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# THE ETHICAL CONTRIBUTION OF CULTURAL DIVERSITY AS A SOCIAL DETERMINANT OF HEALTH

#### A Dissertation

Submitted to the McAnulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for the degree of Doctor of Philosophy

By

Pooja Patel

May 2023

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Pooja Patel

# THE ETHICAL CONTRIBUTION OF CULTURAL DIVERSITY AS A SOCIAL DETERMINANT OF HEALTH

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#### **ABSTRACT**

# THE ETHICAL CONTRIBUTION OF CULTURAL DIVERSITY AS A SOCIAL DETERMINANT OF HEALTH

By

Pooja Patel

May 2023

Dissertation supervised by Gerard Magill, PhD

The dissertation examines how cultural diversity as a social determinant of health, being aligned with human life, human dignity, human rights, and human equity provides an ethical contribution. My explanation of the ethical contribution of cultural diversity as a social determinant of health refers to a quadrant of topics that expands the approach of the UNESCO Declaration of Bioethics and Human Rights. The UNESCO approach addresses cultural diversity in relation to human dignity and human rights my explanation expands UNESCO's approach. I adopt a quadrant of topics that aligns human dignity with human life and human rights with equity. The alignment of these topics in the quadrant (dignity/life and rights/equity) explains the meaning of cultural diversity as a social determinant of health.

In the 21<sup>st</sup> century, diverse cultural contexts can provide meaningful, holistic insights into real-lived experiences which are crucial when serving humanity in the many facets of healthcare.

These insights are important in healthcare because they can support healthcare professionals at large to supply care that meets each individual needs within unique social contextual features. In a pluralistic society having these care needs met can make a vast difference between providing care versus providing care that is effective and adequate for the real-lived experiences of an individual. The ethical contribution of cultural diversity as a social determinant of health aligns life with dignity and rights with equity changing the way healthcare is viewed. In a multicultural world, this ethical contribution can support diverse needs to ensure that the individual gets the care they need despite their differences or care needs. In the current and near future of the 21st century, the ethical contribution of cultural diversity as a social determinant of health will be vital to sustaining the flourishing of current and future generations.

#### **DEDICATION**

#### This dissertation is dedicated:

To my parents, it is their efforts, struggles, and sacrifices that have allowed me to be where I am today. I hope I have made you proud.

To my sisters who continuously share words of advice and provide moral support.

I love you both.

To all the people who I hope this work will help in the future of healthcare.

#### ACKNOWLEDGEMENT

The completion of this undertaking could not have been possible without the participation, assistance, and support of so many people whose names may not all be enumerated. Many have willingly walked with me and encouraged me in this Ph.D. journey, and for them I am forever grateful. Their contributions and time are sincerely appreciated and gratefully acknowledged.

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Mom and Dad, I am forever grateful for your love and encouragement. Thank you for always supporting me to follow my academic and professional interests. You both believed in me every step of the way, even when I didn't believe in myself. Although I will never understand the depth of the hardships you endured, I deeply acknowledge the sacrifices that you made in order for us to grow and flourish. I love you both so much and am grateful for you every single day. You instilled in me the value of hard work, dedication, and persistence that have carried me through this undertaking. I appreciate the wisdom you have shared with me in this process and in my life.

To my little sisters, thank you for always standing by my side. Thank you for always laughing and joking with me. Although you both are younger than me, I can always count on you for sound life advice and emotional support. Thank you for loving me even when I was stressed.

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#### **Chapter 1: Introduction**

The dissertation examines how cultural diversity as a social determinant of health, being aligned with human life, human dignity, human rights and human equity provides an ethical contribution. My explanation of the ethical contribution of cultural diversity as a social determinant of health refers to a quadrant of topics that expands the approach of the UNESCO Declaration of Bioethics and Human Rights. The UNESCO approach addresses cultural diversity in relation to human dignity and human rights. My explanation expands upon the UNESCO approach. I adopt a quadrant of topics that aligns human dignity with human life and human rights with equity. The alignment of these topics in the quadrant (dignity/life and rights/equity) explains the meaning of cultural diversity as a social determinant of health.

This section situates the need for this argument by presenting the state of the question. With the evolution of globalization in society, existing literature and analyses have presented extensive legal guidelines and bioethical principles and frameworks. These standards support 21st-century healthcare because they support human dignity and human rights. Nonetheless, there can be the dangers in these approaches because of lack of attention to cultural diversity.

Assessing the ethical issues related to cultural diversity requires respect for the real-lived experiences of human beings. This dissertation focuses on the ethical contribution of cultural diversity by presenting it as a crucial social determinant of health – doing so requires extending the focus on human dignity and human rights to align respect for human dignity with human life and to align respect for human rights with human equity.

Preceding research and literature on cultural diversity in healthcare have focused on areas such as cultural differences and racial diversity without considering contextual features. This dissertation's approach emphasizes contextual features by exploring the foundations and

processes of cultural diversity in healthcare. In the current literature on cultural diversity, writers structure their arguments on unifying concepts such as social justice and cultural competence, which encourage the protection of diverse people, collectively for the common good. However, this can infringe on individual respect for autonomy because everybody has unique and diverse needs. What protects most people might not be fitting to protect all individuals. As such, social justice and cultural competence are not in themselves sufficient for respect of the practical real-life experiences of individuals. These real-life experiences of individuals are crucial for understanding cultural diversity if we are to address the foundations and processes of cultural diversity in healthcare.

A crucial aspect of cultural diversity is understanding the significance of pluralism in society. Typically, respect for cultural diversity is conditional upon understanding pluralism as enshrined in legal frameworks and universal declarations, such as the UNESCO Universal Declaration of Bioethics and Human Rights. This Declaration has emphasized the need for ethical deliberation in policy formulation, clinical processes, and public and global healthcare sectors by being attentive to cultural diversity from both secular and religious perspectives.

The ethical contribution of cultural diversity in healthcare is rooted in operationalizing ethics in varying aspects of healthcare across cultures - from the clinical care context to bioethical concerns and issues faced in global health. By grounding cultural diversity at the core of ethics discourse, healthcare professionals at large can uphold it as an ethical obligation for current and future generations. Identifying current ethical concerns help in understanding the challenges in a pluralistic society, providing ways to address these concerns in the future.

It is important to acknowledge that respecting cultural diversity cannot just be developed through reading or taking training classes which is the aim of cultural competency curricula.

Rather, respect for cultural competency requires an ongoing process of understanding human needs, risks, and rights in relation with one another. Also, respect for cultural competency requires continuous learning of multicultural population needs at varying levels in the healthcare sector. These levels include clinical care, and national, global, and local health entities.

Ongoing guidance, consulting, or learning opportunities at each level are widely available. For example, healthcare professionals have a duty to uphold the rights of the patient as a person across cultures; governing entities have a duty to create protocols which impact current and future populations from culturally diverse perspectives; and public health professionals support population health and create policies that promote wellbeing for the public across cultures.

The ethical principles and legal frameworks discussed in this dissertation emerge from the current literature to plan the future of healthcare, such as addressing cultural diversity during emergency outbreaks for populations with varying needs, as occurs in pandemics, especially reflecting globalization today. The typical focus of cultural diversity on human dignity and human rights (as explained in the UNESCO Universal Declaration of Bioethics and Human Rights) needs to be expanded significantly. This expansion needs to align human dignity more profoundly with the meaning of human life and align human rights more extensively with the demands of human equity. This combination of the alignment of human life with human dignity and the alignment of human rights with human equity enables cultural diversity to be properly understood as a crucial social determinant of health, as explained in the dissertation.

The dissertation discusses the ethical contribution of cultural diversity as a social determinant of health. The typical focus of cultural diversity on human dignity and rights needs to be expanded. This expansion aligns human dignity more profoundly with the meaning of

human life and aligns human rights more extensively with the demands of human equity. These alignments enable cultural diversity to be properly understood as a social determinant of health.

Hence, the thesis of the dissertation is, The Ethical Contribution of Cultural Diversity as a Social Determinant of Health. The argument unfolds in each chapter as follows. After the introduction to the dissertation in Chapter one, there is an explanation in Chapter two of the significance of cultural diversity in healthcare to set the context for the discussion. The subsequent chapters discuss the ethical contribution of cultural diversity as a social determinant of health, being aligned with human life (chapter three), dignity (chapter four), rights (chapter five), and equity (chapter six). Chapter three discusses the importance of valuing human life, especially given the ethical controversies at the start of life and at the end of life. Chapter four explains the significance of upholding human dignity in multicultural clinical care, considering the role of ethics consultations in bridging cultural competencies in healthcare and adopting an ethics of care approach in cross cultural care. Chapter five explores the need for supporting human rights in healthcare in pluralistic society, focusing on multicultural population health needs and seeking a re-balance between the bioethical principles of autonomy and justice. Chapter six addresses the urgency of cultivating equity in global health, especially though achieving justice in public health responses and addressing equity during pandemics. Chapter seven presents a brief summary of the dissertation.

#### **CHAPTER SUMMARIES**

Chapter 2. The Significance of Cultural Diversity in Healthcare 2.A. The Foundations and Processes of Cultural Diversity in Healthcare

#### I. Cultural Diversity as Foundational for Healthcare

The foundations of cultural diversity as a social determinant in healthcare are ethically grounded in human life, human dignity, human rights, and human equity. According to the

UNESCO Universal Declaration of Bioethics and Human Rights (UDBHR), "human dignity, human rights and fundamental freedoms are to be fully respected," and, "the interests and welfare of the individual should have priority over the sole interest of science or society."

<sup>1</sup> The argument of this dissertation emphasizes the necessary connection of human life with human dignity and of human rights with human equity to clarify the ethical contribution of cultural diversity as a social determinant of health.

In *Human Dignity: The Constitutional Value and the Constitutional Right,* Aharon Barak articulates that "[h]uman dignity as a social value reflects human dignity's place among the values of a given society at a given time...It is expressed in religious and philosophical texts, in literature and in the poetry of nations and societies." Human dignity refers to the intrinsic value that is infused in every human being. In a diverse society, sustaining dignity in healthcare can occur by recognizing cultural diversity as a crucial determinant of health.

Rights are constructed ideas, concepts, or things that can be morally, ethically, or legally justifiable.<sup>4</sup> According to the Universal Declaration of Human Rights (UDHR) preamble, human rights arise from "the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world." Natural human rights "...exists via a dispensation beyond human art or convention..."; they are not man-made such as laws, policies, and principles and as a result, cannot be taken away, depreciated, or rejected. Foundational understandings of natural human rights and human dignity support cultural diversity in the healthcare environment to establish and maintain person focused care. To deliver people centric healthcare, according to The World Health Organization (WHO), patients need to be viewed as individuals who are "participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways. People-centred

care requires that people have the education and support they need to make decisions and participate in their own care."<sup>7</sup> The necessary connection of human life with human dignity and of human rights with human equity highlights the ethical contribution of cultural diversity as a social determinant of health.

### II. The Processes of Cultural Diversity in Healthcare

The processes of cultural diversity in healthcare need to be understood in order to respect the foundations of human life/dignity and human rights/equity. In the UNESCO UDBHR, Article Twelve on Respect for Cultural Diversity and Pluralism states that "[h]armonizing the universal and the particular becomes then a necessary but difficult task; in some cases, a consensus may be achieved, but in others, it is only possible to state a pluralism of standpoints." As a result, the focus of cultural diversity on human life/dignity and human rights/equity is normative for engaging the social determinants in population health within a pluralistic world.

Typically, in healthcare, the skills needed to be responsive to cultural diversity is taught, recognized, or associated with the phrase cultural competency. Cultural competency involves learning skills that help a healthcare provider to deliver care to cross-cultural patients effectively. In "Cultural humility: treating the patient, not the illness," Prasad et al. articulate that "cultural humility may be defined as a process of being aware of how people's culture can impact their health behaviours and in turn using this awareness to cultivate sensitive approaches in treating patients." As a result, cultural humility is a continual process that involves self-reflection, self-awareness, and promotes empathy, compassion, and inclusivity in healthcare.

The meaning of a pluralistic society can be one in which more than one kind of experience, norm, and moral exist side by side homogeneity between different groups of coexisting people and may differ because of cultural differences. In "(Bio)Ethics in a Pluralistic

Society," Ben Gray draws the conclusion that "even if the people in a community were in some respects culturally homogeneous (for example, all the same ethnicity, or all adherent to the same religion), they will not all share exactly the same values and beliefs. Every person is a member of several different 'cultures." As a result, transformation from a broader perspective may be a keystone to shaping clinical encounters, healthcare policy, public health, and global bioethics.

Supporting the growth in multicultural populations may help alleviate ethical conflicts and misunderstandings in hospitals that arise due to differences in values between healthcare workers and patients. Geri-Ann Galanti, in *Caring for Patients from Different Cultures*, stated "[t]he kind of health care provided by the American medical system is often influenced by financial considerations, whereas concern for family, lower on the list of 'American' values, influences much behavior in patients from other ethnic groups."<sup>12</sup> As a result, geographical locations may also have unique cultural impacts on population health that influence various lifestyles or worldviews.

#### III. Cultural Diversity in Healthcare

Awareness of cultural diversity in healthcare has arisen due to changing demographics in the United States and increasing disparities in healthcare access and quality of care received across diverse groups of people.<sup>13</sup> In *Diversity and Cultural Competence in Health Care*,

Dreachslin et al. stated that despite the definition of healthcare disparities, one thing is sure "that groups living in this country, when compared with each other, do not enjoy the same life expectancies or levels of good health."<sup>14</sup> As a result, healthcare systems in the United States need an adaptation to bridge gaps in healthcare due to cultural diversity.

Public health is a facet of healthcare that aims to promote population well-being to prevent disease and injury.<sup>15</sup> H. Alderwick and L. M. Gottlieb, in "Meanings and

Misunderstandings: A Social Determinants of Health Lexicon for Health Care Systems," reference The WHO's description of social determinants of health insofar as they are the circumstances in which individuals are born into and age through and the social contexts throughout life. As a result, social determinants of health affect the population as a whole and not just on individual groups within, for instance, a socioeconomic scale. 17

This perspective highlights cultural diversity as a crucial social determinant of health. If cultural diversity is not taken into consideration, patients may be dissatisfied with the quality of care they receive, they may be prone to poor medication adherence, and as a result, this may lead to poor health outcomes and healthcare disparities. As a result, stereotyping or biases, and uncertainty on the skills needed to provide effective care culturally diverse patients are sources that can contribute to inadequate patient healthcare delivery and treatment.<sup>18</sup>

This approach to cultural diversity as a social determinant of health has significant ethical implications. Bioethics is the area of medicine and medical research where scholars apply morality through the notion of what is in the best interest for the common good. However, the common good, or morality, may vary between different cultures or people from diverse societies. <sup>19</sup> As a result, in order to meet the challenges that emanate from the culture of the 21<sup>st</sup>-century including the advances in technology, medicine, and science, that differ from diverse values around the globe, it is necessary to consider varying considerations of morality or the common good; such as by understanding the ethical contribution of cultural diversity as a crucial social determinant of health. <sup>20</sup> This approach enables bioethics to support human life/dignity and human rights/equity. It is by respecting cultural diversity in this way that a sustainable approach can be developed in global bioethics.

2.B. Sustainability in global bioethics by respecting cultural diversity in healthcare

### I. Bioethical Principles to Protect Environmental and Human Health

Cultural diversity as a social determinant of health is closely related with planetary ecology. In "Environmental Sustainability: Ethical Issues," Reena Patra points out that nature is not an end in and of itself to something but rather a means for something such as a means for life forms that live on planet Earth to survive.<sup>21</sup> The flourishing of a human society that lives within equipoise needs to take into consideration its environment. Article 17 of the UNESCO UDBHR focuses on the protection of the natural environment. Article 17 explains that bioethics encompasses the moral decisions that should be regarded with the consideration of all life forms and that human beings have a collective social responsibility to protect the ecosystem.<sup>22</sup> Bioethical principles such as autonomy, beneficence and non-maleficence, and justice that are prominent in being attentive to cultural diversity may help protect the Earth's natural resources.

In theory, the principle of autonomy would ensure individuals within culturally diverse communities around the globe can sustainably utilize environmental resources and make informed decisions. For instance, Lambert et al. discuss that the autonomous standard of the 'right to know' supports prevention, planning, or precaution such as informing the public of possible contaminants found in food due to toxic environmental exposure to natural resources. An expanded autonomous perspective would help foster a common understanding by creating shared knowledge to help protect people individually and collectively.<sup>23</sup>

Similarly, sensitivity to cultural diversity facilitates an environmental approach to human health from the perspectives of the bioethical principles of beneficence and non-maleficence in decision making. Beneficence and non-maleficence may help identify the difference between safe exposure of contaminants and harmful exposure of pollutants to the environment and humans. Lambert et al. argued that "[f]rom a consequential perspective, communication about

contaminants stems from consideration of whether the contaminant or the communication itself will generally cause good rather than harm (i.e., not from a responsibility to the people)."<sup>24</sup>

Likewise, sensitivity to cultural diversity facilitates an environmental approach to human health from the perspective of environmental justice: "environmental ethics can fortify the moral fabric of the environmental justice movement." Bioethical views should "demonstrate the social facets of environmental ethics in an applied context. For instance, restorative justice represents an ethical framework in which the injustices faced by marginalized groups are acknowledged and honored by others." Hence, cultural diversity fosters an approach to environmental justice that can help sustain ecological justice on a population and environmental health level.

### II. Valuing Cultural Diversity

Cultural diversity brings with it diverse ways of life including unique world views. These diverse ways of life can provide unique past and current world insight to improve future decisions or choices for living in equipoise with nature. Specifically, cultural diversity fosters attentiveness to global environmental concerns, which affect human beings' quality of life on all levels, encompassing environmental and social issues. In "Protection of the Environment, the Biosphere and Biodiversity," within the *Handbook of Global Bioethics*, Johan Hattingh argues the advancements in science and technology that positively empowered human beings ultimately created rapid negative impacts, such as extinctions, on the Earth.<sup>27</sup> Combined, these environmental concerns create risks for the quality of human and the survival of all life forms.<sup>28</sup> As a result, humanity and population health face a multifaceted global environmental health crisis.

Cultural diversity can shed light on the need to respect global human impacts on the health of the habitats of the various eco-systems on Earth. Deforestation, habitat extinction or destruction, and wildlife or natural stressors all contribute to the degradation of the eco-system's health. Hattingh pointed out that the arguments for why the Earth's system require human attention are centered around Earth's instrumental and intrinsic values.<sup>29</sup>

Cultural diversity highlights the need to respect biological diversity. Acceptance and shared respect for cultural diversity are vital requirements that are necessary to foster a mutual empathy among the global population and environment.<sup>30</sup> Cultural diversity can provide a common ground across global populations, recognizing "the irreplaceable element of their own humanity in others."<sup>31</sup> That is, culturally diverse global populations can recognize environmental concerns as a common human concern.

Cultural diversity creates an affinity for the different and shared environments of planet Earth. Section 3 in IOM's "Rebuilding the Unity of Health and the Environment: A New Vision of Environmental Health for the 21st Century" discusses that the relationship between nature, humans, and health are also echoed in other disciplines, such as philosophy, ethics, and the arts; there is evidence that build on this understanding to work towards improving human health.<sup>32</sup>

#### III. Global Bioethical Sustainability

The UNESCO and UNEP Roundtable from The World Summit on Sustainable

Development, Johannesburg, South Africa, the United Nations Millennium Declaration (2000)

shares this attentiveness to environmental differences: "[b]iological diversity represents this

dynamic process spanning hundreds of millions of years, and has been the key to survival,

sustainability and prosperity of those species and the ecosystems in which they flourish." This

focus on sustainability is indispensable for bioethics and is enlightened by attentiveness to

cultural diversity. Achieving global bioethical environmental sustainability is crucial for human and environmental health and healthcare for future generations.

Sustaining the Earth's environment is a growing global concern. Cultural diversity helps to enlighten the challenge of environmental sustainability. In Chapter 5 of *Promoting Global Environmental Sustainability and Cooperation*, the authors assert that there is a "green gap globally" between the concern for taking care of the environment and the practical measures to achieve environmental sustainability.<sup>34</sup>

Natural resources are in danger because of the way human beings interact and recognize the Earth's natural systems.<sup>35</sup> Attentiveness to cultural diversity can help potentially mend the negative impacts of advancements in the 21<sup>st</sup> century which have prioritized long term production for short term comfort.<sup>36</sup> Sensitivity to cultural diversity can contribute to sustaining natural resources, recognizing that individual identity is rooted in a broader cultural context that requires respect.

An appreciation of cultural diversity can help to revitalize biodiversity in a sustainable manner, especially from the perspective of human and environmental health. According to the UNESCO and UNEP Roundtable from The World Summit on Sustainable Development, this revitalization recognizes that "the way of life of most indigenous peoples depends on biological diversity" in a manner that "traditional spiritual values often serve to prevent overexploitation of resources and sustain the systems in which indigenous societies live for their own benefit and that of future generations." Cultural diversity can also help recognize diverse "nature-based solutions," such as creating green spaces in areas where they do not exist, such as urban areas, that benefit humans and their environment.<sup>38</sup>

In sum, cultural diversity is a social determinant of health that can enlighten environmental sustainability and global bioethics. The focus of the UNESCO Universal Declaration of Bioethics helps to appreciate that cultural diversity is ethically grounded in human life/human dignity, and human rights/human equity. The subsequent chapters examine these connected features of cultural diversity, beginning with the importance of valuing human life.

Chapter 3. Valuing Human Life at the Start and End of Life 3.A. The Value of Human Dignity in the Human Embryo.

# I. The Beginning of the Human Life Form

Attentiveness to cultural diversity facilitates an appreciation of the meaning of human life from a variety of perspectives, religious and secular. S.A. Benner's article, "Defining Life," echo's notions from a committee gathered by NASA in 1994, life was defined as "a self-sustaining chemical system capable of Darwinian evolution." The notion of Darwinian evolution, and theory, was examined throughout the article; Benner stated that the concept of random variation within the theory refers to the idea of being unbiased, or neutral to future outcomes. According to the scientific perspective, the human embryo is merely a cluster of cells. The embryo in the form of a blastocyst has no organs, bodily systems, or even bodily fluids because the embryo has not yet been implanted in the uterus. On the contrary, according to varying religious perspectives, the human embryonic stage is a morally pertinent life form.

Biologically, a blastocyst may not always be regarded as a valuable human life because it is composed of cells within a fluid-like substance. As a result, these human embryonic cells are not seen as comparable to a more developed and reasoning, human being.<sup>41</sup>

In *The Sacredness of Human Life*, David Gushee expands that "many Christians have coalesced around the position that a human person with the same moral status as anyone reading this sentence begins at conception—presumable meaning that moment when the egg nucleus and the sperm nucleus fuse to begin the development of human life."<sup>42</sup> From a Hindu perspective,

biologically the human life form is morally valuable because it is viewed as the highest life form. From the Hindu viewpoint the beginning of life is recognized varyingly. Crawford points out that religious traditions and understandings shared insights accumulated over time via analysis and considerations on moral and ethical issues. As a result, religious viewpoints speak to the human species as a whole and address universal concerns related to health and well-being despite the new advancements in medicine and technology over time.

Christians believe human beings are crafted by God in His likeness. A human being's physical body resembles its Creator and human life is valuable. Likewise, man and woman have an elevated status because they are embedded with the ability to morally reason and make sound judgements like their Creator. Hinduism, as a polytheistic religion, regards the birth of a human as the rarest and most respected forms of life. To be respectful of these understandings of valuing human life requires a sensitivity to cultural diversity, including different understandings of the human embryo.

#### II. Why Do People Value Life in the Human Embryonic Life Form?

Life is valuable in a human embryo because the cells at this stage intrinsically characterize what we know to be a morally reasoning human being. Ethically, the human embryo is a valuable life form because it has dignity and sanctity.

Jill Graper Hernandez argues that "the dignity we ascribe to persons comes from the thought of them acting morally because they are capable of setting sound prudential and moral ends, but it is the dignity of morality that makes us responsible to one another as moral agents."<sup>47</sup>

The central ethical dilemma is determining when and how a human embryo, becomes identifiable as human life to the person reading this paper.<sup>48</sup> When human dignity is linked to social relationships and the human being is required to socially participate in society. When

human dignity is recognized in both the individual and the community, based on a shared commitment, then there is duty involved to one other.<sup>49</sup> In this vein the intrinsic value of life in a human embryo is not as apparent on the surface.

Both Christianity and Hinduism regard the human life form as sacred. Christianity regards the human life form as sacred because humans are embedded with the ability to morally reason and make sound judgements just like the Creator.<sup>50</sup> On the other hand, Hinduism regards the human life form as one of the rarest and highest life forms.

Despite the preceding controversy, the inherent moral status is embedded in human existence in the earliest stages of life. In "Ethics and Embryos," Poplawski and Gillett suggest "that the form of a human being extends beyond that present at a given slice of time to take in the breadth of an entire life."<sup>51</sup> As a result, each of these developmental stages are sequential processes of life because each stage is an essential component of the whole human being. Attentiveness to cultural diversity highlights the significance of these developmental stages and the accompanying ethical concerns that are raised.

#### **III. Ethical Concerns**

The ethical concern surrounding the value of life in a human embryo arises when defining what a human embryo is and what moral status it has. The religious, secular, and scientific perspectives can be black and white when describing the biological stages but not the inherent moral value of a human embryo. The polarizing views of the spectrum argue, "[i]f the human embryo is indeed a human being, then there are quite serious concerns regarding its proper moral treatment. If, on the other hand, it is merely a cluster of cells that have a human origin, the moral landscape is quite different."52

Sensitivity to cultural diversity fosters empathy to the complex moral debate on the natural human rights of a human embryo. Socio-culturally and religiously an embryo may be understood as having rights related to human life which are believed to be inherent in its mere existence. However, there are many conflicting views on natural rights as morally equal rights due to the lack of evidential proof to analyze natural human rights as they exist in a human embryo.<sup>53</sup> In order to analyze the basis for the natural human rights embedded in a human embryo one has to deduce the rights from a limited perspective. Poplawski and Gillett discuss how human life develops longitudinally. The moral value of human beings and when that moral value comes into existence cannot be marked or pinpointed. Here, the longitudinal continuum of is a progression that begins at the moment of conception and can continue until the end of life and as a result can be understood in comparison to the progression of color in a color spectrum.<sup>54</sup>

The moral significance of a human embryo is an ethical concern when compared to the moral significance of a developed human. Embryos are living organisms, but they are not developed persons, but they are not fully developed persons. In contrast, others argue that the moral significance of a human embryo is in the embryo's capacity to reason. Robert George and Patrick Lee define capacity for consciousness as "[a] capacity such as that for consciousness is a power to perform a specific type of action." Attentiveness to cultural diversity can help to appreciate these contrasting debates, especially with regard to the meaning of the intrinsic value of human life and concomitant human rights.

#### IV. Intrinsic Value of Life

The intrinsic value of life may be defined as the value that a life has "'in itself,' or 'for its own sake,' or 'as such,' or 'in its own right." When the intrinsic value of life is recognized, it results in empath. In *The Ethics of Abortion*, Christopher Kaczor reasons that "[o]ne could

believe that all forms of life in the universe (including plants and insects) are equally sacred and should all be treated as persons."<sup>57</sup> However, the intrinsic element that gives manifestation to human life from an embryo is the energy behind the biological processes based in the physical. The blastocyst develops into other fetal stages and moves towards "functional rationality."<sup>58</sup> Sensitivity to cultural diversity can help to appreciate the different interpretations of these developmental stages at the start of life and to appreciate the different interpretations that occur at the end of life.

# 3.B. Cultural Diversity in Religious Approaches to Palliative End of Life Care **I. Bioethical Normativity**

Cultural diversity (such as related to ethnicity, religion, and tradition) reflects shared aspects, such as knowledge, between groups of people that influence their ways of life or world views.<sup>59</sup> Similarly, being attentive to cultural diversity can enlighten the varying ethical considerations that arise in palliative end of life care decision making. These varying viewpoints occur in different religions such as Hinduism and Christianity with their normativity of concepts related to the valuing of life, justice in the death and dying journey, and the meaning of community.

Both Hinduism and Christianity illustrate the widespread religious regard for human existence as sacred. Christianity and Hinduism regard the human life form as sacred. This sacredness of life stems from man being created in the image of God, *imago dei*. The human life form is always in harmony between the two entities, the material body and the soul. 61

Awareness of cultural diversity can help to distinguish treatment decisions in palliative care. End-of-life care involves considerations central values of a patient and family's religious tradition.<sup>62</sup> For example, justice toward a natural virtuous death is the core human concept that can be sustained. According to Christianity, due to the sanctity of human life, shortening of life,

or seeking of death, by anybody except God may not be accepted, or considered as a just or virtuous death.<sup>63</sup> Hindu philosophy ties the notion of virtuous death and dying to understandings of higher eternal consciousness, known as *Brahman*.<sup>64</sup> Karmic actions may help to ground the ethics of what should be morally acted or unacted upon based on *dharma*, or duty.<sup>65</sup>

Attentiveness to cultural diversity fosters sensitivity to varying normative approaches in bioethics in these religious traditions. In 21<sup>st</sup> century bioethics the respect for autonomy in decision making is a key principle that "runs as deep in morality as any principle, but determining its nature, scope and strength requires careful analysis." <sup>66</sup> Christianity emphasizes human beings are integral parts of the whole of a community or society. <sup>67</sup> Humans have moral responsibilities that are based in humanity. Human individuals are organically connected as a part of the whole society where that which is benefic cannot be neglected. <sup>68</sup> In "Normative Bioethics in Hinduism," Joris Gielen articulates that deducing Hindu bioethics from the lineage of virtue ethics may help to bring transparency to normative principles. Virtue ethics emphasizes virtuous characteristic traits of an individual person rather than norms that must be followed. <sup>69</sup>

#### II. Ethical Issues in Palliative Care

Attentiveness to cultural diversity is especially important when dealing with ethical issues in palliative care. As advances in technology, medicine, and healthcare continue to increase, so do ethical issues in palliative end-of-life care. Such advancements change the ways in which humans experience the death and dying process. Ultimately, technology and medicine in the 21<sup>st</sup> century have ability to intervene in the death and dying process, reshaping the end of life and empowering patients and their families with the autonomy of choosing and deciding their preferred treatments. <sup>71</sup>

Initiating curative or life-sustaining treatment at the end of life may impact the patient's quality of life.<sup>72</sup> Based on the Hindu approach to bioethics, palliative care is a combination of holistic healthcare and a kind of philosophy.<sup>73</sup> Initiating curative or life-sustaining treatment alongside palliative care can be seen as acceptable if the treatment's risks and side-effects are not worse than the patient's illness.<sup>74</sup> In Christianity, since human life is a sacred gift from God, end of life methods such as physician assisted suicide and hastening death in the form of euthanasia are prohibited.<sup>75</sup>

Understanding cultural diversity helps to foster empathy with varying approaches in endof-life care. Spirituality, and/or spiritual care, during times of distress and suffering help create a
relationship of hope, empowerment, and compassion for patients. In Christianity the "Ethical
and Religious Directives for Catholic Health Care Services," directive number 61 summarizes
that the patient should be kept free of pain and discomfort, so they are able to die with ease and
with maximum dignity, and, later states patients "should not be deprived of consciousness
without a compelling reason."
In other words, the individual's consciousness should not be
taken away without just reasoning. Furthermore, Hinduism may side with the refusal of
treatment by family members or non-intervention may reflect a socio-cultural belief that the
dying patient should be thinking of a deity(s) as they go through the natural dying process — this
is because it is believed that the kind of thoughts one has at the time of death determines the
future destination of that soul.

The contraction of that soul.

Furthermore, sensitivity to cultural diversity can foster empathy with the different meanings of suffering. One of the core concepts of 21<sup>st</sup> century medicine is the prevention or alleviating of pain and suffering.<sup>79</sup> From the Christian standpoint, suffering can be seen as a valuable part of human existence. Suffering has instrumental value because, without pain or

suffering, the human body would not know that it requires attention or care.<sup>80</sup> In Hinduism karmic suffering and pain are at the end of life are seen as a means to reach *moksha*. Ultimately, acceptance and detachment of pain and suffering are operational in helping the patient keep their focus on a higher power.<sup>81</sup>

#### III. Applying Bioethical Normativity to Diverse Approaches to Palliative Care

Attentiveness to cultural diversity can shed light on the role of different bioethical principles when considering palliative care. Bioethical principles such as autonomy, beneficence, non-maleficence, and justice are certainly important in healthcare. 82 However, they can lead to grey areas whenever applying to context-specific situations such as cultural or religious diversity where normative approaches may not always be clear. The goal of palliative care is to deliver support to provide a comfortable quality of life at the end of life. 83 From this perspective, sensitivity to cultural diversity fosters the legitimacy of different approaches to sensitive palliative care. For example, Hinduism and Christianity both seek to support the quality of life to die with dignity, and in this vein support palliative care.

Understandings of death vary from culture to culture.<sup>84</sup> Sensitivity to cultural diversity can facilitate different approaches to the experience of death. For example, naturally dying is highly valuable to both Christianity and Hinduism. In the "Ethical and Religious Directives for Catholic Health Services" directive 57 summarizes that forgoing extraordinary care or disproportionate means of preserving life may be acceptable.<sup>85</sup> Pain and suffering, from the Hindu perspective, as Whitman explains, are not viewed as bad but rather a natural part of the multifaceted human experience.<sup>86</sup>

Furthermore, awareness of cultural diversity can shed light on the importance of intent when making moral decisions in end-of-life care. From a deontological perspective, having the

correct motive and intention for a specific action is more important than achieving the desired result. 87 Human individuals are bound as a part of human society where the common good cis crucial and cannot be forgotten. 88 At the time of death, a patient may include their family, their next of kin, and even the provider as a part of a community. Furthermore, Gielen et al. state "the physicians and nurses agreed that the final decision about curative or life-sustaining treatment has to be taken by the patient and his or her family members. The treating physicians and nurses play an advisory role in the decision- making process."89

In sum, awareness of cultural diversity can contribute significantly to valuing human life at the start and at the end of life. Similarly, sensitivity to cultural diversity is crucial for upholding human dignity in the different clinical settings of patient care, as discussed in the next chapter.

Chapter 4. Upholding Human Dignity in Multicultural Clinical Care 4.A. The Role of Ethics Consultations in Bridging Cultural Competencies in Healthcare **I. Ethical Concerns** 

Attentiveness to cultural diversity shed light on how to address ethical issues that arise regarding respect for human dignity when delivering care to patients with value differences across many different social or religious backgrounds. In an *American Medical Association* (AMA) *Journal of Ethics* virtual mentor article by Henry S. Perkins, when considering the ethical values of patients, physicians must be aware of patient values that are shared, taught, and used to understand their different life experiences and backgrounds.<sup>90</sup>

Awareness of cultural diversity can be especially helpful with regard to patient consent.

Berg et al. discuss that informed consent has been created as a decision-making tool in the cultural context of the United States and in other cultures it may not have the same significance or weight. 91 If the overall framework and intention of informed consent is culturally variable

then its impact may be lost and may lead to a different understanding of the decision-making process. 92

This conflict arises from the informed consent philosophy in American medicine which includes the patient in their diagnosis and prognosis as a key part in building trust and a professional relationship between the provider and patient. Misrepresentation and nondisclosure create disrespect and distrust which leads to people feeling betrayed or manipulated even if the intention was benevolent. In some cultures, withholding information is not viewed as lying but rather as a method of protecting the patient from suffering and gives them hope for the future.<sup>93</sup>

Decision-making for patients is a critical factor in the medical context as it impacts the direction of a patient's treatment based on the decisions that are pursued or accepted. 94

According to Bernard Lo family members in certain states' cultural contexts within the United States, may be presumed to be surrogate decision makers from the patient's side because they have close relationships with the patients and may have discussed healthcare interventions. 95

#### II. Case Analysis

Differing values and goals regarding respect for human dignity between various parties lead to ethical issues in patient care. Culturally diverse understandings contribute to an essential role in how a patient may or may not receive information and how they respond to certain treatment recommendations. <sup>96</sup> An ethics case consultation may help examine and clarify each party's viewpoint to suggest what the best path or paths of care may be in regard to the patient's best interests.

A healthcare ethics case consultation may help guide ethical dilemmas in culturally diverse healthcare. The role of an ethics case consultant is to clarify, analyze, and identify differing values and goals to ultimately help resolve the ethical problems. Healthcare ethics case

consultations may be delivered by an individual ethicist, an ethics team, or an ethics consultant.<sup>97</sup> In ethical cases, the individual ethicist consultation may best be paired with the four topics approach which gives a simple yet clear framework to help guide the consultation process that respects contextual features such as cultural diversity.

The four topics method breaks down the consultation process into four parts: medical indications, patient preferences, quality of life, and contextual features.<sup>98</sup> The four topics approach would be the most appropriate for cases where cultural diversity is a key component because of the focus on the contextual feature of the case.

#### III. The Future of Ethics Case Consults

In "Reducing Disparities through Culturally Competent Health Care: An Analysis of the Business Case," Cindy Brach and Irene Fraser point out that one of the biggest challenges for the American healthcare system is finding ways to deliver superior care to culturally diverse populations. They argue that "[t]he persistence of racial and ethnic disparities in healthcare access, quality, and outcomes has prompted considerable interest in increasing the cultural competence of healthcare, both as an end in its own right and as a potential means to reduce disparities." <sup>99</sup>

Fostering cultural competency (as a function of cultural diversity) is an ethical responsibility that higher education programs have in order to train healthcare professionals. However, not all of the cultural competency issues that arise in a clinical context may be apparent and as a result, providers may benefit from education via an ethics consultation. Ethical consultations can provide an educative or teaching opportunity that is often supported by evidence-based education. <sup>100</sup>

Integrating an understanding of the ethical issues of cultural competency into the clinical setting can help build patient and healthcare provider relationships. While healthcare ethics are essential to patient provider relationships, to reduce healthcare disparities cultural competence is necessary.<sup>101</sup> Ethics case consultations may help improve cross cultural healthcare outcomes by bridging gaps in communication, education, and healthcare provider(s) relationship building.

The literature, experts, and articles mention that communication, other than the native language spoken, may lead to significant disparities in the healthcare context. Often times conscious or unconscious negative attitudes towards a specific racial or ethnic group may negatively impact the healthcare provider and the patient in the healthcare decision making process. An ethicist may help the healthcare provider or team to better understand the context of cultural diversity required for the patient and their family and as a result help guide the healthcare providing team to possibly cater to the patient as a unique person.

Sensitivity to cultural diversity can help to foster a sound approach not only to ethics consultation but also to what can be called cross cultural care.

#### 4.B. An Ethics of Care Approach to Cross Cultural Care

#### I. Ethical Concerns

Sensitivity to cultural diversity is indispensable for cross cultural care. Ethical concerns around informed consent, respect for autonomy, and decision making may be prominent during cross cultural care. A care ethics perspective echoes the notion that individual human needs are fostered, nurtured, and strengthened through human relations. <sup>104</sup> Care attribute are especially attentive to cultural diversity. An ethics of care approach may help support relational autonomy and relational morality in the informed consent and decision-making processes. This is especially crucial in cross cultural care as an ethically sound method of morally upholding the normative component of individual human dignity.

Informed consent has proven to protect patients, enhance communication processes, and increase provider advocacy to improve care outcomes. <sup>105</sup> In certain instances, however, the ethical principles found in the informed consent process may not be applied universally in an independent manner as expected according to traditional Western medicine standards. <sup>106</sup> This is where sensitivity to cultural diversity can be so helpful. In certain cultures, it may be ethically appropriate to value the input of family members during the informed consent. <sup>107</sup> Autonomy is a principle in dominant bioethical theories, such as principlism, that enables an individual to self-decide for themself. <sup>108</sup> It is important to uphold autonomy in cross cultural clinical settings, with the intention that a patient's decision is ultimately autonomous but the patient and their dignity as an individual agent is always in relation to other human beings. <sup>109</sup>

From this perspective, upholding patient autonomy requires respect for the cultural diversity of the patient. In the United States culture, since the individual is viewed as the main agent, concepts of autonomy and independence are highly honored in decision making. In this vein, individuals are required to undertake their own decisions, given they are mentally competent, <sup>110</sup> in a manner that respects their cultural diversity.

### II. Care Ethics Approach

In particular, sensitivity to cultural diversity also sheds light on the contribution of the ethics of care. The promotion of human dignity in cross cultural care should provide human centric solutions to ethical concerns by deepening the understanding cultural diversity and its accompanying values in clinical care. The ethics of care bioethical theory acknowledges that human physical and social needs should be met within a caring, supportive context as a form of honoring genuine lived through human life experiences.<sup>111</sup>

Since individual human autonomy may be less valued and interpersonal consultation may be a norm in certain cultures, honoring informed consent in the cross-cultural context may present challenges. An ethics of care approach deepens the understanding of the informed consent process and justifies the moral boundaries that are necessary for the interdependence of human relations in cross-cultural care.

In an ethics of care approach, relational autonomy can be ethically justified as supporting the collective human flourishing through caring for the individual. A ethics of care approach can enhance provider understanding of the need to foster an integrated view between themselves and the patient as a way of morally developing through the therapeutic relationship. The care ethics theory originates from the relational lens of humans and considers that care is an assumed aspect of human existence. However, it more significantly deems that care is that which intertwines people into a network of interweaving relations that are held with other living beings. Care ethics accepts the notion that human beings are social beings who are a part of a web of relations that reflects cultural diversity.

### III. The Care Ethics Approach to Enhance Cross Cultural Care

Respect for cultural diversity in an ethics of care approach in healthcare should aid in creating and fostering "mutual responsiveness" personally, such as in clinical care, and socially, such as in public health. Working to gain a deep understanding of the patient as a human being can help build strong, trusted patient and healthcare provider relationships. 116

While healthcare ethics are essential to patient-provider relationships, in order to bridge cultural knowledge, strong communication and trust are a necessity to respecting culturally diverse methods of healthcare delivery, such as disclose healthcare information. Furthermore, a "new ethos" should foster the understanding of autonomy and patient freedom as a valuable

source of insight into patient choice and preference based on their own human life experience, social determinants of health, or cultural background.<sup>118</sup>

The concept of patient centeredness was created by Balint in 1969 in order to express the notion that each patient is a person and to advocate for patient's to be seen as people. Somnath Saha et al. articulate that patient centered approaches are important because they may allow healthcare providers to view each patient as a unique person within their own socio-cultural circumstances and this helps to promote trust and confidence in the healthcare provider. When the healthcare provider gains a deep understanding of the patient as a unique person, their cultural values and preferences can help guide how they wish to receive their healthcare.

Shared decision making may help patients make sound medical decisions with the interpersonal integration of their family members as a method of honoring the complexity of human existence. Shared decision making is patient and family oriented and is gaining recognition as another ideal methodology for healthcare decision making. An ethics of care approach can aid in incorporating shared decision making in clinical care. This provides a method of fostering individual human dignity by understanding interpersonal communication methods that lead to particular decisions.

Attentiveness to cultural diversity supports a focus on human dignity in different clinical contexts, such as when adopting an ethics of care approach. This sensitivity to cultural diversity as a pivotal social determinant of health is also crucial for supporting human rights in healthcare in pluralistic society.

Chapter 5. Supporting Human Rights in Healthcare in A Pluralistic Society 5.A. The Ethical Contribution of the Social Determinants of Health Toward Advancing a Focus on Multicultural Population Health Needs in Clinical Care

I. Social Determinants of Health Provide Insight into Sources of Health Risks and Needs

Cultural diversity as a pivotal social determinant of health focuses on human rights in healthcare in pluralistic society. Health risks in diverse populations are an ethical concern because they can create distinct disparities or disproportionate in clinical care access and quality, which permeates over into one's quality of life.<sup>121</sup> In "Non-clinical influences on clinical decision-making: a major challenge to evidence-based practice," F.M. Hajjaj et al. note that medical health factors are just one of the dimensions of clinical decision-making that impact human wellbeing and that nonmedical health factors such as personal and economic stability and social factors (age, race, ethnicity, etc.) also provide a deepened dimension into well-being.<sup>122</sup> These factors are characteristic features of cultural diversity as a social determinant of health.

Another characteristic of cultural diversity is language barriers and communication gaps. In clinical care in the United States, patients who speak English as a second language are among the most vulnerable and predisposed patients to health risks because they face greater challenges when interacting due to language barriers with the clinician. The rising number of diverse patients in the United States means that communication gaps and errors between a healthcare provider, who speaks a majority language such as English, and a patient speaking a minority language, a language other than English, will need to be considered. These errors between the doctor and patients can lead to the latter's' misunderstanding of crucial healthcare information which can be life-threatening. The lack of proper communication even increases the risk severity, thereby leading to further adverse effects: "patients may fail to comply with instructions or choose not to have potentially life-saving treatment."

