming. Yet in some quarters the field seems to be gradually transforming itself into a professional class of moral experts whose primary job is to advise others how to behave: a medically knowledgeable, media-savvy, academic-corporate wing of the advice industry (2002, p. 5).

The change, then, doesn't just seem to be about the loyalty of the individual bioethicist, who might not be sure where their duties lie, whether with their companies and clinics or with their philosophical endeavors. The problem facing bioethicists now also translates to the expectations and the nature of their work. Once merely academics and philosophers, bioethicists are now also consultants, thus joining the advice-giving industry. This shift changes the nature of a bioethicist’s job. The advice-giving industry goes beyond the weighing of choices: it relies on formal recommendations. Therefore, bioethics, as a profession of advice-giving, will need to rely on choosing hard sides, evolving from providing arguments on the possible normative problems that might arise from the use of certain technologies or the adaptation of differing policies in the clinic to choosing specific actions to recommend.

Elliott’s argument is that something has been lost in bioethics, i.e., its ability to be critical and unbiased. However, we can wonder if that critical edge was ever in place to begin with. While it is true that the field has experienced a bureaucratic turn in recent years, which has impacted the research being funded and the papers being published, it is also true that la bioética estadounidense has failed in its own self-examination. As Elliott asserts, outside the United States, the field is seen as "a kind of belligerent, self-absorbed, American academic imperialism" (2005, p. 379). Likewise, I argue that to have a critical edge the field must become critical about itself. Below I will argue that bioethicists have uncritically accepted the normativity of whiteness in bioethics, thus resulting in the exclusion of the Other in bioethical policies and frameworks.

1.2.2 La Bioética Estadounidense and the Normativity of Whiteness

The problem with losing one’s critical edge is that one also loses one’s ability to self-reflect. Bioethics, at its core, is intended to provide ethical frameworks and normative guidelines
that can be implemented by healthcare professionals and in the creation of biotechnologies. However, ethics implies moral behavior, which, I argue, in return demands a caring attitude. We cannot argue that our actions and our theories are grounded in normative thinking if their context is one of colonization and the silencing of groups of people. Mainstream bioethics in the United States fails in this aspect. It has been shown time and again, that, unintentional or not, *la bioética estadounidense* grounds itself in an imperialistic morality.

Bioethics in the United States is grounded on the normativity of whiteness and on western principles disguised as universal in nature. This was best described by Catherine Myser in *Differences from somewhere: the normativity of whiteness in bioethics in the United States*. Myser argues that the inherent whiteness upon which bioethics was constructed needs to be problematized for bioethics to evolve and be decolonized (2003, p. 1). If we do not engage in this critical self-reflection, we risk bioethics functioning as a cultural colonizer. It should come as no surprise that the dominant practitioners of bioethics in the United States are white individuals. The fact of the identity of most researchers in bioethics is important to recognize given that theories and practices are always brought about by individuals writing from somewhere, within a particular context. Myser writes: “That is why I am arguing that we need to be more vigilant and self-reflective regarding our production of knowledge and our cultural practice within the largely racially homogenous (i.e., Caucasian) zone of bioethics in the United States” (2003, p. 3).

Bioethical claims are culturally infused, and bioethics in the United States has been developed within a white normativity. Even most feminist critiques have been delivered by white feminists (2003, p. 2).
One of the main problems about having a discipline that is mostly reproduced by members of one specific racial group is that it presents the reality on which these individuals write as the neutral reality. Mainstream bioethics presents whiteness as the neutral choice, the invisible standard, and anything presented by members of minority groups is “Othered”. For example, it has been shown that in "upper-class, white America" principles that surround the concept of liberty are more popular, as the ideas of freedom and liberty are highly connected to the reality of being white in America (Stovall, 2018). Thus, in the writing and adaptation of principles, theories that promote these ideals are seen as central, and more community-based principles are understood as the alternative, or “that other theory that we could use in addition to this central theory.” Myser argues that one of the consequences of not self-reflecting on the normativity of whiteness inherent to bioethics is that we engage in this type of behavior, where we allow whiteness to become the neutral category of bioethics.

Accordingly, rather than challenging mainstream bioethics theory and practice as intended, it merely stimulates a kind of immune response, leaving the main body of traditional bioethics intact. This is true because researchers of diversity and difference fix our gaze on the other, allowing whiteness to stand as the unmarked or neutral category (unrecognized absence) in relation to which the “difference” of “others” (recognized presence) emerges in high relief (2003, p. 7).

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6 The problem of neutrality in bioethics can be traced back to the arguments of Rawls and their application to the field. Rawls's argument that aspires to metaphysical neutrality in theories still persists in normative and practical ethics. Jeremy R. Garret and Leslie Ann McNolty instead argue that truly useful bioethics should reject this neutral pretense (which they argue is an impossible ideal) and should engage with non-neutral propositions. They argue that there is no moral view from a metaphysical nowhere (2021, p. 32). We all exist in a culture, a race, and a situation. They argue that the Rawlsian project of neutrality fails, especially when applied to the clinic. People are not void of context, of a metaphysical background. When discussing ethical dilemmas in pediatrics, the authors write: "Pediatric hospitals and clinics are not metaphysically neutral zones and there is no veil of ignorance that families, clinicians, or clinical ethicists can slip behind when making decisions that impact the present and future interests of the child and other key stakeholders" (2021, p. 33). We can only work with the cards we have been handed and try to act from our actual social locations.
Consequently, mainstream bioethics needs to seek out the critical voices from diverse settings that can help to rethink mainstream bioethics.\textsuperscript{7}

Sandra Anderson Garcia adds to Myser’s call to decolonize bioethics and decentralize whiteness in the field. However, while Myser calls for self-reflection on the part of white bioethicists, Anderson Garcia adds that minorities also have a role to play in decolonizing bioethics. She writes:

Finally, while I agree with Myser that the onus to bring about the decolonization of the minds of white bioethicists must be placed squarely on their shoulders, it might be useful for her to also consider the need for minority group bioethicists to help bring an end to the silencing, suppression, and exclusion of their vision and voices (2003, p. 28).

While I agree with Anderson Garcia that members of the bioethics community who are also members of marginalized groups should try to make their voices heard, we must also accept that calls for change are unheard by deaf ears. White bioethicists need to be open to this decolonization and to the necessary self-reflection in order for marginalized groups to be heard. This is why I argued at the beginning of this section that ethics demands a caring attitude. If members of the “majority” are not open to self-critique, the voices of the minority will continue to be silenced, no matter how much they try.

The prioritization of specific principles, especially those held and promoted by the normativity of whiteness can be especially damaging in the clinic. Bioethics prides itself on being more than a theoretical study. The principles we develop in the field are later used in the

\textsuperscript{7} This critique on the necessity to include diverse voices when inspecting mainstream theories ties back to my previous comment on Beauchamp and Childress’s inability to include a diverse group of commentators for the new edition of their book. While it was very likely done with no malice, it represents the problem that Myser introduced almost two decades ago. After all this time, the main proponents of \textit{la bioética estadounidense} seek out the voices of others that look like them and keep promoting this normativity of whiteness.
creation of policies and taught to healthcare professionals, who will later deem their practices and their relationships with their patients ethical or unethical based on those theories. The normative foundations used in the creation of ethical principles affect people outside of academia. If our foundations are unfair, then our ethics will negate itself by perpetuating injustice.

Rachel Fabi and Daniel S. Goldberg (2022) provide concrete examples of the negative effects that come about from this unspoken neutrality assigned to whiteness. Fabi and Goldberg argue that the priorities of bioethics funding disproportionately harm people of color. A report by the National Academies of Sciences, Engineering, and Medicine (NASEM) noted that the three funding priorities in the United States concerning bioethics are genomics, research with biomedical technologies, and bioethics capacity-building outside the United States (NASEM 2020). However, a different report by Travis A. Hoppe et al. showed that white scholars are more likely to propose research on those aforementioned topics while researchers of color tend to propose topics related to community and population health. This suggests reasons why the research on people of color is less funded in bioethics (Hoppe et al., 2019).

The funding of projects mostly researched by white scholars has created a gap in funding, with population health and the social determinants of health left largely underfunded. Fabi and Goldberg argue that these funding practices lead to social and epistemic injustice (2022, p. 10). This lack of funding for members of underrepresented groups leads to hermeneutical marginalization and injustice, where their experiences and interests are not included in the knowledge pool. The prioritization of topics researched by white scholars supports Myser’s claims concerning the normativity of whiteness in *la bioética estadounidense*.
Given the normativity of whiteness and the centrality of western-specific principles that guides *la bioética estadounidense*, it’s no surprise that Raymond De Vries and Leslie Rott compared the westernization of bioethics to the indigenous evangelization of Christian missionaries in the past (2011, p. 3). Ademola Kazeem Fayemi and O.C. Macaulay-Adeyelure respond to this comparison arguing that, unlike Christian missionaries, the ethical imperialism taking place in current bioethics seems unintentional (2016, p. 5). They argue that most of the unintended imperialistic attempts from the bioethics being taught and transported to Africa from the United States appear in the form of principles that defy the necessities of people in the country.

In bio-law regulations in many African states, it could be argued that there is the dominance of Western philosophical framework developed within institutional contexts of the West, especially in relation to European and North American legal and policy frameworks. For instance, the Kenyan biosafety law, which is an offshoot of the provisions of the Cartagena Protocol on biosafety, has some regulatory components that are premised on and indebted to principilism. The Kenyan Biosafety (Labeling) regulations seek to ensure that information regarding genetically modified food, feed, or any other product is disseminated to the public so that consumers are able to make informed decisions. In framing regulations as such, it is questionable if the West should be accountable for rarely censored policy framework on bio-regulations in many African states. The logic of ‘bate-passing’ of research ethics regulations in the West, especially as premised on principilism, with little or no modification in many regulations in African states may defy rational cogency (2016, p. 5).

They argue that one of the reasons why the imperialistic project might be an unintended one is because, while western bioethics seems to truly believe that their principles are universal, those on the receiving end of them realize that they aren’t well-suited to address their culture or their ethical dilemmas. Therefore, Fayemi and Macaulay-Adeyelure argue that while bioethics is a necessity in Africa, it would have to be changed from the bioethics presented by *la bioética estadounidense* to consider alternate ethical frameworks, and the African meanings of concepts like health, personhood, and illness (2016, p. 7).
While la bioética estadounidense has symbolized the birth of the discipline and the progression of clinical bioethics, its innate connection with whiteness represents a moral dilemma in itself. Western bioethics takes certain principles as representative of the field, as the neutral position we should strive towards; yet this neutrality, this central morality, results in a morality of whiteness. Founded on concepts of liberty and freedom, la bioética estadounidense becomes incapable of being translated as it is to the rest of the world. This wouldn’t be such a problem if it presented itself as a cultural framework or a local one, but as we will see in the next section, one of the main characteristics of western bioethics is its incessant belief in its universal nature.

1.2.3 La Bioética Estadounidense and its Universality: The Problem with Principlism

One of the main issues we encounter in la bioética estadounidense is its desire to be understood as universal. The central theory of mainstream bioethics, principlism, argues to be derived from common morality, and its principles are those that any individual that cares about morality will share. It is this vision of universality that I wish to reject in this section. I argue that principles are not universal in nature and presenting them otherwise results in imperialistic efforts of colonization in practice. Even when it might make sense theoretically, the practice of implementing universal principles results in an ethical imposition that we ought not to reproduce.

While Beauchamp and Childress have argued that the four principles can be applied universally, one can find examples that would seem to disprove it. In 1995, a study conducted by Joseph A. Carrese and Lorna A. Rhodes showed that the value of autonomy and informed consent is rejected by Navajo culture. They write:

In traditional Navajo culture, it is held that thought and language have the power to shape reality and to control events. Discussing the potential complications of diabetes with a
newly diagnosed Navajo patient may, in the view of the traditional patient, result in the occurrence of such complications (1995, p. 826).

According to the Navajo, discussions that we would deem beneficial concerning advanced care planning, patient autonomy, and informed consent are detrimental and even harmful for members of their culture, who see language as shaping reality. Thus “discussing negative information conflicts with the Navajo view of language and its relationship to reality and with our informants' expectation that communication between healers and patients embodies the concept of hózhó” (1995, p. 829). For the Navajo, hózhó is a combination of the concepts of beauty, blessedness, goodness, order, harmony, and everything that is positive or ideal.

For Beauchamp and Childress, communicating information is an important part of respecting an individual’s autonomy in the clinic; thus, informed consent is a requirement. However, the Navajo place other principles above those presented by Beauchamp and Childress’s common morality. They would place what we might call the “principle of positivity”

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8 Informed consent has been argued to be so ingrained in Beauchamp and Childress’s definition of autonomy that they might be one and the same under their account. M. Therese Lysaught has argued that: “Respect for persons becomes respect for autonomy, defined almost solely by informed consent” (2004, p. 678). Beauchamp and Childress even define respect for autonomy as respect for autonomous decisions, which in the medical setting can only be reached through the understanding provided by informed consent (2019, p. 12; p. 79). Therefore, informed consent becomes a necessity for morality under their account. This emphasis on informed consent and respect for autonomy can become a problem in and of itself. Tony Saad argues that Beauchamp and Childress’s understanding of the principle of autonomy as a respect for autonomy could bring about disconcerting results. Saad argues that their interpretation of respect for autonomy has turned the usual definition of the words, so what is respected is autonomy per se instead of persons (2018, p. 134). The critique states that, under principlism, respect is reserved for persons who are autonomous. Non-autonomous people will fall under the principles of beneficence and nonmaleficence. However, if what we ought to respect is autonomy, then nonautonomous individuals do not fall under the territory of respect, given that they have made it a point to not make “respect” a principle separate from “respect for autonomy”.
above informed consent, suggesting that the universal principles held so strongly by western bioethics are not even shared by cultures within the United States.

To consider another example, in a discussion on the ethics of human papillomavirus (HPV) vaccination, Henri-Corto Stoeklé et al. reject the use of principlism, claiming that it is guided by an ethnocentrism that applies to only a few countries (2022, p. 1). They argue that because HPV is a global problem, principlism is incapable of providing an appropriate moral framework for addressing it. They argue that:

principlism is based on moral duties associated with modern western semantics and focusing on ‘freedom of conscience’ or ‘universalism’, and a contemporary conceptualization originating from the English-speaking world guided by the ‘right to life’ or ‘particularism’, revealing attempts to resolve problems exclusively at the individual level (2022, p. 1).

Yet how can this be true if the principles are supposedly derived from common morality?

Common morality offers a variety of additional principles beyond those presented by principlism. Tom Walker cites studies in anthropology that have shown that, world-wide, people usually follow a combination of three distinct forms of ethics: ethics of autonomy, ethics of community, and ethics of divinity. These are, claims Walker, what form a truly “common morality” (2008, p. 229). The ethics of autonomy addresses respect for autonomy and justice, representing the most influential ethical principle in the West, with the other principles of biomedical ethics being subsumed under it. However, an ethics of community and an ethics of divinity, which could also fall under a shared common morality, do not neatly fall under autonomy, and as a result they are not included within the common morality of principlism.

To exemplify a shared principle that would fall in a different realm from an ethics of autonomy, Walker discusses the principles of respect and purity (2008, p. 230). He argues that
almost every culture would believe it disrespectful and immoral to defecate on a memorial to the dead. However, he notes that this act is not bringing about an "injustice," is not causing harm, and is not interfering with someone's autonomy. In accordance with principlism, the act, which would be considered immoral in a number of cultures, is simply disrespectful. Thus, the four principles don't seem to encompass all the necessary principles of “common morality”–those shared by all morally serious individuals–as argued by Childress and Beauchamp.

However, Childress and Beauchamp acknowledge that their four principles do not include all possible principles, given that different cultures might have their own moral norms. They argue: “‘The universal norms of the common morality comprise only a small set of all actual and possible moral norms… ‘morality’ in the community-specific sense includes the moral norms that spring from particular cultural, religious and institutional sources’” (2019, p. 3). Thus, while the authors speak to principlism’s limitations, they nevertheless imply that the four principles are “the” common morality and that other principles are community-specific. This brings forth two problems: 1) as previously noted, there are principles beyond principlism that are shared by different cultures, thus appearing as common morality; and 2) this separation between cultural principles and common morality brings forth problems of conflict.

Concerning the second problem, Walker argues that Beauchamp and Childress don’t say enough about the weight of the differing principles. The argument cannot be that universal norms have the same normative weight as cultural ones because if they were equally binding, they would all be part of the common morality and would be shared by all. Thus, Walker presents the question: are people just mistaken when they think they are bound to their cultural duties (2008, p. 231)? If the principles of common morality outweigh cultural norms, then individuals could
never feel bound by cultural duties whenever they are in conflict with the principles of common morality. To explore this further, let’s consider Ana’s case, which was introduced earlier in the Introduction.

Under principlism, Ana’s case is, at its core, a case of autonomy versus autonomy. Ana wants to respect her mother’s eroding autonomy by taking care of her; however, this will be difficult for Ana, given that she has a job, and she is not a dementia expert. On one side, we have Ana's desire to be able to take care of herself and her needs, and on the other side, we also must consider Mrs. C’s autonomous request to not be put in a home. Under a principlist review of the case, we could also include the principle of beneficence. We want to make sure that we are helping both Mrs. C and Ana, and that we are not imposing possible harm on their household by making Ana take care of her mother. However, none of these principles are truly the ones bothering Ana. Ana's moral dilemma lies in her familial duties. She is afraid that denying her mother now will mean that she is a bad daughter. Her culture has strong familial duties concerning caring for one's parents. Ana is feeling that call to duty and sees it as her responsibility to care for her mother as her mother cared for her when she was a child.

A duty to care for one’s elderly parents, even when it appears as an inconvenience, is not one presented in Beauchamp and Childress’s common morality. Therefore, we would have to assume it to be one of those external principles that derive from the individual’s culture. Based on their common morality argument and culture-specific principles, we would have to say that either the cultural principles are outweighed by the principles of common morality and moral agents are wrong to feel bound by them, or that they are equally binding. To date, the authors have not clarified this point, so one can only guess. If it turns out that they are equally binding
then having a framework outlining only four principles, which is taught to everyone as “the four principles” will ignore those additional moral responsibilities that individuals seem to have. Walker argues that by bringing light to only four of them, we will ignore or conceal the other principles (2008, p. 231). If the four principles were not dominant, it would be easier for people to find all the competing claims without the blinding light of principlism.

However, one of the strongest arguments against principlism and common morality derives from Andrew Jones’s critique of the theory. Jones (2020) argues that even if it is true that the four principles introduced by Beauchamp and Childress follow the common morality, that does not mean that they accurately apply to the clinic. He argues that there is an incompatibility between principles made for medical ethics and universal principles. Jones does not deny that there might be universal principles but instead argues that institutions like the medical clinic require context-specific duties and principles (2020, p. 638). These necessary principles do not rely on common morality but on requirements that are specific to the clinic. While he criticizes Beauchamp and Childress for following the same mistakes we find in Kant, where their frameworks are defended in a non-normative, descriptive way by appealing to common morality instead of providing true normative claims, his main argument is that medical ethics might not need to follow arguments that are “common to all” (2020, p. 637).

Following the arguments of Rosamond Rhodes (2019), Jones argues that medical ethics and common morality are at times incompatible. Rhodes argues that common morality arguments may be impermissible in the clinic, and arguments that are impermissible in common morality may be a normative necessity in the clinic (2019, 774-775). Moreover, common morality might not have a place in the clinic, as a gut feeling will not be permissible if not
backed up by other medical professionals and scientific discoveries. Rhodes argues that there
will be cases where common morality will become a medical duty, others where permissible
behavior under the common morality is medically impermissible and lastly, cases where
commonly impermissible behavior is a medical duty (2019, pp. 772-774). Jones provides us with
some examples to support Rhodes’s argument.

Examples of the second kind are that in ordinary life we can choose whom we associate
with, whereas medical practitioners must remain nonjudgemental of others’ character or
worth; or that it is permissible to share sensitive information in ordinary life, whereas for
medical practitioners’ confidentiality is assumed in all but exceptional circumstances.
Finally, an example of the third kind is the need for medical professionals to probe into
the details of patients’ lives, which would be morally impermissible in other settings
(2020, p. 638).

Instead, Rhodes argues that medical ethics calls for specific duties that go beyond common
morality. She provides a list of specific duties that healthcare professionals might be bound to,
and which won’t always go hand-in-hand with common morality. For example, she argues that
healthcare professionals might have a duty of policing the profession, to develop and maintain
their own medical capacity, to seek trust from their patients and deserve such trust, and a duty to
base their clinical decisions on scientific evidence (2019, p. 775).

Moreover, even recent interpretations of Beachamp and Childress’s principlism and its
foundation on common morality do not respond to the critique brought by Marvin JH Lee. Lee
argues that their position concerning legitimate moral diversity contradicts their arguments on
common morality. Beauchamp and Childress argue that prescriptive common morality can
coexist with legitimate moral diversity (2019, 20). They emphasize that different decisions can
be reached through common morality, but we must side with the interpretation that can be
proven to stand closer to that common morality. As they claim,
Recognition of legitimate diversity—by contrast to moral violations that warrant criticism—is vital in the evaluation of the actions of others. One person's conscientious assessment of his or her obligations may differ from another's when they confront the same moral problem, and both evaluations may be appropriately grounded in the common morality. Similarly, what one institution or government determines it should do may differ from what another institution or government determines it should do. In such cases, we can assess one position as morally preferable to another only if we can show that the position rests on a more coherent set of specifications and interpretations of the common morality (2019, p. 20).

Therefore, under their account, we can still have a prescriptive sense of common morality while maintaining the legitimacy of moral diversity.

Lee argues that Beauchamp and Childress’s defense of the legitimacy of diversity when combined with their interpretation of common morality culminates in moral relativism, which is exactly what principlism resists (2010, p. 528). By using the example of a blood transfusion for a Jehovah’s Witness child, Lee suggests that their understanding of common morality is simply a morality of the majority. He argues that if we were to follow Beauchamp and Childress’s arguments in a world where Jehovah’s Witnesses represent most of society, then we would have no way of demonstrating that the Jehovah’s Witness approach to blood transfusion for children is not reliant on the common morality (2010, p. 526). In his previous writing discussing this particular example, Beauchamp argues that we need to distinguish between bizarre and unprotected religious convictions from those which are not bizarre and merit protection (2003, p. 271). With this distinction he suggests that societies will protect the religious claims that derive from established denominations (2003, p. 271).

If we follow Beauchamp’s argument concerning the legitimacy of moral diversity and the common morality, then to ‘win’ the argument, Jehovah’s Witness parents would need to present an argument that better resembles the common morality than those presented by the healthcare providers. However, this will very likely not happen for, as expressed by Beauchamp, the
Jehovah argument relies on a “bizarre and unprotected religious view.” Still, this view is only bizarre outside the Jehovah's Witness community. In their community, the parents of the child are acting to secure her well-being, given that they are protecting her soul and ensuring her place in the afterlife. Therefore, Lee argues that Beauchamp and Childress’s position on common morality is better confined to cultures and traditions (2010, p. 527).

However, one could argue that even if the Jehovah’s Witness is presenting a moral case in their own culture, outside of that culture, their views represent a minority. Those views do not correspond to the view of common morality, which is intended to represent the normative beliefs shared by a plurality of morally inclined individuals. This would be problematic, given that it would point to a morality of the majority; thus, a descriptive morality instead of a prescriptive one. Yet, it is unavoidable when basing a morality solely on common morality. Lee argues that if an accident happened and most of the survivors left in the world were members of the Jehovah’s witness religion and their sympathizers, we would have no other representation of the common morality (2010, p. 527). They would be classified as morally inclined individuals looking out for the well-being of their children. Thus, they would represent the common morality. The only difference between that case and the present one is, in that dystopian future, they represent the majority. Consequently, while in theory Beauchamp and Childress’s method for dealing with diversity relies on a prescriptive common morality instead of a descriptive one, in practice, their application does not really separate them.

The last critique of principlism I will consider addresses the “checklist” critique. Principlism presents us with four principles that must always be respected and weighted against each other when addressing medical ethics. The beauty of principlism is supposed to be its
simplicity and the fact that it can be easily used by healthcare providers who are lacking in ethical training. However, in practice, this simply becomes a checklist. An ethical checklist is by no means a problem on its own. It is arguably better for healthcare providers to use a “checklist” and make sure that they are at least doing the minimum when treating their patients. The problem is that we should not be aiming at the minimum. Healthcare providers are in a unique situation that is beyond our everyday use of common morality: for example, if they break the trust of their patients, or are seen as unrelatable, their patients’ health might suffer, and thus their well-being.

By working as a type of checklist, principlism negates other existing principles and duties by obscuring them. The shining light of the four principles blinds its users from additional theories. K. Danner Clouser and Bernard Gert’s famous critique of principlism addresses this very criticism (1990, p. 220). They argue that by trying to focus on particular principles we ignore the moral reasoning that can actually serve as a guideline for our actions (p. 222). This sentiment is echoed by Autumn Fiester who argues that, in practice, principlism has become the de facto theory taught to medical students and healthcare providers. In line with Clouser and Gert, she argues that while principlism argues in favor of some important principles, it is too narrow, and it cannot deal with the more complex cases. In practice, there are additional principles that should be brought to the clinic, the common morality notwithstanding (2007, p. 689). Therefore, Fiester argues that we do a disservice to students by focusing on principlism and presenting the four principles as “the” four principles.

Fiester presents a case discussion to demonstrate that principlism misses important moral considerations. She discusses a patient who denies treatment after the house staff fails to insert his IV. The patient loses his faith in the staff and denies the subsequent treatment, which leads to
his eventual death. She argues that when analyzing this case through the lens of principlism we can only identify two duties: one of respect for autonomy and another of beneficence (2007, p. 684). The staff wanted to do right by the patient, so they explained why he needed the treatment, but when he denied it, they once again did their moral duty by respecting the patient’s autonomy. Thus, even though the patient died, from a principlist view the staff could rest easy knowing that they did everything they ought to do. Fiester argues that this assessment is incorrect: as she asserts, the case should have marked additional principles:

In contrast, I have argued that this case generates four additional moral obligations that must be discharged by the treating team: the obligation to express regret, the obligation to apologize, the obligation to make amends, and the obligation to secure the patient’s trust and confidence (2007, p. 689).

When a framework becomes a checklist, we can miss important duties that could have protected the life of a patient. The stakes are higher when we engage in medical ethics: if we do the bare minimum, people can be seriously hurt. As a framework that presents that bare minimum, principlism is incapable of showing us the full moral picture. We need more.

1.3 Moving Forward

As I have discussed above, there is an inherent fault in la bioética estadounidense. The field has been founded on a normativity of whiteness that imposes its supposed neutrality on the rest of the world, presenting itself as a global ethic. However, this is a problem that goes beyond la bioética estadounidense. Bioethics is rooted in philosophy, and philosophy has been argued to be one of the whitest of humanities (Mills, 1999, p. 2). Contemporary ethical practices have been grounded on thinkers from the West, from Aristotle, Immanuel Kant, and John Stuart Mill to newer practitioners like Peter Singer, Martha Nussbaum, and John Rawls. Therefore, even when
they intend these moral frameworks to apply to a broader context, practitioners are still starting from a very western point of view.

As a solution to the aforementioned problem, Shari Stone-Mediatore has proposed a shift in focus, from western-centered views to what she calls a “coloniality scholarship.” She argues that, while western philosophy has failed to consider the ingrained foundation of its frameworks in colonial thinking and its resulting oppressive history, coloniality scholarship strives to bring to light those aspects of the field and give a voice to the Other.

Coloniality scholarship shares with global-ethics scholarship a concern with transnational moral problems; however, whereas global-ethics scholarship has developed within Anglophone moral philosophy and has tended to present itself as neutral and unlocated, coloniality scholarship has grounded itself in the voices and struggles of globally marginalized communities. In particular, it has embraced the efforts of many of these communities to unbury and resist colonialist legacies (2018, p. 2).

Stone-Mediatore argues that the field has privileged the voices of white men which, given their political and economic power, appear objective and universal, thus ignoring or devaluing diverse and marginalized voices, presenting them as merely subjective (2018, p. 4). On the other hand, coloniality scholarship, which has been championed by philosophers like Anibal Quijano and Enrique Dussel, presents this so-called "globalized ethics" as part of the colonial, euro-centered, capitalist project (Quijano, 2000, p. 533). They argue that the value system defended by this global ethics is not actually universal but ingrained in a terrible and abusive history.

This chapter has demonstrated that *la bioética estadounidense* has been founded on and prolonged a normativity of whiteness; its universal values and principles are not truly universal, but most often correspond with an ethics of the majority. This does not need to mean that principlism must be discarded entirely. However, it does mean that it needs to be reexamined in a new light, through coloniality scholarship. In the following chapters, I will provide a critical
analysis of *la bioética estadounidense* through an ethics of liberation approach and a feminist lens. I will consider the different characteristics that a moral framework must possess in order to avoid committing the same mistakes already seen in *la bioética estadounidense*. Following those discussions, I will propose an alternative framework that considers intersectional identities, avoids the normativity of whiteness, and has at its center diverse and marginalized voices.
CHAPTER TWO
WHEN LIBERATION MEETS INTERVENTION:
BIOETHICS FROM THE LATIN AMERICAN PERIPHERY

The previous chapter discusses bioethical approaches as mainly understood and practiced in the West, especially in the United States. However, while the West may have been the starting point of bioethics, by no means has it been its only proponent. The last two decades have seen a flourishing of the field in Latin America, where the focus has been very different to that proposed by la bioética estadounidense.

In what follows, I will discuss one specific type of bioethics that originated in Latin America, Intervention Bioethics (BI).\(^1\) I will discuss its main tenets and indicate how I think it can and must be applied to enrich our understanding of Western bioethics. Given that Intervention Bioethics bases its moral foundation on Enrique Dussel’s ethics of liberation, I will start this chapter by presenting Dussel’s Latin American philosophy and will then apply BI to Ana’s case, to see the kinds of differences such a framework can make.

2.1 An Introduction to the Ethics of Liberation

Before we delve into a discussion on Intervention Bioethics, it is appropriate that we introduce the basic tenets of the ethic of liberation. In recent years, Intervention Bioethics has moved from a utilitarian perspective to instead incorporating Enrique Dussel’s ethic of

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\(^1\) I will be using the term BI throughout the dissertation when referring to Intervention Bioethics, instead of IB, as to reflect the Spanish and Portuguese translations, Bioética de la Intervención and Bioética de Intervenção.
liberation. Thus, if we are to understand this contemporary approach to bioethics, we must first have a basic idea of the underlying philosophical principles that rest at its foundation. In this section, I will address Dussel’s basic philosophical ideas as they relate to Intervention Bioethics. The ethic of liberation encompasses a much larger discussion that cannot be fully addressed here; for a robust presentation one must consult Dussel’s full body of work.²

As the name implies, the goal of the ethic of liberation is to liberate, to reach a state of freedom where individuals are no longer oppressed, and where life is celebrated. The focus of the theory is on the liberation of victims, those whom Dussel calls “the Other,” through the construction of a pluriverse free of domination (2006). The liberation principle urges moral individuals to always act in such a way that 1) would lead to the liberation of victims, and 2) which would transform our current systems into liberating practices. As he writes,

Any form of ethics must look, as a matter of urgency, at the liberation of the victims whose lives have been plundered and limited. Anyone who acts critically and ethically should transform the actions, institutions or systems which currently dominate the world. This implies that their activities should be orientated towards opening up new possibilities in which the life of every victim can be materially transformed, allowing the victim to abandon his state of perpetual anguish (2006, p. 504).

Moreover, Dussel speaks of the need for a “pluriverse,” instead of a universe, in response to globalization and the assimilation of cultures. A pluriverse would instead present itself as a reality in which every culture can “conserve its own identity while, at the same time, assimilate the developments of this globalizing modernity” (2015, p. 505).

As a rule, the ethic of liberation has as an aim the recognition of the Other, while developing a society and an ethic that moves from la Totalidad to instead adopt a state of

Alteridad. By la Totalidad, Dussel refers to an ontological sameness, lo mismo (1973, p. 41). Lo mismo points to structures with an eternal return to itself, for there is no change in their sameness. La Totalidad does not open to a new future, for it is guided by its own past, which in return will be its future. It is in this eternal repetition that certain structures have stated their dominance. Thus, the structures of la Totalidad are dominant and colonizing. They project their sameness on the Other, instead of recognizing the Other as Other. It is a violent individuality, where the Other is denied, alienated, and forced to join the dominating totality as a thing or as a lesser being (1973; 2013). On the other hand, la Alteridad is a state of recognition of the Other, of facing the Other as Other, instead of projecting the oppressive sameness of la Totalidad. The state of la Alteridad is coming face-to-face with the Other and recognizing them as people with equal value and interests, neither alienating nor assimilating them within sameness. For the Other that has been raised from inside la Totalidad, and thus sees herself as less valuable, finding la Alteridad is that moment when she realizes that she does matter and has value as Other. For Dussel, the ethical consciousness is the finding of the voice of the Other in our state of Totalidad and demanding justice from their distinctive exteriority. In order to achieve a state of Alteridad and demand justice for the Other, Dussel presents us with three principles and guiding norms that would serve us as we move from a dominating society to one ruled by ágape.3

3 By ágape is meant a love for, or the capacity to love, the Other that goes beyond the totality or the sameness of your world. It is an acceptance of the Other as Other through love. This is the ultimate expression of la Alteridad. The term ágape comes from the Christian tradition and it is usually used to refer to the ultimate or highest kind of love (Templeton, 1999). However, Dussel adapted it to this ethical understanding of unconditional love for the Other, or as a love for justice to the Other as an other. Dussel first called it ’amor-de-justicia’ before adopting the term ágape (Dussel, 2013; 1973). The concept of agape in Dussel can be found more commonly throughout his discussion on the theology of liberation (Dussel, 1986).
While Kant’s deontology presents the Categorical Imperative and utilitarianism the Greatest Happiness Principle, Dussel’s ethic of liberation argues for three normative principles, which I will be referring to as the Principles of Transformative Praxis. The principles are divided into 1) the material principle, 2) the formal principle, and 3) the feasibility principle. In his discussion of Dussel’s ethics, Frederick B. Mills (2018) describes the principles briefly as the following:

The material ethical principle expresses the obligation to produce and reproduce human life in community in a manner that is in harmony with the biosphere. The formal principle requires the material principle be pursued by means of symmetrical democratic procedures. And the feasibility principle limits the outcome of deliberation to achievable policies and practices (2018, p. viii).