Another characteristic of cultural diversity is health literacy which is defined varyingly in healthcare literature. The Health Resources and Services Administration (HRSA) defines health literacy as the following: "the degree to which individuals have the capacity to obtain, process,

and understand basic health information."<sup>126</sup> Low levels of health literacy can significantly impact a patient's ability to engage with clinicians and manage their care.<sup>127</sup> These misunderstandings caused by low levels of health literacy can lead to health risks such as mortality due to prescription nonadherence, poor comprehension of medical directions or prescription labels, trouble managing chronic conditions; and sometimes even create feelings of shame among non-native English speakers.<sup>128</sup>

Also, another characteristic of cultural diversity as a social determinant of health is the socio-cultural environment and beliefs regarding healthcare. An individual's values and beliefs are shaped by social and cultural background factors and lead to differences in concepts and beliefs about health that impact behaviors in healthcare management. According to Rebolledo and Arellano in "Cultural Differences and Considerations When Initiating Insulin," false perceptions, views, and/or beliefs, about insulin or diabetes, impact the patient's decision-making and ability to manage diabetes via medially prescribed methods. 130

These characteristic features of cultural diversity as a social determinant of health highlight the need for cultural competence in the delivery of healthcare across multicultural populations.

### II. Culturally Competent Clinical Care Delivery for Multicultural Populations

A. Andermann states a vital point that location is a significant component that can help explain the disadvantages that specific patient populations will face "and will not always be obvious just from looking at the patient," their medical chart, or their medical condition. For instance, in the United States healthcare context, clinicians are very likely to encounter culturally diverse patient populations, such as Latinos or persons of Cuban, Mexican, or South American decent because they are a budding culturally diverse group(s). Furthermore, there are clear health

challenges that this specific population(s) experiences because of SDOH, such as their education levels, immigration status, and cultural beliefs and lifestyle factors. 132

In a pluralistic society, awareness of cultural diversity as a social determinant of health provides insight into unique human experiences and impact's a patient's current medical wellness or illness. <sup>133</sup> In "Back to the Basics: Social Determinants of Health," L. Spruce points out that many clinicians are not trained or do not feel they are in a position or role to address SDOH issues. <sup>134</sup> Larry Purnell in *Guide to culturally competent health care*, presents a framework for healthcare professionals to use in the clinical context that helps clinicians gain knowledge by asking questions on the real-life human situations of a patient during clinical care experiences. <sup>135</sup>

In healthcare, one of the dimensions of patient centered care requires the clinician to recognize the patient as an individual who is a human being, not just associate them with their medical condition. In IOM describes patient centeredness as "[p]roviding care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions. The importance of a patient-centered approach is personalization via robust communication, based on an understanding of the patient's real-lived experiences, goals, and uniqueness.

The unique real-lived experiences that a patient's cultural diversity provide as a social determinant of health can further promote a patient's trust in their healthcare provider. By understanding the patient's real-lived experience, a physician can cater care approaches that empower help patient's to create strong lifestyle management choices or behaviors. According to Dreachslin et al., a "successful healthcare encounter" is rooted in a balanced partnership

between the provider and the patient to support their social disadvantages in a way that "meet the patient where he or she is" to work with the patient's socio-cultural context or world. 140

#### III. Social Determinants of Health Can Expand the Role of Clinical Ethics

Attentiveness to cultural diversity as a pivotal social determinant of health is indispensable for effective clinical ethics. The growing demographic mix in the United States requires approaches to support multicultural population health enhancement. For instance, refugees living in nonnative countries escaping extreme conditions such as famine, natural disasters, and war will all face unique social determinants or challenges that impact navigating their care needs and wellbeing. Attentiveness in clinical ethics to care in a multicultural society requires respecting the unique care needs of individuals and developing the most appropriate method of care delivery suited for them.

Health advocates can strive to improve population health outcomes. Advocates have the ability to serve the underserved populations by creating or negotiating change and raising awareness for health and access to healthcare services. 144 Clinical ethicists are in a great position to serve as health advocates because they are trained to educate and advise clinicians and family members in the clinical care setting. Clinical ethicists' expertise, according to Inguaggiato et al., lies in "...facilitat[ing] a process of moral learning in which new ethical knowledge is co-created together with [healthcare] professionals." 145

Exposure to cultural diversity via competency courses is a responsibility that higher education programs have included in their curriculum in medical, graduate, and other higher education curriculum, especially with regard to clinical ethics. <sup>146</sup> Douglas et al. recommend continuing education to help clinicians and staff maintain their cross-cultural skills in contemporary clinical encounters. <sup>147</sup> For example, educational seminars on type 2 diabetes,

including information on how Mexican immigrants understand diabetes and the linguistic, dietary, and relational approaches to treat it may be beneficial for clinical care providers.<sup>148</sup>

In the *Handbook for Healthcare Ethics Committees*, one of the key functions of ethicists in hospitals is to educate and facilitate learning opportunities using pedagogical methods such as lunch and learns, journal clubs, or case trainings. Sensitivity to cultural diversity is indispensable for training in ethics case consultations to properly engage multicultural populations and their various needs. Cases presented at conferences would be a great resource to be used in training and education because, as Post et al. state, they have already been resolved or at least significant progress has been made. This progress in ethics case consultation must reflect competence in cultural diversity in clinical ethics. When there is a robust focus on cultural diversity, there emerges a re-balance between the traditional bioethical principles of autonomy and justice in healthcare.

5.B. An Ethical Re-Balance of the Principle of Autonomy and the Principle of Justice in Healthcare

### I. Ethical Concerns in Healthcare in a Pluralistic Society

A focus on cultural diversity can help to re-balance the principle of autonomy that upholds human life/dignity and the principle of justice that upholds human rights/equity in healthcare. Attentiveness to cultural diversity shed light on ethical concerns that arise due to differences in values, goals, and behaviors between the patient's cultural norms and the healthcare provider's professional duties. In healthcare, a patient's autonomy and rights are upheld when the provider contributes to delivering trusted medical care and disclosing information in accordance with the patient's right to know, privacy, and confidentiality.<sup>151</sup> Ethical concerns with the principle of justice arise when cultural needs, values, and preferences are overlooked, creating injustices toward treating the patient with fairness.

Participating in the process of informed consent is a patient's basic right, and obtaining informed consent from a patient is a doctor's professional duty.<sup>152</sup> Furthermore, Good et al. give many examples of how providers who care for vulnerable populations such as the minority, or culturally diverse patients, an informed consent documentation does not adequately fit or capture the complex realities of patients.<sup>153</sup> In "The Struggle for Equality in Healthcare Continues," E.O. Rutledge articulates that practices at the provider and organizational level still lack awareness (including diverse workforce, policies, etc.) to recognize the fullness of cultural diversity that is needed and indispensable for promoting justice among diverse patient populations. <sup>154</sup>

In the Western world, such as the United States, healthcare, institutional, and legal frameworks, competent patients have the autonomy to make their own healthcare decisions by using the medical information that the healthcare professional informs them of.<sup>155</sup> In "Challenging the bioethical application of the autonomy principle in multicultural societies," Andrew Fagan expresses that the current normative principle of autonomy does not explicitly reestablish a basis to support the provider and the patient when meeting as social, and as the scholar Engelhardt purports, "moral strangers." <sup>156</sup>

Legally and ethically, justice is the principle that entitles respect and rights affixed to each person, equally and universally.<sup>157</sup> In healthcare, the provider's duty is towards the health and well-being of the patient via the equitable or fair distribution of resources for the patient in their healthcare experiences aside from any conflicts of interest.<sup>158</sup> Balancing various forms of justice and understanding the ethical theoretical underpinnings are necessary to promote social justice.<sup>159</sup>

### II. Re-Balancing Autonomy: Empowering Patient Rights

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In the re-balance between the principles of autonomy and justice that arises out of sensitivity to cultural diversity, empowering the human rights of patients is a crucial characteristic of autonomy. In a pluralistic society, patients bring their own cultural language, behavior, and value norms into the context of healthcare via varying modes of decision-making, information disclosure, etc.<sup>160</sup> In "Examining American Bioethics: its problems and prospects," R.C. Fox et al. express concerns with the individualistic notion of autonomy, one of them being that it is insufficiently weighted according to the interpersonal and cultural preferences, values, and ideals of life.<sup>161</sup> In situations where when understanding of "reasonable' conduct" conflict between the patient and provider, exploring cultural background, models of morality and deliberation, and the like are crucial in the care delivery process.<sup>162</sup>

Although the information presented in consent documents may be sufficient for ethically and legally displaying the medical diagnosis and treatment options per the institution's policies, it is not sufficient for the provider when trying to understand the preferences and values of a culturally diverse patient to understand their life context. <sup>163</sup> For non-native English speakers, Gaurab Basu et al. in "Clinicians' Obligations to Use Qualified Medical Interpreters When Caring for Patients with Limited English Proficiency," state that access to language services is a vital component for successfully navigating the healthcare experience and expressing choices and decisions in healthcare for patients with LEP levels. <sup>164</sup> In some cultures family members are viewed as highly trusted entities, compared to a third party. <sup>165</sup>

In care that is sensitive to cultural diversity, effective communication can help demonstrate respect and appreciation of differences in values between the patient and provider. Brown et al. state that "[w]hen clinicians become conscious of their own beliefs and values, they may become more receptive to those of the patients." One of the reasons for self-

governance in patient and provider relationships is that it gives patients the autonomy and opportunity for their choices and concerns to be expressed or voiced.<sup>168</sup>

Informed consent is an event that requires an interpretative process in the United States medical context that should build trust between the patient and the provider and helps patients gain information to make informed decisions.<sup>169</sup> Adequately informing a patient helps build a strong patient-provider relationship rooted in trust and aids the provider in crafting adequate ways to support patient autonomy in a manner conducive for the patient.<sup>170</sup> The goal of informed decision-making for providers is to give the patient the information that supports them to "consent" (to choose) or reject the most appropriate decision(s) for themself.<sup>171</sup>

Just as empowering patient rights is a crucial characteristic of autonomy that arises out of sensitivity to cultural diversity, similarly the providers duty to protect rights is a crucial characteristic of promoting social justice.

#### III. Re-Balancing Justice: The Providers Duty to Protect Rights & Promote Social Justice

Sensitivity to cultural diversity includes a duty by providers to protect the human rights of patients. In the informed consent process, the duty of delivering justice through fair and equal treatment can translate into the provider's responsibility to protect and promote patient welfare interests. <sup>172</sup> In "Equity and population health: toward a broader bioethics agenda," Norman Daniels suggests that "[i]f society is responsible for causing the initial inequality through unfair policies, it may have special obligations to give more weight to equity than maximization and to consider the speed at which it rectifies the effects of past injustice." <sup>173</sup>

From Douglas et al.'s perspective, "social justice places the responsibility on society... to safeguard the health and well-being of the vulnerable while ensuring the protection of human rights." <sup>174</sup> E. Clingerman's article discusses how a social justice framework coupled with

concepts underscored in cultural competency can support both patients and providers when engaging in and delivering multicultural care.<sup>175</sup> For instance, Good et al. describes that getting to know a patient makes the patient-provider relationship stronger, because the clinician can connect to the social needs of the patient on a human-to-human level.<sup>176</sup>

The notion of cultural safety as a component of cultural diversity was created by Dr. Irahapeti Ramsden and Māori nurses with the intent to deliver utmost care.<sup>177</sup> Cultural safety supports the provider to support the patient. Cultural safety helps the provider meet the patient where they are; this includes supporting the patient's rights and values, safely, despite the providers having their own cultural contexts.<sup>178</sup>

In "Healthcare justice and human rights in perinatal medicine," by Chervenak and L. B. McCullough, the viewpoint of Gregory and Percival who are physician-ethicists on the therapeutic relationship is summarized. One of the three points that is of utmost importance to support sustainable practices for the future is the "preservation of medicine as a social institution or public trust that exists primarily for the benefit of present and future patients and the public health." R. Rhodes builds on John Rawls's justice theory; justice requires meeting the needs of society and ensuring that society can utilize and express freedoms effectively. 180

In sum, sensitivity to cultural diversity as a pivotal social determinant of health is crucial for supporting human rights in healthcare in a pluralistic society. This sensitivity to cultural diversity also is crucial for cultivating equity in global health.

Chapter 6. Cultivating Equity in Global Health 6.A. A Bioethical Perspective to Achieving Justice in Public Health Responses I. Ethical Concerns During Disaster Situations

Awareness of cultural diversity is indispensable for promoting health equity as a means of achieving justice in public health responses. This is especially the case when addressing

ethical concerns during disasters by being attentive to the vulnerabilities of individuals and populations. According to the policy brief "Global equity for global health" from G-20 insights dated September 2021, conclusions include "[i]n a globalized era, health equity both within and between countries is a foundational pillar of global prosperity." 181 Globally, health inequities can worsen during crises for any population but can quickly worsen for vulnerable populations. For instance, the Mayan populations near the Yucatan Peninsula can face distrust due to many underlying factors one of them being overlooked cultural worldview(s), which can impact the way they experience a health crises; cognizance of differing values in the face of globalization is essential. 182 Promoting justice in global health requires mitigating suffering and harm and enhancing one's capacity to function and, therefore, should inspire equity to improve one's quality of life lived. 183 According to Afolabi in "Public Health Disasters," disasters related to public, or population, health represents untouched areas in bioethical discourse. 184 D.B. Waisel summarizes that vulnerable populations are those groups of people at risk of not obtaining adequate healthcare access. 185 In a case presented in Public Health Ethics: Cases Spanning the Globe, many ethical concerns during disaster situations are highlighted; some specifics include lack of prioritization, confusion amongst first responders, and no guidance on who needs help in the evacuation.<sup>186</sup>

Human rights frameworks provide an all-inclusive structure applicable to countless healthcare facets. In clinical research, these human rights are vital to randomized controlled trials (RCTs) in public health studies, such as those related to populations with disabilities, to ensure sustaining legal, political, social, and cultural rights for all. On the other hand, in a pluralistic world, the unified concept of human rights accounts for the uniqueness of individuals. Human rights and equality are typically "...advocated in terms of social protection and to safeguard

entitlements" and to account for rights to access healthcare services. <sup>188</sup> In addition to being a matter of human rights, access to essential survival resources is also important during public health disasters for human flourishing.

Disparities in health status represent an urgent ethical issue. According to Douglas et al., health disparities are the gaps or consequences on specific populations' physical and mental health that cause social inequalities. Social inequities are an ethical concern; they create disadvantage in human flourishing such as suffering and unequal opportunities to achieving optimal health. Thus, Douglas et al. state that "...health promotion should be grounded on the principles of social justice and protection of basic human rights" that aim to support wellbeing. In "Public Health Ethics and Practice" Peckham et al. states that the ethical contributions to the health of the public "will depend upon culture and history and will be – at least to some extent – path dependent; that is, what it is possible to do or achieve depends upon the structures and cultures already in existence..."

Another source of ethical concern is impacted by the challenge to find safe and reliable food and water resources which is the further impact on public health outcomes. Wetter mentioned a vital point that when families tried to "stretch budgets to provide basic food needs," it also constrained other necessities such as medications or stable housing and could further impact the health outcomes of populations. Financial instability can lead to creating a wider gap in health disparities. For instance, older adults who have pre-existing conditions such as diabetes or heart disease who face financial difficulties are impacted by a more significant risk with unmet nutritional needs or go without care. Attentiveness to cultural diversity means understanding that social determinants of health or ill health can create a greater challenge for certain populations to access basic food and nutritional resources making them more vulnerable

in times of disasters. This sensitivity to cultural diversity is indispensable for equitable responses in public health.

#### **II. Equitably Crafting Public Health Responses**

Attentiveness to cultural diversity requires promoting equitable responses in public health. Ethical concerns related to justice in healthcare may arise when individual health (or respect for autonomy) is compromised due to the prioritization of the health of populations (or the greater good). The *Oxford Handbook of Public Health Ethics* states that public health approaches are typically utilitarian, but "there are today prominent calls for social justice in the field." Ethical concerns such as inequity in healthcare access may result in uneven distribution of healthcare services and resources and therefore hinder the flourishing of population health.

Cultivating health equity calls for looking at health as holistic; for instance, looking to medical factors as well as identifying social factors to mitigate and prepare for risks. In "The Social Determinants of Health: It's Time to Consider the Causes of the Causes," Bravemen and Gottlieb note that over time social factors such as environment, geographical location, or socioeconomic status can contribute to an influential role in shaping the health of populations and communities. Health equity requires consideration of social determinants of health.

In conjunction with SDOH, bioethics can be used as a critical tool to promote respect, dignity, and interdependence for the fundamental human virtues in global issues. <sup>196</sup> Health disparities among culturally diverse, ethnic minorities, and marginalized populations are a result of social background factors such as socioeconomic status, environmental conditions, occupation, income, and education. <sup>197</sup> We see more evidence to include culture as a foundational social determinant of health in the *Encyclopedia of Medical Anthropology: Health and Illness in the World's Cultures* which states that "moral values are shaped by socio-cultural values and

beliefs."<sup>198</sup> In population health, health determinants are vital to understanding well-being on a holistic level. Furthermore, the ability to achieve optimal health and human flourishing is intertwined with various SDOH, broadly labeled as culture.<sup>199</sup>

Serving humanity at the public health level requires meeting the unique and diverse care needs of diverse individuals. Policy development enabling equitable access to care and resources should help people seek the care they need at the time they need it. Technology offers new methods for management of health information and new techniques for global healthcare service delivery. Sensitivity to cultural diversity means that equity during public health emergencies ultimately involves serving the unique needs of humanity in a culturally, racially, and uniquely diverse society.

#### III. Methods to Support Equity for Future Populations

Awareness of cultural diversity also provides critical guidance about equity for future populations. Promoting justice in a diverse society requires supporting future populations in emergency responses. In *Global Issues in Healthcare: Issues and Policies*, Carol Holtz argues that human rights should be protected particularly for groups who are most vulnerable due to social marginalization and other factors that hinder autonomy.<sup>201</sup> From a bioethical perspective, justice is a core component to consider.

Field/site work can create trusted relationships in communities by raising awareness and exposure to the real-lived experiences of people. The relationality in caring professions or "caring science" should enable patients to be seen as dignified people; this entails understanding their needs and serving populations well.<sup>202</sup> In "Personalism in Medical Ethics," Paul Schotsmans articulates that the human beings are continuously developing, multi-dimensional, and constantly evolving with their socio-cultural surroundings and that is what formulates who

they are as a person.<sup>203</sup> Personalism supports the promotion of the multidimensionality of human beings. Equally, empathy can support the caregiver in delivering "dignity enhancing care" by considering health holistically on a "...historical, social, and spiritual" level.<sup>204</sup>

Healthcare ethics committees are composed of multidisciplinary members, they can bring together their background knowledge to foster a holistic educational resource for the organization for future organization preparedness tailored for professionals at different levels (nurses, doctors, administrators, etc.). In "Lifelong Learning for Public Health Practice Education: A Model Curriculum for Bioterrorism and Emergency Readiness," D. Olson et al. purport there is a lack of access to training and education materials, that makes it difficult for healthcare systems to react during public health crises. <sup>205</sup> One method to combat this challenge is to is deliver level specific education and training via fieldwork learnings. Olson et al. discuss the need for competency-based core capabilities to prepare public health professionals in the face of "bioterrorism and emergency readiness." Healthcare ethics committees are in a pivotal position within the organization to create and deliver competency-based continuing education, trainings, and learning experiences for staff.

Advocacy," Hubinette et al. articulate that according to the vertical axis, advocacy can take form through agency and activism. Agency includes ways of navigating systems such as healthcare by providing information and education and connecting to community resources. In contrast, activism includes undertaking action that brings about different forms of change, such as political and social.<sup>207</sup> In "The responsibilities of the engaged bioethicist: Scholar, advocate, activist," Jackie Leach Scully articulates the notion that bioethicists have unique responsibilities from professional and academic standpoints. Professionally, bioethicists play an active role in

mitigating "moral trouble;" academically, bioethicist scholars have a vital role in seeking the truth.<sup>208</sup> As such, at the community level ethicists can serve as agents building trust by providing information that is attentive to cultural diversity to communities and health professionals about specific needs and resources during times of public health emergencies.

Insofar as awareness of cultural diversity is indispensable for promoting health equity as a means of achieving justice in public health responses, this awareness needs to be prominent in the emerging role of public health ethics such as in pandemics.

6.B. The Emerging Role of National Bioethics Committees During Public Health Crises: Addressing Cultural Equity During the Covid-19 Pandemic

#### I. Healthcare Ethics Committees

Attentiveness to cultural diversity must be prominent in the emerging role of public health ethics such as in pandemics. In particular, competence in cultural diversity is crucial for bioethics committees whose involvement in pandemics is crucial. Ethics committees were originally established in the 1960's and have evolved into sources of support that facilitate ethics in healthcare. Traditionally, healthcare ethics committees educate, develop policies, and provide advice through case consultations within healthcare institutions. During the Covid-19 pandemic, ethics committees can reassess needs, goals, and impacts to effectively serve institutions and national governments during pandemics by promoting trust, ensuring optimal consent, and transparently communicating in research trials for vaccinees. This guidance and education requires fostering equity for communities in response to cultural diversity. Nationally, bioethics committees can work to undertake urgent needs such as public health crises genuinely and authentically. For instance, in Latin America, a national ethics committee was organized to regulate oversights when gathering research, by UNESCO. However, Kohler et al. state the challenge of gaining resources as much of the literature does.

Ethics committees are composed of members from multidisciplinary backgrounds, such as chaplains, nurses, doctors, lawyers, and ethicists, which inform a holistic evaluation of the ethical dilemma/case. In the United States, healthcare ethics committees are tasked with guiding organizational policy and managing ethical issues, such as making recommendations for ethics cases or providing education.<sup>213</sup> As a result, ethics committees serve as key organizational leaders who help to improve and advance ethics.

One of the challenges with healthcare ethics committees is establishing a stable, thriving foundation in institutions.<sup>214</sup> Develop operating arms within the community, state, or federal overarching structure is one way ethics committees can establish a strong foundation even external to the institution. Post et al.'s literature mentions that new ways to support organizations is needed for committees to achieve stability because some ethics committees survive while others struggle to achieve sustainability over time.<sup>215</sup> For instance, sustainability can include incorporating the ethics committee within the broader healthcare organization or state governance structure by moving from a patient-provider-centered responsibility to a wider community, population, and stakeholder responsibility in the organization. <sup>216</sup>

One of the emerging areas that is most prominent in 21<sup>st</sup> century healthcare is social and cultural dilemmas during global health disasters, especially in a pluralistic society.<sup>217</sup> An emerging role that healthcare ethics committees should have been facilitating ethical considerations on a national level. Kohler et al. articulated that national ethics/bioethics committees can provide vital ethics guidance during crises situations rooted in ethical considerations. However, to achieve sustainability, ethics committees need support, such as "legally mandated, independent, diverse in membership, transparent and sufficiently funded to be effective and visible."<sup>218</sup>

Insofar as awareness of cultural diversity needs to be prominent in the emerging role of public health ethics such as in pandemics, creating an ethos around cultural diversity is indispensable.

## II. Creating an Ethos around Cultural Diversity During Global Health Crises

Fostering an ethos around cultural diversity is especially important in global health scenarios. The ethicist contributes an imperative role during global health crises. According to the Institute of Medicine (IOM), ethicists play a vital role in pandemic preparation and planning by recognizing and raising awareness of the ethical values needed to support public health decisions, communication, and transparency.<sup>219</sup> Creating an ethos of cultural diversity facilitates ethically sound and responsible responses during pandemic outbreaks – this ethos requires planning and communicating in order to deliver human centered responses.

Ethical guidance is needed during global public health responses; Rhodes articulates that outlining clinical policy measures of triage care can provide ethical guidance in challenging clinical decisions of determining resource allocation. Yimer et al. argue that in pandemics, ethics issues in policies can occur in three areas: measures (such as isolation), practices (such as school closures), and responses (such as resource distribution) which include implications on protection of the individual versus the greater good. As a result, national bioethics committees should aid global leaders with ethically meticulous policy recommendations to mitigate power imbalances and equitably distribute resources to meet the needs of a pluralistic society.

Bioethics can help create cultural equity in human centered responses during global health emergencies. Community engagement is an integral part of public health. Furthermore, the IOM's forum articulated that transparency, as well as principles of civilian participation, are two aspects that are key to building trust between government efforts and the public.<sup>222</sup> Planning

and addressing ethical issues related to global health crises can benefit from community involvement. The community can provide a valuable human centered lens through which health professionals can become aware of multifaceted health issues where the concern of priorities from a social lens can also be fostered.<sup>223</sup>

Just and fair ethical guidance is one of the global challenges related to Covid-19.

National bioethics committees can serve as health educators within pandemic planning efforts globally to fill knowledge gaps and reduce health inequities. For instance, as healthcare educators, committee members can identify the importance and impacts of cultural health equity to improve trust and respect of the patient community-level policies and to develop cultural and linguistic competence.<sup>224</sup>

# III. Impact of National Ethics Committees in Multicultural Societies

Fostering an ethos around cultural diversity in public health ethics, such as in pandemics, provides an opportunity for national ethics committees to have a robust impact. Culture as an SDOH brings with it differences in coping styles, behaviors, and social norms which create the need for varying methods to fulfilling care requirements. National ethics committee can contribute to a long-term solution by using past learnings to reduce suffering caused by disproportionate health outcomes and seek methods for mitigation for the future. The Covid-19 pandemic is shedding light on the gaps and barriers in approaches to crises on a population level. Healthcare inequities have become a central concern in the national and global dialogue about Covid-19 in the United States and beyond. 226

National bioethical guidance should help ethically enhance communication methods as a to respect human dignity in a multicultural society. Communication is foundational component for protection and safety of individuals. In "Stigmatization and prejudice during the COVID-19

pandemic," Roberto et al. state public health officials have a responsibility toward cultural competency. A method to address the lack of cultural competency can be through conversing about cultural humility or cultural intelligence to mitigate stigmatization and cultural disinformation.<sup>227</sup>

During the Covid-19 pandemic outbreak, a common public health measure nationally and globally was the implementation of isolation and social distancing measures. Yet, there were many ethical challenges that originated due to solidarity and isolation.<sup>228</sup> One challenge was the unintended consequences on mental health due to isolation, fear of the illness, among others.<sup>229</sup> The ethics of isolation and social distancing protocols becomes a situation where individual human rights need to be balanced with caring for the collective population. This means accounting for the social and cultural norms and behaviors of the community as done in "Does culture matter social distancing under the COVID-19 pandemic?" by Huynh.<sup>230</sup>

Ethical implications of cultural diversity play an important role in healthcare conditions particularly when it comes to the allocation of medical resources. Schoch-Spana et al. goes on to articulate that when state, federal, and local healthcare authorities are aware of diverse cultural, or community, needs, they can better communicate about resource allocation through all phases of a crisis and that too with greater compassion.<sup>231</sup> An ethics-based approach centered on cultural diversity would help healthcare authorities to address multicultural societal needs.

# Chapter 7. Conclusion

The concluding chapter provides a concise summary of the ethical contribution of cultural diversity as a social determinant of health in the 21st century.

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## **Chapter 2: The Significance of Cultural Diversity in Healthcare**

The dissertation examines how cultural diversity as a social determinant of health, being aligned with human life, human dignity, human rights and human equity provides an ethical contribution. My explanation of the ethical contribution of cultural diversity as a social determinant of health refers to a quadrant of topics that expands the approach of the UNESCO Declaration of Bioethics and Human Rights. The UNESCO approach addresses cultural diversity in relation to human dignity and human rights. My explanation expands upon the UNESCO approach. I adopt a quadrant of topics that aligns human dignity with human life and human rights with equity. The alignment of these topics in the quadrant (dignity/life and rights/equity) explains the meaning of cultural diversity as a social determinant of health. Chapter two discusses the significance of cultural diversity.

#### Chapter 2a: The Foundations and Processes of Cultural Diversity in Healthcare

There is increasing attention in the field of healthcare to the notion that an individual's health may be constituted by traditional clinical diagnosis as well as social factors outside of the traditional clinical healthcare setting. According to the World Health Organization (WHO), social determinants of an individual's health may include housing quality, access to healthy food, level of education, and cultural, racial, and ethnic background. Social determinants are often non-clinical factors that impact a person's healthcare journey or provide insight into a person's needs and ability to manage their care and subsequently care outcomes. The WHO recognizes that addressing social determinants of health is "fundamental for improving health and reducing longstanding inequities in health, which requires action by all sectors and civil society." Building on the WHO's preceding recognition, one of the more important methods to address is the current growing gap in healthcare inequities among minority populations. Recognizing

cultural diversity as foundational to addressing social determinants supports and builds healthcare processes in the multifaceted sector at large.

#### I. Cultural Diversity as Foundational for Healthcare

Cultural diversity is a foundational component for healthcare. Human dignity and human rights are concepts that afford equality for all human beings regardless of differences in culture, race, age, ethnicity, gender, etc. According to the UNESCO Universal Declaration of Bioethics and Human Rights "human dignity, human rights and fundamental freedoms are to be fully respected," and "the interests and welfare of the individual should have priority over the sole interest of science or society." Respecting the freedoms that the preceding Declaration outlines, requires recognizing and sustaining individuality in healthcare delivery and professions. From the Latin *dignitas* is related to *decus* (decent, decorous) and etymologically stems from the Sanskrit root connoting "fame, honour, or glory." Moreover, human dignity refers to the intrinsic value that is infused in every human being. In a diverse society, sustaining dignity in healthcare can occur by developing an awareness of a patient's unique life context which requires considerations of social and/or cultural factors.

Similar to human dignity, human rights equality is imperative -- human rights in healthcare translate to patient integrity. Rights of patients in the healthcare context include privacy, confidentiality, right to medical information, non-discrimination and equality. In "Human rights in patient care: A theoretical and practical framework," Cohen and Ezer state that human rights "recognizes the interrelation between patient and provider rights, particularly in contexts where providers face simultaneous obligations to patients and the state ("dual loyalty") and may be pressured to abet human rights violations." To elaborate on this, patient rights and provider rights go hand in hand. Furthermore, since human rights are universal and applicable to

the individual, they apply to each party involved. For instance, public health policymakers, healthcare providers, and patients are all involved in some aspect of human rights in healthcare. It is essential to consider human rights holistically from the patient's perspective and the perspective of members of society who are involved in shaping the healthcare landscape. Dual loyalty would then invite that the public health policymaker consider human rights and how policies affect the broader population; however, there should be space for exceptions due to a pluralistic society where individual human rights are applicable.

Cultural diversity gives depth and meaning to a human being's individualism and identity. In healthcare, cultural diversity contributes to a patient's health and wellbeing as it affects how a patient understands, receives, and manages their healthcare. For instance, if English is not the native language of a patient, there is a communication barrier between the patient and healthcare provider resulting in a negative impact on their therapeutic relationship. To overcome this communication barrier, the healthcare provider must seek translation services or an ethics consultation to help bridge the knowledge gap. Consequently, the patient will be able to comprehend their healthcare information in their native language, leading to better care management. This is one factor to consider when recognizing cultural diversity as a social determinant of adequate healthcare.

While the term "dignity" can be synonymous with ideas of self-respect and worth, human dignity elevates the connotation to include the individual. According to The Center for Bioethics and Human Dignity at Trinity International University, "human dignity is the recognition that human beings possess a special value intrinsic to their humanity." However, the concept of human dignity is evolving and can be conceptually understood and applied. Beginning as a social value that has permeated modern constitutional frameworks, human dignity in modern times can

be used and understood theoretically in various disciplines.<sup>9</sup> As a result, theoretically speaking, every human being should be allotted dignity simply because they are human.

The intricacy of the term dignity can be appreciated when applied to human beings. Throughout history, dignity has primarily been used within the context of human beings' social value. <sup>10</sup> In *Human Dignity: The Constitutional Value and the Constitutional Right*, Aharon Barak articulates that "[h]uman dignity as a social value reflects human dignity's place among the values of a given society at a given time...It is expressed in religious and philosophical texts, in literature and in the poetry of nations and societies." <sup>11</sup> Supporting Barak's statement, human dignity's well-established underpinnings as a social concept can also be applied universally regardless of transient elements such as time, place, and context. Understanding the concept of human dignity from a historically based perspective helps us comprehend its current meanings and subsequent applications within the modern healthcare context.

In the philosophical and religious contexts, dignity has varying notions conceptually. An example of the philosophical usage of the term "human dignity" is by Cicero. A recognized philosopher, Cicero expressed human dignity from two perspectives: one, referring to a high social position and the other, being the intrinsic nature of human beings. From a religious perspective, human dignity is innate to human beings because of their similar nature to God, or the Creator. Religions and cultures such as Judeo-Christianity understand that humanity has a distinct role and place in the context of the world, in comparison to other species. In different religions, ideas of a Creator may vary but, human dignity remains intrinsic. In Christianity, human dignity arises in human beings because of a man being created in the image of God. Human dignity is recognized in both Hinduism and Buddhism as having a similar perspective on the dignity that is present in human beings on various levels, including intellectual and

spiritual.<sup>15</sup> As a result, religiously speaking, human beings have an innate ontological equality based in the anthropological nature of being: human dignity.

Rights are constructed ideas, concepts, or things that can be morally, ethically, and legally justifiable. Although man-made, rights create synergy amongst entities. Myers purports that when a right is articulated there is a kind of mutual duty implied in the one giving that right to safeguard that right. Conversely, natural human rights are inherent and often shape man-made rights based on laws, policies, and legal documents. Myers states that:

A natural right exists via a dispensation beyond human art or convention... To say that our most basic rights are given us by God as revealed in our specific nature is to say they are given to all human beings. Unlike the rights created by human governments, natural rights do not differ from person to person or society to society. Whereas a citizen of the U.S. possesses by U.S. law a different set of rights from those a citizen of Canada possesses by Canadian law, the Declaration affirms the existence of a universal set of rights, possessed by all human beings in common, regardless of any more particular identifications such as national or ethnic affiliation, color, sex, religious creed, social class, and the like.<sup>18</sup>

As a result, natural human rights are the most important rights that human beings possess because just like the concept of dignity, they are innate to the nature of being human. They are bestowed upon everybody regardless of transient factors such as geographic location, socioeconomic status, or other external aspects.

Considerations of human rights are acknowledged on a global scale. According to the United Nations Universal Declaration of Human Rights, human rights arise from "the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world." Benefaction of natural human rights, includes the ability to consciously reason, and an equal duty to use these abilities for the common good. Articles Six and Seven of the Universal Declaration of Human Rights resonate

with the notion that human beings are to be recognized first as people and then understood within the context of the law. Article Six states that "...Everyone has the right to recognition everywhere as a person before the law..." and the first sentence of Article Seven states that "[a]ll are equal before the law and are entitled without any discrimination to equal protection of the law." As a result, it is widely acknowledged that natural rights take precedent.

Natural human rights are equally distributed to all human beings regardless of race, religion, culture, and other differentiating factors. They are foundational to recognizing the importance of cultural diversity in healthcare because they allow recognition of differences of the individual and the collective. In healthcare, there can be many proposed methods of the application of natural rights to patients. When natural human rights are applied to multicultural populations in healthcare, they enable inclusivity to an increasingly diverse population, that considers the person first, and the context of a policy second. Foundational understandings of natural human rights and human dignity support cultural diversity in the healthcare environment to establish and maintain person focused care.

Providing person-focused healthcare supports cultural diversity in the clinical environment. Patient care delivery focused on the individual is important in healthcare because it allows each human to be viewed as a person rather than a patient, member, or a party. According to the National Clinical Guideline Centre (in the United Kingdom),

For people using healthcare services, to be treated as an individual is an essential component of their whole experience and in retaining their dignity...Each patient experiences healthcare in a unique and individual way. For many, healthcare forms a small, but important part of their wider life. Being recognized and treated as an individual remains important to a person when they become a patient.<sup>22</sup>

In other words, it is vital that those delivering healthcare services recognize the patient as a person experiencing a healthcare journey within a broader social framework. Although the National Clinical Guideline Centre provides guidance for healthcare delivery in the UK, this notion can be applied to healthcare delivery in the United States. Furthermore, the National Clinical Guideline Centre surmises that people are individuals who live with their health situation and experience their situation uniquely within more comprehensive contextual or social aspects which also may impact their healthcare journey.<sup>23</sup> In the United States, a country where there is a multitude of pluralism, viewing each patient as a person can build and support cultural diversity.

The WHO echoes a similar notion but phrases it differently. According to the WHO, integrated people-centred [sic] healthcare services "means putting people and communities, not diseases, at the centre of the health systems, and empowering people to take charge of their own health rather than being passive recipients of services." While this concept puts the onus on the patient, in order to deliver effective people-centered care, healthcare systems have a duty to view individuals as "participants as well as beneficiaries of trusted health systems." Healthcare professionals are required to respond to patients' needs and preferences "in humane and holistic ways." In other words, "people-centred care requires that [all] people have the education and support they need to make decisions and participate in their own care (stress added)." The healthcare system truly has to empower individuals with the unique resources that they need in order to understand and have some control of their healthcare.

In a growing demography, such as that of the United States, healthcare delivery that supports cultural diversity is crucial and can protect people's dignities and rights. One approach is to adopt the National Clinical Guideline Centre and the WHO's appreciation of empowering

people in their healthcare journey; doing this not only requires an empowerment of the patient, but also healthcare professionals. Cultural competence is recognized in the healthcare literature as essential to the clinical environment. From the Centers for Disease Control and Prevention (CDC), "[c]ultural competence is the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of services; thereby producing better outcomes." Cultural competence enables healthcare professionals to treat patients as individuals by appreciating and respecting their social aspects such as culture, background, and diversity.

Cultural competence is one step towards supporting cultural diversity and its growth in healthcare. In "Impact of culture on health care" J. Jones-Bussey argues that cultural competency is a building block that is necessary to care for a racially and ethnically diverse population.<sup>29</sup> However, as Jones-Bussey and many other authors argue, cultural competence in care delivery is a continuous process. J. Jones-Bussey states that "[w]e must be willing to participate in lifelong learning that helps integrate the principles of biomedicine with the many beliefs and values of our patients."<sup>30</sup> In order to cater to a diverse patient population the healthcare system needs to recognize the need for cultural competency which includes skills to navigate cross-cultural encounters.<sup>31</sup>

# II. The Processes of Cultural Diversity in Healthcare

The healthcare field is broad and includes many different individuals, industries, and disciplines. The processes of cultural diversity in healthcare need to be understood to support the foundations of human life/dignity and human rights/equity. In the UNESCO Universal Declaration of Bioethics and Human Rights, Article Twelve on Respect for Cultural Diversity

and Pluralism states, that "[h]armonizing the universal and the particular becomes then a necessary but difficult task; in some cases a consensus may be achieved, but in others it is only possible to state a pluralism of standpoints. In all cases, it is essential that the perspective of each belief be presented in a rational, intelligible way that can be understood if not accepted by all sides." Natural human rights and human dignity are universal concepts which are guaranteed, however, pluralism includes the differing experiences of individual cultures. This creates potential for a dual relationship. As a result, processes of cultural diversity in healthcare help evaluate the dualty between the universal and the specific foundations in human dignity and natural human rights.

Furthermore, the Universal Declaration on Bioethics and Human Rights points out that "[t]he principles that form the basis of this reflection may well be different and sometimes conflicting, but the essence of bioethics is to assemble the principles to build a set of harmonious rules, in which all can acknowledge sufficient elements of truth to abide by them."<sup>34</sup> Bioethics can establish a complementary balanced relationship between culture, human dignity, and natural human rights. Ultimately, as the Declaration states, it is "the essence of bioethics" that allows for this assembly of "harmonious rules."<sup>35</sup> Building "harmonious rules" then should require processes in healthcare that enable reaching equipoise between individuals who share differences. <sup>36</sup> In a pluralistic world, bioethics is a valued factor that fosters equity in healthcare. Reaching an equipoise requires humility, empathy, and the intent of finding a shared humanity.

In healthcare, culture is often taught, recognized, or associated with the phrase cultural competency. Cultural competency involves one entity developing respect towards another entity's diverse aspects, beliefs, and practices in healthcare delivery.<sup>37</sup> These diverse aspects may be language barriers, cultural differences, or varying religious backgrounds. Cultural competency

involves learning skills that help a healthcare provider to deliver care to cross-cultural patients effectively.<sup>38</sup> These techniques are taught in medical or graduate school curriculum. However, Sunila J. Prasad et al. points out one of the challenges with cultural competency is that it might not be enough to support a continuously growing diverse population in addition to an intense medical curricula. Prasad in "Cultural humility: treating the patient, not the illness," articulate cultural humility can help foster the appropriate bases for developing competencies to serve a diverse patient population. According to Prasad et al., "cultural humility may be defined as a process of being aware of how people's culture can impact their health behaviours and in turn using this awareness to cultivate sensitive approaches in treating patients."<sup>39</sup> As a result, cultural humility is a continual process that involves self-reflection, self-awareness, and promotes empathy, compassion, and inclusivity in healthcare.

Developing humility in cross-cultural care results from being in a therapeutic relationship with another individual. Cultural humility requires mindfulness towards one's background including their cultural beliefs, practices, and traditions.<sup>40</sup> These unique elements include social components like an individual's family, their history, and their experiences which help provide a depiction of who they are as a person within their life situation. Fostering the skills to deliver care with cultural humility requires life-long learning. Stubbe articulates, "[t]he concept of cultural humility, by contrast, de-emphasizes cultural knowledge and competency and places greater emphasis on lifelong nurturing of self-evaluation and critique, promotion of interpersonal sensitivity and openness, addressing power imbalances, and advancement of an appreciation of intracultural variation and individuality to avoid stereotyping."<sup>41</sup> This approach empowers and inspires the healthcare provider or serving entity to shape unique patient experiences. While these are beneficial to therapeutic care, one of the challenges is that as a process, cultural

humility is not the most efficient in terms of the current all-purpose healthcare system. A way to address this challenge is to shift perspectives from competence where culture is seen as a "finite construct" to humility which then requires including culture as a more active asset in healthcare delivery.<sup>42</sup>

According to Joy Agner, in "Moving From Cultural Competence to Cultural Humility in Occupational Therapy: A Paradigm Shift," cultural competency and cultural humility differ in that the latter "include[s] an emphasis on learning rather than knowing, recognition of patient and client cultural perspectives as equally valid, and critical reflection on how systemic issues and power differences affect health care."43 These learnings require fostering mutual respect, safety, and humility to enhance care delivery. In cultural humility, the emphasis is on exposure to skills that foster learning and thinking rather than studying a culture; therefore, programs can apply the skills underscored in learning within the already existing curricula. Prasad et al. propose incorporating the skills that the humanities provide into already existing features of the curriculum. These skills and assessments include reading and reflecting about another culture rather than just studying another culture. 44 It is crucial for healthcare professionals at large to develop these skills to help individuals reflect on their own identities to the serve other people better. This approach helps the healthcare serving team or provider gain awareness of the perspectives and assumptions they may be applying from their own identities.<sup>45</sup> Ultimately, promoting empathy between the patient and the healthcare provider, connecting on a human level, leads to better care outcomes.

Cultural humility is truly about acknowledging the patients, members, or the individuals being served through a health care service first and foremost as people. To confront cultural preconceptions, or rather support cultural diversity, healthcare providers, and students, can

utilize concrete tools such as self-questioning to learn or become aware of their own personal attitudes. 46 Cultural humility then includes promotion of skills that enable reflections with the intent to mitigate potential power imbalances, such as biases, or support patient's social determinants, fostering strong patient-provider connections. Prasad articulates that without reflection, there is a risk that one's own perceptions may unconsciously appear when providing care. 47 When an individual is seen as a human being it allows the healthcare worker to listen and connect with them on a human-to-human level, to try to understand their life, and positively influences the relationship between the healthcare worker and patient. Processes that foster cultural humility can ultimately support healthcare in a multicultural society.

The term plural in the Merriam Webster dictionary is defined as "relating to, consisting of, or containing more than one or more than one kind or class." Based on the preceding definition, a pluralistic society can be one in which more than one kind of experience, norm, and moral exist side by side. In "(Bio)Ethics in a Pluralistic Society," Ben Gray draws the conclusion that "even if the people in a community were in some respects culturally homogeneous (for example, all the same ethnicity, or all adherent to the same religion), they will not all share exactly the same values and beliefs. Every person is a member of several different 'cultures.'" Supporting Gray's statement, people may share varied cultures, countries, or classes, but still deserve respect as individuals with unique care needs.

It is important to acknowledge the concept of cultural practices in a pluralistic society through consideration of each individual even though they might be a part of a collective culture. Ben Gray argues that although universal morals and norms may be vital, their usefulness or utility may not always be apparent in their application, especially in controversial ethical issues such as the beginning, or end, of life matters. <sup>50</sup> In other words, value differences may give rise to

socio-political disagreements. Gray concludes that the laws reflect the values and viewpoints of those who create them and do not appropriately reflect individuals in a pluralistic society.<sup>51</sup> To overcome the real-time value differences, healthcare professionals must consider challenges faced in healthcare in humanistic ways through mutual understanding, empathy, and respect. Gray recognizes the importance of respecting differences, and considering behavior on an individual level based on the Maslow Hierarchy of Needs.<sup>52</sup> This method echoes cultural humility in that it involves an ongoing learning and application process.

In a society where there are differences in values, goals, and care approaches, respect is a key component to create equipoise. Gray articulates that respect is the foundation for fostering dialogue to help come to an understanding when there are differences in cultural approaches.<sup>53</sup> With a lens of respect, coupled with cultural humility, a healthcare professional, policymaker, or even researcher can gain insight into their ethos to set aside personal standpoints and consider holistic perspectives. This enables the sharing of dialogue between healthcare professionals and the people they serve. When considering respect in healthcare in a pluralistic society, Ben Gray states:

Part of being a member of a culture is that those you share the culture with are 'in your group' and others are 'out.' Your beliefs and values are normal and right and those who do not share them are, at best, different but, more problematically, wrong. Many of our beliefs and values are held implicitly, and may, in fact, clash with our espoused views. The Harvard Implicit Association Test has convincingly demonstrated that, as a result of years of acculturation, the large majority of people worldwide associate black people with unpleasant associations more than white people.<sup>54</sup>

As a result, the adverse effects of one's own viewpoints can be eliminated by taking a reflective approach.

To understand certain healthcare choices, behaviors, and decisions it is helpful to understand differences in values. Using an extension of Maslow's Hierarchy of Needs scale, Clare Graves coined the Spiral Dynamics Scale, which articulates that behavior differs depending on where a person, or the contextual features of their situation, lies on the hierarchy of needs. 55 Gray uses the prime minister of New Zealand, Jacinda Ardern, as an example when applying this methodology. He articulates that Ardern is at a Level 6 on this scale because she recognizes that she is not able to understand every aspect to lead the country on her own and as a result, values cooperation. By collaborating she welcomes different viewpoints and the foundation at which she approaches this is through respect for others. 56 Level 6 of the scale most applies to healthcare when caring for patients of diverse backgrounds. Moreover, Level 6 is the ideal and appropriate level for healthcare workers because it truly embraces the multiple characteristics of inclusiveness, respect, and empathy.

In healthcare, providers, policymakers, and workers can also embrace these levels in order to better understand and evaluate where they stand as an individual. For instance, a healthcare policy maker could follow a similar path to Ardern and focus on field visits in order to collaborate with people from different backgrounds (such as culture, socioeconomic class, religion etc.). Supporting Gray's theories, applying Level 6 in healthcare allows a policymaker to recognize and respect diversity and differences. As a result, policymakers could seek field knowledge to understand the diverse needs of communities and empathize on a personal level. Ultimately, collaboration helps healthcare policymakers understand the impacts of a potential policy to best benefit people from various cultural contexts before it is put into effect. The preceding is a possible method to help reduce healthcare disparities in a pluralistic society. Clinicians who provide healthcare could also adopt a similar approach when recommending care

to their patients. For instance, when disagreements about treatment plans arise one possible option would be to operate from a lens of respect. Operating from a lens of respect relates to Level 6 because the clinician understands that differences are subject to arise. However, clinicians taking extra steps to provide care from a lens of respect, can empathize, listen, and truly understand how to help patients manage their care.

A diverse demography is growing due to immigration and immigration reform.<sup>58</sup> In the United States, a growth in cultural diversity such as via immigrant, refugee, or displaced population constitutes to the health disparities which have been acknowledged in much of the literature. Bridging cultural gaps in healthcare delivery is one method in supporting and mitigating these events. In "Ethics and Multiculturalism in the Patient-Physician Encounter," Robert Deiss points out that in the United States, the aging and older immigrant populations may naturally lean on socio-cultural beliefs and values as a source of support. As such, Deiss refers to using this growth in diversity as a chance to update the current standards and protocols in encounters in healthcare.<sup>59</sup> Concurring with Deiss's idea, there also needs to be an expansion in the way healthcare is delivered because clinical care is only one piece of the overall healthcare system. As a result, transformation to healthcare from a broader, or holistic, perspective is crucial to shaping clinical care, healthcare policy (including public health), and global bioethics.

In clinical care, value differences between widely accepted ethical principles of the healthcare provider versus those of the patient may create misunderstandings. Geri-Ann Galanti, in *Caring for Patients from Different Cultures*, articulated that value differences arise due to varying ethical underpinnings that shape the culture of healthcare and that of the patient's culture. In the United States healthcare delivery system, this entails differences in the culture of the delivery system and culture of the patient population. For instance, in the United States, the

values of independence, privacy, and autonomy are highly prominent, while African culture values social support and relational autonomy. Furthermore, Galanti stated that "[t]he kind of health care provided by the American medical system is often influenced by financial considerations, whereas concern for family, lower on the list of 'American' values, influences much behavior in patients from other ethnic groups." Cultural values ultimately shape an individual's decision-making, beliefs, and even lifestyle choices. As a result, social determinants such as geographical origin or location have a unique influence on cultural values in healthcare and provides insights into other factors such as financial status, social background, and behavioral considerations. If patients' cultural values are not considered disparities in healthcare delivery and outcomes arise.

Public health professionals take part in an essential role in shaping healthcare policies. Whether healthcare policies are legally bound or institutionally adopted, they ultimately impact healthcare culture and delivery. Informed consent is a cornerstone philosophy and legality in the American healthcare system. This supports the rights of patients to receive adequate healthcare information and decide accordingly and places a synergistic duty on the provider to deliver just that.<sup>63</sup> While certain national or institutional healthcare laws and policies, such as informed consent, may not be changed or varied for everyone, it is important to consider their execution in relationship to the patient context.

Insights that the discipline of bioethics provides for a globally growing population is indispensable to cultural diversity. The growth in demography, in addition to differing values, can bring with it multicultural perspectives such as differing views of the world due to geographical uniqueness. Galanti stated that "[t]he second most important concept for understanding people's behavior is to understand their worldview. Problems can result from a

disparity between the worldview of the health care culture and that of the patient population. People's worldviews consist of their basic assumptions about the nature of reality. These become the foundation for all actions and interpretations." An individual's outlook on life may influence healthcare behavior, decisions, and habits. Often, an individual's perspective on life is shaped by social determinants and contextual factors such as culture and religion, socioeconomic status, and level of education. For instance, somebody with a scientific outlook on life "might perceive birth defects as a mistake in the transcription of DNA during the process of meiosis." Somebody who has a spiritual or religious outlook on life might perceive it as "resulting from improper behavior in a past life, and someone who believes that God rewards good behavior and punishes bad behavior might interpret it as punishment for one's sins." On the other hand, somebody who struggles financially might not seek beneficial healthcare services after knowing about a condition. Bioethics underscores notions such as these to recognize that respect in patient healthcare require considerations of cultural diversity, social determinants, and varying worldviews.

#### III. Cultural Diversity in Healthcare

Recognizing cultural diversity as a social determinant of health is crucial in supporting the foundations and processes in various facets of healthcare. While changing demographics is a positive feature of the United States, it brings attention to the increase in disparities in healthcare access and quality of care received. This prioritizes the need to focus on health status across diverse populations of people.<sup>67</sup> In *Diversity and Cultural Competence in Health Care*, Janice Dreachslin et al. stated that despite the varying definition of healthcare disparities one thing is sure "that groups living in this country, when compared with each other, do not enjoy the same life expectancies or levels of good health." Differences in health outcomes and disparities

ultimately impact an individual or population's ability to participate or flourish in society.

Dreachslin argued because the healthcare field in the United States is that which mimics a "system," changes to support a changing demographic need to acknowledge all members of that system. Therefore, transformations must occur at the varying levels of the system. One method to serve and meet the needs of a population or geographic community needs to happen from the top-down. The policymakers and leaders need to establish and implement adaptation methods to bridge the gaps between policy and operationalization in healthcare. Providing practical strategies of operationalizing policy into practice is one way that social determinants can give insight into person centered healthcare delivery.

The United States healthcare field, functioning as a system, gives a positive opportunity to holistically address disparities and gaps in care delivery at multiple levels. For instance, three areas where health disparities can be focused on include individual, population, as well as global levels. Therefore, on a population level, public health can be engaged. According to the American Public Health Association, "[p]ublic health promotes and protects the health of people and the communities where they live, learn, work and play." On an individual level, clinical care can be engaged. Clinical, or medical or health, care as defined by the Merriam Webster dictionary is "efforts made to maintain or restore physical, mental, or emotional well-being especially by trained and licensed professionals." The clinical care context is where interactions between patients, their families, and the healthcare provider or team culminate. Global bioethics should be engaged in issues that permeate humanity globally. As presented in *The Dictionary of Global Bioethics*, global bioethics was first coined by Van Rensselaer Potter to give attention to "ecological and social issues." Global bioethics is helpful in environmental, natural, and global pandemic situations. As a result, in global bioethics, the various leaders,

professionals, and clinicians of the varying facets of healthcare must come together to cultivate holistic approaches that are empathetic to unique individual needs.

Supporting cultural diversity as a social determinant of health promotes positive public health outcomes. Public health is a facet of healthcare that aims to promote population well-being to prevent disease and injury. Public health programs, protocols, and approaches aim to mitigate illnesses. As such, *The Oxford Handbook of Public Health Ethics:* "Distinctive Challenges of Public Health Ethics," states a characteristic of public health includes government involvement and efforts to regulate strategies that enable the advancement of benefic results for the population. Considering the preceding, public healthcare focuses on the good of the population. Individual factors may be considered but do not always take priority which can further account for the growth in healthcare disparities.

Prioritizing social determinants of health supports the broad role of public health. However, individual factors in population health raise challenging questions: to which scope should the public be considered within? and, which boundaries are needed to achieve human flourishing or well-being? Public health challenges are discussed broadly on "crime, war, and natural disasters; to population genetics, environmental hazards, marketing, and other corporate practices; to political oppression, income inequality, and individual behavior." To begin to address these questions, I propose narrowing the scope of the demographic (i.e., socioeconomic class, culture, etc.) to create the necessary boundaries to enable broader human flourishing and public well-being. Considering social determinants of health can help address the individual's unique needs as well the demands of public health. Supporting public health concerns requires recognizing its multidimensional roots embedded in social aspects, or well-being. The Oxford Handbook of Public Health Ethics, states that "[a] central role of public health, grounded in

social justice, is to bring attention to all aspects of the social or natural world that exert a significant impact on the preservation or promotion of health, and not only to those that can be addressed through traditional public health measures or means."<sup>80</sup> To support the preceding notion, public health outcomes include a variety of social determinants, such as factors that impact how people (or populations) function and live.

Social determinants include factors that impact health outcomes. H. Alderwick and L. M. Gottlieb, in "Meanings and Misunderstandings: A Social Determinants of Health Lexicon for Health Care Systems," reference the WHO's description of social determinants of health insofar as circumstances in which individuals are born into and age through and the social contexts throughout life. External factors such as economic and social aspects influence social determinants of health. Social determinants of health are components that can present areas of risk for populations. Alderwick et al. give a snowball effect example of poorer neighborhoods that have unhealthy air quality and are subsequently at risk for further negative respiratory impacts such as asthma, bronchitis, or COPD. Building on this idea, vulnerabilities related to health and well-being are often associated with social circumstances. In addition to individuals, social determinants of health also impact large groups of people who fall within certain determinants of health, for instance, a lower socioeconomic level. In fact, cultural diversity is just one of factor contributing to social determinants of positive public health outcomes.

Clinical care, or health or medical care, is another facet where healthcare disparities are understood. A healthcare provider delivers clinical care to a patient. According to Dreachslin et al., the healthcare encounter is "a planned or unplanned interaction between a provider of health care or related services and a recipient of care or information such as a patient, client, family member, or community member."<sup>84</sup> Adopting this definition, the therapeutic relationship proves

crucial to clinical care delivery extending to cross-cultural care. However, Dreachslin et al. point out that mishaps in care delivery in the cross-cultural context can create power imbalances. <sup>85</sup>

Power imbalances dismantle the therapeutic relationship and ultimately can make the patient feel vulnerable. One way to mitigate power imbalances is to consider social determinants of health such as cultural diversity and their effect on patients' decision-making methods, autonomy, and informed consent processes in clinical care.

Cultural diversity also impacts the patient's experience of clinical care. If healthcare professionals do not consider cultural and social background determinants, the patient may be dissatisfied with the quality of care they receive. In that case, they may be prone to poor medication adherence and, as a result, may face poor health outcomes and healthcare disparities. Likewise, from the providers' perspective, there are documented disparities in healthcare. For instance, the literature discusses documentation of disparities in areas such as physician practices and recommendations. As a result, stereotyping or biases and uncertainty on the skills needed to provide adequate care to culturally diverse patients can contribute to inadequate patient healthcare delivery and treatment.

Graduate programs and medical education curricula often teach cultural competency.

This pedagogical practice aims to provide a baseline education on cultural competence for healthcare providers to respond appropriately to their patient's needs. To mitigate power imbalances, the provider needs to take the initiative in meeting the patient's needs where that patient is. Redagogical practice can support transient factors like social determinants of health. For instance, a person may move between socioeconomic classes throughout life, affecting their healthcare for better or worse. Individuals who move locations geographically must establish relationships with new healthcare providers too, and as Dreachslin et al. state, create "common"

ground" and "shared purpose" in the clinical care encounter. Establishing shared dialogue is one method that can enable a successful healthcare encounter. <sup>89</sup> Therefore, a successful therapeutic relationship requires the healthcare provider to understand the patient's non-clinical, or social, determinants of health in addition to clinical determinants. Considering social determinants of health helps the provider to understand the real-lived experience of a patient.

Specifying cultural competence to skills that foster cultural humility promotes active trust-building in cross-cultural interactions between patients and providers. Dreachslin et al. stated that cultural humility, although challenging, includes an "active engagement" between the patient and provider. 90 Cultivating cultural humility in clinical care may help patients feel heard and felt, and, as a result, providers would be able to build a stronger relationship. Patients being listened to and felt are two of the fundamental aspects of human dignity and human rights in healthcare, empowering patients to be involved and engaged in their healthcare. Dreachslin et al. further articulated that providers may feel they have no control over helping patients with their social stressors. However, one method to remedy this is to invite the "patient's world" into the clinical encounter to help build skills and insights to empower providers when caring for patients from different cultural contexts. 91 Fostering cultural humility on the provider's side would require empathy, compassion, and listening skills to ensure healthcare providers consider the patient's needs. Although this approach may be hard to incorporate in the current healthcare culture, where healthcare providers have many patients and may not be able to give as much time or individualized attention to each, it is important to move towards an approach of this kind. As a result, effectively engaging social determinants in clinical care creates a more practical approach to global bioethical challenges.

Bioethics is the area of medicine and research where scholars apply morality through the notion of what is in the best interest of the common good. However, the common good, or morality, may vary between cultures or people from diverse societies. 92 Unlike the differences in values between patient and provider that are one source of ethics issues in the clinical context, bioethics issues, when considered globally, present an opportunity to create shared knowledge based on a broader shared issue. The concept of morality can be universally differentiated as something good or bad but differs in definition depending on varied community beliefs and practices. What individual groups accept as moral concerning issues such as the beginning of life, end of life, organ donation, or stem cell research can differ. One group of people may regard abortion as morally good, while another may regard it as a moral disgrace. 93 In Global Bioethics and Human Rights: Contemporary Perspectives, Chapter 3, the author Robert Baker argued that "whatever ideals intellectuals from a given society may claim to be universal, objective, or selfevidently true ... they are more likely to reflect the ideals of their own era and culture than ideals universally shared across all cultures or for all time periods."94 Morality is a fluid concept, similar to dignity, based on context, time, and place. Furthermore, the author compared norms from ancient Greece that were acceptable, such as slavery and infanticide. However, today, these concepts are considered morally reprehensible. 95 In the 21st century, bioethical issues and impacts due to environmental destruction, natural disasters, and pandemics are all global concerns. Collective recognition and addressing bioethical concerns on a global scale can bring humanity together to work towards a common good, but it faces challenges.

Ecological issues that affect environmental health and, subsequently, human health are global bioethical issues. One of these issues was and still is, in the 21<sup>st</sup> century, pollution.<sup>96</sup>

Therefore, global bioethics encompasses issues that impact not just this generation but issues that

affect the sustainability of future generations. Ten Have postulates that global bioethics can aid in issues related to protecting the Earth for future generations.<sup>97</sup>

Global ethics issues, such as environmental sustainability, benefit from a bioethical framework. Ecological challenges present an opportunity to create a space for shared knowledge across and between culturally diverse communities. From a historical perspective, Van Rensselaer Potter re-termed 'bioethics' to 'global bioethics' to encompass wider issues that impact human survival.<sup>98</sup> Therefore, global bioethics expands the conversation on social determinants of health by looking at environmental issues, or environmental determinants, impacting human health. Global bioethics encompasses issues that impact not just the present but the future. Therefore, appreciating, and subsequently safeguarding, the relationship between people and their natural habitats is a vital "global responsibility." Implementing a global bioethics framework is essential to environmental sustainability.

In conclusion, cultural diversity is foundational for healthcare and is rooted in widely appreciated concepts such as human dignity and human rights. Patient-centered care focuses on the individual. These approaches help healthcare professionals consider the many factors outside of the traditional clinical healthcare setting that works to uphold the dignity and rights of the patient. Cultural competency is a process in healthcare that supports cultural diversity. A deeper perspective on cultural competency should focus on cultural humility, respect, and methodology to support the growth and to better serve multicultural populations in the United States.

The United States healthcare system is a wide landscape composed of individuals and professionals who receive and deliver healthcare. As such, issues in cross-cultural care permeate many levels. To promote positive care outcomes amongst a culturally diverse population, care providers must consider care delivery through an ethical lens. Some of these facets include

public health, clinical care, and global bioethics/health. As a result, incorporating cultural humility, respect, and shared ethical dialogue provides one method to respond to and engage cultural diversity in the United States and globally.

# <u>Chapter 2b: Sustainability in Global Bioethics by Respecting Cultural Diversity in</u> <u>Healthcare</u>

Bioethics is a discipline that emerged in response to advancements in medicine and technology that now stretch the scope of issues found in many fields. In the chapter "Bioethics reality check" from *Global Bioethics: An Introduction*, Henk Ten Have articulated that the "global" aspect of bioethics includes two concepts. First, the issues that affect humanity on a global scale, and second, the respect for values and norms across countries, populations, and global communities without prioritizing one over the other.<sup>100</sup> Issues and concerns that are global, such as environmental sustainability, benefit from a global bioethical framework.

Sustainability is a concept that gained attention in environmental health field during the 1980's.<sup>101</sup> The environment of the 21<sup>st</sup> century is a source of global concern due to negative human impacts that have led to climate change, reduced air and water quality, and the depletion of the Earth's natural resources.

Every part of the Earth is naturally diverse in climate, landforms, vegetation, and biological life. Some biological life forms, such as plants and insects, thrive in certain regions but will not be able to survive in others. Similarly, the people that live in different spaces, or regions, of the world adapt varyingly to their environment to survive and thrive. This analysis will be adopting the term culture as "the customary beliefs, social forms, and material traits of a racial, religious, or social group *also:* the characteristic features of everyday existence (such as diversions or a way of life) shared by people in a place or time."<sup>102</sup> Diverse cultures, therefore,

are formed of groups of diverse people living together on various parts of the Earth. Cultural diversity is a crucial social determinant of not just to human health but also environmental health.

Issues that encompass the globe have given rise to the notion of global health. <sup>103</sup> One area where global health issues intersect with human health is that of the environment. Human impact harms the environment, and its inhabitants suffer when the environment is not well. <sup>104</sup> Global health governance has primarily been beneficial for infectious disease related issues. However, the concepts that underscore governance established by organizations such as the WHO, UN, and philanthropic foundations can address global environmental health issues. However, there are some gaps in global health governance which include knowledge gaps, policy gaps, and institution gaps. <sup>105</sup> Taking a global bioethical approach when considering bioethical principles provides a more practical governance when addressing and resolving global concerns of sustainability, while respecting cultural diversity in healthcare.

#### I. Bioethical Principles to Protect Environmental and Human Health

Cultural diversity as a social determinant of health is closely related with planetary ecology. The widely accepted bioethical principles provide a theoretical and practical method for living in equipoise with nature. In "Environmental Sustainability: Ethical Issues," Reena Patra points out that nature is not an end in and of itself to something but rather a means for something. From this perspective, nature is a means for survival for the various life forms that live on Earth, rather than a source to use endlessly. Patra states that "[h]umans deliberately and extensively rebuild the spontaneous natural environment and make the rural and urban environments in which they reside. We care about the quality of life in these hybrids of nature and culture." Humans across the globe, like other species live, thrive, and survive in the

different areas of the Earth. Much of the literature echoes the notion that, in 21<sup>st</sup> century culture, there has been less of a focus on the impacts on natural resources, the environment, or even biodiversity and more of a focus on production and innovation. As Patra goes on to state, "ethics arises to protect various goods within our cultures." The bioethical principles of autonomy, beneficence and non-maleficence, and justice provide a framework to protect the Earth within the context of the 21<sup>st</sup>-century innovative culture.

The flourishing of a human society that lives within equipoise needs to take into consideration its environment. Human beings, like all living creatures, use resources on Earth, for survival, and as a result, should have an equal responsibility to take care of the Earth. Article 17 of the UNESCO Universal Declaration on Bioethics and Human Rights focuses on the protection of the natural environment. Article 17 explains that bioethics encompasses the moral decisions that should be regarded with the consideration of all life forms and that human beings have a collective social responsibility to protect the ecosystem. This consideration, or responsibility towards the Earth, should be shared. This study considers four of the many bioethical principles to provide a framework to understand, assess, and restore environmental sustainability. These principles can operationalize a shared responsibility for the global concerns of environmental and human health.

Autonomy in the Western healthcare context is a prominent standard. Autonomy refers to respect for one's individual choices. <sup>110</sup> Choices will differ from person to person due to a variety of social and cultural factors. Furthermore, autonomy is determined by the "nature, scope," or context of the ethical dilemma. <sup>111</sup> As such, autonomy applies to the context of ethical concerns related to environmental and human health.

Autonomy points to individual and shared duty in the factors that impact environmental and human health. In "Ethical Perspectives for Public and Environmental Health: Fostering Autonomy and the Right to Know," Timothy William Lambert et al. proposed that creating mutual relationships support contextual factors and ethical perspectives for issues concerning the environment, creating autonomy. 112 He further proposed to keep an open mind, develop an individual perspective, seek additional knowledge to be flexible in an outlook, understand other's perspective, and develop inspiration to care for one another, all of which help foster an integral relationship with the environment. 113 These factors foster a relationship that balances individual responsibility with shared responsibility. Lambert et al. state, "it is each person in the relationship whose autonomy is being fostered (i.e., the public, public health and environmental scientists, government officials, and industrial representatives)."114 This cultivates a relationship where people are "being-for-others," as community members and in their professional role, as well as for the environment. 115 Fostering an expanded understanding of autonomy creates empathy in the relationship between people and the environment. This relationship is one of respectful, synergistic coexistence, where there is equal consideration for the environment.

In theory, the principle of autonomy ensures individuals within culturally diverse communities can sustainably utilize environmental resources and make informed decisions. For instance, Lambert et al. discussed that the autonomous standard of the 'right to know' informs in prevention, planning, or precaution such as informing the public of possible contaminants found in food due to toxic environmental exposure. An expanded autonomous perspective fosters strategies to help protect people individually and collectively. The right to know principle subsequently provides people more autonomy, and respect, in their own decision making and choices.

On a national or global level, autonomy can be applied to collective choices such as in issues related to agricultural expansion or food lifecycles. Applying autonomy to national agricultural development promotes understanding and informs policymaking to ensure adequate food production and supply while minimizing the use of harmful substances. In *Environmental Health Risk: Hazardous Factors to Living Species*, Marcelo Larramendy et al. pointed out that agricultural pesticides are essential for agricultural expansion in developing countries; however, one of the critical problems of pesticides is their harmful effect on human and environmental health. Pesticides cause adverse health effects on the natural systems and can contaminate water in the natural environment.<sup>117</sup> Organophosphate compounds and pesticides have been used in agricultural production and can be harmful for human and environmental health. Instead, an informed autonomous decision to use recycled plant peels as fertilizer, or composting such as coffee grinds, creates the opportunity for sustainable agricultural expansion and sustainably sourcing food. This example is one way the bioethical principle of autonomy can reduce harm and encourage a more informed reciprocal relationship between humans and their environment.

Considering the principles of beneficence and non-maleficence in policy and decision making is another method to sustaining environmental and human health. Beneficence and non-maleficence include reducing harm and suffering and fostering good. Beneficence includes preventing or mitigating harm and increasing good; non-maleficence includes not causing damage to begin with and consideration of *prima facie*, or that which is beneficial for the greater good. 120

Beneficence and non-maleficence are important to consider in policymaking and communication; Lambert et al. use the idea of safe exposure of contaminants and harmful exposure of pollutants to the environment and humans. Lambert et al. argued that "[f]rom a

consequential perspective, communication about contaminants stems from consideration of whether the contaminant or the communication itself will generally cause good rather than harm (i.e., not from a responsibility to the people)."<sup>121</sup> For instance, if the communication about contaminants causes good, then it is considered benefic. If the communication causes minimal harm (minimal harm as is recognized to come with any potential undertaking), then it is considered non-malefic.

Considerations of the principle of beneficence ensures bioethics is at the center of policy making. A benefic policy would be one where sustainable development helps better current conditions for the future such as by regulating levels of contaminants in water sources. The pollutants that cause harm to aquatic environments negatively impact human health, in addition to depleting natural resources such as fresh water. Additionally, the European Environment Agency (EEA) reported that wastewater treatment, and the quality of the conventional use of water, such as for drinking, has improved over that past two decades. However, the EEA recognized that in order to sustainability, policies are needed where these treatment methods are able to improve the future of water quality as well. 123

Non-maleficence benefits environmental and human health by considering the *prima* facie, the good that outweighs the bad, as well as ensuring harm is not imposed to natural resources. Current water quality and treatment methods have shown to cause adverse effects on the environment and human health. The EEA noted that "algal blooms linked to excessive nutrient levels" resulted in adverse reactions in the form of skin and eye allergies to humans. Ultimately, it is crucial that non-maleficence is considered when balancing the good and bad in policy implementation. The good that comes out of informing the public is a trusted relationship where "turning to others for genuine dialogue about public and environmental health risks" is a

standard or best practice.<sup>125</sup> As a result, beneficence and non-maleficence cultivate ethical decision making that promotes a sustainable relationship between human beings and the environment. This mutual trust relationship fosters a just and healthy environment by keeping nature and its populations at the center of policy and decision making.

Justice, in healthcare ethics, includes nondiscriminatory, unbiased, and equitable treatment within the context of what is owed to a human being. 126 This notion can be extended to the wider respect that is due onto the Earth. Reducing the ecological footprint is crucial to sustaining justice for human and environmental health. Creating ecologically just solutions supports reducing the footprint by fostering equipoise in the interactions between humans and their environment. In "Sharing the Earth: A Biocentric Account of Ecological Justice," Anna Wienhues stated that "[a] robust justification of ecological justice (justice to nature) requires starting at the roots of justice, rather than merely giving, for example, an argument for why certain non-human beings have moral standing of some kind." Wienhues constructed a crucial question: "How can 'we' live well together on one planet with a finite amount of resources crucial for life?" To begin to answer this, we have to realize that our resources are not finite and we need to justly preserve them to sustain life.

To further address justice and planetary ecology, James Dwyer in "How to connect bioethics and environmental ethics: health, sustainability, and justice," stated that an ecological footprint is created by the impacts of living on Earth. For instance, "[w]e breathe air, drink water, eat food, wear clothes, build houses, burn fuels, and produce wastes. Some of us ... drive cars, fly in airplanes, buy computers, and produce children. Even after death, the disposition of our bodies has an environmental impact." Therefore, an ecological footprint impacts the finiteness of natural resources on Earth. For example, the ecological footprint of humans on land and water

can be seen when using Earth's assets for agricultural purposes, waste management, supplying food such as through fishing, etc.<sup>130</sup> As a result, regardless of man-made developments, we still share the Earth and need to treat it justly through policy making, agricultural expansion, and technological developments.

Bioethics sheds light on the importance of reducing Earth's ecological footprint.

Jennings et al. stated, "environmental ethics can fortify the moral fabric of the environmental justice movement." Ecologically just solutions serve as an ethical basis for cultural and biological diversity found on Earth. It can also "demonstrate the social facets of environmental ethics in an applied context. For instance, restorative justice represents an ethical framework in which the injustices faced by marginalized groups are acknowledged and honored by others." Environmental justice, as a result, can help bring clarity to ecological justice at the individual, communal, and even global levels. It can serve as a foundation to guide new policy, technology, or expanded methodologies. Likewise, it can serve to restore current strategies, keeping the Earth's environmental health at the center of decision and policy-making.

Widely considered notions of environmental and public health are often based in social determinants, as social factors impact health outcomes. Similarly, ecological justice can support environmental and human health as a way to give future generations a healthy planet. In *Environmental Health: From Global to Local*, Frumkin stated, "[i]ssues of environmental justice make up a complex web of public health, environmental, economic, and social concerns that require multiple, holistic, integrative, and unifying strategies." Conscientiously utilizing natural resources requires being cognizant that Earth's system is one that all creatures utilize it to survive. From this perspective, ecological justice can be viewed as an expression of empathy. Furthermore, Frumkin purports the concept of sustainability as a central theme of environmental

health; one where sustainable development can holistically impact environmental health in the short-term and long-term. For instance, this could mean in the short-term, improving quality of life which positively supports the health of the current generation. In the long term, restoring sustainability protects the health and well-being of future generations.<sup>134</sup> From this understanding, cultural diversity is an inherent part of ecological justice.

## **II. Valuing Cultural Diversity**

Cultural diversity brings with it diverse ways of life including unique world views. These diverse ways of life can provide unique past and current world insights to improve future decisions or choices for living in equipoise with nature. In "Cultural Diversity and Biodiversity For Sustainable Development," the UNESCO and UNEP high-level Roundtable argued that "there is a wider understanding that reduced diversity in its cultural and environmental dimensions poses a threat to global stability and that it makes the world and its inhabitants increasingly vulnerable." Specifically, cultural diversity fosters attentiveness to global environmental concerns, which affect human beings' quality of life on all levels, encompassing environmental and social issues. Globally, some 21st century environmental concerns include air and water pollution, loss of natural or biological diversity, and climate change. Combined, these environmental concerns create risks for the quality of human life along with the survival of all life forms. As a result, humanity continues to face a multifaceted global environmental crisis.

From a historical perspective, sustainability has a unique interwoven relationship with humans, time, and cultural context. In *Environment and Sustainability in a Globalizing World*: "Chapter 2: Background and History of Sustainability," Andrea J. Nightingale et al. articulated that throughout history, sustainability is a concept that has emerged due to endless human impact on planet Earth. In ancient Greek philosophy, environmental degradation was attributed to

"moral and political decline" within humanity that was not able to live in harmony with its environment. In the Enlightenment Era, environmental viewpoints changed with the transformation of socioeconomic factors, advancements in science and development of technology. With the Industrial Revolution came the exploitation of Earth's natural resources. <sup>137</sup> In "Protection of the Environment, the Biosphere and Biodiversity," within the *Handbook of Global Bioethics*, Johan Hattingh argued that the advancements in science and technology that positively empowered human beings ultimately created rapid negative impacts, such as extinctions, on the Earth. <sup>138</sup> Extinctions have been further impacted by natural destructions. Currently, in the 21<sup>st</sup> century, environmental extinctions are vastly affected by humans. As Hattingh discussed, previous destructive periods were caused by natural disasters, such as volcanic eruptions or tectonic plate shifts, while the current destructive era, or the Sixth Extinction period, is caused by overpopulation, changes to the Earth's health such as increased resource depletion, and environmental pollution, etc. <sup>139</sup>

Nightingale's ideas of sustainability are echoed by both Hattingh and the UNEP in contemporary discourses on environmental concerns stemming from the loss or reduction of cultural diversity and biodiversity in global bioethics. Therefore, to further prevent extinction, sustainability must be considered as a two-way concept; one that provides support to humanity on how-to live-in equipoise with and on the Earth, and the other as a part of how humanity can practically appreciate their relationship and connectedness to the environment. As a result, the culture of humankind needs to make a shift to conserve and support ecosystems and be attentive to cultural and biodiversity.

Globally, human impacts affect the well-being of natural habitats and ecosystems. From a scientific standpoint, the US Environmental Protection Agency (EPA) reported in 2010 about

72% of greenhouse gases were released by coal fired power plants. <sup>141</sup> This not only contributes to adverse effects on human health such as respiratory diseases, but also causes harmful impacts on the environment in the form of natural disaster such as hurricanes and wildfires. <sup>142</sup>

Deforestation, habitat extinction or destruction, and wildlife or natural stressors all contribute to the degradation of the ecosystem's health. From a bioethics standpoint, Hattingh pointed out that the arguments for protecting the Earth are centered around its instrumental and intrinsic values. <sup>143</sup> Instrumental value is necessary for the well-being of humans because of its utility, while intrinsic value can be found in the very nature of what the Earth is. <sup>144</sup> Instrumental and intrinsic values of the Earth are vital to all living species and therefore should be protected. It is our responsibility to recognize our impacts on the Earth in order to protect the ecosystem by considering to instrumental and intrinsic values.

Biodiversity includes the diversity found in the Earth's ecosystem. Loss of biodiversity can present challenges but also is an area that humankind can reverse to support the ecosystem. Robin Attfield, in *The Ethics of the Global Environment*: "Biodiversity and Preservation," summarizes that biodiversity is found in the interrelations amongst and within habitats, organisms, and species. When species and their natural habitats are disrupted there is potential for the natural synergy to become imbalanced. Attfield noted, disruption of certain ecosystems like in Madagascar, Borneo, Brazil, and Nepal cause stresses on species that live and depend on habitats such as wetlands and rainforests. It is crucial to understand that these patterns and losses are happening on a global scale and should serve as a vital warning and incentive to seek balance in the ecosystem to protect the Earth. By being attentive to the instrumental and intrinsic values of the Earth, further adverse effects on the ecosystem can be mitigated.

The Earth's ecosystem needs to be protected because it has value that is essential and needed for utility. However, the challenge lies in finding a balance between using Earth's resources and mitigating the negative human impacts. Hattingh stated that "[u]nder the conviction that the well-being of humankind should be ensured over the long run, it was realized that the goal for resource management should be shifted from maximum benefit to maximum sustainable benefit, that is, benefit that can be maintained over time." The concept of sustainability recognizes that humans do use natural resources but considers the notion of shifting the weight from just using to mindfully using over time; essentially a balance between the principles of beneficence and non-maleficence. The usage of resources for survival is clear but it is crucial they be used consciously. Therefore, it is unrealistic to stop using the Earth's resources but rather be inspired by the concept of sustainability to use responsibly to sustain preservation for the future.

Cultural diversity highlights the need to appreciate and respect biological diversity.

Acceptance and shared respect for cultural diversity are vital requirements that are necessary to foster empathy among the global population and environment. Likewise, cultural diversity is a source of inspiration for the future of sustainability. For instance, the global concerns of the Earth foster unity between diverse ways of life. Cultural diversity can provide a common ground across global populations, recognizing "the irreplaceable element of their own humanity in others." That is, culturally diverse global populations can recognize environmental concerns as a common human concern. Environmental concerns related to depletion of natural resources presents not just ethical issues but challenges to the survival of humans and non-humans.

Pollution of the Earth's natural resources of air and water is one of the biggest issues that humankind is confronted with in the 21<sup>st</sup> century. In *The Ethics of the Global Environment*,

Attfield referred to the World Bank's research that showed, that the lack of access to clean water and water-transmitted illnesses is a massive challenge that over 1 billion people still face. As noted earlier in the chapter, water pollution causes adverse effects on human and environmental health. Attfield articulated that, fresh water is a finite natural resource which has the potential to be adequately distributed to everybody by investing in financial means and effectively developing resources such as irrigation methods, which requires engaging with local people who are knowledgeable about local geographical environments and traditional approaches. Sharing and incorporating knowledge and support from local populations regarding water quality policy is one way to support sustainability of this natural resource.

Similarly, fresh air is another finite natural resource that if polluted impacts the environment and humans. One of the contemporary challenges is the overstressing of the atmosphere and oceans to absorb carbon dioxide. This impacts the air that humans breathe but also the air in which all life needs to survive. Attfield articulated that an international solution is required for cleaner air however, a greater onus should be put on developed countries who emit more harmful carbon emissions. Recognizing a shared responsibility should help create global unity to develop a global strategy to foster cleaner natural resources such as air and water. Sustainability for biological diversity and natural resources fosters respect for the Earth.

Valuing cultural and biological diversity creates respect for a shared planet. Sustainable human development goals thus, require creating coherence with "local cultural aspirations" to tie together "universal developmental goals to plausible and specific moral visions." It is clear that advancements in science and technology are necessary and will continue to grow. As such, the global environmental concerns require a balance between preservation and development.

According to the UNESCO and UNEP Roundtable Document, there is a knowledge gap between

biological diversity and unique practices cultivated within cultural diversity. <sup>156</sup> Understanding the insight that comes with the varying ways of life is crucial to sustainability. The UNESCO and UNEP Roundtable Document articulated that because different cultures possess different understandings, practices, and experiences, "[w]e cannot understand and conserve the natural environment unless we understand the human cultures that shape it." <sup>157</sup> Using the knowledge that varying cultural lifestyles embody about their surrounding environment creates sustainable development for the future by respecting the diversity found on Earth.

Developing shared understandings through varying cultural ways of life is one method of respecting the Earth. As indicated in the UNESCO and UNEP Roundtable, cultures across the globe foster knowledge about their respected environment in an empathetic way that sustains a relationship with the Earth's diversity. 158 For instance, in tropical ecosystems such as those in Australia or the Amazon rain forest, "farmers commonly harbour scores of domestic plant species...varieties adapted to diverse environmental conditions and cultural needs....The biologically diverse landscapes created and maintained by aboriginal Australians through their astute use of fire is but one well-documented example." Acknowledging the relationship between cultural and biological diversity is key to respecting the Earth in the current globalized era.

Ultimately, this environmental practice reflects a cultural understanding of how to sustainably cultivate natural resources. From this perspective, there is a reciprocal relationship between Earth's biodiversity and human beings' cultural diversity. Practically speaking, diversity is found in non-human and human experiences. The universal component of being human urges a shared responsibility to be cognizant of protecting and cultivating the intrinsic value of natural resources for the future of humanity. Culturally diverse people find some part of

themselves on Earth due to the very quality of being human.<sup>161</sup> As such, knowledge, practice, and experience understood and shared between culturally diverse individuals enable local and global biological sustainability.

Current environmental concerns bring attention to the dire need of ethics to develop sustainable actions for the future. The UNESCO and UNEP Roundtable Document discussed that mitigating impacts of globalization is no longer just a financial experience, but rather, a "cultural, technical, and environmental" movement. This is where bioethics and the notions that underscore the field such as collaboration, fostering respect, and creating shared responsibility can be of utility. Section 3 in IOM's "Rebuilding the Unity of Health and the Environment: A New Vision of Environmental Health for the 21st Century" discusses the fact that the relationship between nature, humans, and health are also echoed in other disciplines, such as philosophy, ethics, and the arts; there is evidence that build on this understanding to work towards improving human health. As such, the UNESCO and UNEP Roundtable acknowledged the need of a shared dialogue to prioritize sustainability by creating protocols, strategies, and/or policies that foster a balance between national and global issues associated with globalization.

### III. Global Bioethical Sustainability

Achieving global bioethical sustainability requires valuing the relationship between cultural and biological diversity as an interrelated system. Henk Ten Have, in *Global Bioethics:*An Introduction stated that "culture is often regarded as something of the past: heritage, custom, or tradition. It is, however, just as much orientated to the future; it conceives designs for social life, and it expresses collective aspirations." These collective aspirations, of 21st century culture, represent the vision to sustain the planet for the subsequent generations. In the UNESCO

and UNEP Roundtable summary from The World Summit on Sustainable Development,

Johannesburg, South Africa, the United Nations Millennium Declaration (2000) shares this
attentiveness to environmental differences stating: "[b]iological diversity represents this dynamic
process spanning hundreds of millions of years, and has been the key to survival, sustainability
and prosperity of those species and the ecosystems in which they flourish." This focus on
sustainability is indispensable for bioethics and is enlightened by attentiveness to cultural
diversity.

Issues that pervade future generations, such as pollution or depletion of Earth's natural resources benefit from a global lens. Bioethics, according to Van Rensselaer Potter's perspective, is a bridge that connects people in order to collaborate on global issues. <sup>167</sup> Potter viewed this approach to bioethics as "four bridges at the same time." Envisioning that, "[t]o address contemporary [environmental] problems, the new discipline must bridge the gaps between present and future, science and values, nature and culture, man and nature." <sup>168</sup> In other words, these bioethical bridges promote cultural and biological diversity as a way of attaining long-term sustainability and protecting the future of humanity. From this perspective sustainability is a key focus for the well-being and survival of present and future life forms. These bioethical principles aid in achieving sustainability of the environment and natural resources, and they aid in revitalizing biodiversity for the future.

A bioethical stance on environmental and human health helps attain a broad perspective on the global issue of sustainability. The 21<sup>st</sup> century environmental concerns such as air and water pollution, reduction of natural resources, and deteriorating microbiome of the soil, affect all of humanity regardless of geographic location. In 2015, UN proposed 17 Sustainable Development Goals (SDGs), with a 15-year plan, which they refer to as "the blueprint to achieve

a better and more sustainable future for all."<sup>169</sup> The intent of this is to guide people to foster a healthier planet. As of 2020, UN articulated that there still needs more action to meet these goals in its 15-year plan by 2030.<sup>170</sup> These SDGs address a wide range of global bioethical challenges such as poverty, climate change, deprivation of the environment, and harmony and righteousness.<sup>171</sup> Although all the goals are important, the scope of this chapter focuses on Goal 12, which centers on "ensuring sustainable consumption and production patterns" as it relates directly to environmental sustainability.<sup>172</sup> As a result, a bioethical outlook on global environmental issues aid in achieving sustainability and revitalization of the ecological system.

Sustaining the Earth's environment is a growing global concern. Cultural diversity helps enlighten ways of fostering environmental sustainability. In Chapter 5 of *Promoting Global Environmental Sustainability and Cooperation*, the authors assert that there is a "green gap globally" between the concern for taking care of the environment and the practical measures to achieve environmental sustainability.<sup>173</sup> In other words, people globally recognize that there is an issue but there is a knowledge or resource gap when trying to address it. Furthermore, environmental concerns amongst individuals and consumers are increasing and are still prevalent.<sup>174</sup> The authors also refer to a study which showed that environmental concerns between the years of 2004 and 2006 increased in the United States from about 62% to 77%.<sup>175</sup> As a result, it is evident that people around the globe are generally concerned for the health of the environment. One way to achieve environmental sustainability would be by recognizing the core human element within culturally diverse environmental practices.

Cultural diversity serves as a key pillar for sustainable development. Ten Have uses support from a concept from Buen Vivir which "shows, one can learn from the past and revitalize, for example, indigenous practices that have preserved biodiversity for thousands of

years. The central notion of these practices is harmony."<sup>176</sup> The section titled "Diversity and Sustainable Development" in the UNESCO and UNEP Roundtable also echoes similar notions of harmony. The Roundtable recognizes that it is not just commercial and technical progressions that enable sustainability, but also collaboration and cultural diversity. Likewise, their summary expresses the "[t]angible development can be measured in terms of human health, economic capabilities, commodity flows and physical guarantees of security and productivity. Intangible development consists of the spirit of participation, the enthusiasm of empowerment, the joys of recognition and the pleasures of aspiration."<sup>177</sup> Whether tangible or intangible, these factors promote cultural diversity by creating bridges that invite human participation in individual responsibility and collective sustainable choices.

Sustainable lifestyle choices and practices such as mindful purchasing, usage, or other environmentally conscious decisions are forms of eco-friendly, *green* behaviors. In Chapter 5 of *Promoting Global Environmental Sustainability and Cooperation*, the authors propose that consumers may not be incorporating green behaviors in their day-to-day routines due to financial wellbeing. For instance, green products might be better for the environment in the long term but are more expensive for the consumer in the short term.<sup>178</sup> Similarly, an electric car, such as a Tesla, might be an eco-friendlier choice and more cost-efficient for the consumer in the long term; however, purchasing a Tesla is a costly upfront investment. Organic food prices are another example because organic food prices are typically greater than conventional foods and, as such, create financial barriers to adopting eco-friendly choices for consumers.<sup>179</sup> These are just some of the examples that show the limitations to access and feasibility of eco-friendly, sustainable lifestyle choices. As a result, it is essential to ensure that economically efficient and

eco-friendly choices are available equitably for all people, so everybody is, in some way, able to adopt healthy (for the environment and humans), sustainable choices.