As we will see, each principle depends on the other as they build upon each other. Moreover, they ensure ethical deliberation through the participation of the Other in society and through practical approaches to decision-making and ethical action.

2.1.1 The Material Principle

The material principle as presented by Dussel states the following:

Those who act morally (or ethically) must responsibly produce, reproduce, and increase the concrete life of each individual human, of each community to which they belong, which inevitably is a cultural and historical life, from an understanding of happiness that is shared instinctively and in solidarity, having as an ultimate reference all humanity, all life on Earth. The vitalism of the Right affirms only the same community or nationality (which is also racist). The moral (or ethical) principle overcomes (nationalist) particularism and affirms all humanity: it is universal (concerning analogical worldliness: pluriversal) (2015, pp. 85-86).4

4 Translated from Spanish. “el que actúa moral (o éticamente) debe producir, reproducir y aumentar responsablemente la vida concreta de cada singular humano, de cada comunidad a la que pertenezca, que inevitablemente es una vida cultural e histórica, desde una comprensión de la felicidad que se comparte pulsional y solidariamente, teniendo como referencia última a toda la humanidad, a toda la vida en la Tierra. El vitalismo de derecha afirma solamente la misma comunidad o nacionalidad (además racista). El principio moral (o ético) supera el particularismo (nacionalista) y afirma a toda la humanidad: es universal (en tanto mundialidad analógica: pluriversal).”
The material principle provides the answer to the question that all moral frameworks must answer: what is the intrinsic good, the end-in-itself towards which humanity strives; and therefore, the object of ethics? Different theories in normative ethics have provided a variety of answers to those questions, from Aristotle’s “eudaimonia” to utilitarianism’s traditional “happiness/pleasure”. The answer provided by Dussel’s ethic of liberation (as seen through the material principle) is “living”. Against Descartes, “I think, therefore, I am,” Dussel responds: “Vivo, luego pienso” (2015, p. 85). Dussel argues that living life is the absolute presumption of all human acts, the driving force behind our actions. He states:

El vivir es el presupuesto absoluto (no es una mera condición), de todos los actos humanos, y al mismo tiempo, es la finalidad última (en el sentido de un fin de fines, es decir, de un horizonte ontológico) de todo acto humano. Todo deber ser, o simplemente todo deber se funda en el vivir, y en vivir cualitativamente mejor (2015, p. 85).

Ethical action under the ethics of liberation is guided under the premise that, at its foundation, human action is driven by the prospect and desire of living qualitatively good lives.

The material principle states a formal duty towards the goal of living. To act ethically will be to act in a way that increases or reproduces life. This duty will have consequences that will ripple towards the environment, arguing for the protection of the biosphere as well as individual human lives. While the focus of the ethic of liberation is on humanity, given our interconnectedness with the environment, it will be a priority that we protect non-human life as well. Moreover, the ethic of liberation makes it clear that their arguments for the protection of life is not the protection of the powerful minority, but of all human life and communities. This

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5 Translation by me: “I live, then I think”.

6 Translation by me: “Living is the absolute presumption (not a mere condition) of all human acts, and at the same time, it is the ultimate purpose (in the sense of an end of ends, that is, of an ontological horizon) of every human act. All duty to be, or simply all duty is based on living, and living qualitatively better”.
argument comes as a critique of our current systems, especially our capitalist society, where according to Dussel, the goal of such systems is not the reproduction and protection of life but of profit and individual gain at the expense of life (2006, p. 501).\textsuperscript{7}

\textit{2.1.2 The Formal Principle}

While the material principle states the prioritization of life and living, the formal principle focuses on equal societal participation. The formal principle states:

\textit{Act in such a way that the actions and the institutions are decided always having as supposed the symmetrical participation of those affected, in order to reach a consensus shared by the whole community, through a debate where rational arguments are presented, without violence, by the contention of such a decision (2015, p. 104).}\textsuperscript{8}

In other words, the formal principle argues for the inclusion of the Other in society, presenting it as a normative duty.

The arguments behind the formal principle rest on claims of autonomy and legitimate consensus. Dussel argues that until now, in a society ruled by instrumental reason, the ruling strategy has been the imposition of the dominating ego on the Other (2006, p. 501). Violence and exclusion have alienated the voices of oppressed and marginalized groups, thus limiting opportunities for equal participation. For example, in the United States, a supposed democracy focused on freedom, we have been encountering many voter suppression laws in recent years

\textsuperscript{7} One example that could be provided of the preference of profit over life has been the lack of action concerning climate change and the destruction of the environment that has put so many oppressed communities at risk.

\textsuperscript{8} Translated from Spanish. “Obra de tal manera que los actos y las instituciones, sean decididos teniendo siempre como supuesto la participación simétrica de los afectados a fin de alcanzar un consenso compartido por toda la comunidad, mediante un debate donde se presenten argumentos racionales, sin violencia, por el contendido de la tan decisión.”
that limit the ability of minority groups to vote. The ethics of liberation argue that in order to have a legitimate ethic, policies and decisions must be reached in conversation with everyone, especially those that have been historically ignored and who are victims of our current world. According to Dussel, this can be achieved through the implementation of methods that enable the symmetrical participation of the “affected members in the rational decision-making of such a community” (2006, p. 502).

### 2.1.3 The Feasibility Principle

The last principle presented by Dussel is the feasibility principle, which states:

> Any human act or community institution has a claim of goodness if, and only if, in addition to the affirmation of life (first principle), and by agreement of those affected (second principle), they are empirically possible according to the various fields and systems that enter in its concrete affectation (2015, pp. 121-122).

The feasibility principle tries to accommodate that which is logically, materially, and ethically possible. Solutions that might be an option in certain countries with more resources might not be possible in others where those same resources are more limited. To act as if, in spite of this inequality, solutions were universal would be unsound. The feasibility principle states that not every solution is valid even when it would present itself as reasonable. Therefore, under an ethics of liberation moral action must be directed under the principle of feasibility. Moral action must act according to what is possible while still prioritizing life.

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10 Translated from Spanish. “Tiene pretensión de bondad todo acto humano o institución comunitaria si, y solo si además de la afirmación de la vida (primer principio), y por acuerdo de las afectados (segundo principio), son empíricamente posibles según los diversos campos y sistemas que entran en su afectación concreta”
Frederick B. Mills presents a perfect example of the principle of feasibility in practice. He argues that while:

it was technically possible for the US to deport Salvadoran refugees back to conditions of civil war during the 1980’s, which means it was also empirically and logically possible, but it was ethically impossible because it denied thousands of Salvadorans the right to refuge from fear of persecution, disregarded their appeals, and resulted in loss of life, thereby violating the material and formal principles (2018, p. 94).

It is important to remember that the feasibility principle still holds the material principle as its guiding star. Consequently, even in cases where a solution might appear economically or logically sound, if it violates the material principle and denigrates life while invisibilizing the Other, then it is ethically unfeasible.

An example of a famous moral stance that would be rejected under the feasibility principle would be Kant’s argument on lying. Every time I teach Kant to my students they strongly respond in a similar way: that the absolute prohibition of lying (even in cases where telling the truth might get your friend killed), is simply unfeasible. Always telling the truth and never breaking promises seems unattainable in the real world where there are so many variables to consider. In accordance with Dussel’s account, lying might be the most logical solution in order to protect the material principle (life). To lie in those situations would be morally correct. The feasibility principle does not provide us with general rules or actions that we must always follow (e.g., you ought to never tell a lie), but with conditions that we must ensure through our actions, i.e., our actions must be logically and ethically feasible.

2.1.4 Dussel’s Transformative Praxis

To achieve ethical action under an ethic of liberation all three principles must be executed, for they inform and work in conjunction with each other. The protection of life (the material principle) can only be ensured through the rational, intersubjective discussions provided
by the formal principle where the protection of all life is prioritized. Mills argues that the contrary is also true: just as the material needs the formal principle to be executed, the formal relies on the material principle as well. He claims,

> The formal or procedural principle gets its basic direction from the material principle. This means deliberations by constituents about norms and institutions are to be guided by the objective of building a world in which all persons can live and grow in community (2018, p. 98).

Lastly, the feasibility principle works as a type of “supervisor” for the other two principles. “The feasibility principle ought to condition formal deliberation because what is decided by a symmetrical community of communication in accordance with the material principle ought to be achievable (technically, empirically, and logically possible)” (2018, p. 98). The feasibility principle ensures that the decisions made are not only logically feasible and achievable, but also ethically viable.

Through the incorporation of the Principles for Transformative Praxis we ought to recognize the Other from a place of alterity. We ought to give an equal voice to the Other, for it is only through those voices that we can understand the oppressive nature of our system, a system that victimizes them. Dussel argues that: “In spite of the fact that the criticism made by the victims is not taken seriously by the system and the dominant forms of organization, their criticism proves the system to be illegitimate” (2006, p. 503). We could apply Dussel’s remarks to our previous discussion on mainstream frameworks like principlism and *la bioética estadounidense* in general. The bioethical critiques from oppressed and minority groups that highlight the incomplete nature of the principles and the erasure of cultures outside of the West serve as a red flag that the framework itself is illegitimate.
2.2 Intervention Bioethics (BI)

Bioethics has been a very popular discipline in the United States; of that, there can be no doubt. However, the field has not been limited to the United States, or even the West: indeed, bioethics has global applications. It is due to this growth that there has been a necessity for bioethical theories to be available and comprehensible to all, not just academics and philosophers. This necessity for accessibility has been translated to simplicity in principlism. Principlism has fought to create universal principles, principles that, according to them, rest on a common morality shared and easily understood by everyone. As noted in the previous chapter, this supposed universality has been largely criticized. Yet if there are no universal principles, what is the alternative? The fear is that a lack of universality would lead to moral and cultural relativism. Without a universal set of rules and guidelines we would have no grounds on which to criticize or reject any action whatsoever, even if it contravenes common sense morality.

BI appears as an alternative to principlism, grounded in the view that there is no universal framework that can be applied to every country and every context. BI was born out of the reality that principlism works very well in core countries like the United States but falls short in peripheral countries. Moreover, its implementation shows that rejecting universal principles will not necessarily lead to moral relativism, for supporters of BI do not claim that principles that are important in one place are not ethical in another. Rather, they assert that the reality of different contexts calls for different approaches and priorities. In this section, I will present the foundational ideas behind Intervention Bioethics and what we can learn from it.

BI is a relatively new framework, having been presented around the late 1990s in Brazil (Garrafa, 1995; Garrafa, 1997; Garrafa, 1999). Its leading proponents are bioethicist and
physician Volnei Garrafa and philosopher and bioethicist Dora Porto. However, since its introduction in the 1990s, BI has grown and been adopted throughout many places in Latin America, to the point where it has been called by experts “the most significant development in Latin American thought since Quijano’s coloniality of power” (Ferreira & do Nascimento, 2015). The framework presents a critique of the theories born in the United States, especially principlism, with an intent to create a theory that is capable of dealing with the problems particular to a Latin American context.

The intentions behind the creation of BI are two-fold. Firstly, BI was initially understood as an epistemic resistance, intended to establish itself as "a liberating bioethical perspective, rebelling against the imposition of bioethical knowledge produced in core countries, in order to definitively consolidate its process of epistemological territorialization” (Ferreira & do Nascimento, 2015, p. 279). Intervention Bioethics is an epistemological project that intends to show how supposedly universal principles rest on ideas of colonization and are, therefore, incapable of successfully providing moral solutions to persistent problems in the periphery. Secondly, in addition to criticizing the approaches of core countries, BI’s secondary goal is to establish alternative moral guidelines that are capable of interacting with those persisting bioethical problems in Latin America.

2.2.1 BI’s Critique of Principlism

Proponents of Intervention Bioethics have openly criticized ethical approaches born in the West, critiquing their inability to translate to other parts of the world that do not share the privileges of the West. While Western theories, like la bioética estadounidense, have been praised for their interdisciplinary nature, as Rivas-Muñoz et al. (2005) note, such
interdisciplinarity does not imply that it is cross-culturally applicable. Rivas-Muñoz et al. describe the foundational goals of *la bioética estadounidense* as deeply rooted in capitalism. For example, if we were to talk about frameworks as projects, the project of *la bioética estadounidense* would be based on a model of "Living Better," while the models that will be later presented by Intervention Bioethics can be understood as a project for “Living Well” (Rivas-Muñoz et al., 2015, p.143).

Living Well is the translation used for the Latin American concept of *Buen Vivir*. *Buen Vivir* is a concept born from Ecuador’s and Bolivia’s indigenous communities (Acosta & Martínez Abarca, 2018). It represents a way of living which departs from the capitalist and exploitative world brought by Western colonization. Alberto Acosta and Mateo Martínez Abarca (2018) describe the concept in the following manner,

*Buen vivir* is a concept that aims to dismantle the idea of a universal goal for all societies, including a ‘productivist’ understanding of progress and a one-dimensional understanding of development as technology driven to produce economic growth. *Buen vivir* requires a rich, dynamic and complex vision that is a path in itself, rather than a destination – it needs to be imagined in order to be built. *Buen vivir* provides a unique opportunity to devise new ways of living collectively… *Buen vivir* has been integral to a long-standing search for alternative ways of living and has been shaped by the struggles of indigenous peoples over the past centuries (2018, p. 132-133).

*Buen Vivir* or Living Well is necessarily anti-capitalist and non-anthropocentric. It represents a world led by ethics, where living well is to live in community and in harmony with each other and the natural world (Acosta & Martínez Abarca, 2018, pp. 133-134). Living Better, on the other hand, references the individualistic and exploitative tendencies reflected in Western conduct, where nature and marginalized communities are subjugated for the advancement of certain groups.
Garrafa, the main proponent of Intervention Bioethics, has argued that while principlism has been popular in the West given its successful approach to clinical cases, it remains insufficient in places that do not share the economic and social privileges of core countries.

Garrafa argues that,

Despite its recognized practicality and usefulness for the analysis of practical clinical and research situations - [principlism] is known to be insufficient for a) the contextualized analysis of conflicts that demand flexibility for a given cultural adaptation; b) the confrontation of persistent or daily bioethical macro-problems faced by a large part of the population in countries with significant rates of social exclusion, such as Brazil and its neighbors in Latin America. Despite some occasional criticisms from sectors accommodated with the practicality of the principlist checklist, its adaptation to the study of conflicts and situations that occur in poor countries in the southern part of the world is indispensable and urgent (2005. p. 130).11

Garrafa argues that as a bioethical tool for specific clinical cases, principlism is valuable and successful. However, its insistence on being classified as universally applicable beyond that context is problematic when applied to countries in the periphery.

For example, principlism is presented as a neutral tool without political engagement or political analysis of moral conflicts. Yet, in Latin America, it is imperative that political discussion be integrated with moral decision-making, given the problems of social exclusion and poverty that give rise to many of the health and health care problems that have prevailed throughout the years. As Garrafa claims,

In the case of Latin American countries, specifically, it is imperative that this (ethical) discussion be incorporated into the very functioning of public health systems with regard to the social responsibility of the State; the definition of priorities regarding the allocation

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11 Translated from Portuguese. Original quote: “apesar de sua reconhecida praticidade e utilidade para a análise de situações práticas clínicas e em pesquisa –, é sabidamente insuficiente para: a) a análise contextualizada de conflitos que exijam flexibilidade para determinada adequação cultural; b) o enfrentamento de macroproblemas bioéticos persistentes ou cotidianos enfrentados por grande parte da população de países com significativos índices de exclusão social, como o Brasil e seus vizinhos da América Latina. Apesar de algumas críticas pontuais provenientes de setores acomodados com a praticidade do check list principalista, sua adequação ao estudo dos conflitos e situações que ocorrem nos países pobres da parte Sul do mundo é indispensável e urgente".
and distribution of resources; system management; the organized and responsible involvement of the population in the whole process; more adequate preparation of human resources; the revision and updating of ancient codes of ethics of the different professional categories involved; to the indispensable and profound curricular transformations in the universities (2005, p. 131).\textsuperscript{12}

Bioethical approaches outside the United States and other central/core countries emphasize different principles from the four introduced by Beauchamp and Childress. The needs of the periphery have surpassed questions of autonomy and nonmaleficence to instead center on questions related to solidarity, alterity, and vulnerability. Garrafa argues that it would be morally irresponsible for bioethicists in peripheral countries to reduce the persistent situations and problems faced by the inhabitants of their countries to problems that can be simply solved by autonomy. Instead, a bioethical approach from the periphery will need to consider questions on the responsibility of the State towards its citizens, the training of personnel, and the different forms of interventions that would need to be implemented to achieve moral change and the liberation of individuals (2005, p. 131).

\textbf{2.2.2 The Ethics of BI}

Intervention Bioethics emphasizes two goals: 1) resisting universal approaches as part of their epistemic project; and 2) developing a framework that can effectively approach the problems experienced in the periphery. We can call this second goal the normative project of BI. It is important to understand that Intervention bioethics will see the normative project as a type

\textsuperscript{12} Translated from Portuguese. Original quote: “No caso dos países latino-americanos, especificamente, é imprescindível que essa discussão (ética) passe a ser incorporada ao próprio funcionamento dos sistemas públicos de saúde no que diz respeito à responsabilidade social do Estado; à definição de prioridades com relação à alocação e distribuição de recursos; ao gerenciamento do sistema; ao envolvimento organizado e responsável da população em todo o processo; à preparação mais adequada dos recursos humanos; à revisão e atualização de vetustos códigos de ética das diferentes categorias profissionais envolvidas; às indispensáveis e profundas transformações curriculares nas universidades...”
of political one. Through the epistemic project, BI engages in criticism that deconstructs and
reconstructs the knowledge received from core and colonizing countries. However, the second
project, which consists of the construction of guidelines and the moral analysis of bioethical
situations, falls particularly under a political sphere. The goal of BI is to engage in critical
reflection and to defend practices that will lead to “the transformation of an unjust social reality”
(Ferreira & do Nascimento, 2015, p. 282). This transformation will require political and social
engagement.

Given that politics is a necessary tool of BI, it cannot be separated from bioethics. While
la bioética estadounidense has presented itself as a neutral tool, avoiding topics related to
politics and, in many cases, rejecting direct advocacy, BI has social and political engagement at
its core. BI defenders Saulo Ferreira Feitosa and Wanderson Flor do Nascimento have argued
that one of the revolutionary aspects of BI in bioethical discourse is the manner in which it has
exposed the overlap between political and social issues in order to ethically evaluate bioethical
conflicts (2015, p. 281). Unlike other theories, which might approach bioethics from a more
theoretical dimension, BI demands concrete interventions in the face of bioethical injustices
through the implementation of social and political changes.

Dora Porto, one of the leading and first proponents of BI, defends the necessary
integration of the social and the political with the theory by arguing that the end goal of
Intervention Bioethics is to serve as a path toward utopia (2012, p. 110). More specifically, Porto
describes Intervention Bioethics as an ethical model capable of guiding us toward a utopian
socialism. Interestingly, Porto does not understand or define the word “utopia” as it is usually
understood, i.e., as an unreachable ideal. Instead, Intervention Bioethics understands utopia as:
“a mobilizing force for building concrete, attainable and achievable historical projects” (Ferreira & do Nascimento, 2015, p. 280).

To understand Intervention Bioethics and its priorities, we must discuss the different problems we typically encounter in bioethics and how they are understood under BI. Proponents of BI divide these issues into two different groups: persistent and emerging situations.

From the perspective of Intervention Bioethics, emerging situations involve the traditional problems of the discipline, which relate especially to issues associated with scientific, biomedical, and biotechnological development. On the other hand, persistent situations implicate ethical conflicts involving health and life, which are addressed only tangentially by biomedical bioethics, such as social exclusion, poverty, discrimination, and inequality, problems of a social nature that have affected individuals and groups throughout history, and which are still present in many parts of the world, especially in peripheral countries (2018, p. 434).

Emerging situations can be understood as new advances and technologies in bioethics that cause bioethicists to engage in discourse, sometimes even before they are available to the public.

Many, if not most, of the debates that pervade the field of bioethics in core countries surround these emerging situations, from questions on IVF and predictive medicine to designer babies and enhancement technologies. BI separates itself from the typical bioética estadounidense by instead prioritizing questions regarding persistent situations. Proponents of BI prioritize debates and discourse surrounding topics like abortion, hunger, poverty, and inequality of access to resources for vulnerable groups (Garrafa and Porto, 2003, p. 400). They are especially interested in questions relating to social exclusion, discrimination, solidarity, and social vulnerability.

From its inception, Intervention Bioethics was founded upon a utilitarian framework. Volnei Garrafa argued for,

the prioritization of policies and decision-making that favors the greatest number of people, for the longest period of time and that result in the best consequences, even if to
the detriment of certain individual situations, with occasional exceptions to be discussed (2005, p. 130).\textsuperscript{13}

Given their focus on concrete actions and interventions, it should come as no surprise that BI proponents initially relied on the utilitarian framework to advance their goal of achieving practical and viable solutions for large portions of the population. However, this utilitarian focus has shifted in the last decade and has instead been substituted by a foundation on the ethic of liberation (Manchola-Castillo & Garrafa, p. 2019).

The shift toward an ethic of liberation was the natural step for a theory whose main project is an epistemic resistance against the core countries and the decolonization of bioethical thinking in Latin America. By abandoning utilitarianism for Dussel’s ethic of liberation, BI gives itself the opportunity to be reconstructed entirely out of Latin American theoretical foundations. This seems to be imperative for a theory focused on the problems of the periphery and its persistent situations.

The adoption of an ethic of liberation as the basis for Intervention Bioethics will mean that BI will share the Principles of Transformative Praxis that were previously addressed in this chapter. However, given that the theory was developed for almost two decades before adopting Dussel’s arguments, there will be lingering principles and/or priorities that might differ from the main arguments of an ethic of liberation. For example, Garrafa has established as foundational to BI what he calls the four “p”s: “prevention (of possible harm and iatrogenic events), precaution (in the face of the unknown), prudence (in relation to advances and “novelties”) and protection

\textsuperscript{13}Translated from Portuguese. Original quote: “a priorização de políticas e tomadas de decisão que privilegiem o maior número de pessoas, pelo maior espaço de tempo e que resultem nas melhores consequências, mesmo que em prejuízo de certas situações individuais, com exceções pontuais a serem discutidas”.
(of the socially excluded, the most fragile and underserved)” (2005, p. 130). Therefore, while Garrafa offers some guidance that diverges from the ethics of liberation, the two theories synergize due to their alliance with the most vulnerable members of society, their focus on action, and their prioritization of persistent situations over ‘emerging’ ones.

The four “p”s are an essential part of the normative framework of Intervention Bioethics. Volnei Garrafa, Karla Amorim, Ticiana Garcia, and Camilo Manchola (2017) expand upon these concepts in their article *Bioética e Vigilância Sanitária*. Firstly, Garrafa et al. distinguish the concept of *prevention* in the context of health care ethics as follows:

Prevention is considered to be that action that anticipates the probabilities of health injuries through the search for anticipated acts… Specifically in the area of health, prevention is composed of measures aimed not only at preventing the onset of diseases - such as reducing risk factors - but also at halting their progression and mitigating their consequences (2017, pp. 134-135).

Prevention, as a normative guideline in bioethics, will require decision-makers to have scientific and/or medical knowledge related to specific situations in order to be able to anticipate possible harm. Therefore, the adoption of "prevention" will lead to three benefits: the development of what they call the "anticipatory virtue," a potential for egalitarian methods being adopted for the sake of prevention, and the ability to mitigate conflicts (Garrafa et al. 2017, p. 134). Concerning the egalitarian prospect, they argue that prevention has an extraordinary egalitarian potential in its implementation. As an example, the authors claim that if, “urban sanitation measures and

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14 Translated from Portuguese. Original quote: “prevenção (de possíveis danos e iatrogenias), precaução (frente ao desconhecido), prudência (com relação aos avanços e “novidades”) e proteção (dos excluídos sociais, dos mais frágeis e desassistidos)”.

15 Translated from Portuguese. Original quote: “a prevenção é considerada como aquela ação que se adianta às probabilidades de lesões à saúde através da procura de atos antecipados… Especificamente na área da saúde, a prevenção é composta por medidas destinadas não apenas a prevenir a aparição de doenças – tais como a redução de fatores de risco –, mas também a deter seu avanço e atenuar suas consequências”.

vaccination campaigns are implemented, they could reach the different social classes and have an effect in all nations of the world” (2017, p. 135). An egalitarian approach to prevention could close the gap in health inequalities between different social groups.

The second “p” stands for precaution. By precaution these authors refer to:

The adoption of protective measures concerning possible damage or risks that could be produced by particular products or technologies. Multinational legal tools have been pioneering in the definition of precaution, especially from notions related to the environment, with elements of threat prevention and liability. Along these lines, its primary purpose is to protect humanity and the environment against possible threats from human acts (2017, p. 131).16

Precautionary approaches can lead to diminishing harm and to a greater good. Therefore, BI argues for the supervision and control over the production of goods that could lead to harm over vulnerable populations.17 Intervention Bioethics has a strong interest in the protection of the environment, in addition to vulnerable individuals. Consequently, precaution is seen not only as a way to protect people but also our surroundings from harm caused by people.

Technologies and medical initiatives aimed at improving quality of life in Western countries have historically been implemented on the backs of marginalized peoples. Testing cures for syphilis in Guatemala (Rodríguez & García, 2013), the development of the birth control

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16 Translated from Portuguese. Original quote: “O respeito à precaução é interpretado como a adoção de medidas protetoras relativas a possíveis danos ou riscos que poderiam ser produzidos por determinados produtos ou tecnologias. As ferramentas jurídicas supranacionais têm sido pioneiras na definição da precaução, principalmente a partir de noções relacionadas ao meio ambiente, com elementos relativos à prevenção das ameaças e de responsabilidade. Nessa linha de ideias, seu propósito precípuo é a proteção da humanidade e do meio ambiente contra possíveis ameaças dos atos humanos”.

17 This approach is interesting to consider under a Western framework. The United States has a more liberal understanding of the market, where harmful goods can be mass-produced and distributed under the principles of a free market and the autonomy of the buyer. However, the precautionary approach proposed by BI could be understood as a more paternalistic approach, where goods that would lead to a decrease in well-being and would disproportionately affect vulnerable groups should not be produced in the first place.
pill in Puerto Rico (Liao & Dollin, 2012; Blakemore, 2018), and the increasing number of unsupervised drug trials from American companies (CNN, 2012; Aultman, 2013), are some examples of the many medical advancements that have taken place in Latin America at the risk of their citizens. Therefore, precaution has become a necessary principle in Latin America due to the historical oppressions inflicted on the Latin American people for the advancement of the West.

The third “p” concerns prudence. Prudence, as understood by Garrafa et al., follows the arguments of past philosophers like Aristotle and St. Thomas Aquinas, where it is seen as a type of virtue. Out of the four “p”s, prudence might be the most loaded concept presented by BI. Garrafa et al. speak of prudence as the mother and guide of the other virtues, given that they associate prudence with good judgment and deliberation. They describe prudence in contrast to its opposite, imprudence. If prudence is what we must practice in bioethics, then imprudence is what we must avoid, which they present as the act of negligence (lack of due care), rashness or temerity (lack of deliberation), inconsideration (lack of judgment), and inconstancy (abandonment of a good purpose) (2017, p. 131).

Lastly, the fourth “p” refers to protection. Protection, under BI, is seen as a particularization of responsibility; more specifically, responsibility for communities at risk. The authors claim in reference to protection in bioethics that “to talk about protection in terms of health is to consider that, at a given moment, there will be a social group or individuals in a fragile situation, with the need for norms that can prevent future damage” (2017, p. 133). This understanding of protection refers to the safeguarding of essential needs for all people, like water, housing, health, food, and education. Frameworks like principlism, which engage the
principle of justice without discussing the situations that arise from a scarcity of resources, miss a critical discussion of normative factors that relate to the social determinants of health. Intervention Bioethics, on the other hand, makes it a priority to protect the basic needs of all people as a fundamental part of their framework.

The combination of previous versions of BI with an ethics of liberation culminates in three main characteristics for this latest version of Intervention Bioethics: 1) empowerment, 2) liberation, and 3) emancipation (Manchola-Castillo & Garrafa, 2019). It is the amalgamation of these distinctive characteristics that guides decisive action. Manchola-Castillo and Garrafa assert the need for each of these characteristics (2019, p. 5). They argue that by empowerment, BI refers to a process in which, through education and participation, social groups can increase their confidence and protagonism. The Intervention Bioethical concept of liberation is also closely related to education. Liberation, in this sense, can be understood as the epistemological emancipation of the individual, where students can build their own knowledge and add to the knowledge pool through the creation of concepts, ideas, and paradigms that can shift the individual's history and that of the social circle to which they belong (2019, 5). Thus, education through this lens is seen as a liberating practice.

Lastly, by emancipation, they refer to the ultimate state of liberation and autonomy. The emancipation Manchola-Castillo and Garrafa make reference to is the emancipation defended by Brazilian philosopher, Paulo Freire. Freire’s concept of emancipation refers to the human emancipation from social domination and the dehumanization of oppression (Méndez & Morán-Beltrán, 2019, p. 140). Johan Méndez & Lino Morán-Beltrán describe the concept as “a political intention declared and assumed by all those who are committed to the transformation of the
living conditions of those who have an oppressed existence, contrary to the pessimism and authoritarian fatalism defended by postmodernism” (2019, pp.140-141). Therefore, the call for emancipation in BI is the active engagement, political and social, to work as a community for the liberation of all people.

To summarize, Intervention Bioethics is a framework created in the periphery which has allied itself with the most vulnerable members of society. It is a normative framework that uses politics as a necessary tool to achieve justice and public health for the largest number of individuals. Moreover, it argues for the responsibility of the State to defend more vulnerable population groups when promoting fairness and equality. Intervention Bioethics relies on decisive actions, especially when confronted with persistent situations. BI establishes itself as a liberating bioethical perspective, as an epistemological resistance, to the knowledge of core countries, and as an alternative that serves as a mobilizing force towards fairness and projects of change.

2.2.3 Possible Critiques of BI

As is the case with every framework, Intervention Bioethics is not without its critics. In what follows, I will briefly consider two possible arguments that could be posed against BI. Firstly, it could be argued that Intervention Bioethics is “too political”. BI does not try to

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18 Translated by me from Spanish. Original text: “una intencionalidad política declarada y asumida por todos aquellos que están comprometidos con la transformación de las condiciones de vida de los que tienen una existencia oprimida, contrariamente al pesimismo y fatalismo autoritario defendido por la posmodernidad.”

19 It is worth noticing that BI has not faced much criticism in print. This lack of opposition is not due to BI being a “perfect framework”, but due to the lack of engagement of Western bioethicists with peripheral knowledge. Bioethicists in the West cannot critically engage and oppose Intervention Bioethics, because most of them have never even heard about it. Western-trained bioethicists tend not to look beyond writings in mainstream influential journals; thus, many are unaware of the existence of frameworks like
hide its inclusion and reliance on politics and the State. The inclusion of governmental affairs is a necessary staple of the framework. However, as I will argue in the next chapter of this dissertation, bioethics in the West has been presented as a neutral tool that has rejected the direct involvement of its practitioners.\textsuperscript{20} Bioethicists argue that it is not the job of bioethicists to take a stance or to "choose a side" (Benatar, 2006; Parker, 2019). On the contrary, such development is beneath bioethics, which is intended to be an academic discourse. Intervention Bioethics, on the other hand, argues for the need to take decisive action, which requires taking a political stance to advocate for solutions and to seek ways to implement them. The exposing of problems and the seeking of answers compels Intervention Bioethics to work closely with politics and the law.

However, involving politics can compromise the integrity of the field, as it risks normatively imposing the beliefs and personal arguments of an author. Moreover, politicians and governments have their own interests, which may often diverge from the needs of the people. In their appeal to the State, BI’s proponents depend on the development or amendment of laws and the constitution for many of their arguments. Yet, it is essential to remember that the law does not equal morality. Many laws have existed, and some still exist, that could be deemed deeply immoral. Therefore, to rest morality in arguments of law and the State could compromise the legitimacy of BI’s normative arguments.