A methodology to bridge the environmental consumer gap would be to create equitable policies. In the UNESCO and UNEP Roundtable, H.E. Mr. Jacques Chirac (President of the Republic of France) stated that "[s]ustainable development is not just a technical and economic issue. It is a response to the worldwide ecological and social crisis." Reflecting on Chirac's statement, it is clear that equitable policies are crucial to providing ethical insights into economic and technical advancements. By adopting equitable policies, leader and policymakers contribute to creating ways to support ethical consumer practices, which reduce the ecological footprint and promote the safe and sustainable use of natural resources.

Natural resources are necessary for the survival of all life forms. Attfield articulated that while we see some natural resources as renewable, these energy sources are at risk of becoming nonrenewable through overconsumption.<sup>181</sup> Attfield highlights that natural renewable resources (water, air, trees, soil, etc.) are in danger because of how humans interact with these natural systems.<sup>182</sup> These interactions are largely negative on the environment; often we perceive natural systems as self-sustaining structures. While other organisms use natural resources as well, they are a part of the natural cycle. For instance, the microorganisms that live in soil use the nutrients found to survive, but they also contribute to the soil's health by cultivating the soil.<sup>183</sup> As a result, these microorganisms form a reciprocal relationship with the natural elements as a life-sustaining source. However, humans seem to have a one-way relationship with the environment, where they take more from nature than they give back. Considering this, Attfield applies the Precautionary Principle.<sup>184</sup> The Precautionary Principle enables the achievement of natural resource sustainability by balancing the favorable good over the unfavorable bad.<sup>185</sup> In other

words, balancing the benefic versus non-malefic results ensuring good is prioritized. Applying the Precautionary Principle in policymaking is one method to mitigate future depletion of natural resources actively.

An approach to sustainable natural resource conservation is making climate change policies legally binding. According to the Finnish government, Finland's parliament passed a new Climate Change Act in June of 2022. The Act describes the goals for the next three decades and focuses on carbon neutrality. Many countries around the globe have taken similar approaches to climate change and emission reduction. However, what makes this approach different is that Finland is the first country to make climate neutrality legally binding. This approach not only legally binds climate change actions but also recognizes that just reducing carbon emissions is not enough to conserve natural resources, such as air. There needs to be a balancing of the harmful damage that climate change has already caused with positive actions to offset future damages.

One method to approach carbon negativity is to restore air quality by using the advancements in 21<sup>st</sup>-century technology to reduce future damage or contribute back to mending already inflicted damages, like in Finland. Furthermore, the Finnish government pointed out that they will also work to improve carbon sinks (areas that absorb more carbon than they release). <sup>188</sup> It is evident that we live in a time when technology encompasses our culture or way of life. Using new technologies to remove the damage to the atmosphere is one method of the practical application of bioethical sustainability. Larger countries like the United States have the capacity and resources to adopt and incorporate similar approaches legally and use advancements in technology to achieve carbon negativity. Attentiveness to cultural diversity can help potentially mend the negative impacts of advances in the 21<sup>st</sup> century which have prioritized long-term

production for short-term comfort.<sup>189</sup> As the UNESCO and UNEP Roundtable articulated, cultural diversity in sustaining natural resources is a positive socio-cultural resource.<sup>190</sup> The 21<sup>st</sup>-century technologically driven cultural context should be a fundamental component that reinforces climate law and policy formation to provide practical, ethical solutions. Sensitivity to cultural diversity contributes to sustaining natural resources, recognizing that individual identity is rooted in a broader cultural context that requires respect.

Biodiversity, or biological diversity, is found among organisms, species, and ecosystems on Earth in all terrestrial, marine, aquatic, and ecological systems.<sup>191</sup> The 21<sup>st</sup>-century environmental concerns, such as climate change, pose challenges to human health as well as the health of biodiversity. For instance, increased impacts of global warming such as heat waves, droughts, and flooding have adverse effects on human health and biodiversity health.<sup>192</sup> In 2003, heat waves in Europe caused negative impacts on both humans and the environment leading to large numbers of deaths because of unbearable temperatures and secondarily through deficient air quality.<sup>193</sup> As a result, it is important to consider ways to revitalize biodiversity, specifically ecosystems, to make sustainable decisions for environmental and human health.

Ecosystems are necessary for the healthy functioning of Earth. In *The Ethics of the Global Environment* Robin Attfield used "Anne and Paul Ehrlich's analogy of rivets" an analogical perspective that living populations and groups of species can be compared to rivets that hold together machinery. <sup>194</sup> They point out that while rivets hold together an airplane, some defective rivets may be removed before the airplane's causes concerns or safety issues. However, relying on an airplane with missing rivets is irresponsible. Similarly, one can apply this example to biodiversity loss and extinction. <sup>195</sup> For instance, wildlife in ecological systems could represent rivets in Attfield's analogy. Human impacts adversely affect wildlife and resembles removing

rivets; if not monitored, this removal puts stress and safety issues on systems and leads to extinction. This analogy is similar to the understanding that biodiversity, in some ways, is an irreplaceable part of healthy ecological systems and, as a result, is inherently crucial for survival.

An appreciation of cultural diversity helps sustainably revitalize biodiversity, especially from the perspective of human and environmental health. Revitalizing biodiversity works towards long-term sustainability. One way to support revitalization is to tap into the knowledge that cultural diversity fosters prosperity. For example, "the way of life of most indigenous peoples depends on biological diversity. Cultural and religious beliefs and traditional spiritual values often serve to prevent overexploitation of resources and sustain the systems in which indigenous societies live for their own benefit and that of future generations." 197 Applying cultural diversity knowledge to the 21st century means creating more eco-friendly green living. Eco-friendly green living would promote a positive relationship between environmental and human health. "Nature-based solutions" (NBS) as presented by Marselle et al., is one way to include developing green spaces in urban settings, benefiting humans and their environment. For instance, creating more green spaces in areas where they do not exist such as urban areas can encourage people to adopt different ways of life; such as to go outside for exercise, fresh air, a calming environment, and can also create spaces in which biodiversity and microorganisms thrive. 198 The downside of creating green spaces in cities would be the heavy exposure to carbon emissions, which could potentially stunt the revitalization of biodiversity and even cause harmful air quality. One way to overcome this would be to create electric public transportation methods, bike lanes, or limit the number of automobiles coming in and out of the city to reduce carbon emissions.

Applying principles of global, intergenerational equity helps highlight the ethical practicality of sustaining biodiversity. A global policy using the Pareto principle as a foundation would bring awareness to revitalizing biodiversity. The Pareto principle states that changes should not make anybody worse off than they would have been without the changes. 199 Attfield argues that this is nearly impossible, though, because "[s]uch expectations would be counterproductive to the projects of maximizing overall well-being, of trusteeship and of sustainability alike."<sup>200</sup> For example, expecting the current generation to completely eliminate required carbon emissions for everyday use would disregard this principle and be unreasonable because it would be incompatible with justice for this current generation.<sup>201</sup> In the preceding example, eliminating carbon emissions altogether would create barriers to obtaining needs of survival in the 21st century culture, such as using a car to go to work to earn a living to provide food, shelter, etc. One way to overcome this obstacle would be to take a phased approach to eliminating carbon emissions by adopting carbon neutrality legislation, like in Finland. Furthermore, Attfield uses the Caring for the Earth report by the UNEP and other partners as support, ensuring that sustainability can still be achieved in constructed developments, such as cities, "if developed in ways sensitive to both human and ecological communities." <sup>202</sup> Sustainability, therefore, requires considering a balance between new development and current utility within global policies and contexts that are maintainable in the long-run.<sup>203</sup> As a result, revitalizing biodiversity requires an ongoing effort within varying contexts.

In conclusion, valuing cultural diversity using bioethical principles works towards a global framework for environmental and human health sustainability. Cultural diversity with a bioethics framework bridges the gaps between issues that affect humanity. Autonomy can help foster educated perspectives on the impacts and effects of environmental stressors. Beneficence

and non-maleficence promote good sustainable development while causing the least amount of harm to the environment. Justice comes into practice when making decisions to ensure ethical, moral, and virtuous choices when implementing new technologies or practices. A sustainable environmental culture creates a holistic outlook on planet Earth between humans and nature. We should view Earth as an integral, inherent natural resource needed for the survival of all life forms, and, as a result, we should treat it with utmost care.

We can achieve sustainability of the environment, natural resources, and biodiversity by valuing cultural diversity. Ultimately, we can foster respect for the Earth, cultural and biological diversity, and ecosystems. Humanity can practice environmental sustainability through mindful and conscious individual cultural and environmental choices. Sustainable policies can maintain natural resources by applying principles of precaution that create an understanding where culture and biological diversity are one and the same whenever implementing new policies or technology. Furthermore, biodiversity may be revitalized and sustained through a global policy where each country or groups of people are held responsible for their actions and behaviors. Sustainable achievements foster human and environmental health for current and future generations, leading to a harmonious balance on Earth. Harmony among creatures, mother nature, and human beings can create and maintain a conscious and empathetic environmental relationship.

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# Chapter 3: Valuing Human Life at the Start and End of Life

The dissertation examines how cultural diversity as a social determinant of health, being aligned with human life, human dignity, human rights and human equity provides an ethical contribution. My explanation of the ethical contribution of cultural diversity as a social determinant of health refers to a quadrant of topics that expands the approach of the UNESCO Declaration of Bioethics and Human Rights. The UNESCO approach addresses cultural diversity in relation to human dignity and human rights. My explanation expands upon the UNESCO approach. I adopt a quadrant of topics that aligns human dignity with human life and human rights with equity. The alignment of these topics in the quadrant (dignity/life and rights/equity) explains the meaning of cultural diversity as a social determinant of health. Chapter three discusses the concept of life in the quadrant.

## **Chapter 3a: The Value of Human Dignity in the Human Embryo**

The ethical issues concerning the beginning of life have been significant.<sup>1</sup> Issues such as abortion, advancements in contraception, stem cell research, and assisted reproductive technology all involve the manipulation of a human embryo and they represent the moral and social values of a culture. The value of human life can be discussed based on cultural perceptions of dignity or sanctity. Dignity in terms of human life often stems from a modern secular, or scientific, perspective. However, the sanctity of human life more often than not, stems from a religious perspective.<sup>2</sup> While consideration of the dignity and sanctity of human life can be polarizing, the bioethical field does not have a corrective view, or simple answers, for ethical dilemmas, and ultimately this leaves room for ethical analysis and moral deliberation.<sup>3</sup>

According to a bioethical stance, the value of human life is emphasized in beginning of life issues because each person defines the point at which life is constituted. As medical and

biological research continues to grow, and technology in healthcare continues to expand, individuals may easily be divided as opponents or proponents of the moral value of the beginning of human life. Although there are no single absolute answers at the cornerstone of life decisions, according to P.F. Connell, deducing biological discoveries from a "biblical" outlook can guide individual's toward a just direction, or provide a holistic perspective. In both monotheistic and polytheistic religions, human life has intrinsic value. However, the value of life in a human embryo should not only be religiously based but also scientifically based on its inherent moral status and value. The human embryo in its beginning of life stage has value from diverse cultural, scientific, and religious perspectives. The aim of this research is not to advocate for secular or religious perspectives but rather to provide bioethical insight into the varying perspectives that ethics issues bring with them. My expertise is not in religious or secular understandings, rather it is in providing bioethical insight into how considerations of culture play a role in bioethics as a social determinant of health. Cultural diversity, therefore, encourages an awareness of varying perspectives on otherwise controversial beginning of life ethics issues.

## I. The Beginning of the Human Life Form

Attentiveness to cultural diversity facilitates an appreciation of the meaning of human life from a variety of perspectives: secular, religious, and scientific. S.A. Benner's article, "Defining Life," echo's notions from a committee gathered by NASA in 1994, where life was defined as "a self-sustaining chemical system capable of Darwinian evolution." The notion of Darwinian evolution, or theory, was examined throughout the article; Benner stated that the concept of random variation within the theory refers to the idea of being unbiased, or neutral to future outcomes. Furthermore, although mutations in life forms arise due to variation, they may allow for better survival, similarly, advancements in technology, such as DNA sequence identification,

may allow for better future survival.<sup>8</sup> Another example Benner mentioned was 21st-century engineers. Engineers use their knowledge and skills to help understand problems and solutions, however engineers often "think that they do not generate solutions to problems in a Darwinian fashion." As a result, 21st century, knowledge, skills, and advancements can improve sociocultural circumstances, resulting in an overall benefit for future generations. However, manipulation of human life with the use of technology, contraception, or stem cell research creates the potential for ethical concerns as a result of the intrinsic value and sanctity of life at every stage despite flaws or mutations.

At times, the secular, religious, and scientific ideologically collide. From a scientific perspective, a human embryo is an organism composed of cells and its successful development is what eventually leads to the formation of a human being. While religious perspectives view human life as sacred, the secular perspective expands that determinant into ethical considerations. However, valuing human development and life through a bioethical lens, culminates these perspectives to include socio-cultural considerations of existence; advancing the ideas of what human life is and what human forms are able to accomplish.

The human body is one of the most complex biological forms of life. For the development of a human being, the early stages of the human life form are crucial. Scientifically, the human embryonic life form transforms from a zygote to an eight-cell stage embryo afterward, the embryo starts to compact in the thirty-two-cell stage. Then, the cells bind tightly to each other, gene activation begins, "and the embryonic cells begin to use their own genomes to make proteins." The human embryo at this stage independently develops into what is known as the blastocyst stage. A blastocyst is a cluster of embryonic cells that develops up until day six and has not yet been implanted in the uterus. The embryo in the form of a blastocyst has no

organs, bodily systems, or even bodily fluids because the embryo has not yet been implanted in the uterus. At this stage, the value of human life at this stage is less evident and, as a result, questionable. How can embryonic cells be considered equivalent to a fully mature human being?<sup>13</sup>

Biologically, a blastocyst may not always be regarded as a valuable human life because it is composed of compacted cells within a fluid-like substance. As a result, these human embryonic cells are not seen as comparable to a more developed and reasoning, human being. 14 In Chapter 1: "Ontology and Embryos: On Being an Embryo" in *Human Embryos, Human Beings- A Scientific and Philosophical Approach*, Samuel Condic and Maureen Condic state that although the moral status of the human embryo may be controversial, it is definite that "embryos are distinct from adult humans, and adult humans come from or develop out of embryos." 15 Therefore, the human embryo is not a fully developed human being, however, it is the beginning of the human life form which develops into a rational being. Essentially it is the biological processes within the beginning of life stages that help transform a human embryo into a human adult. 16 The development of trees may also give a comparison to another biological system. Condic and Condic use the example of acorns in that acorns are distinct from their oak trees despite oak trees developing from acorns. 17 Therefore, the essence of the beginning of life in various systems is evident because they develop into fully realized, matured organisms or forms.

To explain the value of life in a human embryo and the importance of context from a scientific standpoint, Condic and Condic differentiate a life's form from its whole, allowing for clear distinctions between the potential of an embryo and the whole human being. According to Condic and Condic, the cells that compose the body - including the skin and even bowl cells - make up the cellular components that continuously undergo change throughout a human being's

life. Despite this continuous change, the human entity that is composed of those cells remains constant.<sup>18</sup> Essentially, Condic and Condic are arguing that at the molecular and cellular level, the human form is transformative. They state:

Johnny is made a whole by a form, yet the form that makes Johnny a whole is not extrinsic to the underlying material but rather intrinsic to it. 'Form Johnny' alters what the material is fundamentally by restricting its range of and causing the material to be something fundamentally different—to be 'Johnny' rather than a merely a pile of carbon, nitrogen, hydrogen, and oxygen. A form that causes something to be what it is in a fundamental way is called a 'substantial form'...Together, a substance and its associated accidental forms are what constitute a finite being.<sup>19</sup>

The human as a "finite being" is fundamentally a transformative life form.<sup>20</sup> The moral outlook that religious perspectives bring with it inform secular or scientific perspectives. This biological makeup and development of the human being get complicated when viewed through sociocultural, secular, and religious lenses.

Crawford points out that religious traditions and understandings represent shared insights accumulated over time via analysis and considerations on moral and ethical issues.<sup>21</sup> According to Crawford, religious viewpoints speak to the human species as a whole and address universal concerns related to health and well-being despite the new advancements in medicine and technology over time.<sup>22</sup> However, without these advancements in healthcare sciences, there could be no socio-cultural considerations. Varied practices and philosophies among monotheistic and polytheistic faiths present varied ideas of what constitutes life and how it does so biologically.

Christians believe human beings are crafted by God in His likeness. A human being's physical body resembles its Creator and human life is valuable. Likewise, man and woman have an elevated status because they are embedded with the ability to morally reason and make sound

judgements like their Creator.<sup>23</sup> In "Instruction for Human Life in its Origin and on The Dignity of Procreation," Joseph Card Ratzinger argues that it is indeed "out of goodness—in order to indicate the path of life—that God gives human beings his commandments and the grace to observe them."<sup>24</sup> Therefore, human life was endowed upon man to live out in *imago Dei*, or the image of God.<sup>25</sup>

In *The Sacredness of Human Life*, author David Gushee cites the opening book of *Genesis*. The chosen passage presents textual evidence of why God created man in His image as a reflection of Himself on Earth. *Genesis 1* reads: "God said, 'Let us make humankind in our image (tselm), according to our likeliness ... and let them have dominion over the fish of the sea, and over the birds of the air, and over the cattle, and over all the wild animals of the earth, and over every creeping thing that creeps upon the earth." According to Gushee, God did not create other species in his image because he specifically gave human beings a certain degree of intrinsic value which sets them apart from other forms of life. Additionally, interpretations of the intrinsic features of man are present in *Sirach*, the book of the Bible, that states that humans have a "tongue and eyes, ears and a mind for thinking.... He filled them with knowledge and understanding and showed them good and evil" (Sir. 17:6-7).<sup>27</sup> Even though religious ideologies are rooted in the spiritual perspective, they also fall back on the biological makeup of human beings, and we need scientific insights to consider ethical perspectives.

Moreover, from a monotheistic perspective, the human life form is valuable because God has created it as a unique arrangement of biological or physical elements. In *The Sacredness of Human Life*, David Gushee expands that "many Christians have coalesced around the position that a human person with the same moral status as anyone reading this sentence begins at conception—presumable meaning that moment when the egg nucleus and the sperm nucleus fuse

to begin the development of human life."<sup>28</sup> This supports the concept that human life is recognized from a religious perspective as existing from the very moment fertilization occurs between an egg and sperm. If there is a recognition of life from conception, ergo every biological stage thereafter contains life. In the creation and development of the human life form, science applies a naming schema to individual stages of existence. These stages only become moral considerations when religious ideologies are applied. For example, a zygote is recognized at conception, an embryo at two weeks, a fetus at nine weeks, and a newborn once a live departure through the birth canal has occurred.<sup>29</sup> Scientifically, the continuous growth of the human embryo is not fully accounted for through naming, or even belief, systems.<sup>30</sup>

As a result, ethical dilemmas arise surrounding the moral status of the various beginning of life stages. Each biological step of the process that helps the human embryo develop are essential building blocks for the next.<sup>31</sup> For example, the moment of conception is the building block for the next milestone step which is fertilization of the egg and sperm leading into the embryonic form. This same building block process is what eventually helps the human being develop after birth into a toddler, adolescent, and eventually an adult human life form.

It has been argued, the biological process may be developed through the aid of the soul or consciousness. Ratzinger and Bovone argue in, "Instruction on Respect for Human Life in its Origin and on The Dignity of Procreation" that it is "[b]y virtue of its substantial union with a spiritual soul, the human body cannot be considered as a mere complex of tissues, organs and functions...; rather it is a constitutive part of the person who manifests and expresses himself through it." When viewed from this perspective, it could be understood that the physical form and the conscious soul work together to help mankind morally from the earliest stages of development. Similarly, Peter F. Connell states in *The Biblical View of the Sanctity of Human* 

Life that: "[m]an was made a 'living soul.' That is, every human possesses an integral soul that was destined to abide forever following his or her creation." Perspectives based in religious notions support the idea that the soul gives humans the ability to embrace morality and to perform ethically. Appropriation of belief systems takes away the importance of the biological stages of development - without biological advancements, there would not be any morality.

Hinduism, as a polytheistic religion, regards the birth of a human as the rarest and most respected forms of life.<sup>34</sup> The origins of human life according to Hinduism are often portrayed in scriptures. H. Inbadas, in "Indian philosophical foundations of spirituality at the end of life," articulates that according to the *Vedic* philosophy, all living beings are interconnected to *Brahman*, or the supreme being, and the human *atman* (soul) is unique because it has a chance to connect with the Divine once released from the physical human body.<sup>35</sup> Furthermore, *Vedic* philosophy holds the notion that enlightened souls have the chance to move towards the direction which eventually reaches the virtue of *Brahman*, and ultimately *moksha*.<sup>36</sup> Unlike all other manifestations of *Brahman*, such as animals or plants, the human *atman* (soul) is, or has the chance to become, of the same spiritual quality as *Brahman*. As a result, the human being is both physically and metaphysically connected to the Divine and such has a responsibility to lead a healthy, virtuous lifestyle.

If all human life forms are created as a projection of *Brahman*, then human beings are considered valuable because they are a unique manifestation of *Brahman*. To be respectful of these understandings of valuing human life requires a sensitivity to cultural diversity, including different understandings of the human embryo. As Sivaraman and Noor point out in their study, because Hindu discourse on beginning of life topics such as embryonic stem cell research is very scarce, the bridging of these subjects can provide essential insights.<sup>37</sup> From a Hindu perspective,

the beginning is recognized as the rebirth of a soul from a previous incarnation, and as such is morally valuable from the earliest stages.<sup>38</sup> Many Hindu philosophies fundamentally include two notions, *karma* and *ahimsa*. As a result, these notions are practiced in secular practices of medicine. For example, the Hippocratic Oath that medical students are obligated to take and uphold echoes the Hindu cultural philosophies and principles of doing no harm or injury. Specifically, *ahimsa* relates to doing no harm to others.<sup>39</sup> In medical terms this means that since the human embryo is a living organism, it is crucial to do no harm (*ahimsa*) upon it.

The Hindu belief of reincarnation is closely tied with the principle of *karma*. The advantage of human life is to use its distinguishing capabilities, such as speech and intellectual faculties (*buddhi*), to move towards the spiritual.<sup>40</sup> The philosophical notion of *karma* places importance on notions such as one's intention, or *sankalpa*.<sup>41</sup> Likewise, in the Hindu scriptures, *Chandogyopanisad*, the human life form is said to have been created from one single point of existence.

In the beginning there was Existence alone – One only, without a second. He, the One [Brahman1], thought to himself: 'Let me be many, let me grow forth.' Thus out of himself he projected the universe, and having projected out of himself the universe, he entered into every being. All that is has its self in Him alone. Of all things He is the subtle essence. He is the truth. He is the Self. And that ... THAT ART THOU! (*Chandogya Upanishad VI* cited in Gupta, 2002, p. 45 re-cited in Inbadas, p. 323).<sup>42</sup>

There are factors that play into philosophies and *ahimsa and karma*. Reincarnation, a fundamental notion found in Hinduism, "believe[s] the soul (*atman*) transmigrates from one life to another and thus the [present] life is a transition between the previous one and the next." Sivaraman et al.'s article summarizes that, denying, harming, or destroying life is viewed as a bad karmic act, unless there are no other options or is done with the intent to provide benefic results for society. For instance, donating embryos with the intent of research purposes and

safeguarding future lives, such as by finding cures for harmful diseases, is justifiable, while killing a human embryo without proper intent or reasoning is not justifiable.<sup>44</sup> However, the termination of a pregnancy is both medically and ethically justifiable if it is done with the intent to protect the mother's life, given that there is a potential health risk.<sup>45</sup> The preceding justifications presented in Sivaraman et al.'s article, consider balancing the good and bad karmic acts, which to a certain extent, mimic the balancing of the widely known principles in 21stcentury bioethics, of non-maleficence (mitigating or doing no harm) and beneficence (promoting good). Moreover, some Hindu leaders, in Sivaraman and Noor's study, responded that in the case of the embryo which is  $\sim 5$  days the soul has not found the body at that point in time, and without the body the soul has no purpose so it would not be considered killing. 46 For cases where human embryonic stem cells may be used to save lives, or in the case of donating a surplus, some Hindus believe that the intent to help humanity is crucial when undertaking research in order to avoid or mitigate any bad karma.<sup>47</sup> Within the Hindu perspective, biologically the human embryo biologically is viewed just as valuable as any other stage. Furthermore, Sivaraman articulates in another similar study that within this polytheistic religion the lack of central guidance is a positive because "the leaders embrace the advantage of an absence of a central authority, which encourages individuals to seek personal understanding from the scriptures."48 As a result, no harm should be done forcefully upon it, nor should the human embryo be denied the chance to undertake its karmic duties as a living human being in the future.

## II. Why Do People Value Life in the Human Embryonic Life Form?

Bringing together the religious and secular conversations on the value of human life, the question remains: why do people value life in the human embryonic life form? The combination of the soul and the physical body give the human life its aura and liveliness; it is infused with

consciousness that embeds the human being with dignity and morality. The ability to repair, develop, and adapt are intrinsic biological characteristics of the embryo. Ethically, the human embryo is a valuable life form because it has dignity and sanctity. Life is valuable in a human embryo because the cells at this stage intrinsically characterize what we know to be a morally reasoning human being. At this stage, while the life form does not have the ability to morally reason it does have the biological characteristics that will help the embryonic form to progress into a fully reasoning human being. Therefore, life is valuable in a human embryo because of the role that these cells intrinsically epitomize, like a human being. As a result, every life form even in the beginning stages has dignity and is considered sacred which is why morally speaking it is valuable.

Dignity is a fundamental factor in valuing human life and is one component of ethical considerations in the beginning of life. In "Human, Value, Dignity, and the Presence of Other," Jill Graper Hernandez states that:

Moral dignity is expressed through the relationships we cultivate, the communal ends we pursue, and the rights we enjoy. Correlatively, human dignity is inseparable from its ground (i.e., morality), and the relationship between these two is best represented for Kant in the humanities formulation. The foundational model of dignity ensures that human value is non-circularly derived, but is ultimately tied to expressions of individual human dignity that comes from the dignity of morality. Linking Kant's dignity of humanity to the dignity of morality affords a unique and efficacious response to the discussion of human value. In one sense, dignity is amplificatory, since its worth is inextricable with that of autonomy and the rights afforded to the autonomous. But that isn't to say that the worth of dignity is merely amplificatory. Rather, human dignity indicates the absolute inner value found in each individual in virtue of being human. That inner worth engenders certain universal rights—derivable from the dignity and fundamental rational appeal of morality—just as it provides for the possibility for a community of beings to seek to live the moral life.<sup>50</sup>

In other words, Hernandez leads us to conclude that ethical dilemmas arise when human dignity is linked to social relationships and the human being is required to socially participate in society. When human dignity is recognized in both the individual and the community, based on a shared commitment, then there is duty involved to one other.<sup>51</sup> In this vein, the intrinsic value of life in a human embryo is not as apparent on the surface. For individuals to consider dignity in an embryo, it is required to deeply analyze and connect the intrinsic value found in the embryo to that which is present in the dignity of a human being. Hernandez argues that "the dignity we ascribe to persons comes from the thought of them acting morally because they are capable of setting sound prudential and moral ends, but it is the dignity of morality that makes us responsible to one another as moral agents."<sup>52</sup> The thoughts that allow a human being to do what is morally right is due to an intrinsic feature of consciousness. This same intrinsic value is present from the very moment an embryo is conceived and ultimately this is why an embryo has dignity that can be equated to the dignity found in a fully developed human life.

Certain religious perspectives hold that human embryo has sanctity, from varying moments in fetal development, and should be morally regarded as valuable. The thinking is that inner value in an embryo is present in every human being and comes into manifestation at the beginning of life. Paralleling the Christian and Hindu perspectives on the sanctity of the human life form may provide alternative insights to ethical dilemmas surrounding the moral value of life in a human embryo through an understanding of its inherent potential.

Both Christianity and Hinduism regard the human life form as sacred. However, in Christianity, the sanctity of life results from man being created in *imago Dei*.<sup>53</sup> A human being's physical body resembles God, and the human life form is valuable because man and woman are embedded with the ability to morally reason and make sound judgements just like the Creator.<sup>54</sup>

On the other hand, Hinduism regards the human life form as one of the rarest and highest life forms. Most Hindus believe that the individual self-survives between various life forms and the spirit is commonly recognized in the form of the *atman*, or soul. 55 The *asrama-dharma* approach expresses one framework for the social values of life on the individual personality level which include *dharma*, *artha*, *kama*, *and moksha*. 56 *Dharma* means to act with virtue in accordance with duty. 57 *Artha* means to pursue wealth and prosperity ethically and morally. 58 *Kama* means to obtain enjoyment in accordance with *dharma*, and *moksha*, or liberation. 59 These religious ideologies support the sanctity of human life from varying socio-cultural perspectives.

Inherent moral status is embedded in human existence in the earliest stages of life. We as rational human beings, "come to recognize the moral status of others, and come to be recognized by others, through our relations with them, but we have an inherent moral status before this status is acknowledged." The ethical debates surrounding embryos and their inherent morality is in question because they are not yet rational beings. Exploring the phases of life and death in, "Ethics and Embryos," Nicola Poplawski and Grant Gillett suggest "that the form of a human being extends beyond that present at a given slice of time to take in the breadth of an entire life. There is a phase of development, a phase of moral engagement with others and a phase of dying (which may be abrupt or more drawn out)." Based on this understanding, the developmental processes of life are sequences of evolving stages. Each of these developmental stages have inherent potential because each phase is an indispensable element of the whole human being.

The embryo in the form of a blastocyst is composed of a cluster of cells, develops up until day six, and has not yet been implanted in the uterus.<sup>62</sup> From a religious perspective the early stage as a zygote may be regarded as a valuable human life because metaphysically an egg that is fertilized "contains the unique DNA structure of the person[s] who will be later

recognized by those who will know them by their traits."<sup>63</sup> Scientifically, the human embryonic stage as a zygote is a developing organism composed of cells that contributes to the biological development process.<sup>64</sup>

While the inherent potential of a human embryo is not as evident, it resides in the fact that as an embryo, the cells are self-maturing, and the inherent morality can only be realized during subsequent developmental stages. Poplawski and Gillett go on to state that "we derive the moral status of an embryo from the whole of which that embryo is a part. An embryo has present applicable rights not because some time in the future that embryo may become a person with rights appropriate to persons but because it is the same individual who becomes a person." Moreover, there is an inherent morality within every human being. Attentiveness to cultural diversity highlights the significance of these developmental stages and the accompanying ethical concerns raised when considering inherent morality.

Humans are said to be morally rational because of their ability to reason consciously. From a bioethics perspective, it is important that human beings use these reasoning abilities to do good in the community and society. The central ethical dilemma is determining when and how a human embryo, an assortment of cells, becomes identifiable as human life to the person reading this paper. <sup>66</sup> Ethical dilemmas around the value of life in a human embryo arise because the embryo is not understood as a fully rational human being at this stage.

The relation of an embryo to a rational being is not evident on the surface. When there is synergy between the importance found in dignity to the notion of morality, then intrinsic value of people comes to the surface.<sup>67</sup> Hernandez argues "[t]hat inner worth engenders certain universal rights—derivable from the dignity and fundamental rational appeal of morality—just

as it provides for the possibility for a community of beings to seek to live the moral life."<sup>68</sup> It is through this inner value that the human being is able to find rational capacity.

#### **III. Ethical Concerns**

The ethical concern surrounding the value of life in an embryo arises when defining what an embryo is and what moral status it has. The religious, secular, and scientific perspectives can be black and white when describing the biological stages but not the inherent moral value of an embryo. The polarizing views argue, "[i]f the human embryo is indeed a human being, then there are quite serious concerns regarding its proper moral treatment. If, on the other hand, it is merely a cluster of cells that have a human origin, the moral landscape is quite different."69 From a religious perspective, if a human embryo is considered to be a fully realized human life form, then morally, there are concerns around scientific exploration and whether stem cell research or abortion is appropriate. From a scientific viewpoint, the human embryo is considered to be just a collection of cells or a blastocyst; it is not a valuable life form because it is not currently a developed human being. It does not have the capacity to reason or feel but instead has the potential to become a human being with moral properties and human rights. Furthermore, Kurjak and Spalldi Barišić, in "CONTROVERSIES ON THE BEGINNING OF HUMAN LIFE -SCIENCE AND RELIGION CLOSER AND CLOSER," articulate the notion of balancing and "protecting the interests of the embryo/fetus and the mother" and as such, highlights the obligations to both the early life and mother. 70 Bioethics based in the secular perspectives, furthermore, can provide insight into dealing with complicated clinical questions, not by choosing one side or the other but by fostering respect and empathy for a holistic perspective.<sup>71</sup> Deducing the understanding of natural human rights of the human embryo and its moral status

from a bioethical perspective provides indispensable insights into otherwise controversial concerns.

Sensitivity to cultural diversity fosters empathy to the complex moral debate on the natural rights of a human embryo. Socio-culturally and religiously, an embryo may be understood as having rights that are believed to be inherent in its mere existence.<sup>72</sup> These rights are natural rights. Poplawski and Gillett point out that the debate around rights includes natural and constructed rights, such as legally binding rights.<sup>73</sup> Natural human rights are therefore essential to the nature of being human. However, there are conflicting views on natural rights as morally equal rights due to the lack of evidential proof to analyze natural human rights as they exist in a human embryo.<sup>74</sup> In order to analyze the basis for the natural human rights embedded in a human embryo, one has to deduce the rights from a limited perspective. Poplawski and Gillett formulate:

If compassion, for example, were seen to be at the heart of moral judgement in general, it follows that to act without it would be to fail in respect to one of the basic features constitutive of moral conduct. We would argue that moral considerations arise in contexts where individuals interact with each other and develop reciprocal attitudes which guide their behaviour. These attitudes embed a sensitivity to the needs and vulnerabilities of others and involve a kind of empathy which informs actions which impinge upon what matters to others. Therefore, we internalize the norm that we should avoid, wherever possible, harming another person. We combine this with the view that the potential to be a person is inherent in the whole (longitudinally realised) form of a human being. This implies that a human being, simply by having a form which at some stage will participate in moral interactions, has a right not to be the subject of gratuitous insult or injury.<sup>75</sup>

This passage presents one perspective of how to weigh the natural rights of an embryo with that of a fully realized human being. To expand on this idea, Poplawski and Gillett discuss how human life develops longitudinally. The moral value of human beings and when that moral value

comes into existence cannot be marked or pinpointed. From a scientific perspective, the longitudinal continuum of human life, as Poplawski and Gillet show, can also be understood in comparison to the progression of color in a color spectrum. As Poplawski and Gillett illustrate, we make color distinctions between shades of color; however, it is impossible to determine where a color transpires on the color spectrum (i.e., shades of red are formed via budding shades of orange, or shades of purple are formed via mixing shades of red and blue). The longitudinal continuum of human life is a progression that begins at the moment of conception and can continue until the end of life; subsequently, this natural process has distinct moral significance. Ultimately, like the shades of color, the complete form of a human being exists in and develops through the continuum of time.

The moral significance of an embryo is an ethical concern when compared to the moral significance of a developed human. Although defining the rights of the fetus, embryo in vitro, etc. becomes challenging and diverse, it is widely recognized that the embryo is the beginning of life. From this perspective, to have human dignity and moral significance, a human being must have certain reached a certain physical or even developmental characteristic/stage. Embryos are living organisms, but they are not fully developed persons. From the Kantian perspective, a person "is a being whose actions can be imputed onto him, a person is a being who possesses this noumenal, intelligible, aspect to his agency, a person is a 'rational being endowed with freedom." According to Kant, human beings contain personhood because they are rational beings, not due to physical or biological attributes. In "Are human embryos Kantian persons?" Bertha Alvarez Manninen surmises that according to Kant:

A person ... is a being that possesses this transcendental, intelligible, aspect to his character; an aspect to his character that cannot be reduced to the phenomenal/empirical world. In making this claim, Kant has effectively argued that a being's personhood is not

reducible to any of his physical aspects, but, rather, that personhood belongs to the transcendental, intelligible, aspect of a human being. Hence, Kant has effectively severed the attainment of personhood from any physical process or occurrence. A being's possession of personhood, rather, can only be understood by appealing to his transcendental, noumenal, self.<sup>81</sup>

However, from a scientific perspective, intelligence and mental function may not always be morally justifiable when considering physical development. For instance, when a person is in a healthcare situation where they are unable to speak, this does not equate them to being any less of a human. Therefore, mental capacity is only one quality of a human being, not the whole human being themself. Kant's perspective restricts the idea of humanity to physical and mental capacity; however, this restriction causes ethical dilemmas when operationalized in the healthcare domain.

From Kant's perspective, the moral significance of a human embryo is in the capacity or functioning, which constitutes the human being the ability to reason. George and Lee define capacity for consciousness as "[a] capacity such as that for consciousness is a power to perform a specific type of action." In this vein, there is a process that occurs "from the basic natural capacity" or potential stage "to perform[ing] an action" or undertaking stage via "the development of the basic power that the organism has from its beginning. Additionally, the "capacity for consciousness" in a human embryo is cultivated through the various stages of life including gestation, newborn, youth, and onwards. The capacity for reasoning ability follows that it "cannot be the case that some human beings and not others are intrinsically valuable, by virtue of a certain degree of development." Rather, as George and Lee go on to purport, "human beings are intrinsically valuable in the way that allows us to ascribe to them equality and basic rights in virtue of what they are; and all human beings are intrinsically valuable." Ultimately human beings are morally significant because they are intrinsically appreciated for

what they inherently are.<sup>86</sup> In fact, attentiveness to cultural diversity can help appreciate these contrasting debates, especially with regard to the meaning of the intrinsic value of human life and concomitant human rights.

Kant's logic on mental reasoning further presents a limited perspective by not recognizing the moral significance of a being when mental capacity is diminished or reduced. Robert George and Patrick Lee, in "Embryonic human persons. Talking Point on morality and human embryo research," argue, "[i]t is clear that one need not be actually or immediately conscious, reasoning, deliberating or making choices, in order to be a human being who deserves full moral respect, for plainly people who are asleep or in reversible comas deserve such respect."<sup>87</sup> The moral significance of a human embryo does not always match the moral significance of a human being because moral significance, from the preceding perspective, is a characteristic, or capacity, such as the ability to self-decide that gives the human being the ability to morally reason. Scientifically speaking, the mental ability to morally reason and make sound judgments is only one factor of being human. As George and Lee question:

why should the nth degree of that property qualify one as having rights? Why not the nth + 1 degree or the nth + 2 degrees and so on? The difference between a being that deserves full moral respect and a being that does not—and might therefore legitimately be killed to benefit others—cannot consist only of the fact that, while both have some feature, one has more of it than the other—one has some arbitrarily selected degree of the development of some feature or property, whereas the other does not.<sup>88</sup>

Therefore, characteristics of being human that have varying degrees cannot be the sole determinant factor of humanity. As a result, the capacity for consciousness that every human life stage consists of cannot be justified as morally significant.

#### IV. Intrinsic Value of Life

The intrinsic value of life may be defined as the value that life has "in itself," or 'for its own sake," or 'as such," or 'in its own right." When the intrinsic value of life is recognized in relation to each life form, it results in empathy. For instance, because we have the ability to have feelings of happiness and suffering, it is essential to understand the context of intrinsic value in human and non-human life forms. Although non-human life forms such as animals, plants, and vegetables may not have the same intrinsic feelings as humans, they still have intrinsic value in their own existence and their relationship to other life forms. For instance, many people regard animals, plants, and vegetables to have instrumental value as food, pets, or objects observed or hunted. However, these non-human life forms also have a context of their own that should be regarded. Animals have social interactions, just as plants and geological objects have a purpose in the natural evolution of the Earth's ecosystem. In "Environmental Ethics" Andrew Brennan and Norva Y. S. Lo, purport that "[t]he deep ecologist respects this intrinsic value, taking care, for example, when walking on the mountainside not to cause unnecessary damage to the plants." Life is recognized to have intrinsic value in both human and non-human forms.

All life forms have innate, intrinsic value, which gives them moral, social, and ethical value. In *The Ethics of Abortion*, Christopher Kaczor reasons that "[o]ne could believe that all forms of life in the universe (including plants and insects) are equally sacred and should all be treated as persons." However, the intrinsic element that gives manifestation to human life from an embryo is the energy behind the biological processes based in the physical. The blastocyst progresses into other fetal stages as it moves towards eventual "functional rationality." Furthermore, the presence of intrinsic elements in a human embryo ensures that like the construction of a house, the development of a human being is "not merely a detailed blueprint of the house that will be built but a tiny house that constructs itself larger and more complex

through its active self-development towards maturity."94 The advancements in science and technology support the intrinsic value of life on a social scale. In The Ethics of Research with Human Subjects: Protecting People, Advancing Science, Promoting Trust, David Resnik states "that most research with human subjects is ethically sound and socially valuable. Research with human subjects has led to the development of medications, vaccines, surgical procedures, medical devices, psychotherapies which have saved millions of human lives, alleviated suffering, and improved the quality of life," as well as providing knowledge that informs public policies and regulations. 95 Although Resnik refers to research with human subjects, the notions of the advancements in science, technology, and medicine can be echoed in the intrinsic value of life in that they all support social value. In regard to the beginning of life, Manninen also purports similar notions in that "[u]sing human embryos for research will allow scientists, and us as a society, to engage in and endorse a practice that has as its intent the hope of curing many painful dis- eases, for example, Alzheimer's disease, which progressively eradicates our rational faculties."96 In other words, the intent to benefit others in the future is underscored in the advancements that science and technology are able to carry out. Socially, morally, and ethically, the advancements of the 21st century aim to aid the future of humanity, which supports the intrinsic value of life.

In conclusion, secularly, religiously, and scientifically speaking, the human embryo is a vital component to the earliest stages of life. Due to its intrinsic and physical value, sanctity, and moral significance, it is regarded as valuable and virtuous from various cultural lenses. Life happens as a combination of biological systems that come in unique forms, such as plants, animals, and humans. However, with growing advancements in medical technology and

research, the ability to modify the beginning of life stages, such as the human embryonic phase, has led to ethical dilemmas.

By exploring research on the secular ideologies on the ethical concerns that arise in the beginning of life, grey areas are revealed when connecting natural human rights and moral significance of an embryo to that of a fully developed human being. The embryo may have natural human rights due to the nature of being an early life form. The moral significance of an embryo is limited in comparison to that of a fully developed human being. This refers to Kant's determinant of a rational being and limits the perspective of human existence. For instance, a fully mature human being has the ability to morally reason and make sound decisions, whereas an embryo has not yet reached that stage of development. In order to provide a greater perspective on the ethical and biological components of life, other cultural aspects, such as religious beliefs and practices, need to be considered.

By looking at religious foundational and liturgical sources, varying considerations arise of when life begins. Monotheistic and polytheistic religions that were explored in this chapter recognized the sanctity and dignity found in the beginnings of life. In this vein, the human life form unites the physical body and the animate soul. From the Christian perspective, human beings can morally reason and make sound judgements just like their Creator and as a result are regarded as valuable from the embryonic stage. From a Hindu perspective, the conception of human life is one of the highest births due to their likeliness to *Brahman*. The Hindu perspectives explored in this chapter showed that some Hindus believe that the karmic cycle of the soul can be renounced in the human life and, as a result, life should be approached with utmost virtue.

Biologically, and bringing the secular and religious together through a scientific lens, life forms, such as plants, animals, and humans, all have intrinsic value. From a scientific standpoint,

the human embryo may not be regarded as a physically valuable form of life due to it not yet resembling a morally reasoning human being. Physically, the human embryo is still present in the continuous chain of life and, as a result, is regarded as a biologically valuable stage of life. Filtering concepts of dignity and sanctity based in the religious and secular through a biological lens, the human embryo can be viewed and valued as a vital developmental stage in the physical continuum of life. Including multiple perspectives from secular and religious standpoints, bioethicists serve as stewards to foster dialogues on conceptions of the beginning of life. This includes shared discourses in healthcare on physical and ethical life stages that are impacted by social and cultural determinants.

## Chapter 3b: Cultural Diversity in Religious Approaches to Palliative End of Life Care

This section aims to further expand on ideas of human existence from cultural, social, and religious perspectives in palliative end-of-life care. Death is a collective experience that all living creatures undergo. The death and dying journey is approached differently depending on one's cultural, social, and religious beliefs and/or practices. Proceeding varying views in the conceptualization of death and the afterlife lead to various approaches to the end of life. As a result, varying attitudes on end of life in healthcare can lead to differences in bioethical conclusions. In healthcare, certain institutional rules and regulations guide patients and practitioners in the clinical setting. Further, accepted social values of end-of-life care help create the whole life experience, which incorporates the individual and the community. Similarly, in consideration of religious communities, the element of the sanctity of life must be balanced with standards of care found within the bioethical context.