\textsuperscript{20} In the next chapter, I will discuss feminist approaches to bioethics. Some of these feminist approaches have argued for the need to directly advocate for patients and engage in things like activism (Ashby and Morrell, 2018). However, they have encountered strong opposition from philosophers and ethicists who believe that direct involvement contradicts the foundational goals of bioethics, which are to serve as an academic observer. This opposition argues that bioethicists ought to present the arguments and dilemmas in a neutral manner. This is one of the central topics of Chapter 3, so I will expand on this debate there.
Secondly, given that BI was initially conceived as a utilitarian theory, it could be argued that it could fall into the same problems as utilitarianism. While, as previously noted, the theory has moved away from that framework to adopt an ethics of liberation, some might argue that its utilitarian roots run too deep. In a paper as recent as 2017, *Bioética E Vigilância Sanitária*, the leading proponents of BI were still referring to the theory as a utilitarian framework. Garrafa et al. argue that,

BI is considered an ‘epistemology from the southern hemisphere of the planet,’ starting from the viewpoint of defense of the ‘most vulnerable band of society’ and considering, among other aspects, that the most just and morally justified public and collective decision-making are those - from a utilitarian and consequentialist position, besides being complementary in solidarity [this is from their arguments on critical solidarity] - that privilege the largest number of people, for the longest period of time, and that result in the best collective consequences (2017, p. 129).21

Therefore, given BI’s normative prioritization of consequences and its arguments for privileging the largest number of people, many of the critiques that have been brought against utilitarianism over the years would seem to apply to it.

Utilitarianism has been criticized for not giving appropriate attention to the means behind our actions or our intentions, and instead relying mainly on good consequences. Bernard Williams (1973), for example, argues that the impersonal nature of utilitarianism fails to distinguish and separate persons and their distinctive agencies. The required neutrality of utilitarianism is impossible to achieve, as we all deliberate from our own perspectives and consider our own projects. Onora O’Neill (1986) indicates a lack of respect for people under

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21 Translated from Portuguese. Original quote: “A BI é considerada uma ‘epistemologia do hemisfério sul do planeta’, partindo da ótica de defesa da ‘banda mais vulnerável da sociedade’ e considerando, entre outros aspectos, que as tomadas de decisão públicas e coletivas mais justas e moralmente justificadas são aquelas – de posição utilitarista e consequencualista, além de complementarmente solidária – que privilegiem o maior número de pessoas, pelo maior espaço de tempo, e que resultem nas melhores consequências coletivas.”
utilitarianism, as reaching the greater good might mean engaging in injustices and even sacrificing unwilling individuals. In her view, while the consequences of our actions merit normative attention, the means through which we achieve happiness ought to matter. Additionally, if we are trying to maximize happiness for the largest number of people, we could be simply following a "mob rule" mentality, where the majority rules. This mentality can lead to many injustices and immoral actions being done in order to satisfy the majority.

The success of Intervention Bioethics depends on its ability to defend itself against such critiques. While it is true that BI was initially conceived as a utilitarian framework, and it still has many of its characteristics, its foundational goals have shifted to focus on an ethic of liberation. And while many of the critiques brought against utilitarianism rely on concerns about oppressing the minority for the sake of the majority, the most important characteristic of BI is the protection of vulnerable groups. Therefore, concerns raised against utilitarianism’s use and abuse of some individuals for the sake of the group do not apply to BI.

Nevertheless, proponents of Intervention Bioethics might accept good consequences even if they come about from less-than-ideal intentions. BI has been proposed as a way to achieve justice and protection for isolated and vulnerable groups that have been historically oppressed. Their goal is to achieve change and justice for these groups through working with political representatives. If, for example, a group of politicians implemented free education for impoverished groups but secretly did it merely to get votes – not because they cared (thus having the wrong intentions) – Intervention Bioethicists would likely find it satisfactory. Their goal is to achieve good consequences for people that need them by making sure that everyone has access
to essential goods and services. Therefore, the intentions of the actors implementing those goals might be a secondary concern for these bioethicists.

Finally, concerning the critique that Intervention Bioethics is "too political," this is a criticism that BI will have to accept. While some bioethicists might disagree with it, proponents of BI argue that it is the political nature of their approach that has led to their success in Latin America. Intervention Bioethics has been able to engage with different projects that go beyond academic theorization, and which have led to change and action for the periphery. Proponents of BI argue that the persistent situations and needs of Latin America require action; and failing to engage in such political action would be a significant moral failure.

2.2.4 BI and its Application to Persistent Situations

I have previously discussed the theory and goals of Intervention Bioethics, but given its emphasis on application and action, it is necessary to consider how the theory has been applied. In this section, I will briefly discuss three specific cases demonstrating how Intervention Bioethics has been used for change throughout Latin America. The three cases I will discuss are 1) palliative care and "dying well"; 2) homelessness and addiction; and 3) the case of COVID-19.

In 2021, Meiriany Arruda Lima and Camilo Manchola-Castillo published an article called *Bioethics, palliative care, and liberation: a contribution to 'dying well'*. In it, they argue that Intervention Bioethics and the concept of liberation can contribute to what we might call the “good death” or "dying well." Arruda Lima and Manchola-Castillo argue that there are many ways in which our society and bioethics fails in their approach to death. Death is presented as

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22 I will address in more detail questions on whether bioethics should be more political and activist-focused in the next chapter.
something to be feared and overcome; it is a taboo, an inevitability that no one wants to address. However, liberation approaches can address such concerns, for “liberation cannot coexist with fear” (Arruda Lima and Manchola-Castillo, 2021, p. 276). These authors argue that liberating practices lead us to confront the reality of death, which is so often avoided. Liberation, as understood by the ethic of liberation and BI, means being able to identify one’s own limitations and fears.

With the combination of the ethic of liberation and Intervention Bioethics, the aim of the framework has been to find concrete ways to achieve a social transformation informed by liberation. Liberation will mean freedom from oppression, both from external and internal forms of oppression. Fear has been the tool of the conqueror and the subjugator. Therefore, it is important for proponents of BI to find ways that they can help people overcome their fears to achieve freedom. As Arruda Lima and Manchola-Castillo claim,

In other words, liberation defends the existence of an individual whose freedom (in relation to misery, but also in relation to suffering and pain) will only be achieved through critical reflection whereby the dominated are no longer oppressed by the dominator, for they are no longer afraid to be free. In the health field, this means breaking the principlist hegemony and escape from biological and cultural determinism (2021, p. 275).

Moreover, these authors claim that while there has been a more recent focus on palliative care, such care and discourse has centered on ways to diminish the pain of death and less on the right to die. When discussing the topic, they argue:

Although such care promotes quality of life, sometimes the discussion skips the right to die since palliative care is not always accessible or made available to all patients. And here is one more point to whose solution liberation-based bioethics can contribute too (2021, p. 275).

Unlike more theoretical approaches, which might argue for the things that should or could be done, BI’s unapologetic stance on the government's role to involve itself in matters of health and
patient rights can help patients achieve access to these services and rights. Proponents of Intervention Bioethics have advocated for patient-focused education in medical schools, which would rely on public policies and interdisciplinary involvement.

The second case for consideration is presented by bioethicist Carolina Soto-Méndez. In 2019, while discussing the problems experienced by the homeless in Colombia, Soto-Méndez brought to attention the false dichotomy between vulnerability and autonomy in bioethics. Soto-Méndez relies on the arguments of Henk ten Have, who identifies the developing concept of vulnerability in bioethics, and how mainstream accounts aren’t able to correctly address the vulnerable, given the focus of mainstream bioethics on individual autonomy (ten Have, 2016). Ten Have argues that vulnerability is something that we experience in society in relation to others and how they treat us. Therefore, concepts of relational autonomy are better suited to address concerns about vulnerability.

Studies in bioethics have mostly assumed that the greater the vulnerability of the patient, the lesser their autonomy (Ten Have, 2016; Rosas, 2015). For example, individuals with mental illnesses or those who suffer from an addiction are seen as less autonomous from a traditional view of autonomy in bioethics. Soto-Méndez argues that this view presents a problem in the application, especially when we consider homelessness and rehabilitation. The homeless are one of the most vulnerable populations, with their vulnerability running the gamut from health to social conditions. In Colombia, the law states that any attempt at rehabilitation by a homeless person must be understood as an autonomous choice on the part of the individual (Soto-Méndez, 2019, p. 99). Any attempt at rehabilitating a nonautonomous homeless person will be deemed inadmissible and no services will be provided. Therefore, in the context of rehabilitation for the
homeless, if we understand vulnerability in a dichotomous relationship with autonomy we will be left with two unpreferable choices. We either accept that this vulnerable group will not be able to receive the help they need because they are not seen as autonomous enough to consent to the needed services or we provide them with services for which they do not possess the autonomy to consent. Soto-Mendez concludes by arguing that we need a way to redefine the relationship between vulnerability and autonomy so that we can better address the needs of the homeless and other street dwellers. She claims,

The phenomenon of homelessness raises the need to delve deeper into the aspects that allow, from a bioethical point of view, a different relationship between autonomy and vulnerability that facilitates the approach to street dwellers without being limited by the sole approaches of a bioethical framework (2019, p. 100).23

Intervention Bioethics presents an alternative way of understanding the relationship between autonomy and vulnerability. Unlike principlism, BI holds a relational account of autonomy instead of the more Kantian and individualistic approach to it. When understood in this way, we can better address the tensions between vulnerability and autonomy. Unlike other frameworks, BI has the capacity to deal with social problems and how they impact health, given the social and political vision that is ingrained in its philosophy.

Andrea L. Ribeiro Valerio and Wanderson Flor do Nascimento offer a distinctively Intervention Bioethics approach to the situation of homelessness and drug addiction. They focus on the vulnerability of homeless individuals and how to approach it in a way that neither creates nor prolongs stigmas in the community nor further exacerbates harm. As they write,

23 Translated from Spanish. Original quote: “El fenómeno de habitabilidad en calle plantea entonces la necesidad de profundizar en los aspectos que permitan, desde la bioética, una relación distinta entre autonomía y vulnerabilidad, que facilite el abordaje en habitantes de calle sin estar limitado por los planteamientos propios de un enfoque bioético.”
In its more biomedical approach, bioethics paid little attention to the issue of harmful drug use, mainly due to a view that favors the dimension of people's autonomy. By paying attention to the social processes that make subjects vulnerable, Intervention Bioethics will seek to observe how the abusive use and, above all, the attention given to the addict subject in harmful dependence establish moral conflicts that impact the (quality of) life of users, the societies and the health systems in which they are inserted, avoiding merely moralizing approaches that blame the drug user and recommend an intervention that disregards the human rights of the drug user population. Intervention Bioethics would be inserted in the reflection of moral conflicts involving attention to users at a harmful level of drugs, avoiding stigmatization and the consequent vulnerability that arises due to the attention, or lack thereof, to the user population (2017, p. 69).

Thus, the approach taken by BI has focused on studying how this vulnerability develops and finding ways to decrease it. For example, these interventionists have worked on social inclusion policies that provide homeless individuals with access to sustainable housing, such as social housing, and low-demand work and treatment options (e.g., the Open Arms Program in São Paulo and Ponto de Cidadania in Bahia) in which the individual is included in every decision in a comprehensive way (Ribeiro Valerio & do Nascimento, 2017, p. 73).

The third and last application of BI relates to the 2020 COVID pandemic. After COVID-19 spread across the world, it was quickly discovered that individuals suffering from sickle cell anemia were at a greater risk than most people (Payne et al., 2022; Panepinto et al., 2020). Additionally, sickle cell anemia disproportionately affects the Afro-descendant population (Pokhrel et al., 2023; CDC, 2022), meaning that Black citizens were at a greater disadvantage.

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24 Translated from Portuguese. Original quote: “Em sua abordagem mais biomédica, a bioética pouca atenção deu à questão do uso nocivo de drogas, sobretudo em função de um olhar que privilegia a dimensão da autonomia das pessoas. Ao atentar-se aos processos sociais que vulnerabilizam os sujeitos, a Bioética de Intervenção procurará observar de que maneira o uso abusivo e, sobretudo, a atenção que se dá ao sujeito adicto em dependência prejudicial estabelecem conflitos morais que impactam a (qualidade de) vida de usuários, as sociedades nas quais estão inseridos e os sistemas de saúde, evitando abordagens meramente moralizadoras que culpabilizam o usuário de drogas e preconizando uma intervenção que desconsidere direitos humanos da população usuária de drogas. A Bioética de intervenção se inseriria na reflexão dos conflitos morais envolvendo a atenção aos usuários em nível prejudicial de drogas evitando a estigmatização e a consequente vulnerabilidade que surge em função da atenção, ou ausência desta, à população usuária.”
during the pandemic than any other group. In Brazil, Intervention Bioethics offered an alternative to addressing patients with sickle cell anemia at that time. It was argued that the pandemic exacerbated the social exclusion and discrimination that they experienced (Gustin et al., 2020). Given BI’s general orientation toward governmental intervention, the theory offered a way to critically address the situation.

Clara Gustin, Willian Pimentelb, Marcelo Sarsurc, and Luciana Dadalto argue that, even before the Covid pandemic, individuals with sickle cell anemia were especially vulnerable in Brazil. They argue that the Sistema Único de Saúde (SUS), Brazil’s public health care system, “did not assume a difference in the provision of services from the regional sub headquarters, which changes the level of quality and effectiveness in the provision of health services” (Gustin et al., 2020, p. 45). The areas where the quality of services is lower coincides with the areas where we can find a higher population of Black citizens and patients with sickle cell anemia. Moreover, a large number of Brazilian citizens with sickle cell disease have been shown to live in poverty, which affects their capacity to access treatments and even pay for transportation to blood centers and appointments (2020, p. 46). Adding to their disadvantage, it has been shown that 85% of individuals with sickle cell anemia in Brazil have low levels of education, which they argue may present difficulties in understanding the guidelines and treatments for their disease (Gustin et al., 2020, p. 46).

Patients with sickle cell anemia were already suffering from social exclusion, discrimination, and lower health than other citizens in Brazil; but this vulnerability was further exacerbated by the Covid-19 pandemic due to the persistent exclusion of these groups and the government’s instability:
In this way, invisibility, which was already latent, can become disastrous in the face of political choices made, over decades, by our rulers. It is important to say that in the current moment in which the COVID-19 pandemic is plaguing citizens, it is necessary for a governmental unit to focus on a single objective: to save lives. However, society witnesses the exacerbation of political differences, divergent statements regarding methods of controlling contagion, and, thus, the certainty that the interests of politicians overlap with the lives of the humblest (Gustin et al., 2020, p. 48).

It is due to the poorly managed governmental assistance and the social exclusion faced by a vulnerable group that Intervention Bioethics was summoned as the needed framework to critically assess the situation in place of any other bioethical theory. Gustin et al. argue in favor of the use of BI by addressing the following:

Intervention bioethics also performs a reflection of human behavior, with regard to individuality and autonomy, in order not to affect the rights of others, emphasizing that tolerance, responsibility, solidarity, and liberation are bioethical references that must be applied to any human act. Furthermore, it establishes that health policies and government actions must be based on equity/fairness, solidarity, and investments that favor the socially less favored classes (2020, p. 49).

Unlike other theories, Intervention Bioethicists are in a position where they can demand action by the government and the SUS. As a solution, they propose an expansion of resources, guidance, and adaptation of the treatments offered by the SUS. The government, and society in general, are to ensure that this vulnerable group is given the attention they have been denied.

25 Translated from Portuguese. Original quote: “Dessa forma, a invisibilidade, que já era latente, pode se transformar em desastrosa diante das escolhas políticas realizadas, ao longo de décadas, por nossos governantes. Importa dizer que o atual momento em que a pandemia da COVID-19 assola os cidadãos, tornase necessária a unidade governamental focada em um objetivo único: o de salvar vidas. Porém, a sociedade presencia a exacerbação das diferenças políticas, as declarações divergentes em relação aos métodos de controle do contágio e, assim, a certeza de que os interesses próprios dos políticos sobrepõem à vida dos mais humildes”.

26 Translated from Portuguese. Original quote: “A bioética da intervenção cuida também de fazer uma reflexão relativa aos comportamentos humanos, no que tange à individualidade e à autonomia, a fim de não atingir os direitos do outro, enfatizando que a tolerância, a responsabilidade, a solidariedade e a libertação são referenciais bioéticos que devem ser aplicados a qualquer ato humano. Ademais, estabelece que as políticas de saúde e as ações governamentais devem fundamentar-se na equidade, na solidariedade e em investimentos que privilegiam as classes socialmente menos favorecidas”.
Brazil needs effective State intervention that can assure a fair distribution of resources to everyone, given that equity was the goal behind the development of the SUS. Thus, the responsibility of BI has been to serve as a guiding factor that can provide practical ways to protect vulnerable populations (Gustin et al., 2020, p. 51).

2.3 Ana’s Case Through Intervention Bioethic’s Peripheral Lens

Having presented the basic tenets of the ethics of liberation and of Intervention Bioethics, let us return to Ana’s case. To recap, Ana’s siblings had assigned her responsibility to take care of their mother, Mrs. C. However, Mrs. C has advanced dementia, which sometimes leads her to have violent outbursts. Ana feels that in order to be a good daughter and comply with her familial duties, she ought to care for her mother herself. Mrs. C had persistently voiced the desire to not be put in a home; thus, doing so would deny Mrs. C this request. However, caring for her mother at home would prove detrimental to Ana’s well-being, given that it would require her to leave her job and subject herself to arduous and unsupported care work.

As previously noted, under principlism this case becomes one of Ana’s autonomy versus that of her mother, and at best, it considers the principle of beneficence as a possible tie breaker. La bioética estadounidense relies on “external principles” to consider the concerns that are central to Ana and the main reason behind her predicament, that is, her familial duties and her love for her mother. When we apply the ethic of liberation and BI to Ana’s case, new principles and normative ‘curiosities’ come into play which were not considered before; these, in turn, could change one’s understanding of the situation.

When considering Ana’s situation from an ethics of liberation, one must consider the principles of transformative praxis. One ought to consider if 1) a (qualitative) life is being
prioritized; 2) if all voices are being taken into consideration; and 3) if the proposed solution is ethically and logically feasible. Under the material principle (the prioritization of a qualitative life) we might see a shift from the argument on autonomy presented by principlism to a discourse on which option presents a better life to both Mrs. C and Ana. It could be argued that even if a nursing home is not what Mrs. C might have wanted, it might be what she needs in order to have a better life. Given her dementia, Ana might not be qualified to take care of her, which might lead to greater harm for both of them, and consequently, to a decrease in their well-being.27

Moreover, an interesting observation when considering the formal principle, is that according to the case, it seems that it was Ana’s family who decided that Ana should be the one to take care of Mrs. C. This would seem to imply that either Ana was not a part of the conversation or that her voice might have been silenced, given how conflicted she is feeling by the assigned duty. In such a scenario, the decision would have been reached without equal participation of all those involved and would go against the formal principle. So, if that was the case, it would be a normative necessity to approach the topic once more, giving Ana an equal right to participate in the conversation.

Lastly, the decision would fall to Ana and what she would consider a logical and ethical choice. If Ana decided that her familial duties are so strong that not taking care of her mother would weigh on her and decrease the quality of her life, it might be the case that she ought to care for Mrs. C at home, even if it imposes certain challenges. However, for the choice to be feasible, Ana would need to ensure that she is appropriately trained to care for Mrs. C, and that

27 BI’s contextual nature might mean that, if deemed prudent, Ana and Mrs. C could attempt the care at home by Ana, to see if it’s feasible. However, as soon as it becomes overwhelming for Ana and dangerous for Mrs. C, moving her to an institutional setting might be required.
she would be capable of providing her mother with a good life. On the other hand, if Ana determines that taking care of Mrs. C will decrease the well-being of both of them, then she ought to put her mother in a home, even if this is not what Mrs. C (or even Ana) desires.

Garrafà’s Intervention Bioethics argues for the examination of each case through the use of the four Ps: prevention, precaution, prudence, and protection. Therefore, we ought to see how the four “Ps” apply to the case. Primarily, we ought to prevent possible harm and to seek precautions in the face of the unknown. Ana has already been hurt by Mrs. C’s violent outbursts. So, if we are to prevent harm and to seek precautions against future possible harm, it might be prudent to seek professional help that can provide Mrs. C and Ana with the help they need. However, we must also consider the fourth “p,” protection of the most fragile and at-risk members of our society. As an elderly individual, Mrs. C is a member of one of the most vulnerable and underserved members of society, so her protection is paramount. Most of us have heard harrowing accounts of the abuse and neglect of the elderly in underfunded homes. Moreover, we also have Ana who, as a woman, belongs to a group that has historically carried an unequal burden of care. Therefore, any decision will need to give priority to the protection of both Mrs. C and Ana, making sure that an unequal care expectation is not imposed on Ana while Mrs. C’s care needs are not rendered invisible, as we are so quick to do with the elderly.

Intervention Bioethicists would argue that Ana’s dilemma is caused by a societal problem, not an individual family’s failures. The solution to the problem rests less on Ana, and more on the government. Families should not fear the possible neglect of their loved ones at a place supposedly designed to care for them. Moreover, in a society where assisted living and nursing homes tend to be economically inaccessible or pose a significant economic burden on
families, caretakers should be offered financial help. Currently, the Family and Medical Leave Act (FMLA) in the United States offers employees up to 12 weeks of unpaid leave which can be used to care for a sick family member (Family and Medical Leave Act of 1993). There is no financial support for individuals like Ana who at times must leave their work to care for their loved ones. This societal failure creates a moral dilemma that falls entirely on Ana’s shoulders. Intervention Bioethics fundamentally aims at addressing the oppression of vulnerable groups; it is not enough to simply identify the problem. As such, it requires society to seek change by working for the creation of policies that will lead to their protection.

Intervention Bioethics adds something often unseen to the field of bioethics: that is, a call to political action. There have been many interesting conversations on the role of advocacy and activism in bioethics, with many proponents arguing against it and some assuming a soft middle ground between theoretical approaches and some level of advocacy. However, the approach taken by ethicists in Latin America has been one that rests completely on the need to be politically active by advocating and involving themselves in the political realm. There is no such thing as a neutral, scholarly stance under Intervention Bioethics. Instead, the protection of the vulnerable and the solution to persisting problems in our society calls for change that practitioners of Intervention Bioethics are actively trying to implement. In line with Intervention Bioethics, I argue that, with an increase in laws that threaten the rights of patients, we cannot take the neutral approach to ethics for which Western bioethicists advocate. Instead, we have a moral obligation to politically and actively work towards the protection of vulnerable groups.

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28 As mentioned before, there is a full section dedicated to this discourse in Chapter 3.
CHAPTER THREE
FEMINIST CONTRIBUTIONS:
INTERSECTIONALITY AND THE THREE AMENDMENTS

In the previous chapters, I have signaled the deficiencies of *la bioética estadounidense* and I have attempted to provide an alternative for its shortcomings through Intervention Bioethics and the ethic of liberation. However, my aim is not simply to decolonize and liberate bioethics from its inherent whiteness, but from its failure to consider intersectional and marginalized identities. In the case of clinical bioethics, the invisibilization of intersectional identities leads to further harm towards patients, who are already a vulnerable population. If our goal is to diminish these injustices and the harm experienced by patients, then we must be able to account for their differing needs. A successful approach to bioethics must be able to understand and include the different necessities that arise from intersectional identities. As I will argue later in the chapter, the intersectionality of identities which are typically oppressed leaves certain individuals open to further harm and to be neglected in the creation of policies and frameworks which were intended to help them. Therefore, the discourse presented here should be seen as taking a step toward correcting this error and thinking about the inclusion of these marginalized identities.

This chapter will focus on the feminist principle of intersectional identities and its relevance to clinical bioethics. Given the failure of mainstream approaches under *la bioética estadounidense* to include intersectional identities, my next step is to consider the feminist critiques and considerations provided in the literature and see if they can provide us with a
solution. I will start by explaining the feminist conception of intersectional identities, given that any account I develop in the next chapter requires an intersectional approach. A study of the literature on intersectional identities in bioethics will lead me to argue that any account of intersectionality in bioethics will have to include three particular approaches, which I will refer to as the three amendments. I will argue that a successful intersectional account in bioethics will 1) hold a relational account of autonomy, 2) incorporate narrativity in the clinic, and 3) practice advocacy/activism to some degree. Moreover, I will apply the three amendments to Ana's case in order to compare the analysis provided by the combination of these feminist approaches to that of principlism and Intervention Bioethics.

I will argue that the feminist-proposed amendments to bioethics should provide us with insight into how to improve the field. However, the approaches I will utilize, care ethics and narrative ethics, while superior to a principlist account, have been accused by critics of being too narrow and ambiguous. Thus, I will argue that by combining a feminist approach with a philosophy of liberation, we can develop a more complete and inclusive framework that recognizes intersectional identities.

3.1 Intersectional Identities

To understand the importance of intersectional identities to bioethics it is crucial to understand what intersectionality entails. The term “intersectional identity” was initially developed by Kimberlé Crenshaw (1989), yet since its introduction, it has been further

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1 I will be referring to these three principles as the three amendments, given their goal to alter what has been already proposed. Feminists throughout the literature have already offered their own accounts of intersectional bioethics. However, they fall short in many ways, given their usual focus on a specific problem. So, what I propose here are amendments to the distinct frameworks offered. By implementing these three amendments to the literature and combining it with Intervention Bioethics, we should be able to approach intersectionality more easily.
developed and supported by many scholars (Arvan, 2023; Anglim, 2023; Varden, 2023; Bernstein, 2020). Different writings on the subject present the phenomenon concerning an individual's combination of different oppressed identities. Crenshaw (1989) argues that the overlap of these various identities creates a new one, different from each identity taken singly, e.g., race and gender. This “new” intersectional identity opens the door to different privileges and/or discriminations (Crenshaw, 1989). For example, an African American woman will be subjected to additional axes of oppression than an African American man. Her intersectional identity as both a woman and African American exposes her to different discriminations than those experienced by a man of the same race.

Crenshaw’s account rests on the claim that there is a harmful tendency to treat the experiences of race and gender as exclusive and independent from one another (Crenshaw, 1989, p. 139). The ills of race and sex discrimination are often only addressed (if at all) when experienced by individuals with some type of privilege, be it class, sex, or race. For example, sexist behaviors and discrimination are often only acknowledged when pointed out by white women, and the injustices of racism when expressed by men of color (Crenshaw, 1989, p. 140). Crenshaw writes: “This focus on the most privileged group members marginalizes those who are multiply-burdened, and obscures claims that cannot be understood as resulting from discrete sources of discrimination” (1989, p. 140). This way of separating the experiences of racism and sexism narrows them to discrete identities, thus overlooking the experience of them as multiple, intersecting identities that are more than the sum of their parts.

Instead, Crenshaw argues that the marginalization felt by an individual who is multiply oppressed creates a new type of plight which differs from those who experience discrimination
on a single axis. Crenshaw claims an individual cannot be reduced to the sum of her parts given that Black women's experiences of racism and sexism cannot be separated from one another. Additionally, intersectional identities are not reducible: for example, including Black women under white women's experiences of sexism, would fail to capture the complexity of Black women's experiences of discrimination as female and Black. As Crenshaw argues, the intersectional experience is greater than the sum of racism and sexism (1989, p. 140). In her article, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, she presents various examples of the harm caused by understanding racism and sexism as discrete forms of discrimination. Crenshaw presents the case of *DeGraffenreid v General Motors* to make her point.

In 1976, five Black women tried to file a lawsuit against General Motors, arguing that the employer’s seniority system perpetuated discrimination against them. The suit argued that General Motors didn’t hire Black women prior to 1964, all of whom lost their jobs in 1970 after a seniority-based layoff (Crenshaw, 1989, p. 141). The plaintiffs claimed that the company had a history of bias and discrimination against Black women. Prior to 1964, the company would hire white women and Black men, but never Black women. As a result, when it came time to lay off workers, the Black women were laid off first, as they had been hired long after everyone else and thus had the least seniority. The case was rejected by the courts on the premise that Black women were not a special group in need of protection. The plaintiffs would have needed to prove that there was either race discrimination or sex discrimination, but the court could not countenance a combination of both (DeGraffenreid, 413 F Supp at 143). Furthermore, because General Motors
did hire white women prior to 1964, the complaint brought by the Black female employees did not apply to *all women* and was thus rejected as a case of sexism. The plaintiffs were recommended to consolidate their case with one brought against the same employer by Black men, which was being petitioned as a case of race discrimination. Yet the women refused, arguing that it would defeat the purpose of the suit, which wasn’t being petitioned merely on the discrimination they experienced as Black individuals, but as Black women. The court rejected their argument out of concern that “The prospect of the creation of new classes of protected minorities, governed only by the mathematical principles of permutation and combination, clearly raises the prospect of opening the hackneyed Pandora's box” (DeGraffenreid, 413 F Supp at 144).

In *DeGraffenreid v General Motors*, it became clear that Black women would only be protected to the degree that their plight coincided with those of white women or Black men. Crenshaw argues that this case perfectly encompasses the plights of marginalized intersectional identities (1989, pp. 141-143). The court refused to acknowledge the experiences of the plaintiffs as Black women, instead narrowing the experiences of sexism and racism to those of white women and Black men. (1989, p. 143). Through its ruling, the court ignored the root of the argument, the way that the complainants’ experiences of racism and sexism together formed the basis for their discrimination.

Moreover, it has been argued that individuals who possess multiple identities corresponding to marginalized identities (e.g., a black woman who is also poor or a Latina that is also disabled) experience *intersectional invisibility* (Purdie-Vaughns and Eibach, 2008). Given that the unification of these multiple identities leads the subject to possess an identity outside the
prototypes of certain groups, they are not even recognized inside those same groups. Women like Ana with a Hispanic heritage raised in the U.S., for example, will experience an invisibilization by groups that define women under a context of whiteness, from Hispanics that are closer to their culture and by members of U.S. culture that also will not recognize her as one of their own. This invisibilization means that these individuals will not be considered when creating policies or frameworks. Crenshaw references this through some of her examples, like the case of women who are immigrants and suffer from domestic abuse. She writes:

In the case of the marriage fraud provisions of the Immigration and Nationality Act [of 1965], the imposition of a policy specifically designed to burden one class—immigrant spouses seeking permanent resident status—exacerbated the disempowerment of those already subordinated by other structures of domination. By failing to consider the vulnerability of immigrant spouses to domestic violence, Congress positioned these women to absorb the simultaneous impact of its anti-immigration policy and their spouses’ abuse (1991, 1241).

Thus, if we invisibilize or fail to count the different vulnerabilities that arise from intersectional identities, we will be subjecting certain groups to further damage. Consequently, we cannot make the mistake of being “neutral” or grouping all aspects under a single identity, e.g., womanhood, for we will not be considering all the other things that encompass the Other. This will result in an account that may do harm to individuals, as is the case with mainstream accounts like principlism.

3.1.1. Integrating Intersectionality in the Clinic: A Literature Review

In 2019, Yolonda Wilson et al. published an article in the American Journal of Bioethics on the need for physicians to incorporate an intersectional approach to their professional interactions. It was argued that an understanding of the intersectional identities of patients could lead to more therapeutic interactions between physicians and patients. The article was immediately followed by a mountain of feedback, varying from strong support to critiques and
arguments on why we should not adopt such an approach. While the article was primarily seen as a positive step in the right direction, what was proposed was but an idea of how to move forward, a foundation in need of development. Throughout this section, I aim to explain the idea further and build upon its foundation.

Wilson et al. present a case study in which a Black female physician is caring for a Black female patient and is unable to gain her trust (2019, p. 11). The argument is that even though the patient and the physician share both race and gender, their identities still differ. The patient expresses discomfort in sharing personal matters with the physician, whom she argues would neither be able to relate to nor understand her situation, for they do not share the same social-economic group. While they share race and gender similarities, the patient feels distant from her physician, given the differences in their class status. Moreover, the patient assumes that, unlike her, the doctor has never experienced sexual violence.

The authors recommend that an intersectional approach to the case would avoid the physician becoming defensive or trying to highlight the things they do have in common to gain the trust of the patient (Wilson et al., 2019, p. 12). Instead, by taking the type of intersectional approach they are presenting, the doctor should understand the privilege she possesses and acknowledge her position of power. The authors argue that: “Rather than pretending that differences do not exist or minimizing their potential impact on the patient-clinician relationship, intersectionality acknowledges how multifaceted differences shape the patient-clinician interaction and forces a reframing that can lead to improved outcomes” (2019, p. 9). Their approach does not call for the concordance of race-gender between doctor and patient, given that it would be an overgeneralization of what is needed. Instead, by trying to understand these
differences in identity, the physician may be able to understand what things she may be overlooking and have a more effective therapeutic interaction.

The proposed need for intersectionality rests on the assumption that reviewing and understanding cases through an intersectional lens will lead healthcare professionals to confront their own biases, even those that may lead them to believe that they are similar to their patients. For example, a female physician may assume that her female patients may share her ideals and preferences and, as a result, may recommend specific approaches to their health based on those biases. The intersectional lens is supposed to complicate the picture by challenging assumptions and clarifying issues that may arise from the different identities of physician and patient (Wilson et al., 2019, p. 13).