In healthcare, bioethical dilemmas arise due to conflicting ideas of standards of care when considering social, cultural, and religious ideologies. The differentiations in end-of-life

care affect decision-making approaches at the time of death. The beliefs around suffering and ultimately the afterlife differ based on varying traditions and/or practices. <sup>99</sup> Culture plays a crucial role in the face of illness and end-of-life decision-making. <sup>100</sup> However, despite one's cultural diversity or social status, there are often religious considerations that must be taken into account. From the multiple perspectives of Hinduism, certain end-of-life care practices vary due to levels of observance, family values, and cultural traditions. Just as *karma* is a broad and central theme in Hindu philosophy that helps ground spiritually moral perspectives based on the beginning of life, it also guides end-of-life decision making. Similarly, Christianity, grounded in philosophies such as *imago Dei*, the sanctity of life, and understanding of suffering has its approach to end-of-life care. <sup>101</sup> On the other hand, because death is universal and all people experience suffering, pain, or illness, a standard of palliative care needs to be established to help guide end-of-life decision-making.

The World Health Organization (WHO) defines palliative care as:

an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.<sup>102</sup>

Palliative care, in terms of death and dying, differs among various religious beliefs, healthcare needs, and cultural backgrounds. However, while navigating bioethical issues at the end of life, these culturally, socially, and religiously diverse patients deserve an established level of palliative care.

Each religion plays a key role in decision-making in palliative care. Varying religions have a standard of care in terms of death and dying. From a Hindu approach, the varying considerations of *karma* in a Hindu patient's way of life should help explain its distinct role in

undertaking or forgoing palliative end-of-life care. From a Christian approach, the sanctity of life, imago Dei, and notions of suffering should help explain the approaches to palliative end-oflife care. Religiously speaking, Hindus and Christians have different levels of beliefs and observances that impact cultural decision-making. While Richardson articulates that the way in which patients and their families approach the end of life is different, similarities exist in the notions of dignity and self-worth are some commonalities on a human level. 103 These varied religious and cultural principles illustrate varying viewpoints on ethical issues that culminate into social practices in the healthcare setting. Differences in socio-cultural values can arise in healthcare interactions. For example, interactions between Christian approaches can occur in a Christian hospital in India while interactions between the Hindu approaches can occur with Hindu patients in the US and/or the UK. These are just two examples of interactions within minority religions and/or cultures in majority countries but cross-cultural interactions permeate the globe. Attentiveness to the religious, cultural, and social in terms of end-of-life palliative care can be navigated by exploring bioethical normativity in shared concepts such as valuing of life, justice in the death and dying journey, and deontology of community.

## I. Bioethical Normativity

Cultural san important aspect that helps shape the way people experience and understand life. Cultural diversity (related to ethnicity, religion, and tradition) reflects shared aspects, such as knowledge, between groups of people that influence their ways of life or world views. <sup>104</sup> Bioethical normativity can help shed light on the shared concepts of valuing of life, justice in the death and dying journey, and deontology of community found across diverse cultural and religious perspectives on a core human level. Similarly, being attentive to cultural diversity can enlighten the varying ethical considerations that arise in palliative end-of-life care decision

making. In addition, religion is one way that shapes bioethical principles, values, and morals across different cultures. For instance, Christian principles outlined by the Church are a primary source of support for bioethical dilemmas in the end of life. Likewise, in Hinduism, bioethical principles are guided by Indian healthcare laws, as well as by religious and cultural traditions. These ideologies show that religion is a prominent aspect of how people within a particular cultural group(s) experience life and how their beliefs shape their decisions. Therefore, religion impacts the overall perspective between people of diverse cultures supporting the social aspect within bioethics in palliative end-of-life care decision-making. Examining the religious and cultural ideas of valuing of life, justice in the death and dying journey, and deontology of community show the importance of social components in healthcare. The aim of this research is to show how the differences can be navigated or overcome using the three shared concepts identified.

From a scientific standpoint, life from its conception until its ending is valued. Similarly, Christianity regards the human life form as sacred. This sacredness stems from *imago Dei*, man being created in the image of God. Being created in the image of the Supreme Being is a high honor. According to Martin Rhonhiemer, a human being who journeys through life is a "suppositum" (real, existing individual thing), whose nature (or 'essence') includes the body and spirit and which we call the human person. In other words, the human life form is comprised of not only the physical body but also the soul. Therefore, the human life form is always in harmony between the two entities, the material body and the soul. From the Christian perspective, the Creator trusts human beings to appreciate and take social responsibility for the intrinsic value of life. 109

From a Christian perspective, the purpose of why God created man and woman in His image was to reflect Himself on Earth. Just as in *Genesis 1* God created man in His image to have dominion over other creation.<sup>110</sup> This priority provides some insight into why man and woman should act out of moral virtuousness. Their actions should represent the goodness of God and imply an inherent dignity.

Hinduism regards human life as one of the rarest and highest forms of life. The concept of karmic action or karmic inaction results from the conscious responsibility that is put upon each individual human being. Karma is understood as an energy exchange between two or more souls reinforced by intent or action. In "Back to the Basics: Reflections on Moral Discourse in a Contemporary Hindu Community," Francis X. Clooney centers on the minority Srivaisnava Hindu community, from southern India, to highlight the significance of character and behavior development among individual community members. Clooney showed that in the Srivaisnava approach, ancient scriptures depicted the virtues that should be held, and in this vein the onus is placed on the individual to act as they want, formulating certain character traits. 111 In other words, karmic action or inaction may be influenced by the many aspects of individual character. The Srivaisnava approach mimics that of many virtue ethics theories in that they value character development as an aspect of human flourishing. An individual's culture, familial role, or profession may result in certain dharma, or responsible duty that an individual may have to carry out. Furthermore, in "Medical ethics in India," Desai articulated that "[t]he law of life stages determines sets of actions. From the stage of apprenticeship to that of a householder, a forestdweller, and finally a renouncer, a person's passage through life calls for actions appropriate to each stage."112 The law of life stages determines certain karmic actions or inactions that an individual might be obligated to fulfill based on what stage they are at in their life. For example,

the dharmic duty of a householder, such as a father, may be to provide for his family. As such, his karmic actions lie in his dharmic duty to obtain work and provide for those in his household, i.e., his wife, children, parents, etc.

In Hindu scriptures, such as the *Bhagavad Gita*, heroic figures, such as Arjun, are portrayed as having lived virtuously.<sup>113</sup> Therefore, the human life is considered valued because the role of karmic actions is to help guide dharmic duties and an individual's samskaras, or traits, in order to undertake a responsible and virtuous way of living. Arjun is faced with a dilemma that interferes with his heart and mind. Krishna, a deity who appears in the human form, comes to aid Arjun and reminds him of his dharmic duties and individual responsibilities. Krishna points out that the good that comes from the karmic action of fulfilling his duties outweighs the karmic inaction of not fighting due to his obligations towards his family.<sup>114</sup> In other words, Arjun's karmic action or inaction is dependent on his individual duties or responsibilities that must be achieved. This lesson extends to human life, as they have a choice to undertake virtuous ways of living based on individual samskaras, or character traits related to their individual souls. Consciously or unconsciously, this has become a social normativity in the field of bioethics, as it takes a personalized approach to decision-making that is dependent on actions or inactions undertaken to shape one's traits to fulfill one's duty.

Regardless of social, cultural, and/or religious perspectives, it is accepted that everyone deserves to die with dignity. However, cultural and religious viewpoints become important in end-of-life palliative care. Distinguishing treatment decisions in end-of-life palliative care involve consideration of the central values of a patient and their family's cultural and religious traditions. For instance, undertaking or forgoing palliative care, or decision-making in palliative care is multifaceted because they are informed by diverse human values. Aaron

Mackler points out that concepts such as "respect for divine sovereignty" and "responsibilities of stewardship" could be weighed in the undertaking of life-sustaining treatment. On other hand, Mackler considers this respect for a higher power and freedom associated with it in certain circumstances may also weigh in on the decision to forgo treatment and accept the inevitable natural death but not with the motivation to actively pursue it.<sup>116</sup> Therefore, justice toward a virtuous death is the core human concept that can be sustained at the end of life.

Cultural and religious bioethical normativity in Hinduism and Christianity can be found in the shared concept of justice. Justice towards a natural virtuous death can be understood as dying well. Courtney Campbell mentions the concept of dying well from Soren Kierkegaard, a Danish philosopher's perspective, as *grand wisdom of life*. This notion of the *grand wisdom of life* puts importance on dying as a virtue. However, advances in medicine such as palliative care cause dying virtuously to look different, sometimes even causing a dishonorable death, leading to ethical issues. As such, exploring justice towards a natural virtuous death in Hinduism and Christianity can help bring clarity to diverse approaches to bioethical normativity in the honor and wisdom found at the end of life.

Christianity regards justice towards a natural virtuous death as a form of art or expression. The *Ars Moriendi*, or "[t]he art of dying well," emphasizes the concept of a good death. The *Ars Moriendi* is a medieval text that helped to display the ideas of good and bad death. However, in the 21st century, the dying process looks slightly different. The dying process can be accelerated or slowed down given the advances in medicine, technology, and the importance of socio-cultural considerations. The *Ars Moriendi* lays out foundational understandings of death and dying; these understandings can be pulled forward into bioethical considerations of justice in palliative end-of-life care. Contemporary healthcare echoes the

notions of dying well tied to the *Ars Moriendi*, as supporting quality of life, and providing comfort care. Although palliative end-of-life care may make the dying process look different, the expression of dying well is still highly regarded in the 21<sup>st</sup> century.

Hindu philosophy ties the notion of virtuous death and dying to understandings of higher eternal consciousness, known as Brahman. 122 This is the foundation for the significance of karma in the Hindu approach to a good death in holy sites such as Varanasi. In "Karma and Moksa at the End of Life in India," Gielen and Kashyap purport notions of a "good death" which deepen the understanding of the role of karma and moksha for the populations who travel to or prefer, Varanasi at the end of life. 123 In ancient Indian philosophy, human beings are composed of a soul, or atman, and components of the natural world such as earth, water, air, ether, and fire. 124 Dying in Varanasi provides significance because it is a way to provide an offering back to the Earth that "renews the cosmos" which is why time in Varanasi is understood as *Satya Yuga*, or a more flourishing era, in comparison to the Kali Yuga, a less flourishing era, which is believed to have permeated in other parts of the Earth and even to some extent in Varanasi. 125 On the other hand, Gielen and Kashyap's study also explained the importance of quality of life and the role that Western biomedicine plays for patients who travel to seek care "...at the pain and palliative care unit of the Dr. B.R. Ambedkar Institute Rotary Cancer Hospital of the All India Institute of Medical Sciences in New Delhi."126 Ultimately, they conclude that factors such as age, environment, and "social and demographic profiles" provide reasoning behind diverse attitudes of the role of karma and moksha in the death and dying journey. 127 In other words, it is clear that socio-cultural determinants of health are key factors in the varying understandings of the role that *karma* and *moksha* contribute for patients within the study they conducted.

S.K. Pandya articulated that increasing good actions, or good *karma*, and reducing bad actions, or bad *karma* provides an opportunity to become closer and closer to "infinite consciousness," or *Brahman*.<sup>128</sup> Karmic actions help ground the ethics of what should be morally acted or unacted upon based on *dharma* or one's duty.<sup>129</sup> As a result, the *samskara*, or individual character traits of that soul, have a chance to become purified and the soul is given an ideal chance through the human life experience to be united with the highest source of consciousness, *Brahman*. Systematically analyzing and regarding the Hindu concepts such as *karma*, *samskara*, and *dharma* to approaches in bioethics, highlights the importance of justice and virtue in the death and dying process.

Attentiveness to cultural diversity fosters sensitivity to varying normative approaches in bioethics in these religious traditions. Social, cultural, or religious hegemony results from groups of people living and participating together in a community. In 21st century bioethics, the respect for autonomy in decision-making is a fundamental principle that "runs as deep in morality as any principle, but determining its nature, scope and strength requires careful analysis." From this perspective, relational autonomy recognizes that individual identity is created within a wider set of social factors (such as culture and/or religion); social factors formed by relationships to others in society such as family, friends, and next of kin help shape an individual. Relational autonomy highlights that each individual is a part of a broader community. In healthcare,

[r]elational autonomy recognises that the patient is not only embedded within relations with her healthcare provider and with her potentially interested relatives, but also that her interests and needs and indeed her autonomy are partly shaped by these relations. It also requires that relationality is acknowledged in the partnership negotiations that will take place with the healthcare provider, to both enhance the wellbeing of the patient herself, and to include potential duties to third parties. Relational autonomy does not require the patient to suffer harm in order to respect the preferences of a third

party, but rather to understand those preferences and take them into account. 132

When it comes to decision making in healthcare, particularly to death and dying, relational autonomy does not involve a patient to abandon their individual needs, but instead recognizes that personal decisions are often made in consideration of broader social and therapeutic relationships. Due to each individual being a part of a community, the deontological duties or social responsibilities, underscored through social (cultural or religious) notions, can be highlighted through this concept in decision making in palliative end of life care and beyond.

Similarly, religious perspectives recognize the importance of relational autonomy. The Christian religion highlights that human beings are an integral part of the way communities are formed. Human beings are integral parts of the whole of a community or society. However, there is the recognition that individual needs should not be overlooked. David Kelly et al. stated "[w]hile it is true that the individual cannot live in isolation and may not rightly neglect the common good, it is also true that the corporate whole of society—the collective, the state—may not rightly trample on individuals." Kelly et al. are trying to depict that the human species is a part of an interconnected community and therefore, requires giving attention to both dualities, the individual and social duties.

Furthermore, Christianity emphasizes that God chose humankind as a symbol of sacraments of His presence and Himself to each other.<sup>135</sup> Due to this notion, humankind has duties towards one another, based on humanity as a whole. People are naturally embedded within society which is why the common good cannot be overlooked, this notion extends to healthcare obligations that are placed on healthcare professionals.<sup>136</sup> However, individual good as previously stated is also essential, and "individualism and corporatism should serve in some sense as correctives to one another."<sup>137</sup> Therefore, human beings have a moral obligation to make

decisions for the common good in end-of-life palliative care that balance individual and social duties within their community.

Relational autonomy is echoed in "Normative Bioethics in Hinduism" by Joris Gielen. He deduced that in Hindu bioethics following the lineage of virtue ethics aids in bringing transparency to normative principles. Virtue ethics emphasizes virtuous characteristic traits of an individual person rather than norms that must be followed. Gielen purports that care is a highly prominent virtue in the Indian culture, even recognized by Gandhi, which extends not just to caring at the beginning of life for children but also at the end of life for parents and other relatives or community members. 138 There is a responsibility placed on each individual to do good actions or fulfill good karma. Deontological ethics may help guide the differences between good karma and bad karma based on individual responsibility and character traits that operate in relation to the greater community. According to Gielen, "[t]he difference between deontological ethics and virtue ethics is that the former directly tells us what we ought to do, while the latter assesses what kind of person we ought to be through the virtues that we express in our actions." 139 As such, deontological ethics might help justify an individual's karma, or actions, rooted within individual dharma and samskara while virtue ethics express the characteristics of an individual person through the karmic actions they undertake.

Deducing Hindu bioethics based on two fundamental components of traditions, philosophical and cultural, highlight the deontological duties of the community. According to Prakash N. Desai, in "Medical Ethics in India," there is significance in passing down traditions, values, or knowledge, from one generation to the next between families, groups of people, and sometimes even "accounts of heroes." People within cultural group(s) look to their community, such as ancestors or family traditions, as a source of justifying their way of life,

which constitutes individual morals, actions, and ethics. The cultural traditions between people belonging to a particular group in India are conserved by the transfer of knowledge. This transfer of knowledge is also viewed as an ancient source of inspiration for the actions, behaviors, and values of people. The inspiration for this knowledge primarily comes from the actions and conducts of mythological heroes depicted in ancient scriptures. For Hindus, one source of ancient inspirational knowledge would be the *Vedic* texts, which correspond to real and experienced traditions. According to Hinduism, the *Vedic* literature is one source of revealed or heard knowledge, or *shruti*, which itself is not read but instead transferred down and learned through word of mouth. Vedic literature, as an elevated awareness, displays how ancient cultural traditions are formed as a source of communal knowledge and practice for future generations.

#### II. Ethical Issues in Palliative Care

As advances in technology, medicine, and healthcare continue to increase, so do ethical issues in palliative end-of-life care. Such advancements change the ways in which humans experience the death and dying process. <sup>143</sup> For instance, palliative care can be seen as prolonging life, managing symptoms, and/or relieving pain and suffering. Ultimately, technology and medicine in the 21<sup>st</sup> century have the ability to intercede in the death and dying process, reshaping the end-of-life journey, and even empowering patients and their families with the autonomy of choosing and deciding their preferred treatments. <sup>144</sup> Decision-making in palliative end-of-life care can change the way a patient experiences death. However, ethical dilemmas arise when considerations of diverse cultural or religious beliefs and practices come into conflict with healthcare decision-making in palliative end-of-life care.

Navigating bioethical dilemmas due to differing cultural and religious approaches to palliative end-of-life care can be challenging, insightful, and inspiring in healthcare. Varying beliefs lead to differing healthcare approaches in end-of-life palliative care within a heterogenous, or pluralistic society, such as that of the United States. 145 Culture and religion help shape the way human beings experience life, from birth to death. 146 Comparing approaches to ethical dilemmas in palliative end-of-life care between Hinduism and Christianity show how diversity may lead to more challenges than solutions. However, respect for cultural and religious diversity creates a more holistic understanding of humanity and its diverse moral viewpoints for end-of-life decision-making. According to the Oxford Textbook of Palliative Medicine, palliative care does not always reach those who truly could benefit from or need it. Some barriers include misunderstandings about what palliative care is and its clinical approach(s); others include unequal distributions of healthcare resources as well as social barriers. 147 In healthcare, some sedative and pain management treatments may present ethical issues because they may impede religious understandings or practices, causing these beliefs to conflict with the clinical goals of palliative end-of-life care.

Ethical issues in palliative care, particularly deciding to initiate curative or life-sustaining treatment, may offer differing viewpoints on prolonging life or survival. Initiating curative or life-sustaining treatment at the end of life may impact the patient's quality of life. <sup>148</sup> The *Oxford Textbook of Palliative Medicine* states that:

[t]ypically, patients with early-stage disease focus on prolongation of survival. They seek disease-modifying therapies as the main priority...in pursuit of prolonging their lives...[while], patients approaching the end of life with debilitating symptoms...often seek treatments that provide symptom relief above all else, even if the treatment needed may impair cognition and communication, and potentially foreshortened survival.<sup>149</sup>

In other words, patients at different phases have differing goals, both personally and clinically, in terms of their quality of life and care plan, respectively. There are different phases (diagnostic phase, trial of disease-modifying therapy, ambulatory palliation, sedentary palliation, terminal [end-of-life] phase) that have different clinical tasks and goals, and these transient factors ultimately impact care goals and subsequently decision-making. Similarly, differing moral viewpoints in Hinduism and Christianity help support undertaking palliative end-of-life care, but not at the expense of quality of life, particularly prolonging life. Social, moral, and religious perspectives provide insight into decision-making methods that consider end-of-life transient phases.

From the perspective of Hinduism, *karma* is a key concept in the birth and rebirth process. <sup>151</sup> *Karma* is a concept that can help justify one's quality of life. It is a combination of an individual's past and current actions and the subsequent consequences that can be experienced either in this lifetime or the next. <sup>152</sup> Therefore, *karma* can justify one's quality of life based on outcomes or consequences that are a result of actions. *Samskaras* are character traits specific to one's nature that make one perform particular deeds. In Geilen et al.'s study, the physicians and nurses viewed *samskaras* as accumulated values learned throughout one's life in modes such as: upbringing, work, and other acts such as education. <sup>153</sup> *Samskaras* are not permanent to an individual but rather can be viewed as transient characteristics, that are informed by nature versus nurture social elements, which may change based on certain actions or inactions. Gielen articulates that "[h]indus are generally not persons who write elaborate ethical treatises, but rather individuals who, in their day-to-day life, are confronted with the ethical issues that arise within the context of modern biomedicine." <sup>154</sup> Hindus may make decisions from the perspective of their individual *samskaras* within the context of their duty when confronted with issues

encountered across their lifetime. In Hinduism, reconciling one's *karma* in the human lifetime and achieving *moksha* is an important goal. Holy sites such as that of Varanasi, in India, hold importance as a site of dying because *karma* can be reconciled here, and *moksha* achieved. Gielen and Kashyap note that those who think their time is nearing an end may reduce intake of nutrition through fasting process; because the journey to Varanasi is arduous this may even sometimes reduce quality of life and accelerate the dying process.

Based on the Hindu approach to bioethics, palliative care is a combination of holistic healthcare and a kind philosophy. <sup>157</sup> Initiating curative or life-sustaining treatment alongside palliative care can be seen as acceptable if the treatment's risks and side effects are not worse than the patient's illness. <sup>158</sup> From this perspective, palliative care would be seen as holistic care that aims at soothing the individual. In addition, palliative care would be aimed at reducing the suffering and distress that are a result of life-threatening illnesses. <sup>159</sup> According to a study conducted by Gielen et al. in "Can curative or life-sustaining treatment be withheld or withdrawn?" the interviewed healthcare professionals explained that curative or life-sustaining treatment would have no meaning if the patient's quality of life was compensated. <sup>160</sup> Prolonging life would not be significant compared to the comfort and quality of the patient's life. As a result, ethical issues might arise when the Hindu patient and their family have differing views on the concept of quality of life or prolonging life compared to that of the healthcare-providing team.

Similarly, Christianity regards life as valuable. Human life is valuable because humans were made in the image of God. Likewise, human life is a gift from God, end of life methods such as physician-assisted suicide and hastening death in the form of euthanasia are prohibited. However, prolonging life is not a necessary requirement for providing human care. In Christianity, "analgesia and sedation to relieve terminal suffering" are acceptable "provided it

does not consciously take away a person's life or opportunity for repentance." As a result, prolonging life at the end of life may not always be required, but somewhat relieving pain and suffering in the form of palliative sedation may be more acceptable. Relieving pain and suffering would provide a comfortable dying experience or, in other words, improved quality of life at the end of life.

Understanding cultural diversity helps foster empathy with varying approaches in end-of-life care. Palliative sedation is another area where ethical concerns may arise due to differing social, cultural, or religious goals. Masman et al. purport that managing end-of-life symptoms and providing comfort are done with the aid of drug therapies. The *Oxford Textbook of Palliative Medicine* discuss a list(s) compiled by The WHO and Lancet Commission of essential medicines, that are used for prevention or symptom relief for common symptoms at the end of life which is what palliative care focuses on. The compiled list(s) provides a standard of care that can be understood and implemented by healthcare professionals with basic training in delivering palliative care. Furthermore, these list(s) recommend that "essential" medications be affordable and available in all parts of the world. The goals of care between social, cultural, and religious aspects of palliative sedation may present areas of difference and potential advancement.

Many cultural and religious beliefs and practices emphasize spirituality during suffering and especially in end of life. Spirituality, and/or spiritual care, during times of distress and suffering can serve as a source of hope or empowerment for patients. <sup>166</sup> For instance, in cancer treatment processes, familial support is one component that provides motivation for the patient. Similarly, another source of support that provides strength and promotes comfort is spirituality, and/or spiritual care. <sup>167</sup> Spirituality can give a sense of support; focusing one's thoughts on

spiritual sources of support in times of illness, pain, and distress may help patients find emotional and mental strength. Deciding to undertake palliative sedation may be seen as an ethical dilemma because the level of a patient's consciousness may reduce. According to an empirical study "Level of consciousness in dying patients. The role of palliative sedation: a longitudinal prospective study," the day-to-day consciousness of a patient who was induced by palliative sedation slowed down until the patient's death. As a result, palliative sedation may be seen as an ethical dilemma because reduced consciousness may impede religious understandings or practices.

In Christianity, the ethical issues in palliative sedation may arise because human consciousness can potentially be decreased. In the "Ethical and Religious Directives for Catholic Health Care Services," directive number 61 summarizes that patients should be kept free from pain and discomfort, so they are able to die with ease and dignity. However, it later goes on to state that the person also has the human right to "prepare for his or her death while fully conscious" and, as a result, "should not be deprived of consciousness without a compelling reason" yet, drug therapies with the intent to relieve pain and not to hasten death may be acceptable. <sup>169</sup> In other words, the individual's consciousness should not be taken away without just reasoning. However, palliative sedation has the potential to provide pain and symptom relief which aligns with the first part of the directive. Therefore, ethical issues may arise when cultural or religious care goals collide with the social goals of palliative care.

In Hinduism, death is when the physical body stops functioning and as a result the soul leaves that physical form and moves to another phase. Crawford reasons that according to the Hindu scriptures, death of the physical body is a process of disengagement, where the subtle body or the soul withers out from the natural world.<sup>170</sup> In other words, death is a process by

which the senses, the biological system, and other functional systems of the physical body shut down in preparation for the soul's departure. The philosophy of *karma* is a common spiritual consideration in the thought processes or state of mind at the time of death for Hindu followers who travel to Varanasi in end of life. \*\frac{171}{171} Karma\* can be applied to bioethical dilemmas in death and dying in a broad manner. For instance, refusal of treatment by family members or non-intervention may reflect a socio-cultural belief that the dying patient should be thinking of a deity(s) or chanting hymns as they go through the natural dying process; this refusal arises because the kind of thoughts one has at death holds significance for the future destination of that soul. \*\frac{172}{172} Spirituality, from this perspective, is a tool that can help the patient connect with a higher power and endure pain and suffering that the patient may interpret as *karma* for past actions.

Furthermore, Crawford proposes that physicians should be able to sense when a patient is experiencing the dying process and, therefore, should not hinder the natural process through interventions or even enunciate death, unless requested. From this perspective, the physician is ultimately deprived of their duty as a caretaker in the death and dying process. While Crawford's explanation of nonintervention in the death and dying process is certainly valid from the philosophical perspective of *karma* impeding spirituality, the approach, from a bioethical perspective, limits the physician of their primary role as a healthcare provider, caretaker, and educator. Although the physician should not be required to intervene in the medical treatment they should be appreciated as a key educator in the patient's end-of-life palliative care options.

Furthermore, sensitivity to cultural diversity can foster empathy with the different meanings of suffering. One of the core concepts of 21<sup>st</sup>-century medicine is the prevention or alleviating of pain and suffering.<sup>174</sup> One of the goals of palliative care mentioned by the *Oxford Textbook of Palliative Medicine* is "optimization of comfort."<sup>175</sup> As discussed in the previous

sections, alleviating pain and/or suffering can be done by providing curative or life-sustaining treatment and/or drug therapies. Although this advancement, goal, and intention are highly commendable, there may be ethical challenges in decision-making due to cultural and religious beliefs or understandings of suffering. In some instances, suffering may not be a problem that should be alleviated. However, suffering can be a valuable part of human existence that makes a "spiritual connection and transformation" possible. From this perspective, pain and suffering at the end of life are a key component of the death and dying. As a result, palliative sedation that is aimed at reducing pain and suffering may be an ethical issue if it collides with varying religious and cultural conceptions of pain and suffering.

According to the Christian faith, suffering can be a valuable part of human existence. Suffering has instrumental value because, without pain or suffering, the human body would not know that it requires attention or care. Human existence allows for this opportunity for pain and suffering as a unique part of life. In other words, there is meaning behind suffering and pain in the Christian belief system that may cause ethical conflicts with the goals of palliative care, which may cause the patient to reject care.

In the same way, the Hindu faith echoes unique notions of pain and suffering. In "Cultural and religious aspects of palliative care," Steven M. Steinberg summarizes notions of pain and suffering articulated by Sarah Whitman in "Pain and suffering as viewed by the Hindu religion." Steinberg expresses that according to the Hindu way of life, pain and suffering are conditions that a patient is understood to be due to karmic events from present and past lives. Ultimately, acceptance and detachment of pain and suffering are vital in helping the patient keep their focus on a higher source of inspiration and detach from worldly desires.<sup>178</sup> In other words, based on Steinberg's articulation, pain and suffering are *karmic* conditions. They can also be

conditions that can aid in mending any pending responsibilities that are indebted to *karma* or alleviating any past *karma*.<sup>179</sup> Following this stance, one might believe that forgoing palliative sedation is appropriate because their suffering has meaning. Steinberg and Thrane's articulations of pain and suffering highlight that reconciling *karma* takes precedence over the quality of life. *Karma* guides one's influence and understanding of suffering and can help relate suffering to past life or deeds.<sup>180</sup> Furthermore, *karma* might help an elderly person justify their suffering from a spiritual perspective. Suffering might be understood as pending duties within this lifetime, which hinder the soul to move forward and undertake the next phase, a new birth or liberation.<sup>181</sup> Varying understandings of pain and suffering from scientific, cultural, and religious perspectives provide differing viewpoints on the meaning of suffering and acceptance or rejection(s) for alleviating pain and suffering.

## III. Applying Bioethical Normativity to Diverse Approaches to Palliative Care

Attentiveness to cultural diversity can shed light on the role of differing bioethical principles when considering palliative care. Bioethical principles such as autonomy, beneficence, non-maleficence, and justice are undoubtedly important in healthcare. However, they lead to grey areas whenever applied to context-specific situations such as cultural or religious diversity, where normative approaches may not always be clear. Therefore, looking to aspects that holistically unite the human species in light of these key differences can be an important source of inspiration for bioethical normativity for palliative care decision-making and beyond.

Moreover, the *Oxford Textbook of Palliative Medicine* seeks similar notions within the context of human rights, stating that:

[t]he modern era has seen the acceptance of a basic proposition: that palliative care is a fundamental human right of all people. That proposition is made in a context of, and in response to, clear inadequacies in the provision of palliative care around the world,

absent or deficient national policies on pain and palliative care, restrictive opioid laws, and inadequate education of health professionals in all aspects of the care of people with life-limiting illnesses.<sup>183</sup>

This research aims to identify holistic notions that the human species can relate to on a collective level: valuing of life, the importance of community, and justice in the death and dying journey. Applying bioethical normativity to palliative care decision-making helps illustrate how shared concepts, or bioethical normativity, are vital in healthcare. Furthermore, palliative care needs to be looked at beyond just the clinical context to foster justice in the death and dying process. Gielen et al. articulate that in India palliative care has been since the latter half of the 1980's however coverage and financial affordability remain a challenge. Likewise, in the United States, coverage of palliative care is still lacking. Palliative care resources need to be accessible and available equitably; this requires pushing policies forward in the broader social sphere, such as in the global, national, or public health realms.

Supporting quality of life at the end of life can help justify the decision to undertake palliative care from social and religious perspectives. The goal of palliative care is to deliver support to provide a comfortable quality of life at the end of life. Operating from this lens, sensitivity to cultural diversity fosters the legitimacy of different approaches to palliative care. Furthermore, on an international scope, agencies such as the UN also acknowledge that dignity is a central theme that is vital in delivering palliative care. Similarly, Hinduism and Christianity both emphasize quality of life as a form of dying with dignity and in this vein, support undertaking palliative care.

The concept of dignity is insightful in healthcare contexts. According to the "Ethical and Religious Directives for Catholic Health Care Services," directives 56 and 57 purport that ordinary care may be undertaken, and extraordinary care may be forgone to preserve human

life. <sup>188</sup> In healthcare, on one hand, distinctions of ordinary versus extraordinary may apply to preserving human life. In end-of-life care, on the other, these distinctions in preserving life may present ethical challenges. <sup>189</sup> According to religious concepts of sanctity and quality of life, extraordinary and ordinary care can be understood as the following: "it is never obligatory to make use of medical measures that are morally 'extraordinary' in order to preserve life." <sup>190</sup> However, it is important to understand that the context of these concepts is "based on the theology of the meaning of human life in its dignity, its destiny, and its integrity." <sup>191</sup> Therefore, dignity from a religious perspective needs to be balanced with the quality of life from a clinical perspective.

Similarly, if a patient or their family members following Hindu beliefs and/or practices, value providing a comfortable quality of life at the end of life, they would consider undertaking palliative care. Gielen et al. state that:

[f]or the interviewees, palliative treatment was the preferred therapy in such a case. In the interviews, the physicians and nurses enumerated many therapies which can be administered to control pain and symptoms. They argued that in the terminal stage of a disease like cancer the symptoms should be controlled in the first place, rather than attempting to prolong life at all cost. 192

For instance, if a patient is suffering from a terminal illness, then concepts such as *karma* would be secondary, and undertaking palliative care would be the primary consideration. Undertaking palliative care would be most preferred because it would make the patient as comfortable as possible and stabilize their remaining time, relieving physical pain or symptoms. In addition, the palliative care intervention still allows the patient to participate in the natural process of death while reconciling *karma*, just without physical suffering or pain. Palliative care would enable a comfortable quality of life for the natural process of dying.

The goal, or value, of dying naturally without any intervention may present a limitation to undertaking palliative care. Understandings of natural death vary from culture to culture.<sup>193</sup>

Sensitivity to cultural diversity can facilitate different approaches to the experience of death. For instance, some patients wish to die without any kind of technical interventions.<sup>194</sup> Likewise, naturally dying is highly regarded according to certain cultural and/or religious perspectives, known as a "good" death. As a result, the decision to forgo palliative care may be derived or justified from this perspective.

From the Christian perspective, if palliative care is used as a form of pain relief aimed at improving the patient's comfort level, that may be acceptable. However, whenever the drugs cause or hasten death, in rare circumstances, this may conflict with the concept of natural death. Although palliative care aims to relieve pain, a patient's body could build up a tolerance to a particular sedative drug and, as a result, more administration may be needed. The greater administration to relieve pain may be medically and ethically correct. From this perspective, in Christianity, forgoing palliative care to participate in a natural death might also be acceptable. In the "Ethical and Religious Directives for Catholic Health Services," directive 57 summarizes that forgoing extraordinary care or disproportionate means of preserving life may be acceptable. Patient's wish, or value, of natural death in certain religious beliefs and practices may be a stance on forgoing palliative care.

In addition, suffering and pain at the end of life have various understandings. In "Pain and Suffering as Viewed by the Hindu Religion," Sarah Whitman states that "Hindu traditions promote coping with suffering by accepting it as a just consequence and understanding that suffering is not random." From the perspective that Whitman presents, suffering can be seen as a result of one's *karma*. Pain and suffering, as Whitman explains, are not viewed as bad but

rather a natural part of existence or just being human.<sup>198</sup> As a result, forgoing palliative care may be justified or decided as an appropriate method of coping with pain and suffering because it provides meaning.

Furthermore, awareness of cultural diversity can shed light on the importance of intent when making moral decisions in end-of-life care. From a deontological perspective, the correct motive and intention for a specific action are more important than achieving the desired result.<sup>199</sup> Individuals are bound as a part of human society where the common good is crucial and cannot be forgotten.<sup>200</sup> At the time of death, patients may choose to include their family, next of kin, and even the provider as a part of a community. As analyzed throughout this chapter, religious philosophies and notions provide context and flexibility when it comes to decision-making; however, the specific role of these ideologies, such as the role of *karma*, is limited. For instance, it is clear thus far that concepts such as *karma* or *imago Dei* do not formally define whether one ought to undertake or forgo palliative care at the end of life; what these concepts do provide is a potential justification for a decision. However, to provide patients with high quality and the option to participate in palliative care, it is vital to implement global and/or national policies that treat patients holistically and advance healthcare.<sup>201</sup>

This research aims to show that deontology can serve as a foundation for the social responsibility required to advance palliative care policy to improve accessibility and availability for patients, their families, and healthcare providers. Policymakers at global, national, and local levels all have a social responsibility to further healthcare access, coverage, and availability for the greater good of humanity. However, to operationalize and/or implement policies that bring about change requires resources (such as funding) as well as changing existing processes that govern professional licensure, reimbursements and standards of care, and/or access to palliative

care medicines.<sup>202</sup> Policies are vital to improving the accessibility and availability of palliative care resources. In addition, policies are only as practical as they prove to be effective. Effective policies require providing a framework and outlining direction that helps achieve an endeavor and continuous evaluation.<sup>203</sup> As a starting point in the subsequent paragraphs, I propose a framework for a palliative care policy that includes education and equitable resource distribution that aim to provide justice in end-of-life care options.

First, as analyzed throughout the section, end-of-life decisions are driven by the patient and their family based on what they perceive as beneficial to the patient's way of life, duty, or role within their community. Gielen et al. express that "[t]he physicians and nurses agreed that the final decision about curative or life-sustaining treatment has to be taken by the patient and his or her family members. The treating physicians and nurses play an advisory role in the decisionmaking process."<sup>204</sup> In the death and dying process, this enables cultural humility between the patient and treating physician; the physician becomes an educator to the patient by presenting the possible options for end-of-life care, and the patient and their family have a greater sense of autonomy over their decision. Furthermore, Gielen promotes greater awareness of palliative care through explicit education. Gielen, however, states that education alone is not sufficient and that there needs to be "a different way of looking at healthcare," meaning that "interiorize the deeper human values which lie at the basis of healthcare."205 The physician may not be fulfilling their duty by taking a certain medical action; however, as Gielen shows throughout various literature, they play the role of a mentor whose responsibility is to inform and let the patient and their family decide what is right for them. In addition, not only do healthcare providers need to understand human values but to advance palliative care awareness, healthcare professionals at

large, such as policymakers, also need to consider human values to ensure equitable access and availability to palliative care resources.

Second, equitable accessibility of resources to meet the unique needs of patients at the end of life requires not just education but also overcoming barriers related to economic resources and funding which otherwise would be used to focus on other priorities. There is increasing awareness in the literature, articles, and other texts that it is essential for practitioners and educators to meet the varying needs of dying patients. However, to do so healthcare practitioners and patients need access to appropriate resources. Using learnings from other countries that balance priorities, resources, and funding can foster approaches in the United States decision-making model for healthcare professionals at large. Drug availability, education, and prioritizing palliative care despite competing economic resources, as done in Uganda and Kerala (Southern India), provide examples that can help drive palliative care policy implementation forward in the future for other countries as well. Empowering patients, their families, and healthcare professionals with the necessary palliative care education and resources creates justice in the death and dying journey by enabling patients to undertake or forgo palliative care on their own terms.

Conclusively, in ethical dilemmas in palliative end-of-life care in decision-making, social, cultural, and religious approaches can be navigated by exploring bioethical normativity in the shared notions of valuing of life, justice in the death and dying journey, and deontology of community. Differing adherence to religious beliefs, healthcare wishes, and cultural background may lead to variation in decision-making in palliative end-of-life care for culturally and religiously diverse patients. Therefore, the shared concepts proposed in this research help navigate ethical decision-making in palliative end-of-life care for patients with varying

adherence to morals on a universally human level. This section has shown the varying moral considerations in palliative end-of-life care decision-making within Hinduism and Christianity. It has also shown how bioethical normativity highlights some shared concepts that help guide ethical issues in deciding to undertake or forgo palliative end-of-life care and the considerations of community in decision and policymaking. In sum, awareness of cultural diversity can contribute significantly to valuing human life at the start and end of life. Similarly, sensitivity to cultural diversity is crucial for upholding human dignity in the different clinical settings of patient care, as discussed in the next chapter.

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## **Chapter 4: Upholding Human Dignity in Multicultural Clinical Care**

The dissertation examines how cultural diversity as a social determinant of health, being aligned with human life, human dignity, human rights and human equity provides an ethical contribution. My explanation of the ethical contribution of cultural diversity as a social determinant of health refers to a quadrant of topics that expands the approach of the UNESCO Declaration of Bioethics and Human Rights. The UNESCO approach addresses cultural diversity in relation to human dignity and human rights. My explanation expands upon the UNESCO approach. I adopt a quadrant of topics that aligns human dignity with human life and human rights with equity. The alignment of these topics in the quadrant (dignity/life and rights/equity) explains the meaning of cultural diversity as a social determinant of health. Chapter four discusses the concept of dignity in the quadrant.

# <u>Chapter 4a: The Role of Ethics Consultations in Bridging Cultural Competencies in Healthcare</u>

A healthcare ethics case consultation is a service carried out by an ethicist, ethics team or committee to patients, medical professionals, and other appropriate individuals involved in a patient's medical care to recommend solutions for ethical dilemmas.<sup>1</sup> A healthcare team provides the most clinical care while a patient's family members or next of kin are there to aid them emotionally and in certain circumstances help them make ethical healthcare decisions.<sup>2</sup> A clinical ethics case consultation, more widely known as healthcare ethics consultation (HCEC), is a service that may be requested when there are multiple parties involved in a patients care team with differing views or goals that conflict on how to proceed with a patient's treatment plan.<sup>3</sup> Ethical concerns in a clinical setting encompass conflicts regarding the well-being of the

patient, decision-making regarding their treatment plan, the responsibilities of the healthcare providing team, and even issues related to justice in healthcare policy.<sup>4</sup>

As the demographics in the United States broaden, healthcare providers will be confronted with budding challenges and chances to deliver culturally competent healthcare services. The rise of cultural competency has been less prominent as Somnah Saha et al. in "Patient centeredness, cultural competence and healthcare quality" explores that "[t]he term 'cultural competence' did not begin to appear consistently in the healthcare literature until the early 1990s. By May 2007, >1,000 articles mentioning the terms 'cultural competence' or 'cultural competency' in their titles or abstracts ... [and] more than three-quarters of them since 2000." Cultural competency is a new topic in the literature that has manifested over the last decade because of racial and ethnic disparities in healthcare and as a result, federal programs have taken steps to create initiatives to encourage cultural competency awareness. Therefore, understanding the ethical issues related to cultural competency may help reduce disparities in healthcare and improve healthcare outcomes.

Joseph R. Betancourt defines "[c]ultural competence...as the incorporation of an awareness of health beliefs and behaviors, disease prevalence and incidence, and treatment outcomes for different patient populations." Healthcare ethics case consultations may be a positive facilitation tool in bridging ethical dilemmas that arise, especially from cultural incompetency, through enabling the identification of ethical issues regarding informed consent, decision making, trust and disclosure. Ethicists in a clinical setting may use various approaches when analyzing a case based on their preferred method, experience, size and scale of the case as well as the organization and institutional structure. The three approaches to ethics case consultations include the four topics method, by Jonsen, Siegler, and Winslade, CASES (Clarify,

Assemble, Synthesize, Explain, Support), developed by the Veterans Health Administration (VHA or VA), and process and format, by Robert D. Orr and Wayne Shelton. To bridge the ethical gaps that result from cultural incompetency, ethicists may approach case consultations using the Four Topics Method because the contextual feature's topic is helpful in identifying and understanding a patient's culture and background.

The following case represents a cultural competency issue in healthcare presented by Bernard Lo in *Resolving Ethical Dilemmas: A Guide for Clinicians*, which involves the family requesting not to tell the patient of her cancer diagnosis.

Ms. Z is a 70-year-old Cantonese- speaking woman, with a change in bowel habits and weight loss is found to have carcinoma of the colon. The daughter and son ask the physician not to tell their mother that she has cancer. They say that people in her generation are not told they have cancer and if Ms. Z is told she will lose hope. A colleague suggests that you tell the patient that she has a "growth" that needs to be removed. <sup>10</sup>

Ethical issues in the preceding case include trust, deception, and nondisclosure surrounding this person's cultural background. As a result, the informed consent process may become distorted, and healthcare proxy's may be needed to act as decision-makers or information holders and translators which ultimately leads to a hindrance in the patient-provider relationship. Therefore, a clinical ethics consultation may be utilized to clarify conflicts between the family and the provider and help guide each party towards a medical path that is in line with the patient's preferences, goals, and values.

Clinical ethicists are not the decision-makers when it comes to ethical dilemmas in a clinical setting (i.e., priority setting etc.); however, they may be analysts, consultants, advisors, moderators, and guardians of values and laws. <sup>11</sup> Clinical ethicists act as clarifiers in improving healthcare quality and outcomes when the various parties involved have differing viewpoints or

cultural incompetence on what is morally correct for the case at hand. <sup>12</sup> The role of cultural competency in an ethics case consultation may help provide an analysis of the ethical issues regarding cultural patient care, culturally competent organizational issues, or culturally fair policy enhancements. Ethics case consultations enable greater communication, understanding, and empathy and, as a result, improve clinical quality outcomes for patient care. Ethics case consultations are a positive resource when confronted with ethical dilemmas regarding cultural competencies in the medical context.