According to these authors, an intersectional approach can enrich clinical encounters by challenging assumptions made about race in the clinic. It has been argued that, as it stands now, the use of race in the clinic is problematic. Yen Ji Julia Byeon et al. argue that the traditional use of race by researchers and healthcare professionals treats all agents of a race as having identical identities (2019, p. 20). Instead of recognizing the variety of factors that contribute to oppression and systemic racism and their effect on health, traditional approaches create recommendations as if people are homogeneous, experiencing only one axis of oppression. Many of these approaches signal internal factors like the biology of race as the culprit of health disparities, ignoring the environmental and societal effects (2019, p. 21). Thus, Byeon et al. claim that an intersectional approach can provide a better social analysis.

An intersectional approach can enrich bioethical analysis by addressing identities outside a narrow, singular understanding. Research study and design may ignore important parts of
people’s identities in the creation of spaces, research, and discourse to practice “neutrality”. This neutral stance stands as a solution to unequal treatment and biases, where neutrality represents a space where everyone is treated the same. Some examples include mental health research in which the gender of the individual isn’t considered (Howard et al., 2017) and in the design of computer software, where technology is presented as a neutral tool (Gayna, 2014). However, it has been shown time and again that this neutrality does not hold. For example, it has been argued that neutrality is a myth in technology use and design because they are created by people who themselves hold biases. Thus, these biases are ingrained in the “neutral” design of technology, which is supposed to prevent discrimination.

When considering the patient, both medicine and bioethics have perpetuated this practice of supposed neutrality. In both disciplines, we often speak of either symptoms or medical and ethical approaches as universal, yet they are in actuality centered on specific patients. In medicine, where the patient is taken to be a ‘standard patient’, the practice has been male-centered (McGregor, 2020). In her book, Sex matters: How male-centric medicine endangers women’s health and what we can do about it, Dr. Alyson J. McGregor (2020) speaks to how women are often misdiagnosed in the clinic as healthcare providers are taught to recognize symptoms as they appear in men but not in women. McGregor argues that men’s bodies are taken to be the standard in medicine:

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2 In a book chapter by Megan E. Hatch (2022), she argues on how amendments and laws by the U.S. government, which were intended to outlaw gender discrimination bringing about a gender-neutral stance, actually lead to disproportionately discriminate against women.

3 In “Race After Technology: Abolitionist Tools for the New Jim Code”, Ruha Benjamin (2019) argues that technology is created within the context of racism; thus, when misused, it can perpetuate and even further marginalized minorities and oppressed groups.
One of the biggest and most flawed assumptions in medicine is this: if it makes sense in a male body, it must make sense in a female body. In every aspect, our current medical model is based on, tailored to, and evaluated according to male models and standards. This is not an abstract statement or even an observation. It’s a fact. All our methods for evaluating, diagnosing, and treating disease for both men and women are based on previous research performed on male cells, male animals, and male bodies (2020, p.7).

Similarly, bioethicists, and even feminist bioethicists, tend to take the standard patient to be white and middle class. In If Physician-Assisted Suicide Is the Modern Woman’s Last Powerful Choice, Why Are White Women Its Leading Advocates and Main Users?, Silvia S. Canetto (2019) argues that while physician-assisted suicide has been framed as an ethical narrative concerning a dignified ‘choice’ for all patients, it has only been a choice for white patients with economic resources. As of 2018 in the United States, 96% of decedents by physician-assisted suicide were white patients (with an almost equal distribution of men and women), while white women represented the majority of advocates for the practice (Canetto, 2019, p. 40). Moreover, Canetto argues that feminist arguments on the liberating choices presented by the practice assume a middle-class, white woman. In contrast to the dominant discourse, she argues that: “choices to advocate for, and/or to die of, physician-assisted suicide, like all choices, are rooted in gendered and racialized contexts” (p. 46). White women disproportionately seek and advocate for this practice. This disproportion can be explained by the fact that white women already have access to more resources than members of other racial groups, tend to live longer, and have better experiences in the medical system, which might contribute to their involvement with a practice that requires both resources and trust (Canetto, 2019, p. 43). On the other hand, a lack of trust in the medical system coupled with the fact that Black patients have a shorter life expectancy, contributes to the rejection of the practice in Black communities (Canetto, 2019, p. 42).
Another example can be seen in *Integrating intersectionality into autonomy: Reflections on feminist bioethics and egg freezing*, where Michiel de Proost rejects the notion of “neutral stances” in egg freezing. As it stands, most of the discourse dedicated to egg freezing technologies delves into the moral problems that arise when we apply the case to middle-class, educated women (de Proost, 2021, p. 28). The central moral dilemma has been how this technology may impact women's autonomy. However, the current discourse does not deal with the autonomy of most other women who diverge from this “standard woman”, women who could not even pay or access such technology in the first place. Many of the technologies and arguments that are intended to deal with and increase women's autonomy rely on the oppression of other, more marginalized women (de Proost, 2021, p. 29). Therefore, de Proost argues that by using an intersectional approach that considers relational autonomy, we may be able to present a clearer picture of the moral problems associated with such technologies. A relational autonomy approach, instead of the autonomy championed by theories like principlism, would fit better with any attempts to develop an intersectional approach to bioethics.4

Moreover, an intersectional approach to bioethics could correct mainstream bioethics’ failure to address embodiment, thus further enriching the analysis. Claudia Barned et al. (2019) have argued that any intersectional approach should include a discourse on the embodied self. For the longest time, conversations focused on identities have centered on the individual's race or gender, which are an essential aspect of a person’s identity. However, when considering the clinic and the medical setting, other ways that our bodies are encountered (beyond being raced and gendered) also has a significant impact on oppression. Bodily differences and the categories

4 I will engage and further explain relational autonomy in the next section.
we associate with them have moral consequences, as we assign certain bodies as normative/non-normative depending on what we consider healthy and unhealthy (Barned et al., 2019, p. 28). The bodies we depict as acceptable or as normative forms of embodiment have perpetuated oppression in the clinical setting, for example, treating fat bodies as a burden to the healthcare system. Therefore, any robust intersectional approach would need to consider how bodies are treated and the prejudices that arise from our embodiment.

Critics have responded by critiquing and adding to the intersectional approach proposed by Wilson et al. One such response comes from Elizabeth Lanphier and Uchenna Anani, who argue that the methods proposed by Wilson et al. might be problematic, especially when considering their solution to the case study in the article. These authors propose that the intersectional approach should be combined with narrative ethics, since the only requirement for physicians on the intersectional approach is to recognize differences and how those differences may contribute to the physician-patient interaction (Lanphier & Anani, 2019, p. 30). They argue that the focus on differences proposed by Wilson et al. turns intersectionality into a type of skill or tool. By contrast, a narrative approach, as they propose it, is not a mere tool that may be used and later put away. It instead helps physicians develop a capacity for listening and the opportunity to be changed through the story (2019, p. 30).

One of the shortcomings Lanphier and Anani recognize in Wilson et al.’s argument is that it may hinder clinician-patient dialogue by imposing unintended assumptions or biases on

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the part of the clinician (2019, p. 30). The conclusion reached by Wilson et al. recommended that physicians recognize differences between them and the patient, and how those differences might impact their relationship. However, when we encounter people we don’t know, all we can do is assume what our differences are, instead of knowing them. Additionally, if we carry biases, those assumptions might be ‘tainted’ and lead us astray. A physician might make a biased assumption about how knowledgeable a patient is due to their broken English, and thus act upon those assumptions in a patronizing way. While it might not have been the intention of the physician to be patronizing, assumptions made without real context beyond observation can be detrimental to the relationship and harm the patient. Therefore, instead of assuming the patient's identity and adjusting due to those observations or assumptions, engaging in the narrative could tell the clinician the patient's actual story. The proposed intersectionality in Wilson et al.’s account could be used as a way for the clinician to turn the patient into an Other through unintended assumptions. By looking for differences beforehand to better serve the patient and recognize those different identities, the healthcare professional may be playing a dangerous game that may lead to the same things we are trying to avoid, i.e., turning the patient into an Other. By looking for differences even before they have gotten to know the patient, they would be creating a barrier between them and the patient. Instead, a narrative approach would lead to the clinician having the actual (or as close to accurate) story instead of assumptions (Lanphier & Anani, 2019, p. 30). Narrativity would allow for assumptions to be either eliminated or given context.

Claudia Barne, Corinne Lajoie, and Eric Racine (2019) also critique Wilson et al.’s intersectional approach for being too narrow. Their concern is that this approach centers too much on the healthcare professional and not enough on the systemic practices that are part of
physician enculturation. For example, Barned et al. criticize Wilson et al.’s presentation of the clinician-patient relationship for over-emphasizing the clinician’s responsibility to adopt this intersectional model while under-emphasizing the institutional policies that stand in the way of them doing so. For example, the time limits imposed on clinicians, who must sometimes limit their visits to a maximum of 20 minutes per patient, would complicate their attempts to engage in narrative discourse with patients or to discover the various identities that contribute to their health issues (Barned et al., 2019, p. 28). Therefore, as the authors claim, the main goal should be to introduce intersectionality clinic-wide via policies and practices rather than focusing on individual physicians.

Patrick Ryan Grzanka and Jenny Dyck Brian expand the previous argument by proposing a larger shift. In Clinical Encounters: The Social Justice Question in Intersectional Medicine, Grzanka and Brian commend Wilson et al. on their attempts to introduce such a framework. However, they also urge bioethicists to realize that intersectional bioethics needs to include social justice at its foundation (Grzanka & Brian, 2019, p. 22). Staying at the microlevel of the doctor-patient relationship does not make proper use of intersectionality. An intersectional approach to bioethics needs to reclaim justice and transform the system as a primary goal; activism needs to go hand in hand with this transformation of bioethics, given that without it, healthcare professionals will not have the institutional support to help their patients flourish (019, p. 23).

Many of the epistemic injustices encountered in the clinic are not at the micro level, but are systemic in nature. On her account on epistemic injustice, Miranda Fricker establishes the
connection between testimonial injustices and marginalized identities, and how they are systematically ingrained:

Systematic testimonial injustices, then, are produced not by prejudice simpliciter, but specifically by those prejudices that ‘track’ the subject through different dimensions of social activity—economic, educational, professional, sexual, legal, political, religious, and so on. Being subject to a tracker prejudice renders one susceptible not only to testimonial injustice but to a gamut of different injustices, and so when such a prejudice generates a testimonial injustice, that injustice is systematically connected with other kinds of actual or potential injustice (2007, 27).

The systematic nature of testimonial injustices results in further injustices. Moreover, because they encompass different dimensions of one’s identity, one can be discriminated against on multiple levels. Fricker argues that injustices rooted at a systemic level need to be addressed through social justice (2007, p. 29). Therefore, battling epistemic injustices and discrimination isn’t an individual project, but one that can be accomplished through social justice and activism at the macro-level.

Grzanka and Brian argue that this macro-level approach to intersectionality in the clinic continues to be underdeveloped. Most bioethicists that have written about it focus on ways to incorporate intersectionality within the doctor-patient relationship, reducing it to a problem of individual interactions rather than treating it as a structural problem. As they argue: “Issues such as universal health care, prison abolition, and reproductive and environmental justice are intersectional problems warranting intersectional solutions that require collaborations and coalitions among clinicians, bioethicists, and activists working outside of clinical and academic settings” (2019, p. 23).

Based on the previous discussion and the critiques that have risen in the recent literature, it seems that an intersectional approach to bioethics should include the following details: 1) it should consider a narrative approach; 2) it must take a macro approach, aiming at the
transformation of the clinic instead of simply focusing on the physician-patient relationship; and 3) its understanding of autonomy should be one of relational autonomy. There are many other critiques that should be considered as well, such as a recognition of the embodied self and the effects of race and social interactions on health. However, I believe that integrating the established three considerations, which I will be referring to as the three amendments, will be a good place to start and may organically lead to other significant changes.

3.2 Feminist Approaches to Bioethics: Integrating the Three Amendments

Given the inability of mainstream accounts to address intersectional identities and gender correctly, feminists have proposed their own approaches to bioethics. This section will briefly discuss some of the most popular approaches to feminist bioethics and how they are able to provide us with the tools for the amendments I noted above. Through an analysis of care ethics, narrative ethics, and Maria Lugones’s account of world-traveling, I will demonstrate that feminist accounts can best implement the amendments and may help us develop a successful account of bioethics that considers intersectional identities. Feminist bioethics lays a strong foundation for the amendments, given that feminist bioethicists tend to reject the universal principles that cater to a generic individual, who is typically a white male (Walker, 2008). Moreover, as I will discuss in the following sections, feminists tend to lean more toward activism and policy changes that can establish social change in the healthcare system while relying on narrative and relational autonomy frameworks.

3.2.1 Care Ethics and Relational Autonomy

One of the three amendments suggested above was to introduce a concept of relational autonomy to any framework trying to incorporate an intersectional model. The traditional model
of autonomy, where the agent is presented as a rational, independent, self-directed individual is problematic when viewed in light of intersectionality. Under an intersectional approach, individuals’ identity depends on their social environments and the relationships that drive them. A relational model of autonomy that recognizes our social embeddedness thus responds more effectively to intersectionality. In this section, I will explain the concept of relational autonomy, its relation to care ethics, and how it has been effectively introduced in the clinic.

For the longest time, autonomy has been primarily understood through the Kantian model of rational beings who can self-guide through laws created by their rationality. For Immanuel Kant, moral autonomy is the capacity to self-impose the moral law: it is our ability to give and follow the moral law through reason (Kant, 1785, 4:40, 4:447, 4:450). In his book, The Invention of Autonomy: A History of Modern Moral Philosophy, Jerome B. Schneewind (1998) traces back the history of moral philosophy and the concept of autonomy, culminating with Kant’s approach to the concept. Kant’s approach is seen as the model, as the framework of autonomy. This model abandons the role of emotions as a moral guide and asks the individual to reach those decisions on their own, rejecting external influences, for those decisions to be truly autonomous (Kant, 1785).

In bioethics, the concept of autonomy presented by principlism through Childress and Beauchamp follows the Kantian model. Under principlism, for patients to be considered}

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6 Mainstream philosophical dictionaries and encyclopedias (e.g., the Internet Encyclopedia of Philosophy, the Britannica dictionary, and the Stanford Encyclopedia of Philosophy), define the concept of autonomy under Kantian terms, as an individual’s capacity for self-determination. Some of the most philosophically inclined of those sources present competitive definitions brought by the feminist movement, as a possible critique to the established definition. However, Kant’s individualistic definition is still presented in the forefront as the standard definition for autonomy. IEP: https://iep.utm.edu/autonomy/; Britannica: https://www.britannica.com/topic/autonomy; SEP: https://plato.stanford.edu/entries/autonomy-moral/
autonomous, they must be able to reach their decisions without coercion or undue influence from others, where an autonomous plan must be a self-chosen one. As they argue:

The autonomous individual acts freely in accordance with a self-chosen plan, analogous to the way an autonomous government manages its territories and sets its policies. In contrast, a person of diminished autonomy is substantially controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans (2019, p. 77).

This model understands that external input would count as a type of manipulation of one’s emotions and would hinder the agent’s autonomy. Indeed, their account claims that external influences are as equally damaging to autonomy as the internal influence of mental illness (2019, p. 79).

As an alternative to this individualistic model of autonomy, feminist care ethicists have presented a relational account of autonomy. Care ethics is a feminist moral theory that emphasizes the role of emotions and interpersonal relations in developing a good, moral character and the protection of the Other (Tong, 1998). According to this account, it is essential to create relations with other people by cultivating virtues that lead to caring. For example, the virtues of empathy, compassion, and benevolence will be encouraged over other more individualistic or “masculine” virtues (Tong, 1998). Nel Noddings describes care ethics as a relational ethic, which focuses moral deliberation on the individuals involved and their relations to each other. The goal of care ethics is to emphasize the importance and maintenance of nurturing and caring relations with a focus on the individual and their particular situation, instead of universalizable moral judgements (1988, p. 218). Noddings writes: “The process of moral decision making that is founded on caring requires a process of concretization rather than one of abstraction” (2013, p. 8). Agents following an ethics of care will be less preoccupied with duties and principles and will instead be primarily concerned with how the decision making will affect
the care relationship at stake. Their moral focus concerns acting from a perspective of caring, what Noddings refers to as “engrossment” in the Other (1988, pp. 219-220).

Virginia Held signals five central characteristics of care ethics. The first three characteristics directly contradict some of the most popular accounts of ethics. Firstly, she argues that: “the central focus of the ethics of care is on the compelling moral salience of attending to and meeting the needs of the particular others for whom we take responsibility” (2006, p. 10). Held argues there is a moral force behind our responsibility to care for others, given that we depend on each other to survive, to progress and to flourish. Secondly, and contrary to Kantian ethics, the ethics of care values emotion rather than rejects it (2006, p. 10). While feelings might need to be kept in check when trying to ‘keep a cool head’, they can also serve as a moral force. Emotions can represent a normative tool to be cultivated, instead of something to ignore. We often think of emotions as the enemy of logic. However, emotions can represent a type of normative alert. For example, on many occasions, feelings of anger signal that an injustice has been committed and experienced and may motivate us to act. Additionally, feelings of guilt can serve as a reminder that we have acted unfairly. Thirdly, Held argues that: “care ethics rejects the view of the dominant moral theories that the more abstract the reasoning about a moral problem the better” (2006, p. 11). A preference for universality has rested on the assumption that the more abstract a theory, the more likely to avoid biases and arbitrariness, and the more easily to attain impartiality. However, care ethics calls into question universalistic and abstract rules, and whether impartiality should be a moral aim. Instead, this approach highlights particularism and is concerned with the specifics of the unique relationships in each case.
As a fourth characteristic, Held argues that care ethics reconceptualized traditional notions about the public and the private realms (2006, p. 12). The traditional view, built into the dominant moral theories, is that the household is a private sphere beyond politics into which the government should not intrude. However, this notion of the “private realm” has been proven to disproportionately affect women, children, and the elderly, rendering them vulnerable to domestic abuse. Care ethics acknowledges that there is unequal power amongst people, and we are sometimes in caring relationships that we did not choose (e.g., we do not choose our parents). Therefore, the protections of the public should expand to the private, and the caring done in the privacy of families should expand to the public (Tronto, 1993; Kittay, 1999; Brugere, 2019).

Lastly, the fifth characteristic mentioned by Held concerns care ethics’ understanding of personhood. This moral perspective works with a conception of persons as relational, rather than with the self-sufficient, independent individual at the heart of dominant moral theories (2006, p. 13).

Critics of care ethics have argued that the theory abandons autonomy for other values like beneficence. However, care ethicists respond to these critiques by arguing that care ethics has not abandoned autonomy, but rather has redefined it. Care ethicists invite us to rethink the human condition. Anette Baier, for example, argues for a restructuring of the concept of persons where personhood is understood as “second persons”. She argues: “Persons are essentially successors, heirs to other persons who formed and cared for them, and their personality is revealed both in their relations to others and in their response to their own recognized genesis” (1985, p. 85). Our identity as persons depends on our interactions with others who care for us and towards whom we may have responsibilities. For Baier, we are relational beings who acquire our sense of
personhood through our history, community, and the place we occupy in history and society (1985, p. 90).

Care ethicists present a critique of Kantian autonomy as too focused on the idea of a self who is free and independent, as a self who is disembedded and disembodied. Instead, care ethicists have argued for the self as relational, as both understanding or conceiving of herself and the world in terms of her relationships and autonomy as the product of social training and social/historical contexts (Verkerk, 2001). Therefore, care ethics does not abandon autonomy and the idea of the self but instead gives autonomy a new place and interpretation. In this view, the “self” does not develop despite the input of others, but because of it.

Relational autonomy derives from critiques brought against care ethics and refinement of the theory following these criticisms (Keller, 1997). One of the main critiques against care ethics is that it puts women's autonomy in jeopardy by focusing too much on care and not enough on justice. It has been argued that overindulgence in care makes women and girls excessively dependent on the approbation of others and causes them to over-identify with the goals of other people, neglecting their own as a result. Critics claim that care leads to a loss of women's identity and autonomy and reinforces women's traditional roles as caregivers.

By contrast, care ethicists critique traditional conceptions of autonomy as empty and unrealizable. Mainstream approaches to autonomy present individuals as existing in a void, where they can reach decisions and create their identities without others. However, this does not

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7 Victoria Davion (1993) criticizes the theory arguing that its relational approach to care and its intertwined nature with others makes care ethics a dangerous approach that may lead women to abandon their own projects and goals to follow those of others. Bill Puka (1991) also offers some insightful critiques of Carol Gilligan’s care theory. Amongst some of the critiques he considers is that of the ‘slave morality’ argument.
fit with people’s lived experiences: we are beings who are embedded in our environments, our social situations, and our relationship with others. As Baier argues, from the moment we are born, we depend on the care of others to exist and to develop our sense of personhood, for “persons are the creation of persons” (1985, p. 86). Therefore, this concept of autonomy as individualistic is criticized as unrealizable. Moreover, care ethicists also question the Western tradition according to which autonomy is the pinnacle of human achievement. This is why relational autonomy is incorporated into care ethics, to offer a conception of the self that fits with an understanding of the individual as socially derived.

Diana Meyers argues for a feminist conception of autonomy proposing we think of autonomy as a competency (a coordinated skill that enables us to perform a specific task); as having the skills needed to guide one’s own life (1987, p. 627). On her account, autonomy is something we accomplish, not something given or that happens to an individual (p. 626). Amongst the necessary skills, Meyers refers to one’s ability for introspection, to use one's imagination, and to reason. She argues:

Roughly, this sort of autonomy requires that people vividly envisage different life plans and seriously entertain them. Attuned to the feelings evinced by their alternatives, they must interpret these feelings correctly, and evaluate them critically. In light of relevant factual information, they must assess the practicality of these options. Likewise, they must judge the merits of sundry proposals in terms of their other values. Moreover, autonomous people must recognize and act on signs of discontent with previous decisions. They must be prepared to acknowledge inner change and must be willing to modify their plans in response to such change (1987, p. 627).

Autonomous thinking would require us to imagine different scenarios, examine them and consider how they make us feel. To be autonomous is to critically engage with one’s feelings and to analyze them in virtue of what we value. Changing one’s mind in virtue of new information or due to further analysis of one’s emotions and values goes hand in hand with autonomy. Cases
where a patient changes her mind about accepting cancer treatment after her family begs her to reconsider, wouldn’t necessarily be classified as unwarranted coercion if the patient changed her decision because what she values above all else is familial harmony. Imagining a scenario where her family suffers due to her decision may be worse than to not follow her initial choice.

This process of considering autonomy invites us to evaluate one’s conduct (instead of the Kantian self-ruling) by thinking if we can take responsibility for this action while retaining self-respect. Self-respect and autonomy are reciprocal and mutually reinforcing under this account of autonomy. In the case of care, caregivers could decide what kind of caregiving they are willing to take responsibility for while still allowing them to retain their integrity and self-respect.

The proposed understanding of autonomy as a competency is made possible by our social relations, given that those skills are learned through interactions with others. This means that individuals who aren’t taught these skills will be at a disadvantage. For example, ingrained discrimination in society through socialized gender roles can lead women to exercise a minimized degree of autonomy (Meyers, 1987, pp. 627-628). Given that the necessary skills for autonomy rely on critical thinking and capabilities that we learn and expand on through practice, and even education, women (and agents with a lack of access to resources and opportunities) can be stunted in their development of autonomy. The goal is thus to help individuals realize the maximal autonomy possible for them given their situations.

Laura Davy argues that, under this account, the social condition underlies and supports our autonomy competency. The agent is relational in the way she conceives of herself, not only in the socially constituted sense but also in terms of the relationships in which she is involved. We learn those skills through others, and we make decisions based on the effects they would
have on us and the world around us. We cannot take others and our environment away from any moral or rational calculation because we only understand ourselves in a social context. The agency and autonomy of individual persons can only emerge relationally through the support of others (Davy, 2019, p. 102).

Davy argues that the Kantian version of autonomy is a myth: the individual who has been presented as the model of independence (usually a young male professional with no care responsibilities) can only be presented in this way when we render invisible the care and relationships that have supported him (2019, p. 105). It is their relations to others that provide those ‘independent’ people with the needed support to become such a beacon of ‘independence.’

The reason most of us can succeed on a daily basis is that there are other people offering us a helping hand, e.g., parents or family members willing to babysit our children so we may go back to school, a partner back at home taking care of the house so that we may work, a friend who calls once in a while to make sure we still have a social life. There is an interplay between care and the relational model. We need other people to teach us and to help us develop the necessary skills to be autonomous, and we later depend on others so we may exercise these skills and make our way in the world.

In the context of the clinic, it has been shown that the individualistic model of autonomy fails to align with patients' preferences at the end of life. In a case study where a patient requests euthanasia, changes his mind after speaking with his priest, and later changes his mind again after a fight with his sister, Carlos Gómez-Vírseda et al. identify four shortcomings in the usual interpretation of autonomy in the clinic. They argue that, firstly, autonomy entails more than possessing cognitive capacity (2020, p. 3). Patients describe a feeling of being split where
rational arguments are not always aligned with other forces. While rational arguments seem helpful, they are described as insufficient by patients when trying to reach autonomous decisions.

Secondly, autonomy is not exercised by patients existing in a social and cultural void (Gómez-Vírseda et al., 2020, p. 4). By neglecting the relational dimensions of autonomy, we place an unreasonable burden on patients and lead them to be isolated from their social environments in a moment in time when they would benefit from others. Studies in oncology suggest that during end-of-life care, patients prefer to share the burden of decision-making with their families and doctors (Paillaud et al., 2017; Elkin et al., 2007). Moreover, additional studies have shown that cultural contexts influence decision-making in end-of-life care, with members of certain ethnicities being less concerned with autonomous decisions and more concerned with familial harmony (Puurveen et al., 2018; Drought & Koenig, 2002; Kagawa-Singer & Blackhall, 2001; Blackhall et al., 1995).

Thirdly, autonomy is not a binary “all or nothing” notion (Gómez-Vírseda et al., 2020, p. 5). Mainstream discourse on autonomy seems to imply that one is either a fully autonomous being or non-autonomous. However, this is not the experience of healthcare professionals who observe autonomous behavior in their patients in terms of degrees. Minors, for example, are still developing their skills for autonomous thinking such that they present varying degrees of autonomy competency. The same could be said of patients with borderline dementia, and different types of mental health conditions.

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8 We could see here the connection back to intersectional identities and the struggle to balance the different responsibilities and experiences that accompany the different parts of the intermingled identities. In Ana’s case, for example, the physician’s advice to institutionalize Mrs. C was presented as the rational choice. However, for Ana, who wants to consider her cultural identity and her mother’s wishes, the “rational” choice may not be the primary basis of her decision making.
Various feminist philosophers suggest that autonomy comes in degrees. Marilyn Friedman argues that the agent’s capacity for self-reflection and critical thinking skills may vary, thus affecting the degree to which one is self-determined. She writes:

Autonomy is a matter of degree. No finite being is thoroughly self-determined. Even self-reflection itself can range along a continuum. The more extensively one reflects on one’s wants and commitments, the greater is one’s autonomy with respect to them. One rich sort of reflection consists in attending to the socialization and other causes lying behind the formation of one’s current wants and commitments. If someone goes on to reaffirm her original commitments after recognizing their socialized origin, then, as John Christman argues, she achieves autonomy with respect to them (2003, p. 7).

Moreover, Diana Meyers has claimed that an agent’s autonomy can vary in degree from minimal to maximal, and from local/episodic to programmatic (1987, pp. 624-626). By local or episodic autonomy, Meyers refers to the capacity to make autonomous decisions concerning particular situations, while programmatic autonomy deals with major life issues. Certain life experiences and oppressions can lead an individual to have reduced autonomy, where she is able to make decisions concerning local matters, but not programmatic decisions. Imagine an oppressed individual in a toxic relationship, where she is restricted from making decisions concerning her financial freedom yet has the critical skills to engage in competent local decisions. Meyers would argue that such an individual has a medial degree of autonomy.

Fourth, and last, Gómez-Vírseda et al. argue that autonomy is not exercised in terms of isolated discrete decisions (2020, pp. 5-6). Patients become more assertive over time as they become more comfortable with making medical decisions. Thus, autonomy would be better represented if understood as a process instead of a series of isolated decisions. This idea contradicts what has been argued by Beauchamp and Childress, who argue:

Our focus in this chapter on decision making leads us to concentrate on autonomous choice rather than general capacities for self-governance and self-management… Some persons who are generally incapable of autonomous decision making can at times make
autonomous choices. For example, some patients in mental institutions who cannot care for themselves and have been declared legally incompetent may still be competent to make some autonomous choices, such as stating preferences for meals, refusing some medications, and making phone calls to acquaintances (2019, p. 77).

These authors focus on autonomous choices and one’s ability to act autonomously in specific cases. The problem with this approach is that it implies that autonomy is something dependent on choices, instead of the individual person. This version relies on a static view of autonomy where each individual decision is either autonomous or not. However, autonomy and decision-making seem to be more evolving in nature. Gómez-Vírseda et al. describe autonomy instead as: “a dynamic and interactive process that evolves over time” (2020, p. 5).

Additionally, the individualistic approach to autonomy has been translated in the clinic to an unfair suspicion against family members and loved ones of the patient, who may wish to intercede or make their opinions known. Family members who interject or who let the patients know when they disagree are seen as placing undue pressure on the patient and undermining their autonomy. In opposition to the idea that patients that defer to family members for decision-making are acting under pressure or that it undermines their autonomy, Anita Ho argues that family involvement and the consideration of the family’s interest can be integral to promoting the patient’s agency and relational autonomy (2008, p. 130). Ho presents the case of a patient who backtracks on a medical decision, presumably, not to upset his wife. Mr. M had initially said he did not want anything extraordinary done in cases of life-extending measures and resuscitation but changed his mind after his wife pleaded with him. The physician in charge of the case thought that the wife had crossed a line and had intervened against Mr. M’s autonomous decision. The physician further reminded the patient that the decision was ultimately his and that
he should make the decision that he wanted without feeling coerced by his family, which seemed to make the patient very uncomfortable (2008, p. 128).  

Cases like Mr. M’s are only possible due to the current hyperfocus on autonomy in Western medicine. This hyperfocus on autonomy was supposed to protect patients from physician’s paternalism. However, it has also led to suspicion and concern about the family’s involvement, especially when we understand autonomy under the Kantian model. As Ho mentions, illness is not an isolated event (2008, p. 130). The experience of illness is a stressful situation that evolves with the family and changes their dynamics. Many patients do not see themselves as individuals separate from their families or from their identity as a part of a group.

Familial care is based on empathy and beneficence, which, in many cases, contradicts the systematic and isolated type of care offered in the clinic. The clinical setting is a place where the patient's diet, checkups, consultation time, bed availability and insurance coverage, amongst many other considerations, are all out of the patient's hands. The type of care offered in the clinic can be impersonal and fragmented (Ho, 2008, p. 130). Therefore, in that type of impersonal setting, the family's involvement is crucial in preserving the patient's autonomous agency. The idea behind protecting individualistic autonomy was to empower the patient and protect their interests. However, the way it has been practiced, by taking an individualistic approach as the

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9 While it is true that familial relationships can be complicated and their input could represent a divergence of opinions in clinical matters, they should not be seen as an obstacle to the patient’s autonomy. The family of the patient can serve many goods, amongst them, the ability to hold the patient to their identity. Hilde Lindemann argues that family members can provide this specific type of care better than professional caregivers. Because families are the primary sites for identity formation, Lindemann argues that family members have a special responsibility to help the agent maintain their identity in moments where they might be losing themselves (Lindemann, 2009, p. 417). Families should not be seen as a problem to be overcome or as a danger to the patient. In most cases, they represent the people that know the patient best. Therefore, in cases of illness, where the patient might experience fear, a loss of memory or a loss of their sense of self, it is the family that can hold them to who they are.
central model of autonomy, has instead left patients feeling isolated and emotionally exhausted in a moment in time where they are already feeling vulnerable due to illness (Ho, 2008).

Implementing care ethics and relational autonomy provides solutions to problems faced in clinical practice. In many cases, relational autonomy can positively impact the clinic by leaving the ultimate decision to the person most affected yet encouraging the consideration of the person's care in connection to others (Dove et al., 2017). By providing a model where care is centralized, and autonomy is understood as embedded in our relations to others and our social environment, we open the door to intersectionality in the clinic.

3.2.2 Narrative Ethics and World Travelling

The second amendment that I argue should be included in any discussion and development of an intersectional approach to bioethics is narrative ethics. Given that intersectional identities bring with them a uniqueness, especially when considering unique types of oppression, it is essential that we consider the stories of agents. As Rita Charon writes:

Unlike the feeling ascribed to Freud that one writes about an unpleasant experience in order to rid oneself of it, we have come to realize that narrative writing in clinical settings makes audible and visible that which otherwise would pass without notice (2007, p. 1266).

Patients’ stories provide us with the opportunity to understand them better when we do not share parts of their identity, and when that identity would be invisibilized otherwise. I argue that in order to ethically engage with the narrative of agents with intersectional identities we need to approach them playfully, as argued by Maria Lugones (1987). Lugones's concept of “world-traveling” offers an interesting approach to narrativity. In what follows below I will discuss narrative ethics as a theory and its contributions to the clinic and then engage with Lugones's
conception of playfulness and world traveling, addressing the possible problems that arise from this approach.

Narrative ethics presents a shift in perspective, where instead of asking the healthcare professional first what the problem is with the patient, we ask the patient and the family to assess what they believe to be wrong (Frank, 2014, p. s16). For narrative ethics, what others understand as the “facts” of one’s life, or what some may call the lived life, are as important as imagination and the life that we imagine for ourselves. The stories, or narratives, that people tell themselves about the life they want or the life they imagine having are essential when making ethical decisions (Frank, 2014, p. s16). Our stories and the narrative that we tell about our lives form the self, so we take responsibility not only for the things we have but for the things we imagine having or wish to have.

This form of approaching ethics allows an understanding of a particular situation by a particular individual. In contrast with other types of approaches, Charon writes: “Logicoscientific knowledge attempts to illuminate the universally true by transcending the particular; narrative knowledge attempts to illuminate the universally true by revealing the particular” (2001, p. 1899). Unlike other forms of ethical approaches, narrative ethics does not intend to formulate the best universal solutions in a case, but instead, it tries to help individuals figure out the best way to act, according to their own narratives.

Narrative ethics should be understood as a hermeneutic and dialogic enterprise (Brody and Clark, 2014, p. s7). Through narrative we interpret and make sense of what we want and who we are. It is through this hermeneutical process of understanding our experiences, our commitments, and our relationships that we are faced with who we are and with our personhood.
(Lindemann, 2020, pp. 286-287). However, this interpretation and understanding is revealed to us and achieved through dialogue. Many of our stories involving our race, social standing, motherhood, etc. only make sense in relation to other people, so who we are is deeply ingrained and dependent on our interactions with others (Lindemann, 2020, p. 287). Charon further explores this in the clinical setting, where she argues that narrativity is an aspect of life enacted in relation to other people, e.g., patient and physician, for narrativity requires a teller and a listener (2001, p. 1898). As is with all cases of literature, where the reader does half of the work by assigning meaning to the words and seeking to understand the master narrative, so is the case with narrative ethics. Charon argues:

The narrative skilled reader further understands that the meaning of a text arises from the ground between the writer and the reader, and that the ‘reader’, as Henry James writes on an essay on George Eliot, ‘does quite half the labor’. With narrative competence, multiple sources of local- and possibly contradicting- authority replace master authorities; instead of being monolithic and hierarchically given, meaning is apprehended collaboratively, by the reader and the writer, the observer and the observed, the physician and the patient (2001, p. 1899).

The hearer complements the story through their interpretations and the role they play as observer.

Patient narratives have been characterized by Brody and Clark as *keeping faith* narratives and *trying on* narratives (2014, p. s7). In the former, one recognizes the narratives that have shaped the self and makes judgments based on an understanding and approval of that identity, while in the latter, one uses narrative imagination to discern possible new stories and the actions that would best fit one's core values. The normative questions approached through this framework are less about principles and more about the type of story we wish to tell. Care providers should thus ask patients about the story they are telling, if they foresee their decisions leading to an ending that they can live with or that any human ought to want. According to
Arthur W. Frank, what matters is giving people the opportunity to tell their stories and to be able to hear themselves repeatedly until they find a version of the story they believe worth living with (2014, s.19).

Each individual has what Martha Montello calls a “mattering map”, which projects what each person perceives as important. By trying to understand other people’s mattering map, we can decipher what is important for that person and what would be fitting choices for that individual, given what they consider overwhelmingly valuable (2014, p. s3). What we consider good and significant depends on previous stories we have heard or experiences we have lived through; thus, what each person considers important differs, for so do our mattering maps. In the clinic, disagreements may come from having different understandings of the good due to the different stories practitioners have encountered before and to what each considers important. Therefore, decision-making in narrative ethics is less about solving a case and more about resolving it. As argued by Montello, it is about “progressing from a dissonance to a consonance” (2014, p. s5). Providing a narrative (and attentively listening to it) is intended to lead not to consensus but to consonance. The physician or the family may not agree with how the story turns out through the decisions made, but they may be able to accept why and how they got to those decisions, thus recognizing the ending as a good or acceptable one, even if it is not the story they wanted to tell (2014, p. s6).

Narrative identity is at the foundation of narrative ethics. Understanding identity through narrativity proposes that a person's identity is formed through a coherent narrative collecting the

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10 While the idea as I am presenting it here is developed by Martha Montello (2014, p. s3-4), she takes the concept of mattering maps from Rebecca Goldstein’s *The Mind Body Problem* (1983).
experiences of the body, our thoughts, and values and giving them meaning. When engaging in narrative ethics, a dialogue between the healthcare provider and the patient can take place where physicians can gain a better perspective on patients’ lives and values and permit patients to be active participants in their care (Saulnier, 2019; Charon, 2014).

However, it has been argued that, while narrative ethics seems to be beneficial given the inherent human need to tell and have our stories heard, power dynamics in the clinic lead to disparities in whose stories are told and whose stories are heard (Saulnier, 2020). The power imbalance between patient and physician and the excess of credibility assigned to the physician and to privileged patients results in marginalized patients failing to have their stories understood or believed. If physicians are, for example, only trained to recognize specific diseases and complaints in cis white men, then they will reject or fail to use their listening skills correctly when trying to make sense of stories that deviate from that “standard” (Saulnier, 2020).

K.M. Saulnier describes two specific types of harm experienced by individuals whose stories are either untold, unheard, or not believed. Firstly, they experience what some have called the diagnostic odyssey (2020, p. 299). This odyssey refers to the years of anguish and frustrations followed by patients with rare diseases who cannot uncover what is happening with their bodies. Secondly, there is the epistemic harm, as explained by Miranda Fricker (2007) in Epistemic Injustice: Power and the Ethics of Knowing, of having one's narrative discounted.

11 For a deeper discourse on the effects of narrativity on personhood see Hilde Lindemann’s discussion in Holding and Letting Go: The Social Practice of Personal Identities. Oxford University Press. 2014.

12 Havi Carel and Ian Kidd (2014) write on the epistemic privilege of healthcare professionals (which is sometimes warranted and, in some cases, unwarranted). Their argument is that, apart from the power imbalance that comes from disproportionate knowledge and training, physicians get to decide whose stories they listen to and which testimonies they believe.
Fricker argues that to have one’s narrative discounted is an intrinsic harm that may prevent individuals from becoming who they are for it leads them to doubt their own capabilities, restricts their future actions, and does not provide them with the necessary tools to understand their situation. Saulnier provides the example of autistic women's journey in the clinic, where they are often misdiagnosed because their stories are not understood given that almost all research on autistic individuals has used men and boys as the subjects of study (2020, p. 300). This lack of research and knowledge prevents girls and women from being diagnosed with autism early enough to understand their situation and to act upon it, a problem not similarly experienced by autistic boys and men.

Something similar is experienced by individuals considered obese, whose stories and narratives are usually unheard. Fatness has been thoroughly pathologized, and consequently, physicians have a hard time seeing beyond the patient's weight when diagnosing and searching for health problems (Saulnier, 2020, p. 302). Many women have told their stories of being misdiagnosed by their doctors simply because of their weight and the repercussions of such misdiagnosis. Some of these stories include women with chronic illnesses who, before being correctly diagnosed, repeatedly visited their doctors to express their pain and whose stories were dismissed by healthcare professionals, claiming that their pain was due solely to their weight (Anderson, 2012). These are women who tried to share their story and their experience in order to seek help, yet healthcare professionals continued to reduce their story to their weight. Moreover, by dismissing their stories, these healthcare professionals have prolonged the stigma around women’s weight and contributed to patients’ stress and experiences of discrimination (Puhl & Brownell, 2006).
There are many other stories where patients in the clinic are simply not believed, as is the case with women in general. Clinical differences in the treatment of men and women have been shown to persist: studies show that fewer women receive electrocardiograms and cardiac monitoring when visiting the hospital for chest pain in comparison to male patients (Pelletier et al., 2014). Moreover, male patients have been shown to receive more narcotic analgesics after appendectomies, and more referrals from general doctors to specialty pain clinics (Hoffmann & Tarzian, 2002; Lehmann et al., 1996; Weir et al., 1996).

Narrative ethics opens the door to a different type of ethical approach, where the narrative of the patient is considered in relation to that of other members of the story. The goal is to help the patient develop their story in a way that works for them and that helps them maintain their narrative self. However, in order to achieve this, patients need to be able to tell their stories, to be heard, and to be understood. This can only be accomplished if healthcare professionals engage with patients’ stories and are open to listening, or to what Lugones refers to as becoming “world travelers.” I argue that healthcare professionals who wish to fully engage with narrative ethics in the clinic need to be able to do what Lugones refers to as playful world traveling and visit the world that patients and family members inhabit.

Lugones argues that people can inhabit multiple worlds simultaneously (1987, p. 10). By “worlds”, Lugones means something that must be inhabited, both by flesh and blood and in some cases even imaginary or dead people. A world in this sense can be an actual society or a

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13 Worlds, as presented by Lugones, can be inhabited by imaginary individuals and the dead to the point that worlds can be incomplete and can be filled with imaginary constructions of others. Let’s elaborate through examples. Suppose I am an avid Dungeons and Dragons player. Every week my group and I meet and travel to the world of Eberron, where my shape changing paladin accompanies my cousin’s artificer and my friend’s barbarian into different adventures. When we talk about our adventures afterward, we talk about our characters as if they were real people, for they are a part of our world at that moment in
construction of a society, or even a construction of a tiny portion of a particular society. A world may contain things in it that are not in that world what they are in other worlds (1987, p. 10). The way that Peter Singer inhabits my world, as someone who I have never met but of whom I often talk about, is not the same way in which he inhabits the world of someone who personally knows him. Moreover, one can inhabit more than one world at the same time and travel amongst them.

Members of minority groups in the United States are world travelers out of necessity and survival. We are usually part of a world that constructs us as a stereotype (e.g., we Puerto Ricans are usually seen as “loud people who can dance”). Yet, we are also part of other worlds in which we can express ourselves to the fullest, where we can be loud and dance without it being seen as stereotypical.

What Lugones means by “traveling” is the ability to shift from being one person in one “world” to being a different person in a different “world”. In a specific world, we may even have traits and abilities that we do not possess in other worlds. By this, Lugones means that we maintain that experience of acting and being different depending on the world in which we may find ourselves. It is not that one acts like a different person; instead, one is someone who uses language or acts in a particularly different way. Lugones provides a personal example on the matter, claiming that in some worlds she is playful and funny, while in others she is described as serious (1987, p. 14). She wonders how she could be both serious and playful at the same time; as a response, she suggests that the reason she is able to be playful in one world and not in time. They inhabit the world with us and even have wants and needs that we wish for them to fulfill. The same could be said of the characters of a book when we engage in discourse about them at book club. Moreover, when we meet real people and inhabit a world with them, and later leave for a different world where they do not inhabit, we can make reference to them, bringing their imaginaries to this world. We do the same with dead people. When we reference the dead or live in a world that was shaped by them and their memories, they also inhabit them, even if they are no longer in the world of the living.
another is that she does not feel equally at ease in each world (1987, p. 14). She can be both serious and playful, because she can be different people when inhabiting different worlds. Lugones concludes that we are a plurality of selves, for we are different people depending on the world we inhabit at the moment, depending on how at ease we are in a specific world. In worlds where we are at ease, we may be playful and funny, while in worlds where we are uncomfortable, we may need to be more serious and guarded.

Lugones argues that traveling to other worlds enables us to be. We are not intelligible on our own, for we lose the possibility of being understood without others. We are dependent on others for this possibility of being seen and heard. Therefore, we need others to travel to our world. Nevertheless, how we enter another's world matters. Lugones claims that in order to travel to other worlds normatively, we must do it playfully (1987, p. 16). The literature usually presents play and playfulness as a game of rules about who will win and who will lose, where competence is presented as the supreme value. To win a game we ought to be combative. We ought to know the rules, to know how to exploit them, and be willing to see the other players as competition. However, this attitude of play when world traveling translates to an imperialist mentality. Agonistic travelers fail to successfully world travel. If the embodied attitude is that of winning, then agonistic travelers do not travel in order to visit the world. Instead, agonistic travelers wish to conquer other worlds, to change them in their image, and make them their own. (1987, p. 16). This idea of agonistic play is not a healthy, loving attitude to have when trying to travel across worlds. In fact, one cannot travel to a world with this attitude. Instead, Lugones claims that, when we travel agonistically, we cannot truly see and visit those other worlds, we can only kill them.
The playfulness Lugones mentions is instead an “attitude that carries us through the activity, a playful attitude, turns the activity into play” (1987, p. 16). It is an intentional activity with no rules, which includes uncertainty, and openness to surprise. Playfulness includes openness to being a fool and not worrying about competence, to being open to self-construction, to not being self-important. It is being able to self-reflect in a different world and inhabit that self fully in order to understand it better. According to Lugones, traveling to another’s world lets us identify with them because then we can: “understand what it is to be them and what it is to be ourselves in their eyes. Only when we have traveled to each other’s worlds are we fully subjects to each other” (1987, p. 17).

It would seem, then, that inviting other people to our world, to a world where we are at ease, may permit them to understand us better. There has been a call in recent years from African Americans inviting white people into their world, into Black academic spaces. As Shannon Sullivan (2004) notes, extending this invitation has been a call for white people to fight white privilege by learning and dismantling what has been considered the established power and formal methods of speech (p. 300). George Yancy (2004) argues that the racism that surrounds many academic spaces tries to eliminate African American Language by assimilating the Standard Language (that used by most white Americans) as the only acceptable language in formal and academic settings. Therefore, he argues that including white people in spaces where the Black languages predominate may help them see it as normal and to fight white privilege (p. 274).

As argued by Maria Lugones, solidarity across cultural/racial differences requires genuine dialogue. However, for this dialogue to be genuine, more than one voice needs to be
included, and they need to be able to understand the other’s way of communicating. As Sullivan argues, if the dialogue only occurs in one of those languages (the standard which has been implemented by white people), then it reinforces a cultural imperialism and the erasure of a culture’s method of communication, of being heard (Sullivan, 2004, p. 301). World-traveling offers a possible solution to the attempt to erase the experiences of Black and other marginalized communities.

However, the problem with inviting white individuals to enter other worlds through language (learning Spanish, for example), is the destruction of safe spaces for minorities. Sullivan speaks of a philosopher friend of hers who, as a Latina, often has to travel to white/Anglo-dominated conferences. Her friend worries that having white people speak Spanish would intrude on the safe world to which she can escape with other Spanish-speaking individuals in the midst of these white spaces (2004, p. 302). There is a desire to preserve these small spaces where minorities may be free of white people and the issues of race and racism that their presence inevitably produces. Historically, the resistance of ‘Negro spirituals’ was only possible because white people did not understand the dialect of Black people (Sullivan, 2004, p. 302). Black academics have been able to show that white people do not have a monopoly on ontological creation by having their own language and dialect in a world where one aspect of white privilege has been what Sullivan refers to as “ontological expansiveness” (2004, pp. 302-303). For white/Anglo people, accepting the invitation to travel to non-white worlds needs to be taken seriously and done carefully. Sullivan argues that in order to accept the invitation, we need to be: “knowledgeable of the racist harm they can inflict with their acceptance, responsible for
that damage and to those in Black worlds who are harmed, and finally knowledgeable of when such an invitation should be responsibly declined” (2004, p. 304).

The same can be said of any type of world traveling by individuals who belong to dominant and historically oppressive groups to the worlds of historically oppressed individuals or to those with a number of marginalized identities. Traveling to their world seems to be necessary to understand others and for them to be heard. Similarly, I argue that we should understand the telling of one’s story as an invitation into their world. To be a good listener to another’s narrative is to accept this invitation responsibly and to travel to that world playfully. Just like a good book or a movie can help transport us to a different world, so can the narrative of others. Storytelling is one of the greatest tools of imaginative “play” that human beings can share. It is powerful in its ability to evoke emotions that make the listeners cry and laugh. As a form of storytelling, narrative ethics offers us the means to practice such playful world traveling.

Healthcare professionals can address patients’ experiences of marginalization and oppression in the medical clinic by becoming playful world-travelers. Doing so requires them to listen carefully without any sense of ego or competitiveness. Physicians who successfully practice this playful activity do not fear relating to their patients or accepting the mistakes they may make as clinicians. Playful traveling requires that healthcare professionals become active listeners who can visit their patients’ worlds, engaging with them, and inhabiting their space without wanting to change or usurp it. By contrast, healthcare professionals engage in agonistic world travel when they dismiss their patients’ worries and fears or reduce them to illnesses and bodies to treat. While often unintentional, the practice of the clinical patient interview tends to focus solely on their illness or medical complaint without putting it into the context of their full
story. This is reductive of patients and their medical needs, and can result in patients feeling marginalized, ignored, or discredited. Thus, the second amendment as I have articulated it reflects the need to engage in narrative in order to travel to the world of patients with intersectional identities, whose worlds the physician may not otherwise know. Normative narrativity makes clinicians responsible for soliciting and encouraging patients’ stories and acceptance of those narratives by the healthcare professional, who (as Lugones phrases it) must travel to their world playfully.

3.2.3 Social Justice, Activism and Feminist Philosophy

The third and last amendment I will consider in this section is the introduction of activism and advocacy to any serious intersectional theory in bioethics. It was previously argued that any theory in bioethics that introduces the concept of intersectionality must include some activist elements, for the oppression of intersectional identities calls for action beyond a theoretical understanding. Activism has been understood as something separate from bioethics, an activity that bioethicists may wish to seek out in their free time. However, recent debates have argued that advocacy and activism may, to some degree, be an essential part of bioethics (Fabi & Goldberg, 2022; Rogers & Scully 2021; Scully, 2019; Rogers, 2018; Ashby & Morell, 2018; Draper, 2018; Gordijn & ten Have, 2015). In what follows, I will consider arguments in favor of and against activism as an embedded responsibility of bioethicists and how it ought to be understood within an intersectional framework.

Until recently bioethicists have been urged to remain apolitical, both in their clinical practice and their scholarship. Any attempt to combine bioethics and activism has been seen as problematic. For example, understanding activism as part of bioethics introduces potential
conflicts for bioethicists, given that without established boundaries, it may lead to the field risking its authority with governments and members of academic societies (Ashby & Morell, 2018, p. 479). David Benatar (2006) claims that mixing activism with the scholarly work of bioethics will negatively impact academic scholarship, for it might instrumentalize it and lead to a neglect of more sophisticated, theoretical considerations. The usual dispassionate stance of bioethics is what has given the field a certain air of detached authority (Ashby & Morell, 2018, p. 479). The worry is that if political neutrality is not practiced, bioethicists may risk alienating those in the field who do not share the same political beliefs; and it may lead to the field of bioethics as a partisan practice.

Furthermore, Malcom Parker argues that holding a normative principle in no way implies one must take direct action. In his view, to be a bioethicist studying a topic does not mean that

\[\text{\footnotesize 14}\text{ Many of the articles discussed were written as a response to David Benatar’s article where he cautions bioethicists against engaging in activism.}\]

\[\text{\footnotesize 15}\text{ The controversy surrounding activism and scholarly work can be seen in areas beyond bioethics. Feminists in general have had to deal with similar claims, where they are told they must choose between activism or theory. Many feminists have argued against the claim and have written on ways that they can incorporate both. For feminists who support the view that feminist theory and activism are linked, see Bell, Emma; Merilainen, Susan; Taylor, Scott; and Janne Tienari. “Time’s up! Feminist theory and activism meets organization studies.” Human Relations, 2018, 1-19; Ackerly, Brooke and Jacqui True. “Back to the future: Feminist theory, activism, and doing feminist research in an age of globalization.” Women’s Studies International Forum, 2010, 33(5): 464-472; Taylor, Verta. “Feminist Methodology in Social Movements Research.” Qualitative Sociology, 1998, 21: 357-379; Gottfried, Heidi. Feminism and social change: bridging theory and practice. University of Illinois Press. 1996.}\]

\[\text{\footnotesize 16}\text{ In an article concerning the turning of Roe v. Wade, Wesley J. Smith (2022) argued that bioethics as a field has become a “homogenous and insular movement that seeks to institutionalize progressive ideology as the reigning paradigm of healthcare public policy” (p. 39). He argues that the field ought to serve the entire society. However, mainstream bioethics has become left-leaning. Therefore, if we were to apply his concern to the claim of understanding activism/advocacy as a crucial part of bioethics, it would mean for the field to officially take a stance that does not reflect the views of the ‘entire society’, nor of the entire field, as it might marginalize some religious and pro-life bioethicists.}\]
one should go beyond an objective study of it; nor does believing a normative claim mean that one must act on it, especially where one’s employer may require a neutral stance (2019, pp. 148-149). Moreover, it does not follow from any organizational structure that they must, as a requirement or duty, facilitate debates surrounding contentious topics. According to Parker if individuals wish to act on partisan debates in their free time and stand with marginalized communities, that is their prerogative. However, this does not mean that bioethics associations or the bioethics community at large must argue or advocate for particular issues (Parker, 2019, p. 150).\footnote{One of these particular issues that has led to a debate on the need for advocacy in bioethics is the petitioning for the rights of undocumented patients and medical students with Deferred Action for Childhood Arrivals (DACA). Some of the following articles demonstrate the engagement that has arisen from the bioethics community to advocate for these particular patients: Kuczewski, Mark; Lantos, John; and Zarna Patel. “Advocating for the DREAM Act: Why Pediatricians should care and what they can do.” Pediatrics Perspectives, 2018, 141(1): 1-3; Sorrell, J.M. "Ethics of Advocacy for Undocumented Patients." OJIN: The Online Journal of Issues in Nursing, 2017, 22(3); Kuczewski, Mark. “The Really New Jim Crow: Why Bioethicists Must Ally with Undocumented Patients.” AJOB, 2016, 16(4): 21-23; Berlinger, Nancy and Rajeev Raghavan. “The Ethics of Advocacy for Undocumented Patients.” Hastings Center Report, 2013, (43)1: 14–17.}

In 2018, Dawson et al. began to question this neutrality norm, arguing that bioethics cannot and should not be neutral in the face of issues like human rights abuses. They call for bioethics associations to abandon the myth of neutrality when confronted with cases where sustained harm is inflicted on vulnerable populations (2018, p. 483). They agree that established associations should remain neutral in contentious cases where people seem to disagree, e.g., abortion and euthanasia; however, in cases of human rights abuses or harms being inflicted on vulnerable populations, they argue that remaining silent means abandoning our normative duties as bioethicists. Dawson et al. propose that bioethicists should instead take an “academic activist”
approach, where our research is understood as powerful knowledge with the capacity to implement change (2018, p. 485).

The usual argument against activism in the field, i.e., the so-called “myth of neutrality”, seems to ignore the normative nature of bioethics, where we are always advocating for a particular position and potentially affecting the world outside of academia. On this view of bioethics as prescriptive, bioethics should be understood as an inherently activist discipline. Bioethicists engage with practical issues and should have a *prima facie* willingness to engage with activism at least to the point of defending their views in public (Rogers, 2018, p. 883). While most of the literature has tried to stay out of making a formal activist “call-to-arms,” Wendy A. Rogers and Jackie Leach Scully argue that there needs to be a more open conversation about activism’s inherent role in the discipline, given that some issues may be so egregious that there may be a moral obligation to stand against them (2021, p. 33). Rogers & Scully argue that, it is sometimes necessary for bioethicists to stand up and speak out, even when there will be no immediate change or effect, for “something that is morally wrong remains so even if it is a lost cause” (p. 33).

Moreover, Bert Gordijn and Henk ten Have argue that most of the arguments presented against activism in the field rely on a defense of scholarly work as separate from activist work. A narrative has taken place where activism and academic work are seen as incompatible. This narrative, however, has been disproven in practice. Some of the most successful stories on the implementation of a right to health have come about because of collaboration and a combination

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18 Lance Wahlert and Autumn Feister (2014; 2012) have made similar claims about the role of bioethics and the need to advocate for queer bioethics. They call bioethicists to expand what has been until now a narrow approach and to expand their resources to advocate for patients who have been dismissed and discriminated against due to their sexuality and gender identity.
of academic research, social movements, and civil society (Gordjin and ten Have 2015, p. 294). The right to abortion has been protected by activist health professionals through social and academic engagement, even in places where it is still illegal (McReynolds-Perez, 2017). And sisters/colleagues Celia and Jenny Kitzinger at Cardiff University use their research to inform and underwrite their activist engagement in petitioning for the rights of families of comatose and brain-damaged patients.19

While both activities have their own concerns, they should not be understood as incompatible. Activism and scholarly work overlap at many points. Wendy Rogers argues that academic scholarship should be seen as a necessary skill of activism, where the individual should not let any biases compromise their activism (2018, p. 886). Academic skills of doing research, like providing arguments and organizing materials, are not only applicable to activism but are indeed essential and helpful. Moreover, Rogers argues that it would also be a mistake to claim that a commitment to a case leads to bias, just as it would be wrong to argue that a lack of an overt commitment, as practiced in academic work, means that an argument is free from bias (p. 887).

In line with Intervention Bioethics, Rogers argues against the claim that bioethics needs to be apolitical in order to be valuable, for this presents a false dichotomy. If politics has to do with the distribution of power and resources throughout society, then it is difficult to identify any issue in bioethics that is not political (2018, p. 888). Bioethics inevitably presents discussions

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19 After losing their sister to brain-damage, Celia and Jenny Kitzinger focused their research on ways to help families in similar situations. This link leads to some of the resources they have made available to the public: [https://healthtalk.org/family-experiences-vegetative-and-minimally-conscious-states/overview](https://healthtalk.org/family-experiences-vegetative-and-minimally-conscious-states/overview). Moreover, they created and directed the “Coma and Disorders of Consciousness Research Centre”, where in conjunction with academics and practitioners from different fields, they offer support to families and campaign for changes in policy and practice. [https://cdoc.org.uk/](https://cdoc.org.uk/)
and discourse on topics that are relevant to the social arena. Given that the job of bioethicists is to make normative judgments, thus taking a stance, there is no natural line or distinction between being an academic bioethicist and an advocacy/activist bioethicist. Instead, Scully argues that there is a continuum of bioethicists’ responsibility to engage with healthcare advocacy and activism, and an associated continuum of commitment towards it that bioethicists cannot escape (2019, p. 873). Because at its core bioethics involves philosophical inquiry, one of its primary responsibilities is the pursuit of truth and knowledge. This nature of bioethics means that bioethicists have additional responsibilities beyond those that may appear on the surface. Because our job entails an expectation to give guidance to policymakers, healthcare professionals, and the general public, we are implicated in processes that have consequences in people’s lives (Scully, 2019). It would seem then that bioethicists have a responsibility towards people who may be vulnerable because of these processes.

Moreover, because of the nature of the bioethicist’s job, we usually find ourselves in privileged positions to identify situations of moral trouble. Scully argues that bioethicists have a moral responsibility to engage in activism and advocacy given their position as moral experts. This expertise provides bioethicists with a professional authority to influence public opinion and policymakers (2019, p. 873). Rogers defends Scully’s argument that without an orientation toward advocacy and activism, bioethics seems hollow and even dishonorable, given that bioethicists possess the skills and training to offer help (Rogers, 2018).

However, Patrick R. Grzanka et al. have argued that engaging in activism and advocacy to contribute to social justice is insufficient if the approach is not intersectional. Unlike approaches that present a single axis critique, intersectionality deals with the different
relationships between systematic inequalities that sustain disparities (2016, p. 27). Intersectional studies deal with the different oppressed identities of the subject and how they interact; any activist or advocacy attempt that does not involve an intersectional view will be incomplete. They argue that without intersectionality, any academic work that attempts to advocate towards the practical will ignore the intimate nature of the different forms of oppression and will obscure the root of the problem. As I addressed in my discussion of Crenshaw’s intersectional approach, addressing only one area of injustice invisibilizes other relevant aspects of an individual and their situation. Activism on a single front will not help individuals whose identity is composed of multiple oppressions.

Returning to the critique that activism and academic work are incompatible, Grzanka et al. argue that it has been the intersectionally-informed work of activists, especially women of color, that has provided many of the insights that have resulted in change within the field of bioethics (2016, p. 28). Zakiya Luna and Kristin Luker, for example, have written on the role that race, ethnicity, class, and sexual orientation play in the distribution of and accessibility to reproductive health; they have advanced the cause through peer-reviewed papers, letter-writing campaigns and journalist engagement. Similarly, Wendy Rogers has been fighting against the illicit usage of organs from coerced inmates in China. Intersectional work has been guiding academics towards social transformation and the revision of bioethics for some time now. Therefore, social justice through advocacy and activism, led by an intersectional approach to

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20 This argument is based on claims made in more general areas of feminism and defended by individuals like Kimberlé Crenshaw (1989) and Patricia Hill Collins (2000) who have argued and shown the need for intersectionality in order to combat institutionalized racism.
ethics, should not be seen as a private activity for bioethicists but perhaps as its most important focus.

It would seem, then, that along with an intersectional approach to bioethics, there needs to be a focus on activism and advocacy. Given the implicit biases within the healthcare system and their effect on health disparities, any approach to ethics that intends to help intersectional patients will have to consider advocacy at the meso and macro levels. To simply focus on the micro, the individual patients, and their relationship with the healthcare professional, falls short. Many of the oppressive norms experienced by patients are effects of governmental or systemic policies, which are guided by combined oppressive behaviors. So, when thinking about interdisciplinary approaches, we would have to consider ways to change the established systems and advocate for better policies.21

3.3 Applying the Amendments to Ana’s Case

As previously introduced, the case of Ana presents us with the dilemma of a middle-aged Latina who has been designated by her family to be their mother’s caregiver. Their mother had made it clear that she did not want to be put in a home, so when she became sick, her children wanted to uphold her wishes. Ana accepted the charge, given that her siblings had children of their own to take care of. However, given her mother’s newly developed dementia and her responsibilities as a working woman, her situation has become problematic. She feels it is her responsibility to care for her mother, yet her mother’s violent outbursts seem to be too much for her to handle. Under principlism, this case had appeared to be one of autonomy versus

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21 I will add that, while individual change is desirable, it is not sufficient to address the systemic problems I am addressing in this dissertation. Individual change can help ameliorate some of the microaggressions experienced by patients, but as argued by Fricker, systemic and epistemic injustice lead to further injustices and discrimination. Therefore, we need to do more than address the problem at the micro-level.
autonomy, where the declining capacity of her mother was being weighed against Ana’s autonomy. Yet this proved to be an oversimplification of the case. Under an intersectional approach, guided by the three amendments, we should be able to appreciate more clearly the complexity of Ana’s situation.

When applying the first amendment from a relational autonomy perspective the ‘autonomy versus autonomy’ interpretation changes. Ana’s autonomy is not separate from her mother’s autonomy in the way that we would understand it under the individualistic model. The autonomous decisions that Ana makes from here on out will significantly affect her mother. When applying a narrative approach, we can see how their stories are inextricably intertwined. Ana’s narrative is very likely being written by her intersectional identity as a woman, a Latina, a loving daughter, and a member of the lower class. It seems to be that, for Ana, her duties as a daughter and upholding her mother’s wishes define some part of her identity and, consequently, may outweigh her own needs and preferences. The narrative being told by Ana is one of love, honor, familial responsibilities, and sacrifice. Moreover, given Mrs. C’s persistent wish to not be put in a home, and Ana’s strong sense of duty, she may feel that the best way to uphold her mother’s identity is to provide the needed care, even if it conflicts with some of her other commitments. Ana may have good reason to believe that the care she can offer her mother – holding her mother’s identity in place – is better than the type of holding that strangers could offer (Lindemann, 2009).

Under an intersectional approach that considers narrativity and relational autonomy, the question would not be: ‘is Ana being coerced by her siblings and forsaking her own autonomy?’ but ‘is this a decision Ana could imagine making and still uphold her self-respect?’ Is this
something she and her mother can both live with? If Ana could imagine a scenario where placing her mother in a nursing home would be better for Mrs. C in terms of being kept safe and well, and it would be something Ana could live with, then she would still be enacting a model of relational autonomy. This approach would provide flexibility and would be open to change as the features of Ana and Mrs. C’s situation shift over time.

Under a principlist account, it would be easy to argue that Ana is being coerced or even oppressed by having been given this responsibility and being put in this position. When one understands autonomy as the self-guided, rational agent, cultural calls to familism may prove problematic or even incomprehensible. However, if (adopting Lugones’s view) we were to travel to Ana's world playfully and lovingly, we may encounter a different scenario. She may have responsibilities, duties, and beliefs that do not exist in the Western mindset making them seem unnecessary to uphold. In Ana's world, there may exist notions of happiness that come from fulfilling those duties which may not be available to la bioética estadounidense. World traveling may help us understand the narrative being told by Ana and the skepticism she feels when the doctor recommends that she put Mrs. C in a home for Ana's own wellbeing. In listening to Ana’s perspective attentively and trying to understand her viewpoint, one may still disagree; but it may be easier to understand that this is how Ana’s relational sense of self is constructed and that it is part of her own good.