### I. Ethical Concerns

Attentiveness to cultural diversity sheds light on how to address ethical issues that arise regarding respect for human dignity when delivering care to patients with value differences across many different social or religious backgrounds. Ethical issues arise when delivering cross-cultural care due to differences in values between patients and providers of different backgrounds. Differences in the background may often lead to differing goals between the patient and the healthcare provider. As a result, a culturally competent ethics case consultation may help specify values and lead to recommendations that are related to the best path of care for the patient. According to Henry S. Perkins's article in the *American Medical Association Journal of Ethics*, when considering the ethical values of patients, physicians must be aware of patient values that are shared, taught, and used to understand their different life experiences and backgrounds.<sup>13</sup> In the case of Ms. Z, cultural values dominate the conflict between the patient, her family, and her healthcare team and, as a result, impede the informed consent, truth-telling and disclosure, and decision-making processes.

Informed consent is embedded as a cornerstone philosophy in the United States medical sector to defend patient safety and encourage patient autonomy.<sup>14</sup> As a result, informed consent

is a crucial element in the patient-physician relationship; it is a fundamental right of the patient and a general duty of the physician. Ethically, it is a physician's obligation to inform patients adequately regarding their health information and to respect their right to generate an self-directed decision. Additionally, by enabling the documentation of the process of informed consent, the patient's entitlements to know their healthcare information is also protected. Berg et al. argues that "if done correctly, informed consent can often lead to better doctor-patient relationships, better patient adherence to treatment plans, and a fuller understanding of the disease understanding on the part of the healthcare provider." As a result, informed consent is a constituent in building the patient-physician relationship and aids in improving the quality of healthcare delivered and patient safety outcomes, which ethically may benefit both parties.

Awareness of cultural diversity can be especially helpful regarding patient consent.

Informed consent has proved to protect patients from poor involuntary care resulting to improved care delivery. However, in certain instances, the informed consent process may not be applied or carried out universally. While all healthcare providers may hope to fully adhere to procedures and processes, the process of informed consent comes with its own respective inadequacies because it may not always be universally applied, and cultural contexts may be a barrier. Berg et al. discuss that informed consent has been created as a decision-making tool in the cultural context of the United States but in other cultures may not have the same significance or weight. The preceding statement presents a restraint, or limit. If the overall framework and intention of informed consent are culturally variable then its impact may be lost and may lead to a different understanding of the decision-making process. For example, in some African cultures, families and patients may not be able to make an autonomous decision without first consulting the authority figures of their family.

In the case of Ms. Z, the informed consent process may not be carried out since Ms. Z's family has requested not to tell her of her diagnosis. In most cases, the physician should specify patient preferences of being informed of their diagnosis or whether somebody else would want to receive this information.<sup>22</sup> In Ms. Z's case, the physician would most likely not be able to inform Ms. Z of her diagnosis or test results, and as a result, create ethical conflicts on the physician's end. This conflict arises from the informed consent philosophy in American medicine, which includes the patient in their diagnosis and prognosis as a key part in building trust and a professional relationship between the provider and patient. Without informed consent, the patient's information may risk full disclosure and possibly misrepresentation.

Misrepresentation and nondisclosure of healthcare information create disrespect and distrust, which leads to people feeling betrayed or manipulated even if the intention was benevolent.<sup>23</sup> In the medical context, building trust is crucial in fostering strong patient- provider relationships. According to Bernard Lo, "deception is broader than lying, and it includes all statements and actions that are intended to mislead the listener, whether or not they are literally true." Misrepresentation includes intentional as well as unintentional statements and actions that may be misleading or false. Nondisclosure would be when the healthcare provider does not disclose the full information to the patient unless otherwise sought out by the patient.<sup>26</sup>

Misrepresentation and nondisclosure hinder a strong patient and provider relationship.

Although misrepresentation and nondisclosure are ethically inappropriate, certain instances justify withholding information from patients.<sup>27</sup> Deception may also be appropriate in certain cultures. In many cultures, it may be considered normal to not tell patients they have a serious illness or cancer.<sup>28</sup> As a result, cultural context is an essential aspect of justifying withholding information given that is what the patient wants. In some cultures, withholding information is not

viewed as lying but rather as a method of protecting the patient from suffering and giving them hope for the future.<sup>29</sup>

In Ms. Z's case, the family does not want her to know of her diagnosis. Furthermore, since Ms. Z is a Cantonese-speaking woman, she may not even ask for such information as there may be a language barrier. Acting as her proxies, Ms. Z's daughter and son tell the physician to not disclose the diagnosis to Ms. Z because it is a norm for people of her age and cultural background to not be informed of such diagnoses.<sup>30</sup> In this case, the physician has limited options: he/she can follow the request of the daughter and son; he/she cannot follow the request and tell her of her diagnosis; or he/she can call upon an ethicist to investigate possible recommendations for both parties. Therefore, misrepresentation and nondisclosure leave ethical concerns for the provider. An ethicist can ethically communicate information and pave the best path of care for Ms. Z.

Decision-making for patients is critical in the medical context as it impacts the direction of treatment based on decisions that are accepted or rejected. Ethically and legally, clinicians must allow patients to partake in choices regarding their own healthcare given they have decision-making capacity.<sup>31</sup> Clinical ethics consultations help the medical team honor patients' autonomous participation in the process of informed consent and be mindful so as to not neglect or influence a patient's decision. Each patient's preferences will be different because of individualized choices.<sup>32</sup> Individualized choices and patient autonomy are directly correlated. The patient's preferences include factors such as their own background or cultural beliefs and values.<sup>33</sup> However, when a patient's native language is not English, and the patient's family represents most of the patient's decisions, some ethical limitations may arise.

According to Bernard Lo, in some states' cultural contexts within the United States, family members may be presumed to be surrogate decision-makers given patient appointments because they have close relationships with patients and may have discussed healthcare interventions.<sup>34</sup> When family members are involved as surrogate decision makers, it is crucial that a patient's wishes and best interests are kept at the forefront of deliberation. Lo states "social, cultural, and religious norms encourage family members to subordinate their own interests for the sake of the relatives in need."<sup>35</sup> As a result, it is imperative to understand each person's intentions for the patient. Understanding the intentions and motivations of the surrogate decision-makers ensure that the decisions are made ethically and appropriately, making sure any form of promoting their own interests is not factored in.<sup>36</sup>

In Ms. Z's case, it is important that healthcare providers understand that it is culturally appropriate to involve her family. It is useful to incorporate her family into the medical situation because she speaks Cantonese, and the family may aid in translating when needed. However, this approach may be prone to ethical errors during the verbal informed consent process. For example, authors in the literature mention that misinterpretation, underlying intent of the family members, and alternate agendas of the family aside from the best interest of the patient create ethical issues. Thus, healthcare providers should consider Ms. Z's autonomous right to making decisions. In the United States, the Department of Health and Human Services (HHS) provides guidance on limited English proficiency (LEP) and standards for using qualified medical interpreters in providing care.<sup>37</sup> To ensure Ms. Z can make her own decision, it would be ethically appropriate to involve a qualified medical interpreter. Since Ms. Z is not mentally incapacitated, she does have decision-making capacity, and as a result, an ethicist may intervene. The ethicist can use an ethics case consultation to recommend an interpreter and work with them

to understand any conflicting viewpoints. Furthermore, healthcare systems can use an ethicist to provide training on collaborating and working with an interpreter to foster strong dialogue between the family and the provider regarding the patient's best interests or wishes.<sup>38</sup>

# II. Case Analysis

Differing values and goals between various parties lead to ethical issues in patient care. Culturally diverse background understandings contribute to an essential role in how a patient may or may not receive particular information and how they respond to specific treatment recommendations.<sup>39</sup> In order to address ethics issues in clinical care, the Joint Commission requires methods to handle such cases.<sup>40</sup> An ethics case consultation is one method that can help examine and clarify each party's viewpoint to suggest the best path(s) of care in regard to the patient's best interests. In Ms. Z's case, it is beneficial to understand the physician, daughter and son, and Ms. Z's discordant values. Cross-cultural ethics consultation is therefore essential in mitigating disparities in care between patients, their families, and the healthcare team.

A healthcare ethics case consultation guides ethical dilemmas in cross-cultural healthcare. When ethical issues in cross-cultural clinical care arise, an ethics case consultation may be required to help ensure quality care is delivered and the patient's best interests are taken into the utmost consideration. According to Brenda Louw, "[p]rovision of culturally appropriate services to individuals and their families is a basic role of all health care professionals, which requires cultural competence and ethical conduct." The four topics approach may be best suited for cross-cultural ethics cases because it allows room for cultural analysis and the potential integration of education. As a result, clinical ethics case consultations may provide education in developing cultural competence in healthcare service delivery and permeate ethical effectiveness in clinical care encounters and subsequently in ongoing education.

In general, ethical dilemmas, as well as those due to cross-cultural care, may arise and lead to disagreements and strong emotions among patients, families, and the healthcare team.<sup>42</sup> As such, an ethics case consultation may be requested. The role of an ethics case consultant is to clarify, analyze, and identify differing values and goals to ultimately help resolve the ethical problems.<sup>43</sup> By analyzing firsthand data and assessing the patient's values and wishes for care and their quality of life, an ethics case consultation can clarify viewpoints and aid the medical team in aligning patient goals and preferences with patient care.

An ethics case consultation may help express the views and concerns of the various parties involved. For instance, the patient, their family members, and the healthcare team may be able to voice their viewpoints and concerns to the ethicist. The ethicist may then use these viewpoints and explain to each of the parties the various interests. As a result, the patient and their family may feel that their voice is heard, and the healthcare team may come to appreciate the family and the position they are in based on an empathic standpoint. This allows them to feel the values and concerns on a holistic level.<sup>44</sup>

In the case of Ms. Z, an ethics case consultation would be beneficial in ensuring that the physician and family members are keeping Ms. Z's best interests in mind, irrespective of whichever path of care that is ultimately taken. An ethics case consultation may improve communication through empathic listening of the son's and daughter's cultural reasoning for nondisclosure of the diagnosis to Ms. Z. Once the ethicist is able to gather necessary information regarding the cultural circumstance, he or she may then relay that information to the physician, and as result the physician may be able to spend more time understanding the cultural reasoning of the son, daughter, and Ms. Z and plan another more appropriate care plan. An ethics consultation in Ms. Z's case may also help because an ethicist can negotiate an acceptable

resolution for the parties involved by leading a discussion that assures each parties' viewpoint is presented and appreciated by the other.<sup>46</sup>

Healthcare ethics case consultations may be delivered by an individual ethicist, an ethics team, or an ethics committee. Each of these three methods has its own strengths and limitations depending on the roles and responsibilities that the case requires. They may use methods that include four topics, CASES, and process and format. An individual ethics consultant may be best suited for urgent or smaller cases where the workload is not overbearing on just one individual. For an urgent request an individual ethicist may easily be able to gather the details and analyze the case to deliver services efficiently and in a timely manner. An ethics consultant may serve at one organization or multiple organizations to ensure that qualified ethics consulting service is accessible.

The ethics team-based approach is suitable for larger requests or requests where more than one viewpoint may be of value. This enables the ethics team to take an educational approach and explore alternate views from colleagues who may have valuable insight into the case at hand. An ethics team-based model may also be best suited for an organization where larger cases are more common and therefore the workload may easily be distributed amongst the team resulting in better work quality. An ethics team-based structure may not be best suited where there are conflicts of cross-cultural care as this may overwhelm the patient and family. However, one benefit of the ethics team-based approach is that sometimes colleagues may have varied backgrounds with different cultures based on their own ethnicity, experiences, or even research knowledge and as a result this approach may be of value. To overcome the team-based structural barriers in cross-cultural ethics case consultations the team may assign one lead ethicist who consults the patient and family and the remaining ethicists as resources of

information for the lead ethicist. In the case of Ms. Z, it may be best that an individual ethicist carries out the actual case consultation in order to build a strong relationship with the patient and family where they feel comfortable expressing their views to the ethicist; however, if necessary, the ethicist could consult other ethicists in the organization to understand any cultural shortcomings.

An ethics committee method may be appropriate for controversial cases that establish court precedent or media involvement.<sup>52</sup> This methodology could alleviate some of the pushback or may help support the case if taken to court. This method is also valuable when an ethics issue surrounds an organizational or policy change as these issues may sometimes involve various parties such as healthcare providers and may affect the mission, vision, and values of an organization. In the case of Ms. Z, an ethics committee method would not be the right approach because the number of people involved might overwhelm the family and Ms. Z. Additionally, the ethics committee often does not gather regularly; instead, the committee meets only on a monthly or quarterly basis due to the number of people involved. In the case of cultural competence, it may be beneficial to share the cultural background and overall results deduced from Ms. Z's case so that physicians, ethicists, and other professionals may become more knowledgeable about other cultures.

Healthcare ethics services may be provided and received through various means. Some hospitals may send quasi-appellate committees composed of representatives from their own ethics committees to other separate committees that handle special cases.<sup>53</sup> While CASES may be used with a team-based ethicist, the four topics method might be best for an individual ethicist and as result enable thorough analysis in cross-cultural cases. In a special case like Ms. Z's, an ethicist from a quasi-appellate committee who has encountered a Cantonese-speaking patient

with a similar family and background might be called upon to help align the patient, the family, and physician's goals and values. Furthermore, to ensure that ethics consulting services are available through a wide geographic range they may be provided as distance consultations, online and off-site via telemedicine services.<sup>54</sup> In online ethics case consultations, the ethicist is dependent on technology such as video, audio, and teleconferencing and must follow proper Health Information Portability and Accountability Act (HIPAA) guidelines ensuring patient confidentiality is not breached.<sup>55</sup> In cross-cultural healthcare ethics cases such as the case of Ms. Z, distance and online ethics consultation may be harder to perform due to the need to build trusting relationships with the family. The ethicist may not be able to see the family and patient or even healthcare team face to face and as a result may not be able to comprehend the full emotions behind the values and goals of the patient. However, for an empathetic ethicist determined to serve people and deliver services, these challenging barriers may be overcome with passion.

According to the American Society of Bioethics and Humanities (ASBH), there are certain core competencies ranging from basic to advanced that an ethicist must possess in order for the consultation methods to be conducted successfully. These competencies fall under three categories: ethics evaluation and examination skills, process skills, and interpersonal skills.<sup>56</sup> Ethical assessment and analysis competencies are crucial when determining the ethical conflict at hand.<sup>57</sup> These skills guide an ethicist in cross-cultural ethics issues to discern and gather relevant information such as the legal or medical dimensions of the ethics case, the social and interpersonal demographics of a patient, or identifying the various beliefs and values of the parties involved in the ethical dilemma.<sup>58</sup>

Ethical assessment and analysis skills help the ethicist develop the ability to access, analyze, and communicate relevant information for ethics issues in cross-cultural care.<sup>59</sup> For instance, in cross-cultural ethical issues, an ethicist may need to know the policies of the institution and how to access an interpreter or translator, the organization's values, and professional codes of conduct to properly carry out the analysis. An ethicist must also understand ethical concepts such as privacy, confidentiality, informed consent, and truth-telling. The preceding concepts fundamentals do not change much over time; however, their operationalization can differ across socio-cultural contexts. As a result, an ethicist must be willing to consult literature such as bioethics journals, books, and peer-reviewed articles to understand how to clarify and handle issues of confidentiality that may be challenged in cross-cultural cases.<sup>60</sup>

After assessing and analyzing the case, the ethicist should comprehend the information and formulate a response. Accordingly, process skills need to be understood because they build realistic expectations around the consultation process. For example, being able to process the consultation request can help determine if a member of the team or quasi-appellate ethics committee may be necessary to bring in cultural knowledge from past experiences. Once the method of consultation is determined, it is valuable to identify the pertinent parties and resources needed for the case evaluation. In cross-cultural healthcare, process skills are highly necessary to ensure that an ethics consultation is communicated, collaborated, and documented clearly so that concerns may be recorded and any underlying issues may be brought to attention. These skills are particularly relevant in cross-cultural care because they are used to understand each party and clarify the cultural background of the patient to the healthcare providing team. Process skills help address concerns at the best level so that the healthcare organization is functioning efficiently.<sup>61</sup>

In the case of Ms. Z, process skills are useful in helping an ethicist understand Ms. Z's culture and background. This will highlight the necessary materials and manpower they will need, and the knowledge they will have to gather from people to know how to document the consultation accurately.

Interaction skills, or competencies, that the ASBH mentions include interpersonal or people skills. <sup>62</sup> We often characterize people skills as communication skills that help facilitate conversation. In cross-cultural ethics case consultations, interpersonal skills are a central component because communication gaps between the relevant parties are often the reason for the ethics consultation. For instance, in the case of Ms. Z, interpersonal skills would enable the ethicist to listen to the interests of the son and daughter. As a result, they would then be able to recognize the moral distress and strong emotional needs of the son and daughter. With this understanding, the ethicist would then be able to educate Ms. Z's physician and other relevant healthcare providers on the various cultural competencies necessary to communicate and understand. In cultural competency ethical cases, the individual ethicist consultation pairs well with the four topics approach, which gives a simple yet straightforward framework to help guide the consultation process and highlight contextual features such as culture and background.

The four topics method, CASES, and process and format are three approaches that may be used to conduct an ethics case consultation. While all of these approaches are used in ethics case consultations, finding the best approach for each patient case is essential. In cross-cultural case consultations such as the case of Ms. Z, the four topics method may be particularly suitable. In order to understand the suitability of four topics, CASES and process and format will also be analyzed to show their limitations in cross-cultural cases.

The four topics method breaks down the consultation process into four parts: medical indications, patient preferences, quality of life, and contextual features.<sup>63</sup> The medical indications topic allows the ethicist to examine pertinent details of the medical situation, recognize possible treatment options, and conclude if and how treatment can support the patient.<sup>64</sup> This topic helps the ethicist gain a clear view of the ethical situation by sifting out the values and goals of each party involved. The patient preferences topic focuses on what the patient does or does not want in terms of treatments related to the case.<sup>65</sup> This topic involves the varying parties of the patient's care team such as the patient, their surrogate decision-makers, and the health care providers to assess what is in the best interest for the patient. The quality of life topic works in conjunction with the findings of the medical indications topic because treatment options, if any, ultimately affect the quality of life the patient will endure, with or without a treatment plan.<sup>66</sup> The contextual features topic gives the ethicist an opportunity to reflect on the holistic factors of the recommendation such as financial and background information, and privacy matters, all of which may affect the parties involved.<sup>67</sup>

The four topics approach would be the most appropriate for cases where cultural diversity is a key component because of the focus on the contextual feature of the care. Since each of the three preceding topics tie into the cultural component, this aids in giving a holistic picture of the patient's situation. A specific addition to the four topics that would benefit the overall analysis of cultural competency cases would be a topic for education. Although much of the education can be done whenever the recommendations are communicated, a specific topic for education would enable the healthcare providing team to gain resources from the ethicist or ethics center and possibly participate in continuing cultural competency education regarding each unique case. As

a result, due to the flexibility and support of cultural analysis, the four topics method is the best approach for ethical case consultations regarding cultural competency.

The effectiveness of the four topics method in evaluating cross-cultural ethical cases can be demonstrated through the analysis of Ms. Z's case:

- 1. The medical indications of the patient are that she has carcinoma of the colon and a possible treatment mentioned is the removal of the harmful substance.
- 2. The patient preferences are not clear as the diagnosis of cancer information has not yet been released to her.
- 3. Her quality of life would possibly improve after removal. Ms. Z is currently having a change in bowel habits and weight loss. Since she is 70 years old, the possible removal may help her to get her bowel movements back to normal and potentially stop her from losing more weight.
- 4. The contextual features topic is one of the most crucial topics in cross-cultural ethics case analysis. The contextual features topic in her case would highlight her son and daughter not wanting to disclose her actual diagnosis to her from the reasoning that she may lose hope.

Additionally, for people who are from her background and her generation, it is normal not to disclose a cancer diagnosis as it may cause them to potentially worry and lose optimism in the time they have left in this life.<sup>68</sup>

The CASES approach was developed by and for the VA and is "designed as a primer, to be read initially in its entirety by everyone who participates in ethics consultations, including leaders responsible for overseeing the ethics consultation function."<sup>69</sup> For ethical issues surrounding cross-cultural care, CASES may not be the best approach. However, its intention is to create a consistent consultation methodology to help effectively approach and resolve ethics issues across the institution(s). The first step includes understanding the consultation request at hand, its appropriateness, and obtaining information to help formulate the main ethics issue. In the case of Ms. Z, this is where the ethicist would be able to realize that the ethics issues of informed consent, misrepresentation, nondisclosure, and decision-making all come forth due to cultural and generational differences between the patient, family, and healthcare team. The next

step is to assemble all the relevant information such as considering what may be needed (medical facts, patient interests, etc.), and who may have that information (patient, health record, family, staff, etc.), and to summarize the consultation by revisiting the ethics issue.<sup>72</sup> In the case of Ms. Z, the physician and the family may have the most relevant information. The ethicist may also have to reach out to other professionals who have experience with cultural incompetency issues or refer to the literature. Subsequently, the information must be synthesized to analyze the ethics issue, to identify who the ethically appropriate decision maker is, and to expedite a discussion considering the ethically permissible opportunities and parties.<sup>73</sup>

In the case of Ms. Z, the ethically appropriate decision maker would be Ms. Z; however, the ethics issue comes into existence because the son and daughter do not want to tell Ms. Z of her diagnosis. It would also be necessary to discuss the possible risks and benefits of withholding information due to cultural context to both the physician and the son and daughter. The subsequent steps include explaining the synthesized information to the parties involved, providing education or resources if needed, and documenting the ethics services delivered. This step would be very beneficial for cross-cultural ethics cases as it indeed provides an area where the ethicist can educate the provider on Ms. Z's cultural background and the reason for withholding information and possibly allow the son and daughter to be the ethically appropriate decision makers. The last step of the CASES approach is to support the consult process via a follow up on the case to evaluate or update any changes to the consultation appropriately. This could be useful in cases like Ms. Z's if the diagnosis changes or other confidentiality issues arise because the case will have already documented cultural and background information of the patient.

The process and format approach by Orr and Shelton highlights a process by which an ethics consultation can be conducted and provides a format for documentation of the consultation. <sup>76</sup> For cross-cultural ethics case consultations, the process and format approach provides an organized process that guides the ethicist when conducting the consultation request.<sup>77</sup> The process piece of this approach helps the ethicist understand each healthcare provider's viewpoint and goals for Ms. Z. However, Ms. Z may feel hesitant to participate in a conference with management because she is Cantonese-speaking and English is not her first language. Her son and daughter may feel comfortable participating; however, ethical barriers still would exist such as what information to disclose in the management conference if the son and daughter do not want Ms. Z to know of her cancer diagnosis. The second piece is to document the case consultation in a consultation report format. In this approach, the report contains information such as the patient's demographics and a summary of the events that led up to the ethics concern, among other things.<sup>78</sup> In the format step of this approach the ethicist uses the report to identify the cultural ethical barriers of informed consent, misrepresentation and nondisclosure, and decision making in Ms. Z's case and to make recommendations.

Four topics, CASES, and process and format pose limitations in each of their methodologies. The CASES approach gives a thorough, in-depth, step-by-step approach to ethics case consultations. However, this approach may not be appropriate for cross-cultural ethics issues as it does not have the same framework to support cultural analysis. Additionally, the steps are very broad and not specified to guide cultural and background thought processes. An alternate option would be to reserve the CASES approach for ethics team-based models where one ethicist may focus on cultural competence and the team may come together to understand the entire ethical situation. Resorting to CASES for team-based models would enhance the

explanation of the synthesis step in cross-cultural issues where additional resources such as educational documents may be prepared to educate the healthcare provider on the cultural background and reasoning for nondisclosure of information in order to reduce worry in Ms. Z's case.

The process and format approach is a technique to analyze and document consultations, however, the ethicist may not get the full experience of the cultural context in Ms. Z's situation because most of the work is done among professionals rather than the patient and family.<sup>79</sup> This approach could be used to train rounding ethicists on how to interact and communicate with healthcare providers which would help build professional relationships and in turn make the communication process easier when relaying cultural information to healthcare professionals.<sup>80</sup>

The four topics approach is a clear and simple method for case consultations, and as a result, it may be best suited for cross-cultural healthcare ethics case consultations. One of the shortcomings in the simplicity of this approach is that it does not present a single topic to formally meet or educate providers and the family and patient to discuss culture and background. Most of the analysis is completed between the individual ethicist and the physician or Ms. Z and her son and daughter which may help the ethicist build a strong relationship with each party. However, following this framework, the ethicist does not get the opportunity to educate the various parties and discuss a solid middle ground between their ethically conflicting values. In urgent cases, there may be very little time amongst parties to meet, and therefore the ethicist may efficiently be able to facilitate a recommendation. If a formal meeting or education topic were to be added into the four topics method, it would be appropriate to do so in or after the contextual feature's topic. The preceding approach may help formulate a more comprehensive view of the case. As a result, the four topics method has barriers that an ethicist may easily overcome while

keeping its four-topic structure with minimal distortion in the methodology and thoroughly considering the cultural competencies of the patient.

#### III. The Future of Ethics Case Consults

In "Reducing Disparities through Culturally Competent Health Care: An Analysis of the Business Case," Cindy Brach and Irene Fraser point out that one of the biggest challenges for the American healthcare system is finding ways to provide superior care to culturally diverse populations. 81 In "Bioethics in Secular, Pluralistic Society," Joris Gielen echoes similar notions stating that "[r]acial, ethnic, cultural, and religious stereotypes and biases based on the assumption that people of a different social group are hard or even impossible to comprehend may obstruct dialogue and lead to inequalities and disparities in healthcare."82 Creating shared dialogue is essential to supporting cultural diversity. Brach and Fraser argue that "[t]he persistence of racial and ethnic disparities in health care access, quality, and outcomes has prompted considerable interest in increasing the cultural competence of health care."83 Communication between the healthcare provider and patients with culturally diverse backgrounds presents a challenge: "[t]hirty-three percent of Hispanics, 27 percent of Asian Americans, 23 percent of African Americans, and 16 percent of whites reported one or more of the following problems: their doctor did not listen to everything they said, they did not fully understand their doctor, or they had questions during the visit but did not ask them."84 However, language barriers only present one factor of cross-cultural health care challenges.

Cindy Brach and Irene Fraser argue that cultural competence encompasses the healthcare system's behaviors, attitudes, and beliefs, related to the culture, race, and social groupings of the patients and healthcare providers.<sup>85</sup> Ultimately, an ethics consultant provides cultural competency services through culturally competent education, recommendations for ongoing

training, and finding a balance in understanding the background of patients and providers. An ethics consulting service may: help change clinician and patient behavior, improve communication, increase trust, and contribute to research, expanding the understanding of cultural diversity in healthcare. As a result, ethics consultants may help provide consulting services to help improve patient healthcare outcomes.

Cultural competence should be taught in medical schools, graduate programs, and other forms of higher education. <sup>86</sup> In order for medical schools to become accredited in the United States, they need to meet certain standards set by Liaison Committee on Medical Education (LCME). <sup>87</sup> Standard 7.6 under the "curricular content" of LCME's 2023-2024 *Functions and Structures* document recognizes the need for "structural competence, cultural competence, and health inequities." <sup>88</sup> Fostering cultural competency (as a function of cultural diversity) is an ethical responsibility that higher education programs have in order to train health care professionals. However, not all the cultural competency issues that arise in a clinical context may be apparent and as a result, providers may benefit from education via an ethics consultation. <sup>89</sup> For instance, in cross-cultural ethical issues, such as the case of Ms. Z, an ethicist is vital to help the healthcare provider, the patient, and their family. Ethicists can prepare interpreters and translators to convey the questions and concerns to Ms. Z, helping bridge the communication gap and addressing the language barriers.

Educating healthcare providers on ethical cultural competency issues in the clinical setting through an ethics case consultation can provide an opportunity for transformative teaching. Ethical consultations can provide an experience-based interactive teaching approach for cross-cultural ethical issues. Evidence-based education supports the transformative teaching approach of theory-based education.<sup>90</sup> Evidence-based education for cross-cultural, ethical

consultations may benefit the provider on up-to-date cultural issues and how to approach the patient uniquely and provide the best care possible.

In clinical ethics, integrating cultural competency can be done by adopting models presented in the literature. In "Cultural Competence and Ethical Decision Making for Health Care Professionals," Brenda Louw articulates that the Process of Cultural Competence in the Delivery of Healthcare Service (PCCDHS) model guides healthcare institutions in developing cultural competency into existing curricula.<sup>91</sup> In clinical ethics, the PCCDHS model can help develop educational approaches to enhance cultural competency in healthcare providers and even in the healthcare organization. For cultural competency ethical consultations, the ethicist may integrate the PCCDHS model into the previously suggested education topic for the four topics method after the contextual topic. The PCCDHS model provides practical methods that may help develop conducive experiences aimed at improving self-assurance, attentiveness, and empathy when delivering culturally inclusive care. 92 An ethics consultant may use strategies to facilitate the PCCDHS learning model in the consultation, including having an open dialogue with the provider. These strategies enable them to discuss the culture and biases as well as the personal perspective to understand patient behavior and promote respect and ultimately positive care outcomes.93

Integrating an understanding of the ethical issues of cultural competency into the clinical setting can help build patient and healthcare provider relationships. While healthcare ethics are essential to patient-provider relationships, cultural competence is necessary to reduce healthcare disparities. An ethicist may help link the ethical philosophies to the ethical principles of healthcare delivery. Ethicists aid in fostering mutual understanding between patients and providers. Ethical principles of healthcare delivery such as autonomy of decision making,

informed consent, honesty, and nondisclosure may all require a tailored approach to delivering services in cross-cultural care. Therefore, an ethicist plays a vital role in bridging cultural competency gaps between the patient, provider, and their family in considering each party's needs, wishes, and values.

Building patient-provider relationships allow for patient-centered healthcare delivery. Somnath Saha et al. note that patient-centered medicine historically began as a narrative way to guide how physicians should engage and converse with patients. 96 Balint devised patientcenteredness in 1969 to capture the idea that each patient has the right to treated as a distinct human.<sup>97</sup> Patient centeredness is one of the 5 core areas of the Institute of Medicine (IOM)'s Health Professions Education: A Bridge to Quality. Patient-centered approaches matter because they allow healthcare providers to view each patient as a unique person with their own story to tell, which promotes trust and confidence in the healthcare provider. 98 As a result, an ethicist may help the provider build a patient-centered relationship by creating a strong sense of trust, confidence, and empathy in the patient and family. An ethicist may help guide the physician towards fostering an understanding of the patient and who they are as a person. By gaining an understanding of the real-life account of the patient, the physician may build a strong patientcentered relationship as well as help cater to the patient in enhancing disease management, releasing diagnostic information, and exploring the illness or disease experience from the patient's perspective. Ultimately, this creates a sense of openness in the patient where they feel they are unique, and the healthcare provider wants to understand them; this therapeutic relationship enables not just a provider-patient relationship but also a patient-centered relationship infused with care, empathy, and unique care management.

Ethics case consultations help improve cross cultural healthcare outcomes by bridging gaps in communication, education, and healthcare provider(s) relationship building. The literature, experts, and articles mention that communication other than the native language spoken may lead to significant disparities in the healthcare context. 99 Often, conscious or unconscious negative attitudes towards a specific racial or ethnic group may negatively impact the healthcare provider and the patient in the healthcare decision-making process. 100 As a result, may negatively affect healthcare outcomes. In "Cultural Competent Healthcare Systems: A Systematic Review," Laurie Anderson et al. state that there are differences in how African Americans and Caucasians receive referrals for cardiac surgeries and medication prescribing patterns which may lead to mistrust or even perceived discrimination resulting in negative healthcare experiences. 101

As a result, an ethicist may help ease or reduce any stigma via and an ethics case consultation. In an ethics case consultation within the context of cross-cultural care, an ethicist may be able to examine the patient's background and, as a result, may be able to consult the healthcare providing team. In consulting the healthcare providing team, the ethicist can point out any disparities they identify as affecting the patient's care route. An ethicist may help the healthcare provider or team better understand the cultural context required for the patient and their family and as a result help guide the healthcare providing team to possibly cater to the patient as a unique person. In extreme cases, the ethicist may even be able to recommend another provider for the patient to ensure that the patient does not get harmed due to cultural context.

In conclusion, ethics case consultations may aid in resolving ethical dilemmas related to cultural competencies in the clinical setting. As the demographics in the United States are projected to grow in diversity, cultural competence will be a key component that healthcare providers will have to take into consideration when delivering care. A patient's culture and

background may impact their ability to give informed consent, potential dishonesty, misrepresentation of their health information, and their decision-making processes. In some cultural contexts, it is normative to have a patient's family be involved in their medical situation. As a result, it may collide with the legal and ethical standards of informed consent, honesty and disclosure, and patient autonomy that healthcare providers in the United States are required to observe. Ethics case consultations help clarify the differing viewpoints due to the cultural frameworks of the patient and the cultural awareness that the healthcare provider may or may not have.

The case analysis of Ms. Z highlights the individual ethicist approach and the four topics method application for cultural competency ethics cases. Cultural competency aids the family and patient feel comfortable sharing and building a reliable relationship with a single ethicist as opposed to an ethics team or committee. As a result, an individual ethicist may be the best approach to carrying out a cross cultural ethics case consultation. Additionally, the four topics method possesses the topic of a contextual feature that highlights a patient's background and culture. The simplicity and structure of the four topics method may even allow for a topic or integration of an education section to aid cultural competency education for the healthcare providing team.

In the current and near-future, ethics case consultations for cross-cultural healthcare ethical dilemmas will be essential. An ethicist acts as an intermediary and analyzes various differing values and goals, helping build patient-provider relationships. Ultimately, with a strong patient-provider relationship, healthcare outcomes may improve, resulting in the delivery of higher quality care. With higher quality care, creating patient uniqueness, and educating healthcare providers, ethics case consultations are a positive resource in bridging the gap in

cultural competency healthcare ethics issues. Sensitivity to cultural diversity can help foster a sound approach not only to ethics consultation but also to what can be called cross cultural care.

## **Chapter 4b: An Ethics of Care Approach to Cross Cultural Care**

With the growing demography in the United States, the need to be mindful of a patient's cultural background will be necessary. The future of healthcare will need to incorporate catered healthcare delivery methods to sustain the unique care needs of diverse patient populations. 102 Social determinants of health, such as culture and background, lead to different patient preferences and values and have been indicated bear greater undesirable effects on disadvantaged, vulnerable populations in the form of poorer health outcomes. 103 Incorporating an ethics of care approach to cross-cultural care may aid in creating a holistic understanding of patient needs and preferences. Furthermore, culture is a diverse determinant of health. For instance, factors (nationality, race, religious affiliation, educational status, etc.) and the degree to which one identifies with their cultural background fall into what Purnell and Fenkl call "variant characteristics of culture." These characteristics shape peoples' views, beliefs, and practices within cultural groups and can vary and change among people over time. 104 As a result, an ethics of care approach can foster cultural empathy to provide ongoing, developing human-centered care.

Ethical values in informed consent, respect for autonomy, and decision-making can be an area of asynchrony in cross-cultural care. Ethical challenges arise when the value of autonomy in dominant bioethical theories that guide Western medicine do not match the values of autonomy in other cultural contexts. A patient's autonomous choice and the importance of informed consent are at the foundation of medical ethics and law in the United States. Concerns that may arise with relational barriers in cross-cultural care include nondisclosure,

weakened trust, coercion, and deception when participating in the informed consent and decision-making processes. An ethics of care approach supports informed consent processes in cross-cultural care and creates an ethically sound method of morally upholding the normative component of individual human dignity, borrowed from personalism.

A care ethics perspective echoes the notion that individual human needs are fostered, nurtured, and strengthened through human relations.<sup>107</sup> Care attributes include attentiveness, respect, patience, and empathy. In healthcare, a care ethics approach highlights the importance of relationality to the human experience. Care ethics emphasizes that an individual experience is shaped by their relationships with other human beings, such as family and friends, which fosters individual development.<sup>108</sup> One of the challenges with the care ethics theory is that its critics recognize its lack of normativity in defining the direction of care. Therefore, when care ethics is viewed considering personalism, care in human relations can be directed from a normative ethical lens as sound methods of promoting individual human dignity.<sup>109</sup>

Personalist bioethics provides a normative element to support the direction and value of human care needs in the care ethics theory. Personalist bioethics is established on human-centered morals, which focus primarily on the nature of the human being as the moral norm. In "A Personalist Approach to Care Ethics," Vanlaere and Gastmans explore that care is a crucial component that helps humans develop throughout their lifetime. Care is not a fixed element but rather a unique factor based on the context of each relationship. "Good care" nurtures humans to grow positively. <sup>110</sup> In contrast, the core of personalism is that it aims at developing a human being's capacity and dignity. Human beings are essentially caring and require care in various aspects and throughout their lives, from birth to death. <sup>111</sup> When care ethics stands on the

normative context of historically developing human dignity found in personalism, then the ethical shortcomings of relationality in cross-cultural care can be overcome.

In many cultures, it is a norm for patients to involve their social web of caregivers, such as family members, within their own health care context. However, a care ethics approach may help strengthen individual autonomy in the United States healthcare context by underscoring human relationality as a form of sustaining individual human dignity. In cross-cultural care, relational morality may help provide new comprehension of informed consent, decision-making, and autonomy in healthcare as a method of promoting individual human dignity. A care ethics approach should build strong communication between the patient and provider, create patient-centered care approaches, and provide new ethical insight on shared decision-making methods to enhance individual human dignity in relational cross-cultural care.

#### I. Ethical Concerns

Sensitivity to cultural diversity is indispensable for cross-cultural care. Dominant bioethical theories highlight the importance of independence and/or autonomy in healthcare as a method of upholding individual dignity. Principlism's cornerstone philosophy of autonomy highlights the importance of self-governed choices in healthcare. Ethical issues of misrepresentation, deception, coercion, or nondisclosure of healthcare information may arise in cross-cultural care if relational involvement is preferred. The patient's social web may extend or stretch the individual autonomy of the patient and ultimately collide with the values of autonomy found in Western medicine. Integrating and understanding culturally catered healthcare approaches should involve supporting patient care preferences to meet the values, customs, and beliefs of the whole human being. This is especially crucial in cross-cultural care as an

ethically sound method of morally upholding the normative component of individual human dignity in relational care preferences.

Informed consent, autonomy, and decision-making are cornerstone principles in United States medicine. The informed consent process involves the communication and collaboration between the patient and provider regarding a proposed healthcare treatment. Autonomy is a foundational principle in the United States healthcare context that grants individuals to make their own freely chosen decisions. Autonomy in healthcare ties together informed consent and decision making. However, in cross-cultural care, a patient's beliefs, values, and goals in the informed consent and decision-making processes may guide, or influence, how they wish to receive care. As a result, in cross-cultural care, autonomy in the informed consent and decision-making processes may extend to a patient's social relations, which involve differences in values and/or lead to ethical concerns of coercion, manipulation, withholding, or nondisclosure of information.

In the United States, informed consent serves to preserve patient well-being, encourage individual patient autonomy, and defend patient safety from researcher or provider abuse related to new medical advances. <sup>117</sup> Informed consent is a crucial element that fosters trust in the physician-patient relationship. It is also a fundamental human right for the patient or research subject and a general duty of the healthcare professional or researcher. Therefore, ethically, a physician must inform patients adequately regarding their health information and respect their right to make an autonomous decision. <sup>118</sup> Additionally, the documentation in the informed consent process enables the researcher or medical professional to be protected from liabilities. <sup>119</sup> In "The Potential Benefits of Informed Consent," Stephen Wear articulates that the benefits of informed consent include developing a robust patient-provider relationship and a fuller

understanding of the patient's situation to give the provider a more holistic view.<sup>120</sup> As a result, informed consent is a constituent in building the physician-patient relationship which aids in the quality of care delivered by upholding patient rights.

Informed consent has proven to protect patients, enhance communication processes, and increase provider advocacy to improve care outcomes. 121 In certain instances, however, the ethical principles found in the informed consent process may not be applied universally in an independent manner as expected according to traditional Western medicine standards. 122 This is where sensitivity to cultural diversity can be so helpful. While all healthcare providers may hope to fully adhere to procedures and processes, the informed consent process comes with its own respective ethical insufficiencies because it may not be commonly valued in all cultural contexts. As articulated previously, informed consent has been created as a decision-making tool in the Western cultural context of medicine. However, many authors, including Tham et al. in Cross-Cultural and Religious Critiques of Informed Consent, point out that in some cultures, it may not have the same significance, weight, or value. 123 In certain cultures, it may be ethically appropriate to value the input of family members during informed consent.<sup>124</sup> Unfortunately, if the overall framework and intention of valuing patient autonomy in informed consent are culturally variable, then its impact, or significance, may be lost and may lead to different understandings in the decision-making process. 125

In a case study presented in "Understanding Cultural Diversity in Healthcare," a "Korean daughter did [not want] to pass on [healthcare] information to her father [regarding] his stroke or [medical] instructions given by the nurse." In this specific case, the informed consent process may not be carried out since the father's family has requested not to tell him of his medical diagnosis. <sup>126</sup> In most cases, the healthcare provider could ask the patient if they would like to be

In this case, the physician would most likely not be able to inform him of his diagnosis or medical protocols, and as a result withholding information would be a source of ethical conflict for the healthcare provider. This conflict arises because of the nondisclosure of healthcare information due to cultural value differences between the Korean patient and the informed consent philosophy in mainstream American biomedicine. Ultimately, the values of the patient's cultural context collide with the patient's right to know, hindering the disclosure of diagnosis and impeding the professional trust building that is an ethical duty in healthcare.

Dominant bioethical theories such as personalism and principlism highlight the importance of individualism and autonomy in healthcare, respectively. The term autonomy is derived from the Greek prefix *auto*, which means the self, and the suffix *nomos* or rule. Autonomy is a principle in dominant bioethical theories, such as principlism, that enables an individual to self-decide for themself. In healthcare, autonomy enables an individual to elect freely in accordance with their own self-selected choices. As such, healthcare providers are required to respect patients as autonomous agents by recognizing "their right to hold views" and beliefs within the decision-making process. Prom this perspective, upholding autonomy comprises of understanding the patient's preferences such as cultural values or beliefs that shape the patient's healthcare experience.

Ethical concerns in cross-cultural care may arise when individual autonomy is not valued with equal respect as relational forms of autonomy. When a patient is obligated to make an autonomous decision when they would prefer to incorporate their social support system, then this could lead to disrespecting the patient's values. <sup>130</sup> In a study presented in Tom Beauchamp and James Childress' *Principles of Biomedical Ethics*, UCLA researchers found that attitudes

towards an autonomous choice of disclosure of information and decision-making differed based on age, ethnicity, or cultural background of a patient. Korean and Mexican Americans were between less likely, around 47% and 65% respectively, to believe the patient should be told of a diagnosis like cancer, while European and African Americans were significantly more likely, around 87% and 88% respectively. Further, Korean and Mexican Americans believed to include their family as vital decision makers particularly in the use of life support. Upholding just individual autonomy in cross-cultural care may require the involvement of relational support such as family members or next of kin. UCLA researchers concluded revising the ideal of patient autonomy because it is not universally applicable and should rather honorably incorporate social web of relations, such as family members. As a result, morally upholding individual autonomy in cross-cultural care may require the relational involvement of the patient's family as a form of supporting patient preferences and rights.

In clinical care, a patient's cultural background may shape their preferences and ultimately impact the way in which they interact with the healthcare provider and make decisions in healthcare. In African cultures, particularly in the concept of Ubuntu, individual human moral development is that which is pointed towards others. Although individuals are viewed as having their own human rights and dignity, the well-being of each individual is ultimately dependent on the well-being of the collective community. <sup>133</sup> As a result, for a patient whose life experience is shaped by the Ubuntu ethos, individual autonomy in healthcare may be valued less than communal autonomy. For instance, from the Ubuntu perspective, an individual's growth and well-being can only be nurtured within the broader social, or community setting; therefore, an individual human being's healthcare decision is still person-centered but also values community engagement and the impact on the community. <sup>134</sup> Communal engagement may lead to ethical

challenges in values because individual autonomy is centered around community consultation in healthcare decision-making.

Ethically upholding individual autonomy for patients from community-based cultural contexts may present challenges in values between the patient and the provider that could lead to poor healthcare delivery. Relational autonomy may coincide with values found in Western medicine, where the patient is valued as an autonomous agent in the intentionality, understanding, and noncontrolled nature of the choices they make. The values that underscore individual autonomy can be prone to coercion and deception and, as a result, must be ethically supported in relational forms of healthcare. Therefore, it is vital to uphold autonomy in cross-cultural clinical care with the intention that a patient's decision is ultimately autonomous. However, the patient and their dignity as an individual agent is always in relation to other human beings. Furthermore, from this perspective, upholding patient autonomy requires an enhanced understanding that sustains the cultural orientation of the patient with the values underscored in autonomy.