Moreover, when we apply the third amendment and consider the case from an advocacy and a social justice perspective, the problem does not simply reside with Ana’s decision; rather,
it includes the bigger concern that no policies are in place that can help her. As with most cultures, taking care of her mother is an additional responsibility bestowed upon Ana without any type of social support or compensation. Most societies lack any system to support caregivers in their sometimes overwhelming care responsibilities. Therefore, if we wish to help Ana, the normative move is to advocate for policies and systems that would make her and others in her position be able to provide care without being punished for it.

3.4. Moving Forward

In this chapter I have argued that any successful account of bioethics must incorporate the three feminist amendments I have presented. These amendments would require an intersectional approach that implements principles from care ethics and narrative ethics, in addition to taking an activist, social justice stance. However, I understand that incorporating these feminist principles may also mean accepting some of the weaknesses of these approaches that have been criticized in the literature. For example, care ethics has been accused of prolonging a slave morality (Paley, 2002), of being too ambiguous and narrow (Rachels, 1999), and of providing an essentialist vision of women (Tronto, 1993). Narrative ethics, on the other hand, has been accused of requiring minority groups to invite oppressive groups into their world in order to be understood, which may lead to an intrusion of safe spaces.

While feminist approaches to bioethics may offer some of our best alternatives in the clinic, there is still room for improvement. In Ana's case, for example, one must be careful given that an overemphasis on caring may lead some to suggest that Ana must care for her mother to

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22 This amendment offers us a bridge between Intervention Bioethics and feminist approaches, as BI offered us a similar perspective concerning the need for societal and governmental interventions in the creation and development of policies.
the point of endangering her own mental health and wellbeing. As a way to move forward, I will argue that combining these feminist approaches with a philosophy of liberation may provide us with a more complete and inclusive account in clinical bioethics. Moreover, given that feminist ethics usually defend the primacy of particular virtues, (e.g., care, relationship, beneficence and empathy), philosophy of liberation will have some critiques and corrections to offer, for they argue that any virtue practiced from *la Totalidad* is in truth but a vice (Dussel, 1973).

The traditional critiques brought against care and narrative ethics, i.e., being too narrow and ambiguous, could be overcome by combining the concepts and principles developed in Intervention Bioethics and philosophy of liberation. These frameworks provide important additional principles that support and address the weaknesses of my proposed intersectional approach with the three amendments. In the next chapter, I will present the additional principles from Intervention Bioethics and philosophy of liberation that I will argue are necessary to flesh out the new bioethical account I am proposing.
CHAPTER FOUR
A MORE INCLUSIVE FRAMEWORK:
BRIDGING THE GAP THROUGH AGAPE

In the previous chapters, I discussed at length the central focus of the two theories that will be at the center of my framework: care ethics and Intervention Bioethics. In what follows, I will address liberationist concerns about care ethics, and feminist concerns about the liberationist approach. This discourse will address the needed changes that the differing frameworks can pinpoint in the other, i.e., care ethics in Intervention Bioethics and vice versa. Lastly, I will bring the two theories together into a more inclusive, cohesive theory through a discussion of their shared interests and moral goals. This work will cement the last step before laying out the principles and rules that will comprise my proposed account, the Agapean framework.

4.1 Addressing Care Ethics Through Interventionist and Liberationist Concerns

While the previous chapter on Intersectionality and the Three Amendments discusses possible critiques and problems in care ethics and other feminist approaches to bioethics, here I want to briefly discuss a point of interest introduced by Enrique Dussel. In his 1973 book, Para una ética de la liberación latinoamericana: tomo II, Dussel introduces an interesting concern with how virtues have been wrongly understood and construed in the West. Dussel’s argument claims that any virtue developed from la Totalidad will instead work as a vice used to oppress the Other. He argues that under la Totalidad, tools that have been presented and used as instruments of morality in Western philosophies are instead tools of oppression and subjugation. Virtues are some of the oldest instruments of normativity that philosophy has had to offer, going
as far back as Aristotle and Mengzi. However, in systems of domination, where power imbalances reign, virtues can be vices in disguise, used to maintain them. For example, in a system ruled by la Totalidad, virtues like humility and patience, when required of persons who are oppressed, can be used to silence and control them. Asserting that “we ought to be humble”, or “we ought to be patient” in the face of injustice can be used to convince communities to accept less than they deserve; for if justice isn’t delivered today, it might be delivered tomorrow. If we apply this critique to care ethics, it might mean that, if understood or practiced incorrectly, the virtues being proposed and envisioned by care ethics may be corrupted and used as vices.¹

Dussel argues that historically, philosophers from the West have promoted virtuous models to guide morality, which in practice have been used to prolong vices disguised as virtues (1973, pp. 81-89). He calls these virtuous vices the virtues from the Totalitarian-totality and the ethos dominador. Under this ethos dominador, virtues like prudence, justice, temperance, and bravery, are used by oppressors to reach their dominating positions. They are accepted as virtues by those in power because they permit dominating individuals to maintain their dominion over others (1973, p. 87).

For example, prudence under la Totalidad is a tool used to prolong the dominance protected by the oppressing Totality. According to Dussel, an action or decision will be deemed

¹ It has been debated whether care ethics is a type of virtue ethics or not, with philosophers like Raja Halwani (2003) and Margaret McLaren (2001) arguing for the merging of the theories and others, like Virginia Held (2006) and Maureen Sander-Staudt (2006), arguing against it. Critics of the assimilation argue against the idea that virtue ethics can provide a better moral framework than the ones already proposed by care ethicists, and instead claim that a marriage with virtue ethics could dilute the focus of care ethics. However, for all intents and purposes, the critique from liberation ethics would still apply, given that their critique is about the usage of certain virtues as necessary for ethical behavior. Given that what ties together the different approaches and versions of care ethics is their focus on beneficence, empathy, and caring for the vulnerable, which are types of virtues, the concerns brought by Dussel would not be limited by care ethics identifying as a type of virtue ethics or not.
“prudent” if it ensures the projects of those in charge, while any action or decision that weakens the Totality will be deemed “imprudent”. As he writes, “In the dominating ethos, the so-called prudence, ‘right interpretation of the mediations to be acted,’ is in truth cunning, negligence, fraud, deceit, imprudence then” (1973, p. 87). The same can be said of justice. Justice understood under a totalitarian morality deems just those that might have their hands clean of murder but who build the prisons to which they will send the Other. The virtue of temperance, which concerns the moderation of one’s passions and self-restraint, becomes under la Totalidad a virtue that is only available to those in power and which permits them to enjoy the comforts that are denied to the Other. Temperance, in this context, is presented as a measure in which legal pleasures, those that are available and praised in the dominator, are seen as evil in the oppressed. The dominator can make it a priority to seek pleasure and still be called virtuous, but in the oppressed, this search for pleasure is a sin to be ignored. The rich can spend large amounts of money on drinks and food without it being considered a vice in la Totalidad, but if the poor were to do that, they would be deemed gluttonous and frivolous. Dussel calls this permissible pleasure the spirit of the bourgeoisie, which sees temperance in regulated self-gratification and sees moderation in gluttony, lust, and drunkenness, all that which promotes their feeling of contentment (1973, p. 88). He writes:

The frightening thing is that the quota of vice mystified as virtue in the dominator is mutilation of the being of the oppressed: the licit comfort that covers up gluttony is hunger in the dominated, the paid sexual relationship is degeneration in the prostitute, the arrogance of the businessman is humiliation in the employee, the pedagogical domination of the father is failure of the son...(1973, p. 89).²

²Original quote in Spanish: “Lo espantoso del caso es que la cuota de vicio mistificada en virtud en el dominador es mutilación del ser del oprimido: el lícito confort que encubre la gula es hambre en el dominado, la relación sexual pagada es degeneración en la prostituta, la prepotencia del empresario es humillación en el asalariado, la dominación pedagógica del padre es fracaso del hijo…”
Under *la Totalidad*, virtues are used to prolong the oppression of the Other and to elevate the oppressor. Those oppressors who embody the ethos of domination, the virtues of the Totalitarian-totality, will say things like: “They are poor because they are lazy! If they worked as I do, they would share my status”. For the oppressor in *la Totalidad*, it is their virtues that make them worthy, and the vices of the Other that makes them unworthy of a life worth living.

Concerning care ethics and the virtues defended by feminist bioethics, then, any virtue being promoted by that framework must be produced from *la Alteridad* and not from *la Totalidad*. When feminists argue for care and empathy, they must make sure these virtues are not being co-opted by the patriarchy to solely press women into service as caretakers. Care must not be used to enslave the Other nor be reduced to a vice used by the dominating sameness of those in power to impose their superiority. For example, under *la Totalidad*, care has sometimes been used to provide harmful aid, which keeps the Other in a cycle of poverty. One of the most common examples is the criminal justice system in the United States. Strict laws that are meant to “protect” citizens and lead to the rehabilitation of offenders have instead led to discriminatory practices against minorities and to a 20% increase in poverty (Tanner 2018; Haugh 2015).

Consequently, as I develop the intended framework in what follows, I will argue that any principle or concept introduced to the theory must be developed through a relationship with the Other. Autonomy cannot refer to an isolationist principle that uses the right to self-determination as a means to abuse another and promote self-interest at every turn. The same can be said about concepts like beneficence, which in many cases can be used in a patronizing manner that belittles the Other by reducing them to the stereotype of a helpless, ignorant individual in need. The
virtues of the dominating Totality must be avoided at all costs, which will call for a deep analysis and descriptive definitions of what we mean by any virtue or principle introduced.

4.2 Addressing Intervention Bioethics Through Feminist Concerns

Intervention bioethics contains many of the foundational elements needed for a framework that prioritizes the Other. By centering itself around principles like the protection of the most fragile and underserved members of society and by using the ethics of liberation as a foundational philosophy, Intervention Bioethics ensures that individuals who are usually invisibilized by other frameworks are considered first. However, we must also consider some of the missing elements from the theory and how it can be enriched through feminist bioethics. The main issue I will be considering in this section is the controversial arguments that can arise when we centralize life as the material principle of a framework, as done by Dussel’s philosophy of liberation. Consequently, I will argue that, given the issues that follow from the prioritization of life, we ought to re-evaluate the usage of life as the material principle of the theory that will be proposed later in the chapter.

As previously noted, according to the three foundational principles in the ethics of liberation any ethical action would need to prolong the material principle. That is, for an action to be morally permissible under Dusselian ethics it must reproduce its foundational belief, the principle upon which all others will be built upon, i.e., that we ought to produce, reproduce, and increase all life on earth. Dussel opens his material principle with the following line:

Those who act morally (or ethically) must responsibly produce, reproduce and increase the concrete life of each individual human, of each community to which they belong, which inevitably is a cultural and historical life, from an understanding of happiness that is shared instinctively and in solidarity, having as an ultimate reference all humanity, all life on Earth (2015, p. 85-86).
The focus on life is one of the central characteristics of the theory and it is so strong that, unlike other theories, it goes beyond anthropocentric arguments and embraces *all* life on Earth, including the environment. While it is this attention to detail and this focus on protection that makes Dussel’s theory strong, it is also what might put it in disagreement with frameworks like those envisioned by feminist bioethics.

A prevalent worry that a feminist bioethicist could have when encountering this material principle is how it applies to the issue of abortion. Feminists have argued and defended the right to terminate a pregnancy and for women to have control over their own bodies for decades. However, when we hear an argument that states that to act ethically, one must produce, reproduce, and increase the life of all *humans*, one’s mind might think of the pro-life movement and its arguments against abortion rights.³ While it is not my intention to create a theory or a framework that *prima facie* accepts certain practices as moral or immoral, it is my intention to develop a framework that centralizes the Other and their struggles. The feminist movement has fought hard for the right of women to have control over their own bodies, a right that has been widely attacked and reduced in recent years. We cannot have a framework whose central concept might undermine the fundamental right to bodily integrity for which feminists have been fighting for so long. We should thus consider how the centralization of life as the material principle of Dussel’s ethics of liberation works in practice and the harms it may impose.

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³ It is essential to have this conversation and consider the material principle when Dussel has chosen to use the word *human* instead of *person* when referring to the principle. While it might not have been Dussel’s intention, through the use of the word human, he avoids the philosophical argument surrounding the debate of fetuses as humans who might not be yet persons, which has been one of the main arguments in favor of abortion.
Let us consider the case of abortion in Brazil and how the centralization of “life” as a principle has been a driving force behind their abortion laws. Brazil, home of Intervention Bioethics, has some of the strictest laws against abortion in the world. It is a crime to have an abortion in Brazil, and doing so can result in three to four years of imprisonment, with the only exception being cases where the pregnancy is life-threatening for the mother, the pregnancy was a result of rape, or where the fetus is anencephalic (Brazil Penal Code 2017, p. 50-51).

The centralization of the principle of life explains most of the arguments given by the Brazilian government in the establishment of its abortion laws. When comparing the moral weight between the autonomy of a pregnant woman and the possible life of the fetus, life, as a concept, is given priority over autonomy. Two out of the three exceptions for the criminalization of abortion in Brazil rely on the concept of "life." For example, in cases where the life of the mother is threatened, she may seek an abortion to save her own life, one which is already an established-life over the potential life of the fetus. The argument for the permissibility of abortion in cases of fetuses with anencephaly also depends on the notion of “life” given that the condition is not compatible with life. Fetuses with this condition seldom survive beyond hours or, at most, days because they lack the parts of the brain that control respiration. As one commentator notes,

According to the Brazilian Penal Code, abortion is a crime against life and against a potential person. A fetus with anencephaly is a fetus without the capacity to live a life outside the womb. The consequence is that it is a fetus for which it is not possible to impute the principle of the right to life since the founding statement is absent: the capacity to survive outside the womb (Diniz, 2007, p. 66).

Therefore, the acceptance of abortion in cases of anencephalic fetuses rests on the medical argument that there is no potential for life and survival outside of the womb; there will be an
absence of life. It is only in cases like those and extreme cases of rape that women are permitted to legally abort in Brazil.

In 2004, Volnei Garrafa (proponent of Intervention Bioethics) was involved in the legislative changes in Brazil that led to the exemption for fetal anencephaly. In an interview, Garrafa expressed that, given the morally pluralistic tendencies of their society, Brazilian law should reflect that same pluralism (Lobo & Andrade, 2004). Thus, he recommended that the Brazilian government leave the final decision in the hands of the mother based on her own moral preferences. However, Garrafa also expressed that: “The discussion should encompass all congenital malformations that are incompatible with life, so that women who so desire, do not suffer, and women whose religion says that that fetus is a person, carry the pregnancy through to the end” (Garrafa 2004, Agencia Brazil). The argument focuses exclusively on cases where the fetus will be born with a malformation; but from a feminist perspective, such limitations are insufficient and lacking. If we use the protection of the Other as a moral starting point, there are many reasons that would explain why a woman might believe it necessary and preferable to have an abortion, even in cases where there would be no birth defects and it would be predicted that the fetus would be born “healthy.”

Moreover, as noted in the previous discussion, we can argue for the presence of harmful ‘virtues’ (vices in disguise) in this case. I had previously argued that, under Dusselian ethics, virtues beings produced from la Totalidad are instead vices used to subjugate the Other. In the case of abortion, women have often been called to embody the virtues of ‘self-sacrifice’, ‘care’, and ‘nurturance’, to care for the fetus when it would be disadvantageous or even harmful for the woman. These are virtues and principles that arise from traditional views on womanhood and
femininity, where woman equals mother, and where they are called to subjugate themselves to
the care of others, be it their partners, children or even their elderly parents. We can argue that
these virtues that embody a protection of life to the detriment of women, are instead vices that
serve to uphold patriarchal power.

Any morally supportable framework must be able to consider the importance of
principles beyond “life” as Dussel frames it. If we focus mainly on the protection of bare life, we
employ some dangerous assumptions that also relate to end-of-life care. For example, consider
the arguments in favor of medical aid-in-dying (MAID): while the practice is illegal in many
jurisdictions, it has gained more global popularity over the past couple of years. In the United
States alone, as of now, there are 10 states (and Washington D.C.) where MAID is legally
authorized.\(^4\) MAID is different from practices like euthanasia, where the medical professional
administers the medication that will lead to the death of the patient. MAID is only available to
patients who are terminally ill (with a prognosis of six months or less to live) and who are
deemed mentally capable (VandeKieft 2020; Vogel 2020). Patients who seek this option are
prescribed the lethal medicine, which they must take themselves.

If we were to engage in a moral discussion on the permissibility of MAID starting from
the principle of life, it would be impermissible. The practice would be comparable to suicide and
would drive arguments pertaining to the ending of one's life before 'one's time.' However,
proponents and defenders of the practice argue for the moral weight of dignity, autonomy, and
compassion. While we might have concerns regarding the implementation of this practice and
how it could be abused by the health care system in a discriminatory context, I wish to discuss

here the morality of the action itself, i.e., choosing to end one’s life. Can we really argue, with complete moral certainty, that the principle of life must always outweigh principles like dignity and autonomy? We praise martyrs throughout history and individuals who sacrifice themselves for their convictions. Thus, we ought to seriously ask how the praising of a martyr is morally different from a patient who is terminally ill and wishes to end their life on their own terms. In both cases, i.e., the case of the martyr and the case of the terminally ill patient seeking MAID, the individuals are accepting the end of their lives to honor something they value more than life. It is a complicated argument that cannot be genuinely appreciated nor morally considered if the central focus of our theory is the protection of life at all costs.

If we go back to the example of Brazil, we see a rejection of arguments that can lead to the acceptance of practices like MAID, just as the state has rejected abortion. Practices that resemble or echo the ideals of MAID are a crime in Brazil, being regulated as homicide under their penal code (Garcia, 2011; Soares, 2020). Instead, medical professionals are to prioritize orthothanasia as the preferred end-of-life practice (De Oliveira Andrade & Barros Garcao, 2006; Santana et al., 2017). Orthothanasia, often referred to as ‘correct death,’ refers to the suspension of prolonging life through artificial methods for patients with no prospects of cure (Cota de Almeida et al. 2021, p. 783). It is a form of “letting die” that allows patients to experience a natural death caused by their underlying medical conditions. The preference for orthothanasia in Brazil rests on their focus on the principle of life. In a discussion of Brazil’s medical system and their end-of-life practices, Janaína Reckziegel and Beatriz Diana Bauermann Coninck recount the different approaches to end-of-life care and their suitability to Brazil. They state that: “In terms of the medical Bioethics, in principle, life is defended” (2016, p. 62); thus, leading them to
argue for the moral superiority of orthothanasia, “It was found that the best solution to solve these existential conflicts is through orthothanasia whose philosophy asserts respect for the natural course of life and its purpose” (Reckziegel and Bauermann Coninck 2016, p. 64).

Feminist bioethics has extensively argued in favor of practices that decentralize “life” in favor of alternative principles, e.g., bodily autonomy and care, signaling the importance of values beyond life. Defenders of life as a centralized principle seem to be arguing for what we could call “bare life”. Policies and laws that prohibit abortion add nothing to ensure the well-being of the child once it is born and instead, focus on ensuring the mere existence of the child. Moreover, this conceptualization of life as “bare life” seems to ignore the pregnant woman, who already possesses more than the capacity for mere existence. If we were to instead understand life as more than the bare minimum, e.g. as the ability to thrive and flourish, then we would need to consider more than the pregnant woman’s bare existence against the bare existence of the fetus. Policies and laws concerning abortion and end-of-life care would need to conceptualize life in a more extensive manner and explain how they support a patient’s ability to flourish and thrive beyond mere existence. My argument is that the centralization of life and the logic of an ethic devoted to its protection sidelines other important values that we ought to seriously consider. Therefore, as we move forward with the development of a theory better able to consider intersectional identities and the protection of oppressed individuals, we must find a substitute for life as the material principle for the theory.

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5 By “bare life”, I am referring to mere existence, to the concept of being alive only in a biological sense. The protection of “bare life” makes no guarantees concerning the quality of a life, only its biological continuance.
4.3 A Cohesive Theory

It is undeniable that approaches in feminist bioethics and Intervention Bioethics (BI) share many commonalities amongst their practices and the ways they each approach their goals. It will be in these shared aims that my framework will find its footing. When discussing feminist approaches to bioethics, three amendments were introduced as a necessary component of any theory seeking to seriously address intersectional identities. I argued that any theory would have to have three normative components: 1) it would have to include a relational account of autonomy, 2) it must have a narrative component, and 3) it will have to incorporate advocacy and activism to a certain degree. Through the usage of the amendments, we can pinpoint the parts of BI that will be helpful in the development of an approach that considers intersectional identities.

BI thrives in the third of these amendments, as it is constructed chiefly around the idea that bioethics needs to be political and that bioethicists must advocate for change that can lead to the liberation and protection of the Other. Therefore, case studies of how BI is implemented in practice can provide many insights into the possibility of integrating advocacy as an ingrained characteristic of bioethics outside of the periphery.

Moreover, both the first and second amendments can trace their interactions with BI to the liberationist concept of la Alteridad. Dussel’s ethics of liberation emphasizes the need to recognize the Other as a prerequisite for recognizing ourselves (even our multiplicitous selves, as in the case of intersectional identities). It is this recognition and need for the Other that leads practitioners of BI and the ethics of liberation to a relational account of autonomy and to incorporate narrativity in their approaches. María Eugenia Córdoba and Claudia Vélez-De La Calle describe la Alteridad as: “the self's discovery of the other, which gives rise not only to a wide range of images of the Other but also to multiple visions of the self” (Cordoba and Velez-
de la Calle 2016, p. 1003). The state of *la Alteridad* is nothing more than the recognition of the Other and our love of the Other as Other. Difference and complexity are celebrated and understood as a necessity for loving relationships. There cannot be a conquering of the Other or an attempt to assimilate the Other into sameness. Engaging with alterity requires a willingness to understand each other and engage in dialogue, thus, engaging in narrative.

An essential aspect of alterity is that it implies putting oneself in the place of the other (González and Arnaiz, n.d.), alternating diverse opinions, ideas, feelings, actions, evaluations, affective tones, customs, or social practices (García, 2012). For Enrique Dussel (1995), alterity is knowing how to think the world from the alternative exteriority of the other, which has, as a consequence, the recognition of the other as different from the self through the face-to-face encounter with the other, the oppressed, the poor; that is, someone who escapes the power of the subject and who responds rather to an experience and a temporality that do not belong to the self (Aguirre & Jaramillo, 2006) (Cordoba and Velez-de la Calle 2016, p. 1003).6

The requirements of *la Alteridad* not only lead us towards a need for narrative but the type of narrative necessary for playful world traveling, as argued by Maria Lugones in *Playfulness, “World”-Travelling, and Loving Perception* (1987).

Narrativity isn’t always a positive framework. If our understanding and construction of the world derives from an oppressive conceptual framework, our narrativity might follow a logic of domination, where the stories we tell ourselves are justifications for oppressive acts. Therefore, the playful nature of world traveling as presented by Maria Lugones is a necessity under *la Alteridad*. World traveling in this manner permits us to come face to face with the Other

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6 Translated from Spanish by me. Original quote: “Un aspecto importante de la alteridad es que esta implica ponerse en el lugar del otro (González y Arnaiz, s.f.), alternando opiniones, ideas, sentimientos, acciones, valoraciones, tonos afectivos, costumbres o prácticas sociales diversas (García, 2012) … Para Enrique Dussel (1995), la alteridad es el saber pensar el mundo desde la exterioridad alterativa del otro, lo que tiene como consecuencia el reconocimiento del otro como otro diferente al sí mismo, a través del encuentro cara–a–cara con el otro, el oprimido, el pobre; es decir, alguien que se escapa del poder del sujeto y que responde más bien a una experiencia y una temporalidad que no le pertenecen al sí mismo (Aguirre & Jaramillo, 2006).”
in a way that is more faithful to how others see themselves. When we world travel, others can show us their world and who they are in that world. Instead of constructing a narrative where the Other is always a victim, someone deserving of pity or even hate, we see them in worlds where they flourish and thrive. Consequently, our narratives can reflect these versions of them.

The combination of the three amendments with Intervention Bioethics will serve as the foundation upon which my proposed framework will be built. Every bioethical framework needs a strong normative foundation, and the ethics of liberation and care ethics provide us with the philosophical roots needed to move forward. However, as we saw in the previous section, the material principle established by Dussel might conflict with some of the principles and foundational beliefs of feminist bioethics. Consequently, in developing the framework I will advocate for an appropriate material principle that substitutes Dussel’s principle of “life” with his conception of “agape,” the highest form of love.⁷

4.4 Creating the Agapean Framework

*Love is a great master. It teaches us to be what we never were.*

-Molière, in *The School for Wives* (1662)

Following the discussion of previous chapters, my proposed framework contains the following six principles and rules as its normative foundation:

1. The framework will hold Dusselian agape as its material principle.
2. The framework will prioritize conceptions of relational autonomy over Kantian autonomy.

⁷ Throughout the chapter, when referring to the term “agape”, I will be using lowercase as to distinguish the term from the Agapean framework, which I will be proposing later in the chapter, and which will be in uppercase.
3. The framework will encourage users to engage with the narratives of others and will hold that such practice ought to be done “playfully.”

4. When possible, the framework will promote and advocate for decisions that lead to social justice and the equal participation of all individuals involved.

5. Decisions reached through the framework will be both logically and morally feasible while promoting the material principle.

6. Decisions reached through the framework will promote the prevention of possible harm and the protection of the socially excluded, the most fragile, and underserved members of our communities.

These six principles can be traced back to the concepts and ideas addressed in previous chapters, from the amendments to the principles discussed in Chapter 3. My hope is that the framework will function as a starting point for individuals engaging with bioethical cases. The framework should be able to provide more guidance than singular frameworks like care ethics while making sure not to use reductionist arguments for moral universality and common morality, as in the case of principlism. In this section, I will discuss each of the six guiding principles and will engage with possible critiques that could be levied against them.

4.4.1 The Framework’s Main Principles and Values

4.4.1.1 Principle #1: Dusselian Agape as the Material Principle

When we refer to the material principle of anything, we are asking about that out of which something is made, ‘the substance of the thing’ or its underlying nature. When discussing the material principle, Aristotle made reference to the bronze of the statue, the material out of which the object was constructed, that which was given form to create something new. Aristotle said:

We speak of ‘a statue coming to be from bronze’, not of the ‘bronze becoming a statue’… The underlying nature is an object of scientific knowledge, by an analogy. For
as the bronze is to the statue, the wood to the bed, or the matter and the formless before receiving form to any thing which has form, so is the underlying nature to substance, i.e. the ‘this’ or existent (Book 1, Part 7).

In theology, the material principle has been used to explain the central doctrine upon which different faiths and religions have been built, i.e., a religion’s central teaching. For example, in Lutheran theology, they refer to the material principle as the ‘justification by faith’, that by which the Church stands and falls. In the *Concordia Theological Monthly*, F.E. Mayers explains it as the following: “When Lutheran theologians speak of justification by faith as the material principle of theology, they merely wish to indicate that all theological thinking must begin at this article, center in it, and culminate in it” (1953, p. 4). In normative ethics, the material principle will point to the unifying belief or the foundational good that a framework will try to maximize.

The material principle should be the guiding star of a framework, the intrinsic good that each theory will strive to achieve, and which will determine the rules concerning how we ought to act. If we are utilitarians, we ought to maximize happiness/pleasure through the Greatest Happiness Principle, while followers of Kant’s deontology are to achieve a good will through reason and the Categorical Imperative.

As we attempt to develop a framework capable of considering all identities and the needs of the Other, we must consider what the material principle of such a theory ought to be. As the theory I am proposing takes feminist bioethics, especially care ethics, and the ethics of liberation as the foundational philosophies for this framework, the material principle must resonate with both theories and be born out of the ideas of care, liberation, and an acceptance of the Other as Other (*Alteridad*). I propose to adopt the concept of *agape* as the material principle of the framework I am developing. While agape is used in Christianity to refer to the highest form of
love, that of God’s unconditional love for the people and the people’s unconditional love for God, I will be defining agape through Dussel’s understanding of the concept.

Under the Dusselian approach, agape (sometimes also referred to as “moral love”) means love for the Other as Other. It is the recognition of the Other and the complete acceptance of their Otherness. For Dussel, this love is necessary for the praxis of liberation:

The ethos of liberation is other-directed pulsion or metaphysical justice; it is love of the other as other, as exteriority; love of the oppressed not, however, as oppressed but as a subject of exteriority. The traumatic condition of the human being endowed with freedom, the other, reduced to being an instrument in a system, is rightly called misery. To discover the other as other and place oneself together with that person's misery, to experience as one's own the contradiction between being free and having to endure slavery, being distinct and someone and at the same time only a different internal part; to hurt from the pain of this cleavage is the first attitude of the ethos of liberation. It is not friendship or fellowship (among equals) but love of the oppressed because of their real dignity as exteriority (1985, p. 64-65).

This love for the other implies an understanding of the Other in their Otherness instead of a pursuit to change the Other into our sameness. Dussel further argues that when we encounter the Other and reach agape, we will share in their misery. Thus, coming face-to-face with the other is a transformative experience that elicits change. Those that feel agape will wish for the destruction of a world that would oppress the Other (1985, p. 61). A man in a patriarchal society who has come face-to-face with a woman and had the epiphany in which he could see her in her Otherness and loved her in that understanding will want to change the society that oppresses her. Therefore, agape is the transformative experience of coming face-to-face with the Other and loving them in their Otherness.

Agape could be understood as a similar concept to the “love thy neighbor” ideology but through the lens of la Alteridad. La Totalidad, love for the Other, has been understood through ideas like tolerance (Barnes 2001). However, tolerance implies that there is something to
tolerate, something we devalue, and yet we ought to put up with. The argument of tolerance has been used many times to refer to minority groups and people who experience discrimination (Stevenson, 1988; Oswald et al., 2018). Philosopher and poet Audre Lorde said it best when referring to the toleration of lesbian and non-white women:

Advocating the mere tolerance of difference between women is the grossest reformism. It is a total denial of the creative function of difference in our lives. Difference must be not merely tolerated, but seen as a fund of necessary polarities between which our creativity can spark like a dialectic (2007, p. 112).

This type of acceptance and “love” for the other is patronizing at best, for toleration is not the same as respecting and accepting the Other. Dusselian agape, on the other hand, refers to coming face-to-face with the Other and seeing them for who they are. This coming face-to-face is an acceptance and a loving of what makes them different from us.

The moral priority and the intrinsic value of loving the Other as Other will be the material principle upon which my proposed framework will flourish. All other suggested principles will be born out of this centralization of agape. Thus, they should serve as guides or facilitators towards achieving this love for the Other in practice. In cases where the proposed principles prove themselves insufficient, users of the framework should default to this central principle. Users should ask themselves: “Which action or decision will most likely help me achieve agape?”

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8 I have included two interesting studies on the topic of tolerance concerning the LGBTQ+ community. In the study by Stevenson (1988), we see an interest in increasing tolerance towards the community, while in the study by Oswald et al. (2018) we are shown the difference between tolerance and support for LGB parents in their communities.
4.4.1.2 Principle #2: Relational Autonomy

The proposed Agapean framework will hold relational autonomy as the default conception of autonomy. The discussion of autonomy in Chapter One highlighted the importance of maintaining a relational account of autonomy when considering intersectional identities. Intersectional identities are not only understood and defined by how they see themselves (the self) but also how others see, interact, and define them. Moreover, I had also discussed how even our capacities for autonomous behavior are dependent on others, either because they were taught to us by others or because we depend on others so that we might act ‘independent’ or ‘autonomously’ (e.g., I need schools and babysitters to educate and take care of my children so that I might work and be financially independent). I had already established the need to incorporate relational autonomy into any proposed framework and deemed it one of the three feminist amendments. However, it is also important to explore its relation to agape.

A love for the Other must recognize how we are changed by our relationship with that Other. Part of the argument of Dusselian agape is that coming face-to-face with the Other transforms us. Therefore, a framework constructed around the idea of agape will have little to say on Kantian autonomy. The rejection of emotions in favor of the rational will, and the conception of autonomous individuals as those who are uniquely self-driven, will very rarely coexist with agape. The concept of agape that I defend brings with it many societal assumptions that negate this conception of individuals as self-driven. A love for the Other means that there is an Other to love; it also means that given agape’s aspirational moral value, this type of love is not necessarily the norm. Instead, we have talked about *la Totalidad*, and how oppressive interactions can rule everyday life. Both loving and oppressive relationships have an impact on
how we understand ourselves. Consequently, even under *la Totalidad* we can see the effects that our relationships with others can have on agape, even if it is for the worse and they work as an obstacle to reaching agape.

Part of agape is seeing the Other as Other, in their exteriority and Otherness; thus, the combination of agape with a relational account of autonomy should open the door to rejecting some of the common criticisms of relational autonomy. Some might fear that relational accounts of autonomy erase individuality to prioritize relationships. For example, in the case of a sick patient, a fear might be that if a patient wants to go through with a treatment, but their spouse does not want them to, they might need to reject the treatment in order to salvage their relationship. However, part of agape is loving others in their differences. Therefore, while it is true that a patient might reject a treatment after engaging in narrative reflection with their loved ones, that may not be the case. The Agapean framework might help the patient and their family to navigate their differences so that the family accepts the patient’s choice to refuse treatment.

Relational autonomy is not about acting in accordance with what others, with whom one has strong relationships, want. Instead, it concerns recognizing those relationships, seeing how they might affect one’s understanding, and recognizing their effect on one’s needs and wants.

Consider Hilde Lindemann’s account of holding. Lindemann argues that there is moral worth in holding our loved ones in their identities. When referring to identities, Lindemann uses a narrative account of the term:

> An identity is a representation of the self. It consists of a tissue of stories, constructed from not only first person but also many third-person perspectives, depicting the more important acts, experiences, relationships, and commitments that characterize a person and so allows that person and those around him to make sense of who he is. Because we change over time, some stories in the narrative tissue cease to depict us faithfully and—
ideally—recede into the background, to be replaced with newer narratives that—again ideally—represent us more accurately (2009, p. 417).

Our identities are then a collection of narratives which inform how we act and how we respond to our experiences. Consequently, Lindemann argues that families and loved ones have a responsibility to remind each other of their identities and of who they are. However, there are different ways of holding others to their identities: we can do so well, or we can do it badly. To hold people correctly, we must be truthful about who they are (Lindemann 2009, p. 419), thus upholding their identity correctly. We cannot hold others in identities that we wished they had or that are rooted in oppressive narratives, as these would be bad forms of “holding.” Just as trying to hold someone in an identity that is not their own would be considered ‘bad’ holding, erasing someone’s individuality, or trying to turn their Otherness into sameness would be considered ‘bad’ loving. To love someone is to uphold their narrative through our relationships, to see them for who they are, even when they differ from us. We can add this notion of ‘good’ holding to Dusselian agape.

4.4.1.3 Principle #3: Playful Narrativity

Narrativity plays a central part in the acceptance and loving of the Other. Many times, it is through our narratives that we are capable of coming face-to-face with each other. Enrique Dussel argues that mutual listening is a condition for agape. In a discussion of Dussel’s approach to pedagogy of liberation, Linda Martin Alcoff makes reference to the relationship between listening and agape. She argues:

The cross-generational encounter can neither be a one-way process of imparting Truth, nor one that abdicates the responsibility of the older generation or denies their influence. It must evolve a relationship through the praxis of mutual listening, what he [Dussel] calls the conditio sine qua non of agapē or moral love” (2016, p. 28).
In order to achieve agape we must engage in the sharing of our narrative and the vulnerability that comes with such a practice. This sharing cannot be one-sided: if we are to achieve agape, it relies on the sharing and the acceptance of the information being relinquished. Dussel describes it as a sending and receiving through which the Other reveals itself to us (2019, p. 166). Therefore, listening to the voice of the other presents as a necessary condition for agape, towards the coming face-to-face with the Other.

The discussion of Maria Lugones's “world traveling” in Chapter 3 sets the stage for the necessity of this principle for any framework that intends to benefit and prioritize intersectional identities and identities associated with Otherness. When discussing world traveling, Lugones argues that traveling to another's world lets us identify with them, given that through travel we can “understand what it is to be them and what it is to be ourselves in their eyes” (Lugones 1987, 17). Lugones sets out the relationship between love for the Other (agape) and the openness to understand the world of the Other that are necessary to my re-vision of bioethics.

Using what I believe to be one of the most honest and beautiful examples in literature, Lugones discusses her inability to love her mother correctly. She describes the love for her mother as imperfect, a love consistent with abusing her mother (1987, p. 5). To love her mother was compatible with using her, with treating her like a servant with whom she denied any possibility or willingness for self-identification. Identifying with her mother, welcoming her world, would mean becoming like her, a willingness to become what she had been taught that her mother was, i.e., someone that could be abused, someone from whom we could take, and who in return, would have little of herself left (1987, 5-6). Lugones argues that while she was taught not to love servants, she was taught that her view and treatment of her mother as servant was
consistent with love. This contradiction arises from the self-deception that constituted an essential characteristic of the imperfect love she felt for her mother.

To love those whom we oppress requires that we lie to ourselves. Through self-deception, we can narratively present existing oppressive dynamics as loving ones. Lugones argues that in this deceptive love “servitude is called abnegation and abnegation is not analyzed any further” (1987, p. 6). By shifting the narrative from servitude into abnegation, we obscure the oppressive nature of the relationship, given that while servitude might be understood as an improper way to classify your loved ones, there is nothing wrong with abnegation. Abnegation appears as a virtue under *la Totalidad*, a synonym of temperance and self-sacrifice. The Other, whom we treat as a servant under this oppressive dynamic, is not our servant, but someone that I can love and in return gives me their all, someone so humble that they ‘choose’ to live in abnegation. This diminishing state of abnegation practiced by the Other appears to us under *la Totalidad* as “beautiful and noble” (Lugones 1987, p. 6). Here we can see once again how *la Totalidad*, armed with our own self-deception, can twist our understanding of virtues as a tool for subjugation.

With the vocabulary given to us by Dussel, we can look at Lugones’s example and see that the type of love she was referring to is the love taught to us by *la Totalidad*, a love consistent with toxicity, taking for granted, using, and abusing the Other. Lugones had proposed breaking free from this toxic love and world-destroying traveling by substituting these conquering practices with a loving eye and playful world travel. Both concepts serve us as guides on how to approach others lovingly. Marilyn Frye’s concept of the loving eye is the contrary of the arrogant eye, which diminishes everything to a comparison to the self. While the arrogant eye denies what is different and the complexity of selves (it is a colonizing, oppressing eye), the
loving eye instead recognizes the Other as a subject who is different and complex (Frye 1983, p. 52–83). Lugones’s playful world travel, on the other hand, asks us to travel to other worlds with openness, with the ability to engage in self-reflection and to be changed by those other worlds, instead of trying to change the world itself. It is through these practices that we can achieve true love for the Other, by traveling to their worlds and seeing who they are there and by encountering them with a loving eye that recognizes their differences.

There are many ways to world travel. However, for the sake of this framework and its applicability to everyday cases, I propose narrativity as the leading way to achieve this loving connection. When engaging in the use of this framework, users should prioritize the sharing of their narrative so that others can travel to their world and might understand them better, and vice versa. They must listen to the narrative of the other while being open to being changed through the story. The sharing of narratives is an act of vulnerability that permits us to see each other for who we are, not necessarily because the stories are factually perfect, but because through their narrative, other people show us what their priorities are and what it is that they value.

4.4.1.4 Principle #4: Social Justice and Equal Participation

The fourth principle of the framework combines one of the amendments discussed in Chapter 3 with one of the central tenets of the ethics of liberation. This principle states that, when possible, the framework must promote and advocate for decisions that lead to social justice and the equal participation of all individuals involved. This guiding rule makes reference to the feminist amendment on the need for advocacy and activism in bioethics, and to the ethics of liberation’s formal principle, which argues for symmetrical participation in society.
Let’s take access to healthcare in the United States as an example. After the implementation of the Affordable Care Act in 2010, approximately 20 million individuals, of the 46.5 million who were uninsured at the time, were able to gain access to health insurance (Tolbert et al., 2023). However, as of 2021, approximately 27.5 million individuals in the United States reported being uninsured, which in a system that is highly dependent on health insurance, means that millions of people continue to lack secure access to healthcare. Of the 27.5 million uninsured people, most belonged to low-income households, and were non-white (Tolbert et al., 2023). The Agapean framework requires symmetrical participation in society and open advocacy for social justice. Given that millions of people are not able to access healthcare equally, which some might call a ‘human right,’ the Agapean framework would demand changes in the policies that regulate the healthcare system. Given the emphasis on the symmetrical participation of society and the protection of the vulnerable (Principle 6), the goal of the Agapean framework would be to advocate for a universal healthcare system where everyone can have access to their basic needs.

As mentioned previously, all the proposed principles can trace their origin and importance to the concept of agape. This principle is no different. The need for advocacy and social justice is born out of the transformative experience presented by coming face-to-face with the Other. The fourth principle is enacted after we have reached the state of agape. Dussel had proposed that truly encountering the Other changes us, for their misery will become our misery. Consequently, we will want to change the world that oppresses the Other. Reaching agape brings with it a want for justice, for when we love someone, we want the best for them. Therefore, if narrativity is what comes before, advocacy is what comes after. Through advocacy and activism,
we attempt to fight for a world where the Other is treated fairly, justly, and is loved and accepted in their Otherness. It is by advocating for the Other that we combat la Totalidad through Alteridad. Moreover, an essential way of advocating for the Other is by highlighting their voice, a voice that at many times drowns in a sea of sameness, of patriarchy and domination. Ensuring the symmetrical participation of all the individuals involved in a case is a basic call of agape.

Because we are starting from a position of historical asymmetry, where for the longest time only a small group has been able to share their voices, it might be necessary to overcorrect at first. To gain symmetry, we might need to allow for some asymmetry while we attempt to fix centuries of oppression. For a time, it is very likely that agape will call for the prioritization of those voices that have been historically drowned and silenced. Thus, even if the goal is symmetry, there will be cases that will call for asymmetry in order to highlight voices and knowledge that have been systemically ignored and marginalized.

When discussing political love, which is a type of love even if it is not agape, Martha Nussbaum argues for the necessary connection between love and justice (2013, pp. 378-398). Without love for each other, we cannot achieve a state of social justice. However, even when we might have a desire for love, the evils of society, i.e., prejudices, stereotypes, rooted envy, and selfishness, might stand in the way of developing such a love. Therefore, Nussbaum argues for the need to intervene against these evils through the cultivation of ‘public emotions’. She proposes different ways in which the state or groups in power have cultivated such love through projects that extend feelings of compassion and where impeding emotions are discouraged. These projects of love can take many forms, depending on the cultural context, and on what each specific society understands as valuable (2013, pp. 200-201). Nussbaum gives the following
examples of ways in which governments can encourage ‘public emotions’ that can lead to compassion and unity:

Government, more broadly conceived, generates public emotion through many strategies: through public artworks, monuments, and parks, through the construction of festivals and celebrations, through songs, symbols, official films and photographs, through the structure of public education, through other types of public discussions, through the public use of humor and comedy, even by shaping the public role of sports (2013, p. 203).

While Nussbaum's argument may not be perfect, it points us in the right direction. There is more than one way in which we can engage in advocacy and activism, in which we can work towards change and advocate for a love that can bring justice. We ought to use all the tools at our disposal, from civic change and protests to art and education.

It is worth noting that I have added the “when possible” addendum to the principle. I have added this while understanding that it might reduce the strength of the principle. It is not the same to argue that we must “always” advocate for what we believe is right than to argue that we must do so "when possible." This addendum was included to consider the realities of our world.

As philosophers and moral theorists, it is easy to ask others to always voice their moral views and fight for what they believe to be correct. However, we must accept that there is a reality we should accommodate: it is not always safe to do so. Moreover, the weight of advocacy cannot always fall on the same people. Black women, for example, have shown a commitment to activism (Ross et al., 2022). However, that commitment, in combination with everyday racial battle fatigue, has led to activist burnout in the community. Therefore, when I argue that one

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must engage in advocacy and activism “when possible,” I wish to bring attention to the argument that while they are an essential part of agape, when practiced asymmetrically, they can lead to unequal participation and create undue burdens on the communities that we ought to be protecting.

4.4.1.5 Principle #5: The Feasibility Principle

The feasibility principle is straightforward as it derives from Dussel's own feasibility principle. The principle states that *all decisions made through the framework must promote the face-to-face encounter needed for agape in a way accordant with ethics and logic*. Dussel’s feasibility principle argued for decisions to be born out of the material principle of life. The feasibility principle of the Agapean framework centers around agape, as do all other five principles. The function of this principle is to encourage the reaching of logical decisions in addition to ethical ones. To consider Ana's case once more, someone could argue that the best, most moral decision Ana could reach is putting Mrs. C in a comfortable nursing home, where she will get the attention she needs while enjoying the many amenities available at such a place. However, while that might be a lovely decision, it is not a logical one. For Ana to be able to afford such a nursing home, she would have to go into serious debt. Moreover, we could argue that in order to protect the Other and fight for their rights, everyone ought to engage in activism every time they have a chance to make their voices heard. However, I have already argued that such an approach can harm members of marginalized communities. Therefore, this principle serves as a reminder that any decision we reach, any suggestion or policy recommended, must be both ethical and logical if they are to protect and serve the Other.
4.4.1.6 Principle #6: Protection Through Prevention

The last principle of the framework states the centralization of the protection of the socially excluded, i.e., the Other and patients with marginalized intersectional identities, through the prevention of possible harm. Out of the four “Ps” discussed by Intervention Bioethics, I will be focusing on prevention and protection through the development of the Agapean framework. I have chosen these two principles due to their importance to the discussion of marginalized communities and intersectional identities. BI’s principles of prevention and protection go hand in hand, one building upon the other. Some of the best ways to engage in protection is through prevention. If you wish to protect yourself while riding a bike or a motorcycle, you should wear a helmet to prevent unnecessary harm. Garrafa's definition of protection already includes the concept of prevention. He discusses the principle of protection, arguing that it entails the need to prevent future damage to groups or individuals in fragile situations (2017, p. 133). In what follows, I propose the idea of establishing protection through prevention as one of the central principles of the Agapean framework.

When making reference to the principle of protection, Garrafa et al. use some of the concepts and definitions proposed by Fermin R. Schramm and Miguel Kottow. Schramm and Kottow have worked on developing another Latin American framework known as the ethics of protection (Schramm and Kottow, 2001). Their framework focuses on ways to develop a Latin American framework better suited to address cases in public health. Through a discussion of solidarity and responsibility, Schramm and Kottow argue for a practical approach to protection that can be implemented by the State to protect its citizens (Ribeiro Possamai and Siqueira-Batista 2022, 12). Schramm and Kottow correlate protection with the meeting of essential needs.
Under their approach, to protect the members of a society, the State ought to provide them with ‘essential needs’, those needed for people to be able to satisfy other needs or interests by themselves. For example, while we might believe that it is necessary and just for everyone to spend quality time with their loved ones, it is hard to make the time when you are struggling to survive and making ends meet.

Garrafa et al. comment on this application of protection by arguing that, to protect communities, the State ought to guarantee indispensable items for all: “Reinforcing this understanding, protection can be understood as the safeguarding or covering of essential needs - health, education, food, clothing, water supply, security and housing” (2017, p. 133-134). Using the definition of Schramm and Kottow, Garrafa et al. stress the consolidation of protection with prevention. Protection assumes a state of vulnerability for the one that needs protection; thus, the best way to approach this vulnerability is to provide regulatory policies to reduce it. For example, it has been proven that there is a strong correlation between education and health disparities, where adults with higher educational attainment tend to live longer, healthier lives (Raghupathi & Raghupathi, 2020). According to the Centers for Disease Control and Prevention (CDC), “individuals with less education are more likely to experience a number of health risks, such as obesity, substance abuse, and intentional and unintentional injury, compared with individuals with more education” (CDC, 2023).

Moreover, in addition to knowing that education is an important resource for health justice, we also know that certain groups have less access to education than others. Anna Zajacova and Elizabeth M. Lawrence write on the historical-political context that has led to the education disparity in the United States and how this has led to poor health in marginalized
groups. They argue that access to education in the United States is dependent on external factors that, at many times, rest on racist and unjust facts. “American youth have experienced increasingly unequal educational opportunities that depend on the schools they attend, the neighborhoods they live in, the color of their skin, and the financial resources of their family” (Zajacova & Lawrence 2018, p. 2). Therefore, if we were to apply principle #6 to develop policies that seek to protect vulnerable individuals against health disparities, we ought to create preventative measures that ensure fair and equal access to education. As Garrafa et al. argue: “the purpose of protection is to regulate the actions of human beings by predicting/foreseeing positive implications and preventing possible negative consequences” (2017, p. 133).

The Agapean framework centers itself around the concepts of moral love or agape. It is undeniable that protection is a common symptom of love. When we love someone, we wish to protect them from all types of harm, from physical to emotional wounds. We can think of the example of parents with their children. There are few things parents will not do for their children. We have all heard the legends of mothers lifting cars and fighting bears to protect their young. If we go back to the argument of advocacy and activism, one of the underlying motivations of advocating for a cause is the protection of rights, be it your own or the rights of another. There is a connection between the principle of protection and the principle of advocacy, as the latter can be born out of the former, and they are both a result of encountering agape. When we love someone, we will wish to protect them (the transformative experience described by Dussel), and in order to protect them, we will advocate for their rights and needs.

If we go back to the example of Ana, one of the main critiques is that Ana shouldn’t be in the position in which she finds herself to begin with. Her situation of trying to choose between
her freedom, her autonomy, and her familial duties, should never have come to be. To protect women like Ana, we need preventative measures that would ensure social responsibilities for the type of burdens being experienced by her and other women like her. Our social and political system has been rigged against women, ensuring that they bear the burden of care and the responsibility to clean up the messes created by our imperfect society. In our patriarchal and racist system, Black women have carried the weight of activism on their backs (Ross et al., 2022; Smith, 1995). Being consistently on the forefront of the fight for racial justice has led to their exhaustion and mental health problems caused by burnout (Danquah et al., 2021). Therefore, protecting women will mean preventing situations in which marginalized and oppressed groups are put in a position where they need to fight for their rights and for justice to the point of burnout. To avoid burnout, the burdens of care and social/political engagement ought to be shared by all, instead of being relegated to the most marginalized. Addressing situations like Ana’s or the ‘activist burnout’ being experienced by Black women in the US will mean taking the necessary steps to ensure the prevention of the circumstances that have led to these events. It would require engaging in protection through prevention.

In the case of bioethics, the centralization of the concept of protection through prevention should aim to minimize negligence and possible patient harms brought about by healthcare providers. For example, playful narrativity presents itself as a prevention technique that can help healthcare professionals to combat assumptions and stereotypes about their patients. If the goal is to protect patients, we should start by preventing possible harm, which can be easily avoided through honest conversation or through other means. For example, if we anticipate that a medical prognosis may cause emotional distress to a patient, we ought to encourage them not to come
alone to the doctor's office, so they might have a loved one present to help shoulder the emotional burden. Moreover, if we can anticipate that a policy or technology could hurt a specific community, we ought to prevent such an outcome, either by seeking a way to counteract such an outcome if it were to happen or by seeking a way to protect the community before the implementation of that harmful policy or technology.

While the other two “Ps” presented by BI, the principles of prudence and precaution, should be ever present in bioethics, I have decided to put them on the back burner while I develop the initial principles and the foundational ideas behind the Agapean framework. This does not mean that I will not return to them in the future or that they won’t be considered throughout the analysis of certain cases. For now, I do not consider them a foundational part of the Agapean framework, though that might change later on. The main reason why I have decided to move on without them is due to a lack of clarity surrounding the principles of prudence and precaution. In my reading of prudence, it is unclear how one would exemplify and embody this virtue. Through Garrafa’s description of the principle, we could assume a negative description of prudence, defining it by what it isn’t: imprudence. Garrafa et al. compare imprudence to negligence, to a lack of care and deliberation (Garrafa et al., 2017, p. 131). While imprudence in this manner is to be avoided, I believe that, instead of being a separate principle, prudence ought to be a virtue of prevention efforts. To be negligent is to fail to take adequate precautions, a failure to care appropriately and to foresee possible harmful consequences. Thus, for now, instead of considering prudence separately, I will refer to prudence as a necessary virtue of anyone engaging in prevention and the protection of the vulnerable.
The same has been done with the concept of precaution, which has been added to the framework through the concept of protection. Garrafa et al. define precaution as: “the adoption of protective measures concerning possible damage or risks that could be produced by certain products or technologies” (2017, p. 131). Under Garrafa, precaution deals mainly with the production of new technologies, which can be harmful to marginalized communities. While the need for precaution in bioethics is on the rise, the term as defined by Garrafa might be too narrow. Therefore, for now, I will absorb the concept of precaution under protection. Given the development of worrisome new technologies that could affect marginalized communities, we ought to ensure their protection through research and the questioning of these technological developments. Historically, it has often been the case that technologies and treatments that benefit the populations of developed countries are tested on vulnerable populations in the periphery. For example, while the contraceptive pill is now hailed as a champion of women’s reproductive rights, its history is not as righteous. In the 1950’s, Puerto Rico was chosen as the testing ground for Enovid, the first birth control pill. The women involved in the clinical trials were never explained the possible side effects of the pill, and when they came forward sharing their negative experiences, they were dismissed and labeled ‘unreliable historians’ (Liao & Dollin, 2012; Blakemore, 2018). The effects were either deemed ‘psychosomatic’ or were simply ignored, as were the deaths of three participants (Pendergrass & Raji, 2017). Moreover, the women were never compensated nor were they given access to the drug once it entered the market. Instead, the drug was only available to wealthy women in developed countries who could pay for it. Given the historical injustices that have risen in the testing of new technologies, the protection of vulnerable communities that could be affected ought to be a priority.
Consequently, none of the four ‘P’s is being erased; instead, some of them have been absorbed by the others through the initial development of the framework. The main principle being proposed is protection through prevention, where prudence is a virtue of prevention and precaution a need of protection. While these absorptions might change in the future, they help to simplify the principles for now.

4.4.2 Embracing the Mess: Critiques and Responses

In the following section, I will continue working on the development and the fleshing out of the Agapean framework through a discussion of possible critiques and implications that might arise from the discussion so far. There are two particular worries in which the discussion will center: 1) the fear that a call for a love-centered framework might translate into more responsibilities for women, and 2) the concern that this framework might be too demanding, and consequently, might result in moral “messiness.” I understand these critiques to concern two different aspects of the framework, the first concern regarding the theory and the foundational arguments in the framework, and the second critique regarding its application.

4.4.2.1 Love and Care as the Job of Women

In a society free from patriarchy and sexism, we wouldn’t need to worry about the effects of arguing that our ethics ought to be centered on loving perceptions for the Other. Sadly, this is a worry we ought to consider when developing such a framework in our imperfect and unequal society. Women have carried the burden of care throughout history, up until this day. This burden has translated to both paid and unpaid labors of care. According to the US Census Bureau women make up three-quarters of all full-time health care workers (Day & Christnacht, 2019). However, it has also been shown that “women spend two to ten times more time on unpaid care
work than men” (Ferrant, Pesando & Nowacka, 2014, p. 1). Women are usually in charge of
caring for the household, children, sick and elderly relatives, in addition to any paid work they
might have. This unfair division of unpaid labor, which rests on gendered assumptions of care,
has led to a decrease in women’s well-being and an increase in mental health problems like
depression (Seedat and Rondon, 2021).

Covid-19 serves as an eye-opening example of these gendered assumptions. A study by
Collins et al. (2020) showed that during the Covid-19 pandemic, the gender work gap increased
by approximately 20-50%, given that women with children were shown to decrease their work
hours at a larger rate than fathers of children of the same age. As they note, in 2020:

Comparing mothers’ and fathers’ work hours, Hausman tests confirm that the reduction
in work hours between February and April was significantly larger for mothers than
fathers among parents with children aged 1–5 and children aged 6–12. Consequently, the
gender gap in hours worked grew during the COVID-19 pandemic. In February, mothers
of children aged 6–12 were predicted to work about 4.7 hours less than fathers of children
this age. By April, this gap grew by one third to 6.3 hours. Similarly, among parents with
young children aged 1–5, the gender gap in hours worked grew from 4.9 hours in
February to 6.2 hours in April. This constitutes an increase of over 25 percent in the

Even with parents of children in the same age range, where both parents belonged to the
workforce, mothers were seen as the primary caretakers. Though many families were
quarantining together during the pandemic, women were still the ones to sacrifice at larger rates
to care for the children.

Our society has cemented the idea that care is a woman’s job. Therefore, when we argue
that care should be at the center of our moral responsibilities, feminists worry that this will
translate to ‘more of the same’ for women. This critique has been central to care ethics. It has
been argued that centering on care maintains a traditional account of “womanhood” or
“femininity” in which women are seen as the carers (Keller, 1997; Davion, 1993). Consequently,
when I argue for the centralization of agape, we might ask the same question: Will this not translate to women, once again, being called to embody those ‘special virtues’ that have been historically assigned to women, e.g., caring, loving, and sacrificing for the Other? It might be unclear to readers how the Agapean framework will escape the problems presented against care ethics and the fear that a call to love will unjustly and unequally burden women, who are typically seen as “motherly” and naturally “caring” and “loving”.

Unlike older accounts of care ethics, the Agapean framework is not centered on gendered assumptions or narratives. Care ethics, while valuable to my proposed framework, has been criticized for relying on the imagery of women as mothers and as carers, and consequently, as a model that we ought to imitate in our normative engagements. In the original introduction of care ethics, the framework was presented through an essentialism in which women held an inherently different morality from men, with women portraying an ethics of care and men an ethics of justice (Gilligan, 1982; Noddings, 1982). These gendered divisions have been highly criticized by contemporary care ethicists who have moved away from these assumptions, while maintaining the primacy and the importance of caring relationships. We could look at Sara Ruddick’s account of maternal thinking (1980) as an example of a foundational, feminist theory, that while maintaining the importance of caring relationships, sought to avoid the inherent essentialism found in Gilligan. Ruddick refers to maternal thinking as the connections, the unity, between the reflection, judgements, and emotions experienced by mothers through the practice of mothering; a practice governed by the interests and the demand of children for preservation, growth, and acceptability (1980, p. 348). However, Ruddick argues that ‘maternal thinking’ is not a biological or gendered trait inherent to women. Instead, it is a social category that arises
from caring relationships; thus, it can be experienced by both men and women who engage in work or relationships that require caring for others (1980, p. 346). Ruddick argues that not only can men engage in mothering, but that they ought to be doing so.

Nevertheless, even with the attempts of feminists like Ruddick to effectively distance care from patriarchal and sexist assumptions, it can be hard to escape the critique and the fear of how this philosophy might be interpreted and applied. Given the application of care and the division of labor in ‘traditional’ households, there is a valid fear that centering on care can lead to women being stuck in positions where they are expected to carry undue burdens of care.

While the Agapean framework argues for Dusselian agape as its material principle, hence focusing on ‘love for the Other’, I have separated this idea of love for the Other from perceptions or imagery of the “loving woman”. The feminist arguments that have been centralized throughout the discussion and the development of the Agapean framework have been the arguments for a playful narrativity and the use of a relational account of autonomy, which is developed through a care ethics perspective. I have shown that the usage of a relational account of autonomy is necessary when engaging with intersectional identities, especially marginalized and oppressed identities, which have been the focus of this dissertation. However, I have not relied on arguments that center on the ‘special virtues of women’ or that present women as inherently caring or loving. I have instead argued that women have been socially pressured into accepting these responsibilities of care, to their own diminishment. Part of the argument I am making is that love and care are an essential part of any flourishing society. However, by letting women carry this responsibility alone, we have turned this essential need into a burden.
Given the way in which I have presented the framework there should be no gendered assumptions imported into the notion of agape. Under Dusselian ethics, agape is never understood as a characteristic, or a virtue embodied by women: it is instead presented as a necessity for liberation and a transitional account from *la Totalidad* to *la Alteridad*, and as a characteristic that should be embodied by the Other to ensure their own liberation and by the oppressor to escape their state as oppressor. Agape is not just a call to love the Other, it is a call to leave our state of totality, to see ourselves and love ourselves in our differences and our otherness. An agent that loves and understands themselves as free will not allow others to subjugate them.

However, while I stand by the argument that there should be no gendered assumptions or unjust burdens in the Agapean framework, that does not mean that they won’t manifest during its application. After all, if we go back to the example of the Covid-19 pandemic, there was no real reason for there being such a disproportionate gap in work hours in households where both parents of children worked. Yet, this was the reality in a society that is quick to burden women. It is due to the unjust division of love and care that I have centralized social justice and activism as part of the Agapean framework. Intervention Bioethics and the ethics of liberation serve as a tool that proves critical in the face of this worry. Social justice requires a high degree of politicization and social change that goes beyond normative theorization. Therefore, the Agapean framework will require a demanding account of advocacy and political engagement that goes beyond what theories like care ethics have proposed. This, however, leads us to the second worry we ought to consider.
4.4.2.2 Getting Messy: A Demanding Framework

A secondary concern with the Agapean framework might relate to its application to the real world. As presented in this chapter, I have argued for an emphasis on activism and advocacy and presented them as an inherent part of a framework that prioritizes social justice. In Chapter 3, I presented some of the criticisms that have been brought against bioethics adopting an activist perspective. Critics claim that activism and advocacy are not the concern of bioethics and that instead, our focus should be merely academic. I have already demonstrated why these critiques fail; what I wish to discuss here is a criticism that can arise from the reality of activism and advocacy in practice.

As previously mentioned, activism – especially when concerning marginalized groups – has been shown to be largely led and carried by women, especially Black women (Ross et al., 2022; Smith, 1995). Therefore, a worry could be raised that the Agapean framework supports political and social engagement in a society where the fight has been disproportionately left for women to fight. Given that it has been proven that the phenomenon of ‘activism burnout’ is real and largely felt by women of color, it could be again argued that the proposed framework could be imposing an unjust burden on women. Moreover, activism and advocacy can be very demanding, both physically and mentally. Therefore, the fear could be that the Agapean framework is itself too demanding, especially of women, given their active social role in advocacy.

On this point, I will bite the bullet. Given all the work that needs to be done, it would be unrealistic to argue that the needed change won’t be demanding or maybe even burdensome at first. Change demands work. However, while hard work is inevitable, the demands and burdens of change should not be carried by women alone. This fight should encompass everybody. The
Agapean framework and its principles require that we all fight for the oppressed and the vulnerable, whether because we are oppressed ourselves or because we possess the freedom that everyone should possess. Agape’s coming face-to-face with the Other and its emphasis on world-traveling, demands a sharing of burdens. To feel agapean love means that one takes the suffering of the Other as our own. Therefore, leaving women and marginalized groups to fight for themselves would show a lack of it.

In this way, my framework is demanding. It requires that those with power give up some of it out of love for the Other. The framework rejects “business as usual”, where those in power enjoy their privilege without a felt duty to help the Other. Most ethical frameworks have sidelined and downgraded our positive duties towards others, i.e., beneficence. Ethical norms that call to action are secondary to negative duties of inaction. However, in the case of our treatment of the Other, it has been inaction that has led to so much suffering. We ought to let ourselves be changed, transformed, by the plight of the Other even if their plight demands action that may be burdensome. Thus, there is no escaping it; the Agapean framework is demanding.

4.5 Testing the Framework: Some Historical Case Studies

Below I will apply the Agapean framework to some select and relevant cases of historical importance to compare the applicability and sensitivity of the Agapean framework with that of other accounts. These historical cases represent different problems that have emerged and haunted clinical bioethics in Latin America, and which represent the exploitation and oppression of the Other, as presented by feminists and Dussel. Through a discussion of these cases, I aim to show how my revised feminist liberationist account goes beyond the scope of mainstream frameworks in bioethics.
4.5.1 *The Case of ‘La Operación’ in Puerto Rico*

Reproductive freedom for women, a long-sought goal, includes freedom of choice and opportunity. True choice was taken away from Puerto Rico’s women through much of the island’s history as a colony of the United States. Through the implementation of Eugenic Boards and federally funded initiatives, about one third of all Puerto Rican women had been sterilized by the end of the 1970’s through a procedure so commonly performed, that it was simply referred to as ‘la operación’ (*trans.* the operation) (García, 1982). The argument was that Puerto Ricans were ignorant individuals who engaged in reckless breeding (Ramirez de Arellano & Seipp, 1983). For the longest time, the governments involved have denied the racist and imperialistic roots of the campaigns that led to this mass sterilization, arguing that *la operación* was simply the preferred method for women in Puerto Rico to achieve their reproductive rights and that they actively chose to engage in the procedure (AVS News, 1975). These arguments, however, have been proven false through the many letters written between US government officials arguing for the need to end the poverty in Puerto Rico through sterilization and, most importantly, through the many testimonies and narratives of the women who went through the procedure (López, 2008; Mass, 1977; Presser, 1969).

Iris López, a CUNY professor and writer of *Matters of Choice: Puerto Rican Women's Struggle for Reproductive Freedom*, researched the topic of forced sterilization in Puerto Rico for 25 years and wrote about the connections between women ‘choosing’ to go through the operation and the societal pressure and misinformation they experienced throughout (López, 2008). The government ran television commercials promising women freedom and riches if they were to conform to the ‘American dream’ of the two-child household, and healthcare providers
(who were mostly doctors from the mainland in federally funded hospitals) offered compensation to women who went through the procedure. Quiara Alegría Hudes, recipient of the Pulitzer Prize, narrates the story of her own grandmother, who was subjected to the procedure back in the day (Hudes, 2021). Hudes argues that there was a sense of shame in her grandmother, who believed herself responsible for having fallen into the trap. Hudes’s grandmother was offered a cash voucher (to which she would later refer to as “candy to catch you”) to go through the procedure, and was told that la operación was impermanent, which was, of course, a lie. Her grandmother was not the only one to have been told this lie. In the documentary, La Operación, many Puerto Rican women who had the procedure were interviewed and shared the same experience of deceptive tactics (García, 1982). These women were promised a better life through a reversible procedure, and instead they were stripped of their reproductive freedoms through a procedure rooted in racism and eugenics. In an interview with Refinery29, Iris López argued that “these programs developed within a colonial, eugenic social context, where the belief was that some people are more fit to reproduce than others and that poor brown people in a so-called underdeveloped nation were not fit to reproduce” (Reichard, 2020).