Decision-making is a critical factor in the medical context because it impacts the direction of the patient's health based on current and future treatment decisions. In the United States culture, because the individual is viewed as the main agent, concepts of autonomy and independence are highly honored in decision-making. In this vein, individuals are required to undertake their own health care decisions given they are in a mentally competent condition. Legally, it is the ethical duty of clinicians to allow patients to undertake or reject a healthcare treatment option based on their own preferences and choices. It is important to note here, and as discussed in the previous section of this chapter, that each patient's preferences in decision-making will be different as a result of individualized choices. Ultimately, individualized

patient choices reflect socio-cultural beliefs and values that guide how a patient wishes to receive and decide their healthcare choices.

When patients prefer to include their family members in decision-making, ethical limitations may clash with upholding individual human dignity in the form of autonomy in decision-making. Ethically, concerns in the form of coercion and deception may lead to challenges in upholding a patient's right to choose. In Caring for Patients from Different Cultures, Geri-Ann Galanti points out that some

cultures are agriculturally based, since subsistence farming requires the coordinated efforts of a large family...Even when they are no longer farming, they may continue traditional patterns of decision-making. What affects one person, affects every member of the family. Unfortunately, health care providers are often ill prepared to deal with patients who refuse to make decisions until they consult with family members.<sup>140</sup>

Galanti's perspective leads us to conclude that in certain cultures the norm for decision-making could include consulting family members; however, this methodology coincides with upholding the patient's dignity since other parties may coerce or influence the patient in some way that may digress from their own choice. As a result, the healthcare provider needs to understand the intentions, goals, and values of these multiple parties who are involved in upholding patient dignity morally.

In a case study presented in *Caring for Patients from Different Cultures*, Mrs. De Luiz, a Latina woman in her late fifties, is living with uncontrolled diabetes and is currently under diabetes medication. Her physician, Dr. Moustafa, would like to prescribe her insulin as an alternative treatment method. Mrs. De Luiz lived with her husband, her son, and his family and told Dr. Moustafa that she would have to consult with her family before taking the insulin treatment option. Dr. Moustafa was confused and slightly bothered because this was her own

personal health.<sup>141</sup> As a result, Dr. Moustafa was having a hard time understanding the idea that family involvement in healthcare is a norm in some cultures. To ethically uphold Mrs. De Luiz's shared decision-making preference, healthcare providers, as caregivers, should have a caring duty to ethically understand the patient's specific care needs.<sup>142</sup> In this specific case, Mrs. De Luiz's unique care needs included her preference to incorporate her family prior to deciding. An ethics of care approach can help recognize the importance of qualities such as understanding, sympathy, and historical development in catering to cultural preferences and values in clinical care. An ethics of care approach would also overcome ethical concerns of coercion or manipulation in shared decision-making by ethically caring for the need to uphold the patient's individual human dignity. Ultimately, cultural differences between healthcare providers and their patients may lead to a lack of understanding of shared goals and be a source of ethical conflict.<sup>143</sup>

### II. Care Ethics Approach

In particular, sensitivity to cultural diversity also sheds light on the contribution of the ethics of care. In *Moral Boundaries: A Political Argument for an Ethic of Care*, Joan C. Tronto articulates that care-based ethics has evolved throughout the 20<sup>th</sup> century which has tried to create change in public spheres, such as politics. <sup>144</sup> In healthcare, care is essential to the whole and individual actions of providing care. However, care "can easily be forgotten given that in public and academic discourse, issues such as costs, prevention, the just distribution of scarce resources and the patient's personal responsibility often figure more prominently than care." <sup>145</sup> In other words, if healthcare is viewed as a system or industry merely as a means to an end, then care can mistakenly get lost in the overall equation of the quality of patient care delivered.

The ethics of care bioethical theory acknowledges that human physical and social needs should be met within a caring, supportive context as a form of honoring genuine lived human

experiences. <sup>146</sup> The ethics of care theory can strengthen the idea of individuality. Human relationships on any scale, political, economic, medical, or familial, would not exist without a level of care and concern that is catered to each human being's need. <sup>147</sup> In order to sustain societal aspects of human life, R.E. Groenhout in, *Connected Lives: Human Nature and an Ethics of Care*, states that ethics of care theory "provides a guideline for evaluating human lives and social structures, but it also incorporates a certain respect for indeterminacy and fluidity." <sup>148</sup> This theory protects the notion that care is a relational and moral component of individual selfworth. Individual self-worth is enhanced when engaging in societal relations, and levels of care from relation to relation may vary based on personal needs. As a result, the ethics of care theory provides the flexibility necessary to deepen the understanding and practice of the relational, moral dimension of human life for adequate cross-cultural clinical care.

From a care ethics perspective, autonomy in clinical care should incorporate the relational interdependence of human life. Furthermore, the insufficiency in the direction of clarified care practices from a moral point of view can be mended with the normative element of human dignity derived from personalism. In "A Personalist Approach to Care Ethics," Vanlaere and Gastmans articulate that personalism allows for care to be valued as a feature that develops the human person, or their dignity, in relation to others. <sup>149</sup> The personalist concept of human dignity can provide a normative ethical element for upholding relationality in autonomy, interdependence, and shared decision-making in the ethics of care approach to cross-cultural clinical care. According to Groenhout, interdependence is the feature of human nature that embodies human life as interactions within a web of social relations. <sup>150</sup> In clinical care, interdependence is essential to appreciating autonomy and shared decision-making as a method of catering to culturally unique patient preferences and care values. Groenhout states that "[t]he

combined features of recognition of the social construction of meaning and of embodiment provide for an ethical theory that accepts cultural differences as ethically important without making such difference into an absolute."<sup>151</sup> The notion of interdependence gives caring professions a deepened understanding of the significance of the relationality of human life. A care ethics foundation that aims to support individual human dignity can foster interdependence in informed consent and relational autonomy in decision-making to meet patients' needs and preferences in cross-cultural care.

The ethical limitations of informed consent can be encountered when a competent adult patient does not or chooses not to participate independently in the informed consent process as an autonomous being. Ethical limitations primarily arise because the informed consent process could lead to nondisclosure or possibly hinder trust building when a patient's cultural norms, values, and preferences involve their social relations. Since individual human autonomy may be less valued and interpersonal consultation may be a norm in certain cultures, honoring informed consent in the cross-cultural context may present challenges. Ethical limitations may be presented in upholding trust and disclosure of information when a patient participates relationally with their social web due to cultural beliefs, norms, or values, which ultimately coincide with the notion of individual autonomy in dominant bioethical theories in Western medicine.

In the United States, the doctrine of informed consent is embedded in the healthcare system to protect individual human rights. Douglas et al., in *Global Applications of Culturally Competent Health Care: Guidelines for Practice*, purport that protecting human rights in healthcare is crucial to ensuring that human dignity is upheld for everybody, as mentioned in Article 25 of the Universal Declaration of Human Rights (UDHR). Human rights are crucial to sustaining human dignity in healthcare, especially considering social determinants of health.

Furthermore, not only is Article 25 of the UDHR pertinent, as Douglas et al. point out, but Article 10 of the UNESCO Universal Declaration of Bioethics and Human Rights (UDBHR) focuses on "equality, justice and equity." At the end of Article 10, the UDBHR states it "offers a new starting point, and a new opportunity to reflect about ethical principles;" in healthcare, justice, equality, and equity can be further advanced and protected by considering SDOH. Addressing the ethical limitations of autonomy in informed consent in Western medicine from a care ethics lens rooted in the normative element of human dignity borrowed from personalism should help ethically justify the relational components to enhance cross-cultural care.

An ethics of care approach deepens the understanding of the informed consent process and justifies the moral boundaries that are necessary for the interdependence of human relations in cross-cultural care. Boundaries connected to morality in human relationships can be viewed in two ways: according to Dorothy Emmet, morality is the notion that explains how one directs their relations with other people and their awareness, consideration, and preparation of likes and dislikes or agreements and disagreements; John Dewey defines morality as one's interest in learning and understanding all contacts and areas of life from the framework of moral interest. According to both Emmet and Dewey morality is one's way of understanding and relating to the world as a human being. In addition to being rational and logical, the healthcare application of moral boundaries should consider morality as a concept that is historically developing and nurturing. From a care ethics perspective, morality in the informed consent process can be understood as an all-inclusive concept in clinical care interactions that considers ethically disclosing information and building trust.

In many cultural contexts, moral boundaries (in the form of individual human rights) are connected to the rights of the collective communal. The ethics of care approach highlights the

notion that human beings are individually autonomous, however, requires cooperation and attentiveness at a relational, interdependent level.<sup>157</sup> Groenhout argues that it is not all emotions that are necessary for human life but particularly the emotions related to "tending to the physical needs of other, dependent humans, [which] holds a central place" in care ethics.<sup>158</sup> In healthcare, care is the value that morally supports the needs of patients to be interdependent on others, such as the doctor, family members, and the healthcare providing team. When the patient is interdependent on caregivers, the caretakers ultimately uphold that patient's dignity.

In the previously presented case of the "Korean daughter [who] did not pass on [healthcare] information to her father about his stroke or [medical] instructions given by the nurse," the ethical concern of withholding information and nondisclosure would hinder the informed consent process from being carried out individually with the patient. From the ethics of care approach to interdependence, social relations incorporate the value of care and respect. In this specific case, the family did not want to disclose information to the father because they did not want to harm him; by not harming the patient, it can be implicitly understood that they care for the patient enough to ensure he does not lose hope in his medical treatment journey. However, due to withholding, this patient's trust in the provider in the future may be broken. Although withholding information and nondisclosure is ethically inappropriate, certain crosscultural instances may justify withholding certain information from patients. Lo articulates that in many cultures, it may be considered normal not to tell patients they have a severe illness or cancer. In "Culture and Moral Distress: What's the Matter and Why it Matters" Nancy Berlinger points out that

a family member may tell a team member that withholding a diagnosis or prognosis from a sick person is appropriate within their culture. This type of culturally framed behavior may reflect agreements within a culture that family members should shield a

sick person from the burden of this information and bear it themselves or a more specific belief that hearing bad news or talking about the possibility of death is inauspicious and will lead to a worse outcome.<sup>162</sup>

As a result, cultural context is essential in understanding if justifying withholding information is ethically appropriate. In some cultures, withholding information is not viewed as deception or misrepresentation but rather as a method of caring for and protecting the patient from suffering or giving them positivity for the future. <sup>163</sup> A care ethics perspective can bring to the surface the intentions of withholding or nondisclosure of information directly if that is what the patient wishes. As a result, an ethics of care approach can aid in justifying withholding based on a normative component considering an appropriate method to upholding the patient's human dignity within the context of the patient's cultural norms and preferences.

The ethics of care approach grounded in personalism's normative component of individual human dignity can ethically justify relational autonomy to enhance cross-cultural care. The personalist bioethical theory contributes to a budding theory where morality is applied to individual human behavior, understanding that humans develop and progress "in-relation-with" life experiences. <sup>164</sup> In certain cultures, looking toward a more morally developed person in the community can be a source of support and inspiration, particularly during healthcare decision-making. From the Ubuntu ethics outlook, individual human rights are considered to fundamentally contribute to Africans' cultural, religious, and collective awareness. <sup>165</sup> From the Ubuntu worldview, humans are moral beings contributing to developing the collective consciousness of the whole community. Furthermore, "moral maturity" is a normative concept that encompasses the notion that the decisions undertaken by one impact the whole. <sup>166</sup> The anthropological integrity seen in the Ubuntu ethical norms supports the adoption of the personalist normative component of human dignity in a care ethics approach from the

perspective that individual human potential is developed through engaging in collective, social human relations rooted in care.

The care ethics approach supports the Ubuntu ethics notion of cultivating the individual through engaging in the collective whole. In a care ethics approach, relational autonomy can be ethically justified as supporting collective human flourishing through caring for the individual. <sup>167</sup> In cross-cultural care, healthcare providers can be recognized as historical beings working towards understanding each patient's cultural needs and preferences as a method of upholding individual human dignity. According to personalism, the human person cannot be a classified being that exists within a clear context but rather an integral being that should be incorporated within all social, cultural, and environmental dimensions. <sup>168</sup> As a result, a care ethics approach enhances provider understanding of the need to foster an integrated view between themselves and the patient as a way of developing morally through therapeutic interaction.

Ultimately, personalism provides a normative component of relationally upholding human dignity in care ethics to alleviate sources of ethical concern such as coercion or deception. Ethical concerns can be mended by morally caring for and guiding the individual autonomous human view in the informed consent and decision-making processes. In cross-cultural relational forms of care, upholding individual human dignity might require going one step further and understanding another human being who is related and socially connected to that patient.

Through relational communication, healthcare providers can "encounter sufficient consensus to confirm that our notion meaning, or fulfilment is not simply a projection of our individual desires but is actually shared with other individuals and even groups." <sup>169</sup> In the case of Ubuntu ethics, relational autonomy is embedded in worldviews especially in communicating, incorporating, or

consulting a more morally developed community figure to sustain or foster individual human flourishing.<sup>170</sup>

Furthermore, respect for individual human dignity in personalism provides a normative supportive element for the coexistence of human beings to support the value of care in relationality found in a care ethics approach. The communication fostered in relational dialogue must align with the patient's values, goals, and preferences in a manner that honors their individual human dignity. Personalism provides a normative component for relational autonomy in care ethics; a human being's individuality can only be considered when the human person is understood as an accumulation of the whole of the material reality of the world, including other relational and societal groups.<sup>171</sup> As a result, upholding dignity provides a normative component to the care ethics approach that supports the understanding that an individual is developed through interactions with others.

The care ethics approach should support individual human dignity in interpersonal decision-making in cross-cultural care. The care ethics theory originates from the relational lens of humans and considers that care is an assumed aspect of human existence. However, it more significantly deems that care is that which intertwines people into a network of interweaving relations that are held with other living beings.<sup>172</sup> Care ethics accepts the notion that human beings are social beings who are a part of a web of relations that reflects cultural diversity. The personalist theory provides a normative component to care ethics from the perspective that from birth to death, humans are historical beings who develop and grow because of their interactions with a network of people.<sup>173</sup> The human life experience, from birth to death, is hallmarked by how each human connects to one another through interactive connections while maintaining individual human dignity within those relations. Care ethics accentuates that within this network

of relationships, interpersonal care-based relations are the strongest and most vital.<sup>174</sup> As a result, the hierarchy of care deepens the understanding of interpersonal decision-making in cross-cultural care as a method of morally sustaining human dignity in connection to the patient's preferences and values with other human beings.

Personalism provides normativity for individual human dignity in the ethics of care as a method of respecting collectiveness in cross-cultural or interpersonal decision-making. From this perspective, care can be acknowledged as respect for the dignity of human beings rather than a form of just upholding one's rational capacity. Further, a diverse workforce fosters interpersonal patient and provider relationships in healthcare are crucial in the quality of medical care a patient receives, especially for multicultural patients.<sup>175</sup> For instance, in some cultural contexts, family involvement and input may be valued as a form of interpersonal decision-making. Therefore, the provider should recognize this as preserving that specific patient's human dignity.<sup>176</sup> In the case of Mrs. De Luiz, involving her family in the decision to undertake insulin was a natural response for her as a method of understanding her care plan and the impact that would make on her familial role.<sup>177</sup> An interpersonal hierarchy of care would deepen the understanding and intentions of Mrs. De Luiz's wishes for familial involvement for the attending healthcare provider. To ethically uphold Mrs. De Luiz's dignity in interpersonal decision-making, the provider would need to understand both Mrs. De Luiz's values and preferences in relation to that of her family. By understanding the family values, the physician could promote those values that enhance Mrs. De Luiz's human dignity and mitigate coercion. As a result, interpersonal decisionmaking methods would help clarify the preferences, wishes, and values of all parties involved to mitigate ethical concerns and build trust and cultural respect in the patient and provider relationship.

## III. The Care Ethics Approach to Enhance Cross-Cultural Care

The ethics of care approach can enhance cross-cultural clinical care by promoting unique patient care values to sustain human dignity. A care ethics approach in healthcare fosters "mutual responsiveness" personally, such as in clinical care, and socially, such as in public health.<sup>178</sup> Held argues that in instances of limited purposes, such as when making independent, autonomous, or rational decisions for achieving individual benefits, laws and policies may help maximize the process.<sup>179</sup> In other words, interconnectedness should help underwrite the construction of the principle of autonomy. Therefore, in healthcare, ethics of care provides a connected approach for applying laws, policies, and principles on a grander level to promote human dignity.<sup>180</sup> Care helps foster a relationally ethical, universal approach to bioethical thinking in cross-cultural clinical care that encompasses a holistic view of human life.

In the care ethics approach, relationality in informed consent, autonomy, and decision-making is needed to deepen understanding of the relational aspect of human life in clinical care. In clinical care, individual autonomy in the informed consent process and decision-making could give an inadequate awareness of the family's role in healthcare decision-making, stray away from patient-centered care, and cause injustice in decision-making. Ethically and legally, clinicians have to allow patients to partake in autonomous individualized choices through the informed consent process regarding their health care. Laura Sedig in "What's the Role of Autonomy in Patient- and Family- Centered Care When Patients and Family Members Don't Agree?" articulates that it is common for patient to prefer consulting family members. As such it is an ethical duty for providers to consider social factors, while ensuring the intent for the patient is aligned with the patient's goals and wishes. As a result, the medical team should honor relational patient autonomy by participating in the process of informed consent but ensuring that

the relational involvement in decision-making is not coerced as a method of ethically upholding individual human dignity.

The care ethics approach may help support culturally unique ethical philosophies and practices in the informed consent process. <sup>184</sup> Supporting the cultural preferences of a patient can serve as a critical component in creating positive or higher patient satisfaction outcomes. <sup>185</sup> Ethical principles in healthcare delivery, such as autonomy in decision making and informed consent, as well as honesty and nondisclosure, may all require a tailored approach to delivering care services in cross-cultural care. As a result, an ethics of care approach should help build strong provider and patient communication, create patient-centered care approaches, and just, shared decision-making methods by fostering a deep understanding of the intentions, goals, and interests that come with the involvement of a patient's social relations.

Integrating a care ethics approach can help ethically justify interconnectedness in the informed consent process. <sup>186</sup> By ethically incorporating a patient's cultural preferences through their social web of relation, the provider can understand the patient as a holistic human being. Working to gain a deep understanding of the patient as a human being can help build strong, trusted patient and healthcare provider relationships. <sup>187</sup> Furthermore, while healthcare ethics are essential to patient-provider relationships, in order to bridge cultural knowledge, strong communication and trust are necessary to respect culturally appropriate methods of healthcare delivery. <sup>188</sup> As a result, an ethics of care approach enhances cross-cultural clinical care by providing theoretical underpinnings to support an empathetic understanding of cultural beliefs and values that shape communication methods in the patient and provider relationship.

In Western bioethics, autonomy is a crucial pillar in how the physician and patient interact.<sup>189</sup> However, in certain cultures, individual autonomy values and beliefs may differ

vastly from Western medicine. For instance, in the Navajo culture, disclosure of an adverse health diagnosis may pose a risk for patient perception due to the cultural belief that language can describe the material world and also has the power to shape reality. Therefore, a patient may process an adverse health prognosis as dangerous. 190 Nondisclosure may cause ethical concerns and difficulty upholding patient autonomy in the patient and provider informed consent process. Furthermore, the provider may be prone to the fear of sharing certain medical diagnoses and/or fearing patient reaction. Beauchamp and Childress' argue that rather than viewing mainstream autonomy as opposed to including the social web of relations, it would be beneficial if it is viewed as an evolving concept that can be contextually enhanced.<sup>191</sup> In the case of a Navajo patient, it may be ethically appropriate to consult an ethicist to help educate on differing cultural values. The provider can understand traditional Navajo communication preferences, such as using positive restorative language and catering to communication accordingly. 192 In addition, the ethicist can use a care ethics approach to understand the patient's values and preferences. If the patient would prefer to include their family, they may be a source of support for suggestions on communicating the adverse prognosis culturally and safely. As a result, a care ethics approach in cross-cultural care requires understanding cultural preferences and norms to deliver culturally unique care.

Furthermore, relationally strong patient and provider communication in cross-cultural care can enhance the patient's freedom while still honoring the patient's dignity as unique. Wear presents the idea that a new philosophy is necessary to ethically respond to valuing freedom in healthcare as individually unique. Wear states "the new ethos of patient autonomy;" to build on this, a "new ethos" should foster the understanding of autonomy and patient freedom as a valuable source of insight into patient choice and preference based on their own human life

experience. <sup>193</sup> To further elaborate, patient choices and preferences are impacted by social determinants of health and/or cultural background which factor into decision-making. By loosening the concept of individual autonomy, a provider can incorporate relational autonomy to uphold culturally appropriate patient care needs, particularly in the informed consent process. Wear suggests that a more positive aspect of freedom within the informed consent process includes the healthcare provider assisting the patient in recognizing and evaluating their own choices within the framework of their unique cultural values, beliefs, background, and life experiences. <sup>194</sup> As a result, a new ethos for patient freedom incorporating relational autonomy in informed consent can help support unique cultural values and preferences in cross-cultural care within Western medicine.

Building a strong patient and provider relationship may allow for the delivery of human patient-centered care. Saha et al. point out that patient-centered medical care provides an illustration of the manner in which healthcare providers should engage and interact with their patients. As previously stated in the chapter, Balint created the concept of patient-centeredness to advocate for patient's truly being seen as people. Saha et al. articulate that patient-centered approaches are important because they may allow healthcare providers to view each patient as a unique person with their own socio-cultural circumstances which helps to promote trust and confidence in the healthcare provider. When the healthcare provider gains a deep understanding of the patient as a unique person, their cultural values and preferences can help guide how they wish to receive their healthcare.

An ethics of care approach in cross-cultural clinical care should help guide the physician towards fostering an understanding of the patient as a person who is shaped by cultural beliefs and values to serve their unique care needs. By understanding the patient's narrative and life, the

physician may build a robust human-centered relationship and cater to the patient in enhancing disease management, releasing diagnostic information, and exploring the illness or disease experience from the patient's perspective. Ultimately, patient-centered care creates a sense of openness for the patient where they feel that their unique care needs are being listened and attended to. An ethics of care approach may help link unique cultural and ethical philosophies to the dominant ethical healthcare delivery principles, such as autonomy. For instance, in the case of Ubuntu ethics, patient-centered care may involve communicating with the patient's family or becoming comfortable with the patient by consulting community figures as a form of relationally respecting that patient's dignity. Ethically upholding a patient's cultural norms should help foster mutual patient-centered care built on empathy and understanding in clinical care between patients and providers.

A care ethics approach may help enhance clinical care by ethically upholding individual human dignity in shared decision-making in cross-cultural care. Shared decision-making may help patients make sound medical decisions with the interpersonal integration of their family members as a method of the provider honoring the complexity of human existence. Shared decision-making is oriented to both the patient and family and is gaining recognition as another ideal decision-making method. Shared decision-making reflects how the patient would like to involve their family within their healthcare context. A care ethics approach can aid in incorporating shared decision-making into clinical care to foster individual human dignity by understanding interpersonal communication methods that lead to decisions.

In the case of Mrs. De Luiz, from a care ethics perspective, just shared decision-making included incorporating her family into her medical care decisions to uphold her dignity and preferences based on how she experiences her daily life. Mrs. De Luiz was one of the primary

caretakers of her son's family and her husband, and as a result, the family's needs needed to align with her health care needs.<sup>201</sup> However, this approach may be prone to coercion during the verbal autonomous informed consent process. For example, coercion might include the family persuading the patient to undertake a decision that is not aligned with the patient's goals or wishes. A care ethics approach ensures that Mrs. De Luiz's family can make decisions with her safeguarding the intentions of all parties uphold her human dignity. In this case, Mr. De Luiz's intentions were pure as he was just making sure she would still be able to care for their family and, if she did undertake insulin, understand how that would impact her health, particularly in terms of diet choices and food to cook.<sup>202</sup> Furthermore, since Mrs. De Luiz is not mentally incapacitated, she does have decision-making capacity. As a result, an ethicist or healthcare provider may intervene and consider the ethics of care approach to understanding conflicting viewpoints between the family and the provider regarding the patient's best interests to ensure sustained dignity.

In conclusion, an ethics of care approach aids in enhancing cross-cultural care by ethically upholding human dignity and incorporating relational aspects of human life in clinical care. The ethics of care bioethical theory recognizes that care is an essential component of the life experience of being human. The dominant bioethical theories of principlism and personalism highlight the importance of autonomy in healthcare to support individual human dignity. Ethical challenges may arise when the significance of autonomy in dominant bioethical theories that guide Western medicine does not match the significance of autonomy for a patient due to relational aspects of their cultural preferences. Care ethics critics find that care ethics lacks a normative component that gives care direction in human life. As a result, a care ethics approach

with the normative component borrowed from personalism normatively sustains individual human dignity in relational forms of cross-cultural clinical care.

Relational autonomy may raise ethical concerns around trust, coercion, communication, and disclosure in healthcare through informed consent and decision-making processes. When the social influence of a patient hinders individual autonomy, the care ethics approach may help ethically guide the intentions, goals, and values in relational autonomy. Personalism's human dignity provides a normative element in the care ethics approach to help ethically sustain relational morality. As a result, a care ethics approach can enhance and provide new insight into cross-cultural clinical care by fostering trust, understanding, strong communication, unique human-centered care approaches, and moral interpersonal decision-making. Attentiveness to cultural diversity supports a focus on human dignity in different clinical contexts, such as when adopting an ethics of care approach. This sensitivity to cultural diversity as a pivotal social determinant of health is also crucial for supporting human rights in healthcare in a pluralistic society.

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## **Chapter 5: Supporting Human Rights in Healthcare in A Pluralistic Society**

The dissertation examines how cultural diversity as a social determinant of health, being aligned with human life, human dignity, human rights and human equity provides an ethical contribution. My explanation of the ethical contribution of cultural diversity as a social determinant of health refers to a quadrant of topics that expands the approach of the UNESCO Declaration of Bioethics and Human Rights. The UNESCO approach addresses cultural diversity in relation to human dignity and human rights. My explanation expands upon the UNESCO approach. I adopt a quadrant of topics that aligns human dignity with human life and human rights with equity. The alignment of these topics in the quadrant (dignity/life and rights/equity) explains the meaning of cultural diversity as a social determinant of health. Chapter five discusses the concept of rights in the quadrant.

# Chapter 5a. The Ethical Contribution of the Social Determinants of Health Toward Advancing a Focus on Multicultural Population Health Needs in Clinical Care

With the increase in health disparities among racially, ethnically, and culturally diverse populations, bioethics in the 21<sup>st</sup> century will need to be cognizant to socio-cultural factors, such as social determinants of health (SDOH). Giving attention to health risks, such as SDOH, can improve health promotion and outcomes faced by some of the most vulnerable populations. Lawrence O. Gostin, in "Health of the People: The Highest Law?" argues that "without minimum levels of health, people cannot engage in social interactions, participate in the political process, exercise rights of citizenship, generate wealth, create art, [or] provide for common security." In summary: the ethical implications of individual health affect a population's engagement and flourishing in American society and should be honored. To build on this, I will

show that the SDOH forms a holistic picture of an individual's health and is a vital constituent in understanding general health advancement for multicultural populations.

According to the U.S. Department of Health and Human Services (HHS), SDOH includes access to education and healthcare, social, community, and environmental contexts, and economic stability, which impact an individual's health and quality of life, in other words human flourishing.<sup>3</sup> Health promotion is often a goal of community or public health initiatives and interventions that intend to foster positive population health outcomes, such as via health education.<sup>4</sup> Although public health goals aim to advance population health needs at large, they lack the appropriate acknowledgment of the risks present in individual health experiences that are often only targetable in clinical care. According to C. Trinh-Shevrin et al., health equity frameworks require SDOH to move beyond just pinpointing health risk information to operationalizable methods that healthcare professionals at large can use to improve health outcomes.<sup>5</sup> A focus on health equity can help put theory of SDOH into practice by examining, taking action, and advocating for the future of clinical care. As a result of this technique, the ethical insight of the SDOH will advance from being discussed in healthcare literature and public health initiatives to being applied practically in clinical care.

The following case represents unrecognized social needs that lead to health risks, presented by D. Lie et al. in "What do health literacy and cultural competence have in common? Calling for a collaborative health professional pedagogy." In the subsequent case, health risks arise due to the healthcare team's lack of knowledge and understanding of the SDOH in clinical care:

Mr. Morales is a 45-year-old car mechanic with type 2 diabetes. He was born in Mexico, did not complete high school and speaks English as a second language. He now requires transition to insulin therapy because of failed lifestyle management and [nonadherence]

to] oral anti-diabetic medication therapy. His attempts at weight loss were challenged by the need to participate in family social gatherings and to show appreciation for his wife and mother's cooking. His primary care physician had sent him to a dietician who provided him with information about an 1800 calorie diet from the American Diabetes Association. He did not understand the written instructions and did not share them with his wife. He also believes that insulin causes blindness and kidney failure and does not intend to use insulin but will instead use Mexican remedies such as prickly pear, offered by his mother.<sup>6</sup>

Mr. Morales has many health risks in the preceding case: unrecognized communication errors, low levels of health literacy, and conflicting cultural background values and beliefs between Mr. Morales and the healthcare providers. The lack of insight into Mr. Morales's SDOH failed his healthcare team to provide the utmost care resulting in poor care outcomes. In chapter 5a, I will show that the SDOH ethically contribute toward advancing a focus on multicultural population health needs by providing new insight for clinical care.

## I. Social Determinants of Health Provide Insight into Sources of Health Risks and Needs

Cultural diversity as a pivotal social determinant of health (SDOH) focuses on human rights in a pluralistic society. Health risks in diverse populations are an ethical concern because they can create distinct disparities or disproportionate care access and quality, which permeates over into one's quality of life.<sup>7</sup> SDOH, or nonmedical factors, in multicultural population health are areas that require attention because they can lead to health risks and disparities that create barriers for an individual to flourish in life. In "Non-clinical influences on clinical decision-making: a major challenge to evidence-based practice," F.M. Hajjaj et al. note that medical health factors are just one of the dimensions of clinical decision-making that impact human well-being and that nonmedical health factors such as personal and economic stability and social factors (age, race, ethnicity, etc.) also provide a deepened dimension into well-being.<sup>8</sup> On the one hand, medical factors include clinical influences related to medical diagnosis and prognosis. On

the other hand, nonmedical factors include nonclinical influences such as socioeconomic status, values and beliefs, and patient education that influence outcomes in healthcare.<sup>9</sup>

While clinical diagnoses impact health status, much of the literature has revealed that social contextual features aside from clinical care have shaped health outcomes and explain disparities across various social and environmental factors. While clinical diagnoses provide a deep understanding of the internal functioning of the human physical system, SDOH offer an understanding of the patient and the specific health risks they may be prone to experiencing. Expanding on public health dynamics is vital; health advocacy, or the SDOH, is just as vital for improving quality of life and standards of care within care contexts in the public health domain, such as by preventing health risks in care delivery for diverse populations. 11 In clinical care, both medical and nonmedical factors provide deep patient insight for advancing a focus on multicultural population health needs. In the case of Mr. Morales, the SDOH would have helped provide a deeper insight into his current social standing, limited health literacy, and reasons for poor lifestyle management. Had the doctors evaluated his SDOH, they would have found out he had different beliefs on diabetic medication, he did not have a very high level of education, and his wife played a crucial role in his dietary habits. Deep patient insight helps clinicians understand socio-cultural background factors and would have helped prevent poor health outcomes in Mr. Morales's clinical care.

Another characteristic of cultural diversity is language barriers and communication gaps. In clinical care in the United States, culturally diverse patients who speak English as a second language, or have limited English speaking proficiency (LEP), or are non-native English speakers are among the most predisposed patients to health risks because they face more difficulties interacting, due to language barriers, with their care provider. R.F. Meuter et al.

purport and show in their study that the growing diversity in the United States, or any country with a majority speaking provider and minority speaking patient, means that communication gaps and mistakes between a healthcare provider and a patient speaking English as a second language will need to be considered. If or when language barriers are overlooked, it can lead to adverse outcomes. Language barriers lead to errors with miscommunication for patients as they attempt to successfully communicate with a doctor who speaks a language other than their own. These errors between the doctor and patients can lead to the latter's misunderstanding of crucial healthcare information, which can be life-threatening. The lack of proper communication even increases risk severity, thereby leading to further adverse effects: "patients may fail to comply with instructions or elect not to have potentially life-saving treatment." Effective linguistic communication, verbal and non-verbal (such as written), in the clinical context, can mend vulnerabilities in understanding healthcare information.

Health risks arising in care due to improper communication or communication errors provide deep insight into the need to improve patient safety and trust between the patient and provider. The literature notes that non-native or limited English-speaking populations experience greater health risks, errors, and patient safety issues, lower healthcare service quality, and ultimately worse health outcomes than dominant English-speaking patients due to communication errors. These health risks can be improved using linguistic resources such as a translator or interpreter to mitigate communication errors. In "Misinterpretation: Language proficiency, recent immigrants, and global health disparities," K. Pottie articulates that effective communication is one of the "prerequisites" for the safe implementation and delivery of healthcare services. Translator services can help bridge communication gaps between the patient and provider. Pottie further reasons that interpretation services can improve patient safety

outcomes and develop a strong, trusted patient-provider relationship when used effectively.<sup>17</sup> Effective communication is imperative to increase the patient's trust in the healthcare system and mitigate health risks such as poor quality of care delivery or outcomes.

In the case of Mr. Morales, limited English proficiency led to ineffective communication with the doctor and dietician, resulting in communication errors that led to misunderstandings of diabetic therapy management information. <sup>18</sup> In most cases, an interpreter or translator is ethically and legally necessary to help patients with language barriers, limited English speaking abilities, etc. to be heard, seen, and valued in English majority speaking healthcare contexts. <sup>19</sup> In this case, the SDOH of Mr. Morales are that he was born in Mexico, and English is his second language. Thus, he did not adequately understand his doctor's and dietician's directions. Had the healthcare team correctly recognized his SDOH, they would have had insight into the communication barriers that led to his current health status. Learning about Mr. Morales's ability to speak and understand English as a second language would have helped mitigate health risks. As examined in this case study, the patient's limited understanding of English led to an improper care experience. Developing a proper understanding of a patient's SDOH advances a focus on the unique nonmedical needs that require attention in clinical care to prevent health risks due to communication errors and health illiteracy.

Another characteristic of cultural diversity is health literacy which is defined varyingly in healthcare literature; the Health Resources and Services Administration (HRSA) defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions." SDOH, such as socioeconomic factors, provide insight into one's quality of life and ability to manage their health. Socioeconomic factors equally serve an important role in human flourishing, even outside

of the United States, such as in countries like Poland that explain: where one can afford to live, the type of education one can access, and sometimes even the type of job one can seek.<sup>21</sup> In multicultural populations, these socioeconomic factors help explain levels of health literacy due to factors such as limited English-speaking abilities and varying levels of baseline education contributing to low levels of health literacy. Low levels of health literacy can significantly prevent a patient's ability to engage with clinicians and manage their care.<sup>22</sup> As a result, multicultural patient populations that lack a baseline education may struggle with low, or nonoptimal, levels of health literacy and have trouble understanding and comprehending medical directions from their clinician, medical terminology, and adhering to medications resulting in more significant health risks.

Health literacy, patient understanding and outcomes have a dependent relationship. Thus, presenting health information in a manner that the patient can understand and comprehend is vital in healthcare. In a study conducted by Kathleen T. Hickey et al. presented in "Low health literacy: Implications for managing cardiac patients in practice," low health literacy among first-generation immigrant Hispanic populations (who reported as having low income) was found to be greater than compared to White populations who had some level of education. This study concluded that there is an important parallel between low, or nonoptimal, levels of health literacy and adverse patient outcomes. Low, or nonoptimal, health literacy levels lead to misunderstanding and miscommunication between the patient and provider in medical care. These misunderstandings caused by low, or nonoptimal, levels of health literacy can lead to significant health risks such as prescription nonadherence, poor comprehension of medical directions or prescription labels, and trouble managing their care conditions; sometimes even creating feelings of vulnerability among non-native English speakers. In other words, low

levels of health literacy can create knowledge and understanding gaps between the patient and provider, leading to health risks due to the inability to properly follow care directions needed for optimal patient healthcare outcomes and survival.

Low health literacy levels provide deep insight into improving care management and preventing adverse health outcomes. Based on findings from Hickey et al.'s study, it is crucial for healthcare professionals to assess comprehension of healthcare information for non-native English speakers, such as Hispanic patients, and culturally diverse individuals by using visual and educational resources, or documents in a patient's native language or that are population specific.<sup>25</sup> Healthcare professionals can implement the preceding practical approaches in their clinical care settings for minority patients to support patient comprehension. Much of the literature, including Purnell and Fenkl's text, discusses how materials written at a lower grade level and visual resources ensure better understanding and improved knowledge on the patient's end.<sup>26</sup> Easier-to-understand materials can assist patient comprehension, improve care adherence rate(s) and promote positive care outcomes. SDOH ethically contribute to personalizing health literacy materials for multicultural patients.

The highest level of education that Mr. Morales completed was high school.<sup>27</sup> He could not effectively understand the doctor or dietician's lifestyle management directions, which could have a strong correlation to his limited education and limited knowledge of English. This factor failed to provide him with the proper knowledge base to help him understand the protocols of his healthcare team. Had the healthcare team considered education as a SDOH, they would have gained insight into his low health literacy levels and could have found the reason(s) why his treatment was not working and subsequently catered to his medical directions in a personalized, comprehensible manner. By integrating adequate linguistic, educational, and instructional

resources to engage with patients despite low levels of health literacy, providers can effectively cater care to promote positive patient outcomes such as following medication protocols and conducive lifestyle changes.<sup>28</sup> The SDOH ethically contribute to providing insight into non-medical factors, such as the reasoning behind low levels of health literacy. This insight helps advance a focus on the SDOH that can cause health risks in multicultural clinical care.

Another characteristic of cultural diversity as a SDOH is the socio-cultural environment and beliefs regarding healthcare. An individual's culture inspires particular worldviews which then also impact real-lived experiences and even influence the healthcare context.<sup>29</sup> However, negative beliefs and misinformation (and/or lack of knowledge) create health risks such as uncontrolled chronic conditions due to the improper use of therapies. An individual's values and beliefs are shaped by social and cultural background factors and lead to differences in concepts and approaches to well-being which impact behaviors in healthcare management.<sup>30</sup> Ethical concerns arise when a patient's beliefs and reasoning falsely influence their views on certain medications or other medical advice the healthcare provider gives. According to Rebolledo and Arellano in "Cultural Differences and Considerations When Initiating Insulin," false perceptions, views, and/or beliefs, about insulin or diabetes, impact the patient's decision-making and ability to manage diabetes via medically prescribed methods.<sup>31</sup> False beliefs due to personal experiences, inaccurate information, or health misinformation, from family and/or socio-cultural worldviews may contribute to health disparities and even long-term complications. As a result, although negative, or false, perceptions can make it difficult for clinicians to converse about diabetes or chronic conditions among patients; SDOH provide insight to clinicians to help understand their patients' culture and any false understandings or misinformation. Ultimately, SDOH provides deepened insight into areas of potential health risk.

A patient's socio-cultural environment and beliefs provide deep insight into the need to cater to patient-centered care management to prevent failed lifestyle management. Providers can use socio-cultural patient insight to educate patients about their condition and treatment options to prevent misunderstandings and support proper care management.<sup>32</sup> The education clinicians provide to the patient can reduce any patient misinformation that may arise from family or friends. In Caring for Patients from Different Cultures, Geri-Ann Gelanti articulates that it may be appropriate in various cultures to include family members in their healthcare journey and decision-making approaches.<sup>33</sup> One approach is encouraging relational members, with consent, to partake in the patient's healthcare journey and educate them as well on a treatment process. Rebolledo and Arellano point out that discussions with patients, and family via consent, about the function of insulin early on in diagnosis and education about how the disease is scientifically shown to advance, during office visits can help prevent future barriers in condition management, such as prescribing insulin. They also encourage relational entities, such as family members, to ask questions to prevent nonadherence to medicines in the future. Furthermore, incorporating family members may even be key, such as educating family members on how to use insulin pens and devices may support the patient.<sup>34</sup> As a result, to provide catered patient care plans, providers need insight into the SDOH that can support them to be cognizant of a patient's cultural values and reasoning behind a patient's autonomous decisions. Insight into cultural values can help providers enhance the notion of individual autonomy in care management plans with relational components by ethically incorporating collective family components to promote positive health management.

In the case of Mr. Morales, social and cultural background factors such as valuing his family's cooking, participating in social gatherings, and his family-provided false belief that

prickly pears are a substitute for insulin led to his failed attempts to manage his weight and lack of adherence to insulin.<sup>35</sup> Mr. Morales's socio-cultural background involved his strong preference to participate in family social gatherings by appreciating his family's cooking. In this case, the SDOH would have provided the healthcare team insight into the social and cultural background factors of Mr. Morales that led to poor progression in his diabetes care management. The physician would have uncovered that Mr. Morales was not taking his insulin based on his false worldview and misinformation about insulin causing blindness. The physician could have educated Mr. Morales about diabetic therapy and insulin usage. Furthermore, although the physician did carry out his ethical duty to recommend a dietician for lifestyle management, the physician did not work to build an understanding with Mr. Morales to recognize the social, familial, or cultural factors that led to his health behaviors. By taking the time to learn about Mr. Morales's SDOH and possibly involving his family members in the care appointments, the healthcare team would have realized Mr. Morales valued his family. Sharing instructions with his wife could have helped his diabetic dietary needs as she did most of the cooking. The SDOH ethically contribute to a deepened understanding of the socio-cultural aspects of patient lifestyles and behaviors that can uncover false beliefs and the importance of social or familial aspects to providing culturally competent care. These characteristics of cultural diversity as a SDOH highlight the need for cultural competence in delivering healthcare across multicultural populations.

## II. Culturally Competent Clinical Care Delivery for Multicultural Populations

SDOH are non-health or social factors that impact an individual's well-being.<sup>36</sup> A.

Andermann states a vital point that location is a significant component that can help explain the disadvantages that specific patient populations will face "and will not always be obvious just

from looking at the patient," their medical chart, or their medical condition.<sup>37</sup> For instance, in the United States healthcare context, clinicians are very likely to encounter culturally diverse patient populations, such as Latinos or persons of Cuban, Mexican, or South American descent, because they are a budding culturally diverse group. Furthermore, there are clear health challenges that this specific population experiences because of SDOH, such as education levels, immigration status, cultural beliefs, lifestyle factors, etc.<sup>38</sup> As a result, clinicians need to undertake culturally competent care delivery methods to assess, communicate, and learn about the social disadvantages of multicultural patient populations. Clinicians can use these learned insights to reduce health risks and meet the multicultural health needs of diverse groups of patients in clinical care.

Research has shown that culturally competent forms of care delivery benefit providers by enabling them to be cognizant of knowledge that explains socio-cultural determinants to enhance patient satisfaction with care delivery and experiences.<sup>39</sup> Clinicians can use a patient assessment to gain insight into the social determinants that pose health risks for their patients. In the case of Mr. Morales, the clinicians would benefit from a deepened insight into the social determinants that create risks for Mr. Morales's poor medication adherence and lifestyle management. By learning more about Mr. Morales's cultural factors and foreign upbringing, the clinicians would have a deepened understanding and be able to cater care approaches to support his limited English-speaking abilities, social lifestyle preferences, and limited health literacy.

Patient assessments can support healthcare providers empower and expand their knowledge about a patient's social health risk factors and facilitate communication to provide optimal care. In a pluralistic society, awareness and assessment of cultural diversity as an SDOH provides insight into unique human experiences and impacts a patient's current medical wellness

or illness. 40 In "Back to the Basics: Social Determinants of Health," L. Spruce points out that many clinicians are not trained or do not feel they are in a position or role to address SDOH issues. 41 Patient assessments can help clinicians understand the effects of the severity level of SDOH, such as language barriers, low literacy levels, and false beliefs that negatively affect patient health and, subsequently, patient outcomes. Spruce elaborates, stating that clinicians, such as perioperative nurses, acknowledge the impacts SDOH have on their patients but do not always know how to assess patients' SDOH. For instance, Spruce states, "patients with chronic conditions that require treatment who are of lower socioeconomic status may lack support systems and adequate access to health care." This knowledge gained from patient assessments is essential because it helps clinicians to create patient-centered care and support culturally competent care delivery methods. Without understanding a patient's socio-cultural features, a clinician may be missing a crucial understanding of why a healthcare plan is not benefiting the patient.