In the case of la operación, we see different levels of coercion at work, with some women being lied to, others being taken advantage of through incentives due to their low socio-economic status, and other more extreme cases in which it has been reported that clinicians either did not ask for consent before doing the procedure or threatened and denied services to women unless they agreed to go through la operación (García, 1982; Kinnear, 2015; Gonzalez, 2020). If we were to analyze this case through principlism, it would be clear that the main ethical issue involved is that of coercion, which can be reduced to the principle of respect for autonomy.
Many of the women involved were lied to and did not understand what they were agreeing to. Therefore, there was a lack of informed consent, which is one of the main issues discussed by Beauchamp and Childress in their chapter on autonomy (2019, pp. 89-92). Moreover, by lying to the patients and coercing them to agree to a procedure that they do not fully understand we are harming them, thus violating the principle of nonmaleficence. However, given the narrow scope of the four principles, a principlist could say that, to fix the problem, what we ought to do is ensure that the women being offered the procedure fully understand what they are agreeing to. Informed consent ought to be prioritized so that autonomy is respected. However, my argument is that the four principles can’t address all that is wrong and deeply morally important with this case. The Agapean framework, on the other hand, can.

The Agapean framework would have had much to say about this case during its time. These sterilization practices were not motivated by love, which is the framework's material principle, but by hatred and fear, by the sentiment of ‘us vs them’ that characterizes la Totalidad. Thus, the mass sterilization suffered by Puerto Rican women was driven by la Totalidad. It was an attempt to erase the Other, either by literally keeping them from reproducing or by erasing their Otherness. As explained before, while la Alteridad is the state of seeing the Other as other, la Totalidad seeks to erase the Other by destroying their otherness and substituting it with their sameness. The television commercials that ran at the time presented the life of Puerto

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10 We can see this erasure of their otherness through the upholding, using coercive measures, of the Western ideal of the two-child household, which stood for progress and modernity. Puerto Ricans were seen as an overcrowded, ignorant people who needed to change, if they were ever to achieve the needed progress. During the time period that la operación was being practiced and imposed on Puerto Ricans, there were alarmist notions concerning overpopulation, which were traced back to the developing world. In his book, *The Population Bomb*, P.R. Ehrlich (1968) wrote: “The world, especially the developing world, is rapidly running out of food” (p. 36) and argued for the need to engage in efforts towards population control (p. xi).
Ricans as lesser, as something to be overcome to achieve the American dream, or to speak more plainly, to be like “the whites”. To love the Other through agape means being able to come face-to-face with the Other and letting yourself be changed by the interaction. There was no attempt to encounter and engage with the needs of the Other, which in this case were the Puerto Rican people. It has been argued that their poverty was not rooted on the ‘overpopulation problem’, but by the fact that the changes introduced by the US government in Puerto Rico’s economy left many Puerto Ricans displaced from their homes and farms; thus, leaving them unemployed.\textsuperscript{11}

The practices implemented in Puerto Rico were driven by the arrogance of world conquerors, of those who travel to worlds to destroy them, not to playfully engage with the narrative of its inhabitants. One of the principles of the Agapean framework demands that we playfully world travel to the world of the other when we engage in narrative. Instead, what was done in this case was a mass erasure of the narrative of Puerto Rican women’s needs, who were dismissed, manipulated, and coerced into decisions that they might not have made under different circumstances.

The application of the Agapean framework would have demanded that any procedure introduced in the island were motivated by a love of the other that corresponded with the needs and narrative of Puerto Rican women, after having engaged in systems and procedures where they were given equal participation and the ability to have input regarding their reproductive

\textsuperscript{11} At the time when the arguments and fears on overpopulation started, there were less than 1 million people on the island. Statements from the Governor a couple of years before stated that the island could maintain five times the current population. However, unemployment was a huge issue. The United States had implemented laws in Puerto Rico that limited the amount of land that farmers could possess and had engaged in different efforts and policies that had changed how the economy on the island worked. These efforts led to many people losing their lands and their main forms of income (Ramirez de Arellano & Seipp 1983).
future. Moreover, any procedure would have needed to comply with the principle of prevention and protection of vulnerable groups, where we ought to make sure that no vulnerable populations are being used and exploited. Instead, social justice ought to be achieved and respected through any decisions made using the framework. Therefore, while the Agapean framework reaches the same decisions as principlism on the immorality of la operación, the analysis and reasoning behind it is different. A different analysis means a different way of moving forward. Without an analysis that truly engages with the heart of the problem, the chosen framework can lead us to solutions that are not ideal or that serve as a type of bandage, instead of solutions that can lead us towards liberation and the avoidance of the same problem in the future.

4.5.2 The Case of the Syphilis Experiments in Guatemala

The Tuskegee experiments are well known in the history of bioethics, often being used as a warning on the need for supervision and strict ethical norms in human experimentation. In the Tuskegee experiments Black men with syphilis were observed in order to record the progression of the disease (Vonderlehr et al., 1936). The participants were not asked for informed consent and were told that they were being treated for “bad blood”. What made the experiment even more horrifying is that treatment for syphilis was widely available at the time and could have been provided. The Tuskegee experiment is usually cited as a terrible act of racism and discrimination (Brandt, 2000; Reverby, 2013; Howell, 2017). However, a less well-known experiment was the one which took place in Guatemala around the same time, and which included some of the same individuals who would later join the late stages of the Tuskegee experiments as researchers.
Unlike the victims of the Tuskegee experiment, who were already infected with syphilis, the victims of the experiment in Guatemala were healthy individuals, who were infected by the researchers in order to study the disease. The horrifying experiment conducted by investigators from the United States was funded by the National Institutes of Health (NIH). Thus, the US government not only had knowledge of the experiments but funded them. The experiment targeted vulnerable populations on the periphery who were then infected with different venereal diseases without their consent.

The study involved at least 5128 vulnerable people, including children, orphans, child and adult prostitutes, Guatemalan Indians, leprosy patients, mental patients, prisoners, and soldiers. Between 1946 and 1948, health officials intentionally infected at least 1308 of these people with syphilis, gonorrhea, and chancroid and conducted serology tests on others (Rodríguez & García 2013, p. 2122).

The human abuse committed during the experiment defied all logic, with the targeting of not only adults, but children. The researchers exploited the bodies of the victims to their limit, transforming the victims from persons into objects. In the case of Berta, one of the victims, as soon as the researchers noticed that she might die soon, they took it as an opportunity to do whatever they pleased with her. In her case, the Presidential Committee writes:

Berta was not treated for syphilis until three months after her injection. Soon after, on August 23, Dr. Cutler wrote that Berta appeared as if she was going to die, but he did not specify why. That same day he put gonorrheal pus from another male subject into both of Berta’s eyes, as well as in her urethra and rectum. He also re-infected her with syphilis. Several days later, Berta’s eyes were filled with pus from the gonorrhea, and she was bleeding from her urethra. On August 27, Berta died (Presidential Commission for the Study of Bioethical Issues 2011, p. 52).

In the case of the Tuskegee experiments, which took place in the United States against American citizens, a federal program known as The Tuskegee Health Benefit Program (THBP) was created to provide medical care to the survivors of the experiment, in addition to monetary and medical compensation to their families. Moreover, when a class-action lawsuit was filed on
behalf of the victims, there was a settlement of $10 million for the victims and their families (CDC, 2022). This was not the case for the victims of the Guatemalan experiments. For the Guatemalan victims there was no compensation from the United States government, neither for the survivors of the experiment nor for their families (Rodríguez & García, 2013, p. 2123). Moreover, when a lawsuit was filed against the United States government on behalf of the victims, the lawsuit was dismissed on the grounds of ‘sovereign immunity’ (CNN, 2012). Therefore, there were never any consequences for the harm done to the victims nor any compensation.

What was done to the people in Guatemala has no ethical explanation or possible justification. I would say that absolutely no ethical framework would be able to justify what was done to people like Berta. However, just like in the case of la operación, there are some important insights on how the case was handled that ought to be discussed. Therefore, I do not wish to discuss the obviously unethical behavior of the researchers. Instead, I wish to focus on the response provided by the ethical experts in the nation.

In 2011, The Presidential Commission for the Study of Bioethical Issues released a 220-page long paper titled: “Ethically Impossible” STD Research in Guatemala from 1946 to 1948, in which they discussed the case and what they claimed to be the main ethical issues associated with the experiment. The document barely focused on the racial and discriminatory nature of the experiment, focusing instead on issues of justice. They addressed that racism was a possible motivation for choosing Guatemala as the site for experimentation, but that was as far as they went. “A possible remaining but clearly unacceptable explanation for choosing Guatemala would reflect the notion that the Guatemalans were a suitable, if not preferable, experimental population
by virtue of poverty, ethnicity, race, remoteness, national status, or some combination of these factors” (PCSBI 2011, p. 106). Racism was presented by the US government as a possible explanation of what had been done. This negation of discrimination, when combined with the fact that no compensation or legal action was taken beyond a public apology by President Obama, appears morally suspect.

The absence of a racial discussion seems particularly ethically bankrupt when compared to the official discussion of the case released by the Guatemalan government, as a response to the Commission's issue. La Comisión Presidencial para el Esclarecimiento de los Experimentos Practicados con Humanos en Guatemala (trans. The Presidential Commission for the Clarification of Experiments on Humans in Guatemala) argued that racism was at the root of the experiment, which was explicit throughout. The Presidential Commission wrote:

El racismo, con su carga de prejuicios, menosprecio y discriminación estuvo presente a lo largo de todo el proceso de los experimentos, de manera explícita y consciente. Ello constituye un agravante en contra de las víctimas y la dignidad del país (Comisión Presidencial, 2011, p. 97).\textsuperscript{12}

Additionally, Michael A. Rodriguez and Robert García corroborate this missing perspective by arguing that throughout the US report there was very little said about systemic racism and the violations against human rights committed throughout the experiment, which would have opened the door to a discussion on the protection of vulnerable groups (Rodríguez & García, 2013, p. 2122).

\textsuperscript{12} Translation from Spanish by me. “Racism, with its burden of prejudice, contempt, and discrimination was present throughout the whole process of the experiments, explicitly and consciously. This constitutes an aggravating factor against the victims and the dignity of the country.”
In a second issue released the same year, the Presidential Commission for the Study of Bioethical Issues (2011) re-addressed the issue of Guatemala and human experimentation, which was intended to serve as a guide for future researchers on how they ought to act and what are appropriate compensations for victims. In this second issue, they engaged more deeply in ethical ruling, using principlism as their northern star. There was still no talk or discussion of race and discrimination. Instead, on a footnote at the end of the issue, they addressed that “The Commission here focuses on the issues of justice”, and provides three references on racism on human experimentation, all concerning Tuskegee (PCSBI, 2011, p. 130).

Just like in the case of la operación, mainstream frameworks are capable of addressing the Guatemala syphilis study to deem it immoral. However, such analysis will either open or close the door to possible alternatives. It is not a strange occurrence that the victims of the Tuskegee experiment, an experiment done on American soil, were compensated to some degree while the people of Guatemala were not. The people of Guatemala have intersectional identities that differ more greatly from people in the Commission than victims from the United States. It is harder for la Totalidad to attempt to turn this specific Other into their sameness; therefore, it is easier to ignore them.

Because the commission focused on principlism they had no reason or excuse to contemplate the inherent racism and colonialism in the experiment. Instead, they were able to limit the discussion to concerns about justice and the violation of autonomy. Yet this assessment of the case clearly doesn’t reach the heart of the matter, or at least, doesn’t consider the narrative of the victims. The issue released by the Presidential Commission pondered that racism was but a

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possibility of what had happened (PCSBI, 2011). However, the document released by Guatemala makes it clear that the very foundation for the study and the actions of the researchers was based on racism (Comisión Presidencial, 2011). As a result, the narrative of the victims was either dismissed or deemed unimportant. This violates two of the principles of the Agapean framework: 1) they failed to seek social justice through symmetrical participation (which would have been achieved through the centralization of the victims and their involvement on judgements on how they could achieve reparations), and 2) they failed to world travel and engage with the narrative of victims. Moreover, through the dismissal of the lawsuit and the failure to provide reparations and compensation, there was a lack of agape. Federal officials all argued that what had happened was horrible and even offered official apologies, yet the lack of action signals a lack of love. Agapean love requires coming face-to-face with the other and letting yourself be changed. True outrage and the feeling of pain of the Other would have meant that direct actions, in line with social justice, would have been taken.

4.5.3 The Case of ‘Lucia’ in Argentina

In 2021, many Argentinian women celebrated the long-awaited legalization of abortion in their country, where the law was modified to permit abortions through the first 14 weeks of pregnancy (Argentinian Penal Code, Law 27610). Before that, abortion was illegal in all cases, with the exception of cases in which the pregnant woman was a victim of rape or in which her life was at risk. However, as I always tell my students, the law does not equal morality, or as in this case, fairness. Even if it is now legal for women to seek abortions, that does not mean women will be granted their requests or that they will have access to the procedure. Healthcare providers are allowed to deny women their legally sought abortions under the premise of
‘conscientious objection’. A pediatrician interviewed by Agustina Latourrette, a BBC World Service journalist, shared that: “As soon as the law was passed, I declared myself a conscientious objector,” to which he added that he estimates that about 90% of the doctors in his hospital (which is the main hospital in the province) immediately did the same (BBC, 2023).14 Thus, while abortion might be legal in Argentina, it is by no means ‘accessible’.

However, the case I wish to discuss took place in 2019, two years prior to the legalization of abortion; a time where, nevertheless, Lucia’s abortion request was still deemed legal in Argentina. Lucia (a pseudonym used by officials to protect her real name) was 11 years old when she was raped and impregnated by her grandmother’s boyfriend, a 65-year-old man.15 Under the Argentinian law of the time, it was legal for Lucia to seek an abortion, given that the procedure was permitted in cases of rape. As a result, Lucia’s mother took the 11-year-old to the hospital seeking help and an end to the unwanted, and harmful pregnancy. Instead of providing the legal abortion they were seeking, healthcare providers at the hospital engaged in different tactics to delay for time and to convince the child to give birth. Amongst the tactics used were the prescription of drugs to accelerate the development of the fetus (which they told Lucia were multivitamins) and the allowing of anti-abortion activists to gain access to Lucia’s room. Healthcare authorities even gave interviews and conferences in which they argued that the child


15 I provide a summary of the case. However, the case was highly covered in the news. I have included here a number of articles from news outlets that covered the case and which can be accessed to read more about it and to confirm many of the facts I mention. NYT: https://www.nytimes.com/2019/03/01/world/americas/11-year-old-argentina-rape-abortion.html
did not want to abort, arguing that it was Lucia’s wish to carry the fetus to term. This was, of course, a lie. The child, Lucia, had gone as far as to try to commit suicide in order to not carry the pregnancy and constantly asked the healthcare providers in the hospital to “take out what the old man put in me” (BBC, 2019).

After some time, desperation, and emergency lawsuits filed by activist groups, a court order was provided demanding that the hospital take ‘immediate action.’ Sadly, the healthcare providers at the hospital refused to perform the abortion, claiming their right to conscientiously object. Private doctors had to be called upon and, given the length of the pregnancy at this point, they argued that abortion was no longer a safe option for Lucia. Instead, the healthcare professionals opted to take ‘immediate action’ by delivering the fetus and performing a C-section on the 11-year-old girl. Lucia’s case led to a nationwide outrage, some arguing that the hospital had put Lucia in danger and had kept her from her legal rights, and many others arguing that Lucia should have carried the pregnancy to term, which would have increased the chances of survival for the fetus.

Lucia’s case is a terrible one, and, sadly, it is just one of many other similar cases. The mistreatment and denial of a legal procedure to a desperate child exemplifies the dangers of incorrectly prioritizing and emphasizing bare “life” above all else. In the case of Argentina, the prioritization of life as a moral dictate reached its epitome in the form of the slogan “Salvemos las dos vidas” (trans. let’s save both lives), a saying that was echoed in Lucia’s case. The slogan has been used to argue that in cases of abortion one life is always abandoned and killed, i.e., the life of the fetus. However, in cases where the life of the mother isn’t obviously at risk, by making the pregnant women give birth, we are maintaining two lives instead of just one. This way of
thinking exemplifies the protection of life, not as presented and defended by feminists, but the conception of “bare life” I previously presented. In the case of Lucia, to demand that she give birth at her age, and under her circumstances, does not truly consider the quality of life she will have available to her after the fact nor the risks to both her physical and mental health.

Cases like Lucia’s shine a light on the need for a feminist-centered framework that focuses on liberation. The Agapean framework would be able to handle Lucia’s case better than the alternatives. Loving Lucia, in the way required by agape, would have meant to help her, to listen to her. It would have meant that all the healthcare providers who denied her their services would have had to travel to her world and see the world through her eyes. They would have had to engage in her narrative, instead of prioritizing their own autonomy above all else.16 The doctors that day engaged in Kantian autonomy, which is secondary to relational autonomy under the Agapean framework. They prioritized their own beliefs and wished to impose them on Lucia, even if it meant her losing her life or having to go through a pregnancy and even motherhood at 11 years of age. Coming face-to-face with the Other is a transformative experience, in which, if you truly see them and see their suffering and their state of oppression, you will be changed by the experience. Their plight ought to become your plight. Engaging in the Agapean framework would have meant providing Lucia the care and empathy defended by feminists and coming face-to-face with the Other as demanded by liberation ethics.

16 Under the Agapean framework, physicians and healthcare professionals who seriously morally object to abortion would not be required to perform an abortion on Lucia, or other patients like her. However, they would be required to not actively block patients from receiving an abortion. Moreover, they would be required to ensure that the patient receives the needed abortion in a timely manner by a different healthcare provider. This would be an appropriate way of practicing agape and the Agapean framework, as it would require the provider to actively listen and engage with the narrative of the patient, recognize the social implications of having autonomy over one’s body, and would lead to taking decisive action that would help the patient.
4.6 Final Remarks

This chapter serves as the pinnacle of the discourse that has taken place throughout the rest of the dissertation. While the previous chapters served to discuss the problems that prevail in bioethics, this chapter proposes a solution through the introduction of the Agapean framework. The Agapean framework symbolizes a marriage between care ethics, philosophy of liberation, and Intervention Bioethics, posing the protection and prioritization of the Other. The intention behind the framework is to provide a moral framework that appropriately engages with intersectional identities. Given the complex nature of intersectional identities, they tend to ‘fall through the cracks’ in bioethical discussions, which has led to the further marginalization and invisibilization of these identities.

I started the chapter by addressing the different ways in which care ethics and the ethics of liberation can strengthen one another. According to the ethics of liberation, virtues in *la Totalidad* are but vices disguised to continue the oppression of the Other, while the focus on life argued by liberationists can sideline other important principles. Thus, to ensure the protection of the most vulnerable and marginalized, I argued for the centralization of Dusselian agape. Dusselian agape refers to the unconditional acceptance of the Other in their otherness. To be moved by agape is to see the Other for who they are and to let yourself be changed by it. This concept is at the center of the Agapean framework for which I am advocating.

My revised Agapean framework proposes six central principles in its introduction. To be applied correctly, users most keep in mind that: 1) Dusselian agape serves as its material principle; 2) conceptions of relational autonomy are given priority; 3) there must be a sincere engagement with the narrative of the Other through playfulness; 4) when possible, the
framework will promote and advocate for decisions that lead to social justice and the equal participation of all individuals involved; 5) decisions ought to be both logically and morally feasible; and 6) the protection of the most underserved members of society must be pursued through the prevention of possible harms. The framework is intended to serve as an additional tool in the toolbox that is moral philosophy. It is not intended to serve as a replacement of theories like care ethics or principlism. However, I have shown through the application of the framework to different case studies that it works better than other frameworks when concerning intersectional and marginalized identities.
CONCLUSION

My aim in this dissertation has been both theoretical and practical, with the former presenting as a negative project and the latter as a positive one. My theoretical objective was to present a critical analysis of mainstream bioethics, specifically of *la bioética estadounidense*, and the urgent need for reconceptualizing some of the notions and principles we have accepted as universal under this mainstream account. On the other hand, my practical objective was the creation of a framework that could serve as an alternative to mainstream principlist accounts, and which could address the problems presented through the theoretical project. The first three chapters of the dissertation served to accomplish the negative project while setting the ground for the positive one, which was accomplished through the fourth chapter and the introduction of the Agapean framework.

I established a critique of principlism, the champion of *la bioética estadounidense*, as an incomplete framework, incapable of addressing the needs of marginalized others and intersectional identities. The focus on simplicity and a common morality will mean that, in practice, principlism will not be able to recognize important plights when they diverge from the predicaments and values of white, middle-class individuals. I argued that the centralization of western values and principles, as if they were shared by all, promotes a normativity of whiteness in an imperialist and colonizing mentality. After presenting my critique of principlism, I presented an alternative from the periphery, which served as a demonstration of the falsehood of principlism as a common morality. Intervention Bioethics and the ethics of liberation argued for
differing values in Latin America where there is a centralization of persistent situations instead of emerging ones. Moreover, bioethics in this context is deeply ingrained with politics and social justice which diverges from the more academic and neutral approaches to the field in the West.

The work done in chapter two, through the discussions of Latin American works, also provided me with the opportunity to engage in a third goal for this dissertation. There is a lack of engagement in the West with philosophies from the periphery. While philosophers seem more than willing to learn European languages like German, French, and even Latin, to be able to read the works of Kant and Descartes in their original language, there is less of a willingness to engage with non-translated works from the periphery. Therefore, one of my side projects for this dissertation was to translate passages from works written by Latin American philosophers, many of which are not found in English. My hope is that these translated passages can serve to spark an interest in these works and call attention to the great pieces of moral philosophy that can be found outside of core countries.

After providing a critique of principlism and engaging with philosophies from Latin America, I centered on questions about the patient and how to serve them better. Principlism has proven itself incapable of addressing values that diverge from the four principles. Therefore, it was important to address the patient that principlism seemed incapable to serve, the intersectional patient with a multitude of marginalized identities. Through a discussion on feminist accounts of intersectionality and the needs of the intersectional patient, I argued that the development of any account intending to correct for the shortcomings in principlism would need to consider three amendments from its inception: 1) a relational account of autonomy, 2) an engagement with narrativity, and 3) a willingness to engage in activism and advocacy. An
account capable of adopting and correctly applying these three amendments would serve as a worthy replacement for principlism.

Finally, after a thorough discussion of what was needed and possible options, I presented my own framework, capable of addressing intersectional identities better than all the other accounts on their own. Using Enrique Dussel’s account of agape, as a love for the Other as Other, I introduced the Agapean framework with six central principles, which emerged through a discussion and combination of feminist bioethics and Intervention Bioethics. The six principles state that the Agapean framework: 1) holds Dusselian agape as its material principle, 2) prioritizes conceptions of relational autonomy over Kantian autonomy, 3) encourages users to engage with “playful” narrativity, 4) promotes and advocates for decisions that lead to social justice and the equal participation of all individuals involved, 5) centralizes the achievement of both logically and morally feasible decisions while promoting the material principle, and 6) states that decisions reached through the framework ought to promote the prevention of possible harm and the protection of the socially excluded, the most fragile, and underserved members of our communities. I applied the framework and its principles to three different historical cases to demonstrate its advantages over mainstream accounts of bioethics.

It is important to restate that the Agapean framework for which I am advocating is intended to serve as a necessary tool in the moral toolbox, one that has been missing but which is sorely needed. However, that does not mean that it is intended to be the only tool in the toolbox. Other accounts and frameworks might prove themselves more relevant to specific cases. For example, I am willing to accept that in cases where speed and time are of the essence, principlism might be better suited to address the situation. One of the reasons why principlism is
so popular in the West is due to its accessible, narrow, and quick nature, which are the same reasons why the framework is incapable of addressing appropriately the cases I have discussed. However, in cases of emergencies, where healthcare providers do not have the time to understand the complexities of the patient, the four principles approach offers a way to maintain some level of normativity in decision-making where there would otherwise be none. My argument is that in cases of intersectional identities, especially where there is an oppressed Other, the Agapean framework offers us a chance to better address the needs of the patient than other available accounts. However, in cases where there is no time to engage with the narrativity of the patient, and thus, the alternatives are either no ethical approach or an approach like principlism, which reduces patients into ‘two-dimensional characters’, principlism will be preferable.

I used the case of Ana throughout the dissertation as my touchpoint. Ana felt distressed by having to choose between her duties as a daughter and maintaining her mother’s wishes. She could either abandon her job to take the mantle of caretaker for her mother (as many daughters do in our society) or institutionalize her mother in a nursing home. I argued that this case presents us with a more complicated and layered moral discussion than it would appear under mainstream accounts of bioethics. Under principlism, Ana’s case largely becomes one of autonomy versus autonomy. On the one hand, we have Ana’s requirement to change her life to accommodate for unpaid care work, while on the other, we have Mrs. C, who has been very adamant in her wish to never be put in a home. We could also consider the principle of beneficence and what is better for Mrs. C given her condition. We could even consider the principle of non-maleficence, as Ana had already been hurt during one of her mother’s episodes.
All these considerations are morally valuable; however, I have argued that they are incomplete, as they do not fully grasp all that is normatively significant in the case. Incompletely addressing a case might lead to reaching non-optimal moral decisions or decisions we might come to regret later. Therefore, we ought to ensure that our normative considerations of a case are as thorough as possible.

Integrating both feminist bioethics and an interventionist account helps us to more fully develop a coherent and significant analysis of Ana's case. The three feminist amendments provide us with additional considerations integral for cases where the individual possesses an intersectional identity. Through a relational account of autonomy, it is difficult to separate the “good” for Ana and her mother, given how deeply intertwined they are at this point and how the actions of one party deeply affect the other. Moreover, a focus on familial duties and caring relationships might point to Ana’s narrative as one of love and sacrifice. I argued that through the implementation of narrative considerations the question would shift from one of coercion and lack of autonomy, to one on livable narratives. Which is the story that, upon repetition, Ana can live with? What is the narrative that she will consider a ‘good’ story?

Intervention Bioethics and the ethics of liberation focus on the protection of the Other and the prevention of harm. Through an interventionist account we will need to consider how both women and the elderly have been turned into an Other by our societies. Women have been deemed caretakers through social biases and then abandoned by the governments that do not offer them assistance with the imposed care work. The elderly have also been marginalized and left unprotected in underfunded nursing homes. Therefore, both feminist and interventionist accounts will deem it necessary for governments to get involved in cases like Ana’s to offer the
assistance she might need. This governmental involvement may take many forms, from offering care workers paid leave, to successfully funding public nursing homes where the elderly are appropriately taken care of.

The Agapean framework takes the best from the feminists and interventionist accounts and adds principles that would better serve people like Ana. By proposing agape as the material principle, the conversation shifts to one concerning love, liberation, and acceptance. Through the proposed material principle, we can encompass many of the principles and values of mainstream accounts while also ensuring that we pay attention to the needs of the Other. With the centralization of agape, the Agapean framework is capable of doing everything that frameworks like principlism can do, but better. A love for the Other, as defended by agape, will relate to issues of autonomy, beneficence, justice, and non-maleficence, as pursued by principlism. However, it will also encompass questions concerning honor, dignity, caring, liberation, and happiness, while promoting the active protection and liberation of people. The Agapean framework can encompass all of these principles and consideration through Dusselian agape, given that when we love someone, in the way required by agape, we ought to be transformed by the face-to-face encounter. The fears and worries of the Other also become ours, therefore, their need for liberation and for being seen will become a call to action. Accepting the other and loving the Other will mean that to do so properly, we ought to hold them in their identities, to protect and understand their stories, keep them from harm, and make sure they are heard. The centralization of agape can help us achieve much more than other available principles. Patients deserve the best options available when it comes to their health and the protection of their well-being. Therefore, we shouldn’t settle for frameworks like principlism, which even though
concern important principles, ignore many others which are crucial to a well-rounded analysis of normative cases in the field.

A discourse of Ana’s case through the Agapean lens permits us to discuss questions on Ana’s intersectionality and how that affects her understanding of the situation. Her dual-culture, gender, socio-economic status, and what she holds as valuable, all have a role to play when discussing the case. By using the Agapean framework instead of competing frameworks, we can talk about relational accounts of autonomy and the effects that our bonds with others have on our decisions, without falling into the trap of coercion. Moreover, by playfully visiting the world of Ana we can also better understand what worries her about the case and what are the parts of the story that she can or cannot live with. Through the liberationist-inspired principles, we can make sure that Ana maintains her voice, and that no decisions are being imposed on her by her family or by a lack of viable options. The protection of both Mrs. C and Ana, and the prevention of future harm, will always be present in any discussion of the case. Lastly, if Ana’s problems lie with a lack of options due to an unfair system, then the Agapean framework will advocate for change and for a system in which she can make the right decision without feeling she has no other choices.

The Agapean framework synthesizes core ideas and principles from both Intervention Bioethics and feminist bioethics, helping in the cultural and normative translation of these concepts. The notions and principles proposed by these accounts largely synergize, becoming stronger when together, though they have been kept apart. Both Intervention Bioethics and feminist bioethics maintain the need for political action, and activist/advocacy work. Moreover, they both shine a light on marginalized and underserved communities that have been oppressed
and invisibilized by mainstream accounts. Together, they provide us with a needed normative account, better suited to accommodate the needs of the Other.

The work done in this dissertation should serve as a guideline for what needs to change in the field and a way to address this shortcoming moving forward. Arguments on the universality of principles and on a common morality point to an epistemic bubble around mainstream bioethics in the West. Certain principles, ideas, and topics have predominated the field and have left out diverse voices and invisibilized their plights. The focus of *la bioética estadounidense* on emerging issues instead of persistent ones has cemented a prioritization of issues that mainly affect groups that already enjoy societal privileges while ignoring the needs of the worst off. Without an active engagement to open the field to diverse and marginalized voices we will continue down this path of epistemic injustice. It is rare for knowledge produced in the periphery to reach the episteme of the core countries, be it by lack of translations or a lack of interest. However, if we don’t actively search or invite these differing works into mainstream spaces in the West we will continue to strengthen this epistemic bubble. The work produced from this bubble ignores relevant voices that speak to the needs and values of others. In a field rooted in morality and justice, we ought to do better; we ought to burst the bubble.

Moving forward, I do not argue for the abolishing of frameworks like principlism. The four principles account has been an important development in the field and has helped practical approaches to healthcare be better than they used to be. Nevertheless, I have shown throughout my work that, even if helpful in time-sensitive situations, principlism is an incomplete framework. Without the input of theories centered on the plights of the Other, the four principles fall short in practice. Still, the Other takes many forms and the periphery does not encompass
only Latin America. I centered my discussion on the values and frameworks developed in Latin America due to the large number of LatinX immigrants that pass through the U.S. healthcare system every day and due to my personal connection with the region, as a native Latina myself. However, Intervention Bioethics is not the only framework developed from the periphery of the world (it's not even the only one in Latin America!). African bioethics, for example, has frameworks and principles focused on the concepts of Ubuntu and Igwebuike, which present themselves as conflicting with the four principles approach (Sambala et al., 2019; Kanu, 2022). Just as bioethicists in Latin America and Africa have proposed their own sets of principles, there must be other peripheral spaces in which the same has been done. Yet, without an open invitation and active engagement with peripheral knowledge, it is unlikely that they will reach mainstream spaces in the West. There is a need for Western bioethics, as a field, to practice playful world-travel. If, as bioethicists, we would engage in the type of world travel argued by Lugones, we would be more intentional about our engagement with peripheral knowledge, and more interested in what is out there. We need to do a better job as a field to break out of our epistemic bubbles.

The Agapean framework is an example of cultural translation in which respectfully engaging with the work done in other parts of the world can inform our own work. The mere existence of frameworks like Intervention Bioethics and the frameworks developed in Africa point to the argument that there is not a ‘common morality’ that guides the field. Instead, there is a cultural preference over certain values that inform the work done in core countries. A cultural translation of concepts like ‘patient’ can help us move towards a more accepting notion. We need concepts capable of encompassing notions that diverge from a concept presented as universal but
which, in actuality, only considers the values of the culture from which it was conceived. Therefore, I have presented a revised Agapean framework as a model of the work that needs to happen as we move forward. Just as I have blended the concepts of intersectionality with the ideas of liberation to present a notion of the patient as an individual with intersectional identities who ought to be liberated and protected, we could do the same with other peripheral frameworks. The work done in this dissertation serves as a blueprint of a needed alternative, the combination of different notions and ideas into a coherent translation.

Coming face-to-face with the Other will require the abandoning of the simplicity of a common morality, for a more complicated and demanding project that seeks to open our spaces to diverse voices. Only through this demanding work can we commence the work of culturally translating deeply rooted notions in the field. However, without it, we will continue the invisibilization of people like Ana, whose plight is reduced to set principles which ignore her intersectional complexity. Given the real-life effects of diminishing and invisibilizing the needs of the Other in healthcare, it is urgent that we engage in this intersectional work. Let us evolve as a field towards a state of alterity, where the totality of commonality and sameness can be discarded for the transformative call of agapean love.
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