Clinicians can obtain SDOH information by incorporating nonmedical questions as a critical part of patient medical assessments. In *Global Applications for Culturally Competent Healthcare: Guidelines for Practice*, Douglas et al. purport that experienced healthcare provider's will know when a deepened understanding is needed in care delivery despite the issue of time constraints; patient assessments of social and cultural factors are necessary to reveal clinicians the critical information that influences a patient's life. <sup>43</sup> Clinicians can adapt care plans and interventions acceptable for both patient and provider using patient assessments. In *Guide to culturally competent health care*, Larry Purnell presents a framework for healthcare professionals to use in the clinical context that provides insight into real-life patient situations

during clinical care experiences.<sup>44</sup> Some of Purnell's questions that specifically provide insight into multicultural patient populations include:

- 1. How many years have you lived in the United States? ...
- 2. Have you lived in other places in the United States/world? ...
- 3. What is your educational level (formal/informal/self-taught)? ...
- 4. What is your primary language? ...
- 5. What other languages do you speak? ...
- 6. Which foods do you eat to maintain your health? ...
- 7. Which foods do you eat every day? ...
- 8. Who does the cooking in your household?<sup>45</sup>

Supporting Purnell's framework, understanding real-life human experiences can help clinicians feel empowered to support patients in holistic ways to reduce risks by understanding patient needs in healthcare. Purnell articulates some factors for which the "Purnell Model" is formulated based on, one of them being that healthcare providers who have the skills and methods to support patients in a culturally competent manner can make a positive impact in the health of the person, family, or community they care for.<sup>46</sup> Clinicians can benefit by learning about nonmedical factors as a part of patients' medical assessment to understand and/or respect the socio-cultural aspects that influence a patient's real-life human experiences.

In the case of Mr. Morales, a patient assessment would have provided his primary doctor and dietician information to understand his lifestyle choices. The healthcare-providing team could have asked questions using the Purnell Cultural assessment tool to understand his sociocultural factors such as spoken dialect, role in the family, and primary foods eaten to maintain health.<sup>47</sup> The healthcare team would have found that English is his second language, he had low levels of health literacy, and his cultural views affected his insulin nonadherence.<sup>48</sup> Patient assessments provide a deepened understanding of a patient's social and cultural aspects to aid clinicians in delivering culturally catered care. The nonmedical patient assessment would have also provided the dietician insight into Mr. Morales's wife's role in his diet planning. The

healthcare team would have found that she did most of the cooking, and by including her in his lifestyle management plans (with consent), she could have played a vital role in him adopting a healthier diet.

Clinicians can use the deepened understanding of the SDOH obtained from patient assessments to deliver patient-centered care. One of the dimensions of patient-centered care requires the clinician to recognize the patient as an individual who is a human being, not just associate them with their diagnosed illness or medical condition. Incorporating SDOH is one method clinicians can use to understand a patient's uniqueness. Delivering patient-centered care is vital to improving the quality of healthcare delivery by creating inclusivity in approaches to patient care. Delivering patient-centered clinical care for multicultural populations requires recognizing their unique care needs, such as socio-cultural aspects that lead to health risks (such as communication errors, medication nonadherence, and trouble understanding health information). Patient-centered care encourages collaboration and establishing shared aims on the provider's side. It includes the provider incorporating patient specific aspects central to designing and managing a customized and comprehensive care plan for the patient. As a result, patient-centered care delivery can aid clinicians in delivering high-quality, culturally competent care centered around the patient's socio-cultural specific needs.

Patient-centered care is also one of the Institute of Medicine's (IOM) pillars of quality-of-care delivery. The Agency for Healthcare Research and Quality point to IOM's description of patient-centeredness as "[p]roviding care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions." To support IOM's definition of patient-centeredness, SDOH assist providers in delivering holistic care by identifying patient preferences, needs, wishes, goals, and values. The importance of a

patient-centered approach is in the personalized care strategies that include robust communication based on understanding the patient's real-lived experiences, goals, and uniqueness. SDOH should aid in providing deep insight into these patient background factors. For instance, a patient's native language choice may inform a provider of certain linguistic services that can help the patient better understand their health information or risks. Kressin et al. articulate that the relationship between SDOH and cardiovascular health support patient-centered care to improve health management such as adherence to prescriptions, recommendations, or therapies. In other words, care that revolves around the person can promote positive care outcomes. Therefore, providers can use the insight provided by SDOH to adopt patient-centered approaches to improve the quality of clinical care delivery as well as patient contentment.

In the case of Mr. Morales, SDOH would have aided in delivering patient-centered care. The healthcare providing team could have improved their quality-of-care delivery by engaging Mr. Morales as an active member in his healthcare journey. Caregivers can use SDOH information to understand patients' socio-cultural elements and engage with them by using the appropriate resources for their unique needs.<sup>55</sup> In Mr. Morales's case, the healthcare providing team should have used his SDOH to understand his cultural and lifestyle behaviors and choices in care delivery to engage in approaches that encourage the patient to undertake a healthy routine that fits with their lifestyle and/or life situation.

The insight from the SDOH can help clinicians recognize the socio-cultural care needs of multicultural populations and create a balanced therapeutic relationship. The unique real-lived insight that a patient's SDOH provide can further promote trust in healthcare. Dreachslin et al. articulate that a "successful health care encounter" is rooted in a balanced partnership between the patient and provider. According to Dreachslin et al., a successful healthcare encounter is

when the provider collaborates with the patient to support and "meet the patient where he or she is" to work with the patient's socio-cultural context or world. J.E.Rohrer et al.'s article also supports patient centered care insofar as physicians can cater care approaches that empower patients to create strong lifestyle management behaviors. As a result, the ethical contribution of the SDOH provide promising insight to help providers foster culturally competent methods of care to support patients in their real-lived experience, and create successful, positive healthcare encounters.

Positive patient-clinician relationships incorporate listening to patient values, making them feel seen as people, and creating strong communication, which is essential for both.<sup>58</sup> Strong communication between the patient and provider can lead to effective service delivery for diverse community members, such as implementing preventive care measures and treatment plans in a timely manner at the phase of diagnosis.<sup>59</sup> In "Defining and implementing patientcentered care: An umbrella review," S. Grover et al. articulate that patient-centered care includes implementing strategies and recognizing barriers at provider, patient, and systems levels; to build on this it should also encourage organizational culture transformations to promote positive longterm care outcomes from the broader healthcare organization. 60 Cultural transformations in the healthcare organization can support the organization or public health system to empower workforce and support patients' needs making it easier for patients to undertake healthier behaviors. Empowering individuals by recognizing social determinants acknowledges inequitable social conditions and the provider can help the patient develop more control over their life and the "power being 'given'" to their patient within their healthcare journey. 61 On the other hand, empowering individuals on the organization, public health, or health system's side requires leadership to recognize the challenges underserved populations encounter and to

allocate resources equitably to support the workforce to mitigate patient vulnerabilities. The literature widely discusses balancing of power in the clinical relationship between the patient and provider; the previously mentioned idea can also be seen as a balancing of power in the broader healthcare facets between the relationship of the public and the leadership. In sum, culturally competent care delivery results in patients being able to self-manage their conditions both in the short term (immediately after a doctor's visit) and long-term regardless of social barriers and conditions.

Addressing and using SDOH can be an effective method of improving the health of multicultural populations. The US Department of HHS recognizes social and community context as a SDOH and defines them as "[p]eople's relationships and interactions with family, friends, co-workers, and community members." Since humans are social beings, social interactions have a significant impact on health and well-being, when the health of one individual is positively impacted, the health of their community also has the potential to be positively impacted. When patients feel seen, heard, and valued according to their life situation, they will feel more empowered to use those self-directed behaviors and values within their own communities and pass those along to generations to come. Individual behavior changes, such as medication adherence, healthier lifestyle choices, and self-management that fit with the patient's social and cultural contexts, are more likely to be passed down collectively for generations to come because of the practical application of the SDOH. Addressing SDOH can amplify the voices of underserved, vulnerable, diverse, and minority individuals, families, and populations to promote positive care outcomes.

In the case of Mr. Morales, culturally competent modes of healthcare delivery would have promoted positive care outcomes. Mr. Morales's cultural views involved his alternate

beliefs about insulin leading to blindness.<sup>64</sup> In cases where there are language barriers between the patient and the healthcare providing team, the cultural and linguistic tools support communication and systematic cultural competence such as efficient care delivery.<sup>65</sup> Using these tools, the healthcare providing team could have empowered Mr. Morales to participate in his care journey as an active member. Mr. Morales's changed behavior could have a chain reaction on his wife, mother, and broader social circle to be empowered in their own health, such as keeping up with doctors' visits and relaying medically verified diet plans. By promoting positive behavior changes, the Latino community at large can participate in healthier lifestyle choices and long-term benefits in managing chronic conditions. Therefore, improved communication, building trust, balanced healthcare encounters, and patient-centered care delivery would have resulted in behavior changes leading to positive outcomes such as medication adherence and lifestyle changes in Mr. Morales's case.

#### III. Social Determinants of Health Can Expand the Role of Clinical Ethics

Attentiveness to cultural diversity as a pivotal SDOH is indispensable for effective clinical ethics. The growing multicultural populations (refugees, immigrants, etc.) in the United States will face different social strains (or social determinants) that can impact their health. 66 In "Key Findings About US Immigrants," Gustavo Lopez et al. echo this notion in a bar graph titled, "[t]he number of immigrants reached a historic record high of 43.5 million in 2015, is currently at 44.5 million, and is estimated to grow to 78 million by 2065." A normative ethical perspective supports Lopez's statistics regarding the growing demographic mix and social needs. For instance, refugees living in non-native countries escaping famine, natural disasters, and war will all face unique social determinants or challenges that can impact navigating care needs. 68 Conditions such as social and housing instability can correlate to, or worsen, certain health

conditions for refugees displaced in a new country. Although refugees receive aid for approximately 90 days for resettlement, once this time frame ends, they often struggle resourcewise to try to adjust fully.<sup>69</sup> This kind of gap in resources mimics the resource gap in benefits, what is referred to as the "donut hole" in Medicare pharmacy benefits in the United States, witnessed especially by patients and providers financially in retail pharmacies. Therefore, SDOH provides insight into clinical care to educate and raise awareness of the needs of the growing migrant population.

The growing demographic mix in the United States requires approaches that support multicultural population health enhancement. To SDOH illuminate social considerations and contribute to advancing multicultural population health because they represent varying unrecognized social factors that impact healthcare outcomes. Attentiveness in clinical ethics to care in a multicultural society requires respecting the unique care needs of individuals and developing the most appropriate method of care delivery suited for them. The future of advancing multicultural population health in clinical care requires using SDOH to aid in providing culturally appropriate or competent forms of care. For instance, refugees represent vulnerable multicultural populations because they encounter specific health challenges that can trace back to "trauma of war... natural disasters...and refugee camp living" conditions that need to be considered by healthcare professionals within the clinical care context. DOH illuminate the need to advocate for recognizing different nonmedical health needs. Two methods to raise awareness for SDOH in clinical care are education and case trainings to help healthcare professionals at large become cognizant of the impact of unique social needs.

Health advocates can strive to improve population health outcomes. Advocates have the ability to serve vulnerable, underserved populations by creating, or negotiating, change, raising

awareness for needs, and serving as a voice for equitable health and access to healthcare services.<sup>73</sup> Clinical ethicists are in a great position to serve as health advocates because they are trained to educate and advise clinicians and family members in the clinical care setting. While clinicians have a key role in treating medical conditions, clinical ethicists have a key role in supporting clinicians in their patient care experiences. Clinical ethicists' expertise lies in "facilitat[ing] a process of moral learning in which new ethical knowledge is co-created together with [healthcare] professionals."<sup>74</sup> In most cases, ethicists mediate between ethical dilemmas using case consultations, but they are also great resources for health education and training.<sup>75</sup> They can incorporate the insight of the SDOH in their education and advisement to advocate for the needs of the future multicultural population in clinical care. M.C. Fadus et al. point out that cultural competency education and the operationalization of those competencies in clinical or medical training is one step towards improved healthcare outcomes for diverse and vulnerable populations using deepened knowledge. 76 Thus, increasing competency requires advocating or incorporating SDOH in clinical training as ongoing education. In Singer, Pellegrino, and Siegler's, article "Clinical ethics revisited," mentions clinical ethicists identify issues and analyze problems in clinical practice and "revisit" their findings; one way to further build on their revisitation is for clinical ethicists to take their skills and utilize them in teaching or activities to raise awareness of diverse needs in the clinical setting.<sup>77</sup> As a result, the insight that the SDOH provide should serve as a vital resource that clinical ethicists can use to advocate for the needs of the growing minority and underserved populations.

Clinical ethicists can serve as health advocates for the growing cultural demographic in healthcare by educating various hospital departments. In the growing cultural demographic of refugee populations, the clinical setting will need to consider the circumstances refugees have

faced in their medical care. According to the ASBH Core Competencies, one of the competencies that ethicists in the clinical setting are required to have is knowledge of the healthcare institution they serve and the perspectives and beliefs of the local population, including patients and staff.<sup>78</sup> Clinical ethicists can be utilized as a resource to reduce crosscultural barriers in the future of primary care. For instance, clinical ethicists can learn about the cultural groups living within their communities and develop social, cultural, and linguistic aptitude within the healthcare organization. In the clinical setting, the ethicist can provide insight into the SDOH of a patient that would be a source of an ethical dilemma. In "Depression in Latino and Immigrant Refugee Youth: Clinical Opportunities and Considerations," Milangel T. Concepcion Zayas et al. argue that demanding relocation experiences among refugee populations can negatively affect their mental or psychological well-being.<sup>79</sup> Advocating for SDOH among refugee populations is crucial to prevent further challenges such as falling into a silo in a time when support is vital for their flourishing in a new environment. Concepcion Zayas et al. articulate that there is an absence of evidence-based operationalizable interventions for refugees in clinical care. Therefore, recognizing and empathizing with the experiences of refugee populations is a starting point for assessing their unique challenges. 80 Understanding these dilemmas would allow the clinician to develop a more compassionate care approach for the refugee. In turn, the clinician can pass on these learnings to the rest of the healthcare organization, leading to more awareness, or even organizational culture and policy changes, for the unique needs of patients which fall under the "Metropolitan Medical Center Code of Ethics: Organizational Principles" mentioned in Post et al.'s text. 81 Clinical ethicists or ethics committees can serve as advocates within the healthcare organization by developing programs to

promote socio-cultural competence focusing on population needs, such as refugee, displaced, immigrant, etc. populations.

In the case of Mr. Morales, an ethicist could have served as a health advocate for his social needs. By calling in a clinical ethicist to learn more about Mr. Morales's needs, his SDOH could have been advocated and cultural preferences and values assessed. The clinical ethicist could have also educated the team on his background, as that is a key function. 82 In both Mr. Morales's case and focusing on the future of multicultural population health needs, healthcare teams can benefit from ethical advocacy. For refugee populations, clinicians "have a unique opportunity to advocate and provide a space of healing" for children and family members. 83 Clinical ethicists can serve as educators providing ongoing education and case training to raise awareness for the varying SDOH that multicultural patient populations encounter.

Ongoing education in clinical care can equip clinicians with the awareness of vulnerabilities and risks that the changing population within the United States, such as refugee populations, are more prone to experiencing. Exposure to competency courses and modules is a responsibility that higher education programs have included in their curriculum, especially in regard to clinical ethics. However, one of the challenges with cultural competency education is that not all forms of exposure in graduate or higher education may be enough to equip healthcare professionals for the reality of a pluralistic society. Douglas et al. recommend continuing education to help clinicians and staff maintain their cross-cultural skills in contemporary clinical encounters. Sustaining the skills and competencies to carry out culturally catered care, especially with the continuously growing multicultural populations in the United States, should be an ethical responsibility for the future of clinical care.

Ongoing cultural competency education can be a resource that provides immense value to leaders of healthcare institutions as well. Most healthcare organizations must be culturally competent to gain accreditation from the Joint Commission. 86 However, healthcare professionals and leaders come from different educational institutions, resulting in a lack or gap of knowledge in application in and after completion of graduate curricula, leading to gaps in knowledge.<sup>87</sup> As such, ongoing workforce development can be a vital resource for improving population health where the onus is placed on healthcare organizations. The business model level is one place to incorporate ongoing cultural competency education and new resources within healthcare institutions. Resources should also include hiring and "[r]ecognizing that diversity in faculty and students promotes inclusion and culturally competent ... practice."88 As well as, including cultural competency should be incorporated into the business model of organizations to develop their workforce, which "requires a comprehensive and coordinated plan, which includes interventions at different levels of ...program administration and evaluation, the delivery of service, and enabling support for the individual."89 Advancing a focus on SDOH processes at this level includes workforce development that serves and cares for the patient -- for instance, using technologies and methods to empower clinicians to understand patient SDOH easily. 90

Furthermore, to support the challenges with uneven or transient cultural competence skills and knowledge, Dreachslin et al. suggest the most effective way to revamp cultural competency education is to use a trainer who focuses on specific areas of healthcare service delivery and population groups. Ongoing cultural competency education provided by ethicists who can cater to providing SDOH knowledge may be an asset in a growing multicultural society. For example, a concrete example Dreachslin et al. use is fabricating seminars on type 2 diabetes, including information on how Mexican immigrants understand diabetes and the linguistic,

dietary, and relational approaches to manage it effectively may be beneficial for clinical care providers. Furthermore, Kaiser Permanente has developed training and educational materials, such as their physician handbooks on culturally competent care; each focused on a different population group among the patients Kaiser serves such as Asian and Pacific Islander populations, African populations etc. Similarly, ethicists can develop educational resources for their clinical staff to focus on a different population group among the patients their organization may serve, such as immigrants, refugees, etc. Developing and operationalizing comprehensive ongoing education at the organizational level is key to advancing population health and advocating for unique care needs in a pluralistic society.

Ongoing cultural competency education for the healthcare team that provided care to Mr. Morales would have been very beneficial in recognizing the SDOH that led to his gaps in care. His rural upbringing, appreciation of his wife's cooking, and incorrect beliefs about insulin led to challenges in his healthcare outcomes. 94 In this case, an ethicist could have provided cultural competency education after the clinical team learned about Mr. Morales's struggle with lifestyle management. The conflicting cultural and social factors between Mr. Morales and the healthcare providing team could have been easily analyzed by an ethicist. An ethicist has the skills to analyze and assess differing factors between the patient and provider; this helps develop an equipoised understanding needed to improve patient safety. 95 If the healthcare institution had provided ongoing cultural competency training, the healthcare team would have been able to effectively respond to Mr. Morales's SDOH to culturally competently craft an effective diabetic therapy management plan that considered his cultural beliefs and background. In the future, Mr. Morales's case can serve as a training resource to educate clinicians on recognizing the impact of SDOH on clinical care outcomes for multicultural populations.

The SDOH provide new insight into the growing culturally diverse demographic that can be used in cultural competency training to provide continuing education. Clinical ethicists are generally employed to perform case consultations to resolve ethical dilemmas between the values and goals between patients, providers, and their family members. In the *Handbook for Healthcare Ethics Committees*, one of the key functions of ethicists in hospitals is to educate and facilitate learning opportunities using methods, such as lunch and learns, journal clubs, or case trainings. Clinical ethicists can use the insight they have acquired from case consultations to help the organization advance a focus on multicultural population health needs.

In clinical care, ongoing education using case training may be the most appropriate, effective, and valuable tool since ethics case consultations can change with the growing diverse population. Case training should be used to advance the awareness of ethical issues focusing on SDOH. Cases presented at conferences would be a great resource for training and education because, as Post et al. state, they "have already been resolved or at least significant progress has been made, so that there is no current need for ethics intervention." This growth in ethics case consultation must also reflect competence in cultural diversity in clinical ethics. The purpose of the case training should be to educate staff in identifying and analyzing the ethical issues that arise during their current practice, such as barriers related to patient outcomes and SDOH.

In the future, Mr. Morales's case can be used in case trainings to note how his sociocultural factor should have been utilized to enhance the patient-provider relationship and meet multicultural population health needs in clinical care. Clinical ethicists can use this case to share, converse, and educate clinicians on identifying and using SDOH insight when caring for patients.<sup>99</sup> Mr. Morales's case can be used to show clinicians the importance of a patient's SDOH and the health risks they pose if not considered. Case trainings can inform ethics committees of

new policies and guidelines for patient needs that can be implemented into future clinical care practices. <sup>100</sup> Mr. Morales's case is just one of the many cases that the future of clinical care will need to consider advancing a focus on meeting the needs of multicultural populations.

To conclude, the SDOH ethically contribute toward advancing a focus on multicultural population health needs by providing new insight for clinical care. SDOH help recognizes that health is a multidimensional component of medical and nonmedical health factors. When the SDOH are not considered, ethical concerns and health risks for multicultural populations arise. In cross-cultural care, a patient's linguistic, health literacy level, and cultural values often serve as crucial contributors to health needs and pose potential risks in the medical care context if overlooked. As a result, SDOH ethically contribute to advancing a focus on multicultural population health needs by providing holistic insight to reduce risks and promote positive healthcare outcomes.

SDOH related to multicultural populations gives insight into health risks such as communication errors, medication adherence issues, and failed lifestyle management. When a patient's social influence hinders optimal health outcomes, the SDOH provide new ethical insight to guide clinical care delivery. In the case of multicultural population health, SDOH promote individual human dignity by encouraging patient-centered care approaches in clinical care delivery. SDOH ethically contribute to clinical care by providing new insight to meet the needs of multicultural populations such as immigrants and refugees. Using this new insight, health risks for these populations can be reduced, patient-centered care can be delivered, and clinical teams can be continuously supported. When there is a robust focus on cultural diversity, there emerges a re-balance between the traditional bioethical principles of autonomy and justice in healthcare.

## <u>Chapter 5b. An Ethical Re-Balance of the Principle of Autonomy and the Principle of</u> <u>Justice in Healthcare</u>

With the growing cultural diversity in the United States, there is a need to re-balance ethical principles to craft culturally comprehensive approaches for guiding moral conduct in healthcare. The existing methods in "bioethics largely overlook" the realities and contexts found in multicultural societies where 21st-century healthcare ethics issues develop; a specific example is that of the Navajo patient worldview and the worldview of contemporary healthcare provider. 101 According to The SAGE Handbook of Health Care Ethics: Core and Emerging Issues, ethical principles found in a common morality framework serve as action guides, directing the conduct of behavior. 102 In clinical care, the notions of autonomy and justice are two bioethics principles that achieve virtuous, ethical conduct within the interaction between the patient and the provider. The SAGE Handbook highlights mainstream bioethics characteristics while pointing to a significant inadequacy: they were "developed within a particular cultural and social context" and as such the principles are shaped by perspectives grounded within Western traditions, beliefs, and values. 103 As a result of this shortcoming, the principles of autonomy and justice rarely focus on the uniqueness of multicultural patients and the culturally competent ethical framework needed to guide moral conduct in clinical care, leading to ethical concerns. In chapter 5b, I will introduce methods to re-balance the relationship between patients' autonomy rights and clinicians' duties and discuss their effects on promoting justice in healthcare.

The following case represents ethical issues with the current application of autonomy and justice in multicultural clinical care, presented by Geri Ann Galanti in *Caring for Patients from Different Cultures*. In the subsequent case, ethical issues arise due to the lack of ethical rebalance in the current principles of autonomy and justice. The existing principles in this case

inadequately uphold the patient's autonomy rights and do not provide the clinicians an adequate method of delivering justice or ethically guiding moral conduct when carrying out the informed consent process:

Andrew Chan, the son of Wen Chan, a seventy-five-year-old Chinese man, was angry with his father's physician. His father was scheduled for an angiogram at noon. The nurse had explained everything to Andrew the day before, and he intended to come to the hospital that morning, speak to his father's physician, and help his father with the [informed] consent form. When he arrived at his father's room at 9:30 a.m., however, his father handed him the [informed] consent form, which he had already signed. Andrew walked over to the nursing station and furiously demanded to know who had made his father sign a consent form in English when he did not speak the language. After further discussion with Mr. Chan, it was determined that the physician had visited him at 8:00 that morning, and seeing the unsigned consent form on the bedside table, handed it to him to sign. The physician did explain the procedure to him, in English. He had no idea that Mr. Chan did not understand a word, because he was constantly nodding in agreement. Smiling and nodding is a common response in any language, when people do not understand. It is often done in an effort to be polite. Why did Mr. Chan sign a form he could not understand? Out of respect for the authority of the physician. Chinese culture is hierarchical, and physicians are held in high esteem. 104

There are many ethical concerns in the preceding case, such as misunderstanding, mistrust, and unethical obtainment of informed consent due to differences in values and language between Mr. Chan and the healthcare clinicians. As a result, the informed consent process was unethically carried out; the son became the patient information holder instead of the patient, Mr. Chan. The conventional un-balanced principles of autonomy and justice failed to guide moral conduct ethically between the patient and provider when carrying out the informed consent process. In chapter 5b, I will argue that an ethical re-balance of the principle of autonomy and justice offers a map to guide moral conduct in healthcare in a pluralistic society, empowering patient rights and supporting the provider's duty to promote social justice.

## I. Ethical Concerns in Healthcare in a Pluralistic Society

Attentiveness to cultural diversity sheds light on ethical concerns. A focus on cultural diversity can help re-balance the principle of autonomy that upholds human life/dignity and the principle of justice that upholds human rights/equity in healthcare. Ethical concerns arise due to differences in values, goals, and behaviors between the patient's cultural norms and the healthcare provider's professional duties. 105 A patient's cultural morals and values may conflict with mainstream ethical and legal values that healthcare providers uphold when delivering patient care. In healthcare, a patient's autonomy and rights are upheld when the provider contributes to delivering trusted medical care and disclosing information per the patient's right to know, privacy, and confidentiality. 106 While the current application of the principles of autonomy and justice intends to uphold rights for every patient, the principles lack affording clinicians a deepened understanding of the patient's values and preferences when delivering cross-cultural healthcare. Unfortunately, patients' rights in healthcare may be unfairly eroded when providers are ill-equipped with the culturally safe methods needed to carry out informed consent ethically. In the case of Mr. Chan, misunderstandings, miscommunication, and mistrust are dominant ethical concerns between Mr. Chan, his son, and his assigned caregivers. The current application of the principles of autonomy and justice impedes Mr. Chan's autonomy rights in the informed consent process. It fails to offer approaches for the provider to support person-centered care.

Participating in the process of informed consent is a patient's fundamental right and obtaining informed consent from a patient is a doctor's professional duty.<sup>107</sup> Informed consent is a process that includes the providing of information by the provider to the patient for decision-making.<sup>108</sup> Autonomy and justice are two principles that impact the facilitation of the informed

consent process and present ethical challenges when not sufficiently balanced for clinical care in a pluralistic society. In *Shattering Culture: American Medicine Responds to Cultural Diversity,* M.J.D.V. Good et al. echo that clinicians have a legal and ethical obligation to receive adequate consent for service delivery to protect patients. Adequate consent intends to promote patient safety, build trust, and enable autonomous decision-making in healthcare, especially for vulnerable patient populations. However, Good et al. give many examples of how providers who care for vulnerable populations such as minority, or culturally diverse patients, an informed consent document does not adequately fit or capture the complex realities of patients. <sup>109</sup> Thus, the clinical relationship between the provider and patient may be compromised unless a deepened awareness is operationalized.

Currently, these two principles need balancing in context specific ways because they depict that which can be shared amongst all people. However, when applied to specific contexts, they do not effectively consider approaches to unique cultural contexts, thereby constraining provider duties to uphold patient rights in healthcare ethically. An insufficient approach to obtaining informed consent leads to ethical concerns such as misunderstanding and mistrust in a pluralistic society. In "The Struggle for Equality in Healthcare Continues," E.O. Rutledge articulates that practices at the provider and organizational level still lack awareness (including diverse workforce, policies, etc.) to recognize the fullness of cultural diversity that is needed to promote justice among culturally diverse populations. Building on Rutledge's articulation, the current principle of justice fails to support clinicians to obtain consent ethically while accounting for a patient's cultural norms and behaviors. Consequently, un-balanced principles lead to ethical concerns between the patient and provider in the verbal and written informed consent process, leading to a troubled relationship.

In the case of Mr. Chan, the cross-cultural challenges with applying the current principles of autonomy and justice are evident in the procurement of informed consent. The physician carried out his ethical duty to obtain autonomous consent from Mr. Chan for his medical procedure. However, the autonomous consent was inadequately obtained because Mr. Chan did not understand the medical information presented to him. The provider adhered to the informed consent philosophy and code according to American medical norms, which includes the provider's duty to support patient autonomy rights in disclosing diagnosis and prognosis information and decision-making. However, these principles failed to help the provider recognize the fuller aspects of Mr. Chan's cultural norms to adequately uphold his autonomous patient rights and deliver just patient-centered care. Ineffectiveness when carrying out informed consent may fail to uphold patient's rights (such as Mr. Chan's in this case study) and possibly lead to a weakened patient and provider relationship.

In the Western World, such as the United States, healthcare, institutional, and legal frameworks, competent patients have the autonomy to make their own healthcare decisions by using the medical information that the healthcare professional informs them of.<sup>114</sup> In other words, patients have the right and are responsible for participating and making their own decisions in healthcare, considering they are competent and able to do so. In "Challenging the bioethical application of the autonomy principle in multicultural societies," Andrew Fagan expresses that the current normative principle of autonomy does not explicitly re-establish a basis to support the provider and the patient when meeting, as the scholar Engelhardt purports 'moral strangers.' Supporting Fagan's point, the current principle of autonomy limits the ethical foundation to regulate a robust patient-provider relationship. One of the challenges with the individualistic understanding of the principle of autonomy is the informed consent process.

The informed consent process lacks taking into deliberation the relational considerations of vulnerable patients. This gap in informed consent processes can fail to uphold patients' rights equitably. The For competent patients, social or cultural factors require further analysis or present nonideal factors. In multicultural care, limited English proficiency (LEP) levels lead to barriers in patient and provider dialogue. Therefore, lack of understanding and absence of direct information disclosure to patients leads to inadequate autonomous patient participation when carrying out the informed consent process.

In healthcare, individual autonomy presents itself deeply in the informed consent and, subsequently, decision-making processes. 117 According to E. Gordon in "Multiculturalism in medical decision making: the notion of informed waiver," one of the constraints with individual autonomy is that it is aligned with laws within the Western world and poses limitations when extended to patients who hold different cultural values, needs, and preferences for relational forms of autonomy. 118 Consequently, the current application of the principle of autonomy fails to recognize adequate autonomous participation for non-Western patients whose socio-cultural factors are aligned with relational support. Language barriers can lead to weakened communication and a low level of understanding between the patient and the provider, creating ethical constraints when obtaining informed consent. Good et al. articulate that patients agree to sign the consent documents (even when presented in their native language) with a lack of understanding. Patients ultimately put their trust in and agree with the doctor rather than being able to express their views or concerns about their healthcare treatment autonomously. Furthermore, Good et al. give an example that shows how clinicians view that the amount of time it might take to thoroughly explain to patients their rights can instead be spent on the already time-constrained therapeutic context. 119 As a result, the current principle of autonomy

does not adequately outline the support to respond to culturally sensitive forms of communication necessary to inform patients in cross-cultural clinical care ethically.

In Mr. Chan's case, he did not speak English nor understand the physician's dialogue. <sup>120</sup>
Language and communication barriers presented nonideal conditions in the relationship between Mr. Chan and his caregivers. The nurse explained everything [Mr. Chan's medical information] to Andrew, Mr. Chan's son, the previous day. <sup>121</sup> Mr. Chan's patient autonomy rights were inadequately supported due to his inability to converse in English adequately, which led the nurse to communicate with Mr. Chan's son rather than Mr. Chan, the patient himself. Because Mr. Chan did not speak English, he did not even ask for medical procedure information the following day when the physician facilitated the informed consent process. <sup>122</sup> Therefore, a breach in Mr. Chan's autonomous patient's right to know and the healthcare team's failure to recognize Mr. Chan's lack of understanding leave ethical concerns for the providers in this case. An ethical re-balance of the principle of autonomy would be required to equitably facilitate the informed consent process and empower Mr. Chan to participate in consenting autonomously, building trust, and strengthening the patient-provider therapeutic relationship.

Legally and ethically, justice is the principle that entitles respect and rights to everyone, equally and universally.<sup>123</sup> Justice can be viewed as an interdependent duty, a duty placed on one individual that helps to protect another individual's human rights, such as the equal and fair right to participate in society. In healthcare, the provider's duty is toward the health and well-being of the patient via the equitable or just distribution of resources for the patient, especially when there are any conflicts of interest.<sup>124</sup> The provider can adequately uphold their duty when equipped with the proper insight to re-balance the principle of justice and, as a result, provide equitable care services to the patient.

Nancy S. Jecker distinguishes in *Bioethics*: "Justice," that there are two branches to the principle of justice: non-distributive and distributive. Non-distributive facets of justice distribute resources amongst society equally, "giving people their due." Distributive facets of justice determine how services (or scarce resources) should be distributed amongst society specific to everyone's needs. 125 Ethical concerns in multicultural clinical care arise when justice is delivered to the patient in a non-distributive way, failing to consider social circumstances. For instance, non-distributive justice would distribute food sources across society equally, while distributive justice would distribute food sources across society equitably, prioritizing those worse off. Understanding the ethical theoretical underpinnings of justice from multiple perspective such as utilitarian, libertarian, etc. is necessary to prioritize social justice in public health. <sup>126</sup> In a pluralistic society, prioritizing justice in multicultural clinical care, such as in the informed consent process, should require balancing distributive justice approaches. For instance, building trust because of socio-cultural factors could lead to differences in levels of understanding and care needs. Therefore, the resource of time that is needed to educate the patient and their family should be distributed justly.

The physician-patient relationship can become severely weakened if patients do not receive the proper communication regarding their healthcare information. Good et al. state that in the mental health clinical setting, legal documents required by administrators, insurance companies, and EHR documents are supposed to facilitate communication and empower patients but do not always end up fulfilling that because they do not include the true reality of sociocultural contexts. Sometimes, standardizes processes of legal documentation hinder ethical discussion in patients' real-life experiences. Good et al. state that clinicians are worried that "technological mode[s]" and documentation "...delete(s) the complexities of patients' lives, may

be most problematic when caring for minority and poor patients." Good et al. summarize that populations that face complex social circumstances may be categorized negatively, leading to exclusion. Furthermore, when legal documents are filled out just for legal purposes, they may hinder ethical discussions between a doctor and a patient. In addition, many mental health clinicians feel that documentation disengages them from their patients. Good et al. articulate that in psychiatry, continuous recognition of their patients as who they are is vital to understanding contextual features of patient's lives without an expectation of an end-all-be-all answer to who they are. Ethical discussion helps create openness and recognition for the patient rather than containing their life experiences to legal documentation. In cross-cultural care, failure to consider a patient's cultural values and contextual features in their narrative formation can further weaken the patient-provider relationship.

In Mr. Chan's case, the weak patient-provider relationship displays the ethical concerns of the current application of non-distributive justice and improper time or resource distribution in multicultural clinical care. The doctor and the nurse did not take the time to create interpretative dialogue or communication exchange between Mr. Chan. Ethical concerns arose due to the healthcare provider's inability to take the time to foster trust and understanding with Mr. Chan regarding his nonverbal cultural behaviors. In Mr. Chan's culture, physicians are held as higher figures; such trust was autonomically put in the physician consenting to the procedure without proper verbal communication. Misunderstandings due to communication barriers in the informed consent process between Mr. Chan and the physician resulted in a weakened patient-provider relationship. As a result, the provider should ethically be encouraged to take the time to understand the patient's cultural values and norms, building ample trust with their patients.

## II. Re-Balancing Autonomy: Empowering Patient Rights

In the re-balance between the principles of autonomy and justice that arises out of sensitivity to cultural diversity, empowering the human rights of patients is a crucial characteristic of autonomy. The current common morality framework for the principle of autonomy needs an ethical re-balance to help patients and providers meet as "moral strangers," particularly when carrying out informed consent. In a pluralistic society, individuals bring their cultural language, behavior, and value norms into the context of healthcare by varying modes of decision-making, information disclosure, etc. 133 Leigh Turner supports the idea of an ethical rebalance of the principle of autonomy. In their article, "From the Local to the Global: Bioethics and the Concept of Culture," they argue that when understanding of "reasonable' conduct" conflict between the patient and provider, exploring cultural background, models of morality and deliberation, and the like are crucial in the care delivery process. <sup>134</sup> Building on Turner's argument, culture includes a patient's central values, social practices, and methods of interpretation. Respecting a patient's cultural background requires exploration of the patient to support their right to know and understand healthcare information in a way that is conducive for them.

Language resources give patients an equitable method to express to their doctor their preferences in how they wish to receive medical information and a fair chance to participate ethically in the informed consent process. Empowering patients' rights should include methods of language translator-supported autonomy. In "Examining American Bioethics: its problems and prospects" R.C. Fox and J.P. Swazey express concerns with the individualistic notion of autonomy, one of them being that it is insufficiently weighted according to the interpersonal and cultural preferences, values, and ideals of life. Language resources support autonomy and are one method to balance Fox et al.'s concern about the lack of interpersonal weight in

individualistic autonomy. Translator, or interpreter, supported autonomy can aid in creating interpretative dialogue to overcome the challenges with the current principle of autonomy and in helping patients express themselves to their clinician. In Mr. Chan's case, his healthcare team overlooked his cultural values, such as nodding to show respect and understanding Mr. Chan's understanding of the procedure, causing the team to not expand in further dialogue. In Asian culture(s), people are taught to value harmony and accommodation. This means that instead of disagreeing or causing dishonor with doctors, who are seen as authority figures, they agree out of respect. Galanti states "[i]t is important not to take smiles and nods of agreement for understanding when dealing with Asian patients... Patients should always be asked to demonstrate their understanding." Empowering Mr. Chan's patient autonomy rights requires recognizing his cultural values and beliefs to carry out the informed consent process ethically.

The principle of autonomy grants an individual the right to autonomy in choosing and/or deciding. In cross-cultural healthcare, patients may need interpersonal support to uphold their right to know, self-determine, and even participate in the informed consent or decision-making process with adequate understanding. Language barriers present patient safety and quality issues in healthcare delivery; interpreters (oral communication) or translators (written communication) should be used to communicate ethically and safely with patients. In one-native English speakers, engaging in interpersonal dialogue via a linguistic resource(s) can support the intent of autonomy. Dive and Newson, in "Reconceptualizing Autonomy for Bioethics," point out that autonomy intends to help enable the patient, or research subject, to express choices or consent underscoring "intentionality, understanding, and noncontrol" as conveyed by Beauchamp and Childress. Gaurab Basu et al., in "Clinicians' Obligations to Use Qualified Medical Interpreters When Caring for Patients with Limited English Proficiency," articulate that access to

language services is vital for successfully navigating the healthcare journey and expressing choices and decisions in healthcare for patients with LEP.<sup>142</sup> Supporting patients' right to know and mitigating nondisclosure of information due to communication barriers may be resolved when the intent to empower the patient is supported using a linguistic resource(s), such as an interpreter or translator.

In cross-cultural care, ethically re-balancing autonomy with relational forms can help support patient communication and mitigate concerns such as miscommunication and misunderstandings due to language barriers. In many cultures, relational and social members may be culturally normative sources of support. In Asian cultures, the family is involved in healthcare contexts because the decision impacts not only the individual but also the family. In some cultures, disclosing information directly to the family is preferred and valued. Hurthermore, in certain cultures, family or relational members may be an option to translate or interpret information only if there is no other option and if information being given is not confidential. Hurthermore to a third-party interpreter. Including relational forms of the translation may still be ethically appropriate as long as the patient is free to decide for themselves. Supporting individual autonomy by providing patients with communication tools should empower them to participate ethically with the provider in the informed consent and decision-making processes.

Communication barriers highlight the importance of relational dimensions of life as a method of expressing individual preferences. Although the information presented may be sufficient for ethically and legally displaying the medical diagnosis and treatment options per the institution's policies, it is not sufficient for providers when trying to understand the preferences

and values of culturally diverse patients or their life context. Ae-balancing autonomy would involve the provider having the tools to present medical information adequately. Furthermore, patients could use these same tools to communicate with their doctors to make informed decisions. Good et al. show what positive patient experiences look like from the patient's perspective, such as fostering communication that is effective which incorporates giving advice, resources, and information that is useful to that patient. To build on Good et al.'s notion of a positive patient experience, linguistic resource-supported autonomous communication aids in facilitating informed consent that abides by institutional values of empowering patients in conjunction with their unique needs. Linguistic resource-aided autonomy promotes empowers patients to consent (or reject consent) ethically and facilitates strong communication between the patient and provider using a family member or translator.

In the case of Mr. Chan, an interpreter or translator was not employed; instead, Mr. Chan's son was used as the language mediator between Mr. Chan and his healthcare team. 148

Having either Mr. Chan's son or a linguistic resource(s) present would have resulted in Mr. Chan adequately understanding the medical procedure and enabled Mr. Chan to give proper informed consent. Employing linguistic resources that support autonomy would be a beneficial tool to enable patients' rights with high-quality care delivery. 149 To ensure Mr. Chan can make his own decision, it would be ethically appropriate to involve a qualified medical interpreter to either receive permission to incorporate Mr. Chan's son as his healthcare translator or incorporate the interpreter to assist Mr. Chan directly. Tools such as certified interpretation services or a translator help ethically support a patient's limited familiarity with English's verbal and written methods. 150 Furthermore, relational forms of autonomy, such as Mr. Chan's son, would have helped mitigate the ethical errors due to patient miscommunication and misunderstanding in this

specific case. Employing linguistic services to support Mr. Chan would have helped him ethically be involved in his care plan in a personalized manner and empowered his autonomy and rights as a patient.

An ethical re-balance of autonomy in cross-cultural care between a non-native English-speaking patient and the provider requires relational factors to enable both parties to meet as moral strangers and foster a strong, trusted clinical relationship. Dive and Newson use Dworkin's notion of "critical reflection" in autonomous decision-making. Dive and Newson further build on Dworkin's idea, pointing out that factors such as family members, healthcare providing team(s), and other priority members of social dimensions of human life are involved in healthcare. For instance, relational dimensions, such as family members or translators, may even help a patient voice and express their social dimensions or values to the provider.

Integrating relational autonomy may give a holistic picture of an individual's socio-cultural context in informed consent and decision-making processes. Trusted relationships are built when the doctor can consider a patient's possible preferences of family involvement or translators to help express their needs.

Another method that clinicians can use to mitigate interaction obstacles, subsequently fostering trust, is proposed by Edwina Brown et al. in "Supportive Care: Communication Strategies to Improve Cultural Competence in Shared Decision Making." Brown et al. propose a two-step reflective strategy for provider utility to understand patients' views on illness and support their preferred approaches to decision-making. The first step is where providers, or clinicians, self-reflect to become aware of their inner values and beliefs. Brown et al. state, "[w]hen clinicians become aware of their own beliefs and values, they may become more receptive to those of the patients." The second step is where providers, and even healthcare

professionals at large, use interpretative dialogue when communicating with a patient to understand how the patient wishes to be involved in their healthcare journey, rather than just going through administrative steps. The second step engages communication methods that are genuinely aimed at understanding the patient's preferences as a person better. Engaging in dialogue to become aware of underlying patient beliefs or values ethically guides patient autonomy and decision-making on the healthcare system, or even the provider's end. Tailored communication methods can provide patients with equitable ways to participate autonomously in the informed consent process. As a result, ethically facilitating communication to understand individual cultural care values, preferences, and beliefs can lead to trusted relations in crosscultural clinical care.

Building trust between the patient and provider should also include empowering patients' autonomy to express themselves. One of the reasons for self-governance in patient and provider relationships is that it gives patients the autonomy and opportunity for their choices and concerns to be expressed or voiced.<sup>156</sup> In cross-cultural care, however, the current, universally applicable principle recognizes that the concept of autonomy should be context specific. However, it overlooks providing practical methods to empower the patient's autonomy and expression while respecting cultural values. In Eastern cultures, physicians are honored and respected as experts.<sup>157</sup> These hierarchal social values in some cultures can result in paternalism between the patient and provider, particularly when carrying out the informed consent process. Enabling the patient to express themselves helps them feel seen and heard. One way to uphold autonomy in cross-cultural instances is to support unique patient cultural modes of communication. In *Textbook for Transcultural Health Care*, Larry Purnell states that "gaining trust by listening attentively" is one communication strategy.<sup>158</sup> Supporting Purnell's articulation, a trusted patient

and provider relationship empower the patient and their family's cultural values and preferences to be seen, heard, and understood when seeking informed consent.

Building trust between Mr. Chan and the healthcare team would have required an ethical re-balance of the principle of autonomy. In the case of Mr. Chan, he blindly put his trust in the physician and approved the informed consent form.<sup>159</sup> This is because Eastern cultures view physicians as experts or authority figures in medical care; therefore, patients may feel obligated to comply to their recommendations.<sup>160</sup> A translator, language mediator, or family interpreter is required to aid Mr. Chan in effectively communicating his cultural preferences and values, even with his limited English-speaking abilities, and establish trust with the healthcare team. Ethical deliberation, such as relational autonomy, is a highly valued aspect in Eastern Asian, such as Japanese and Chinese, cultures because it recognizes how a patient's health journey may impact those around them.<sup>161</sup> Incorporating relational forms with clear intentions and linguistic resources to facilitate communication can help the physician understand the cultural values of Mr. Chan and craft a treatment plan that is catered to his needs. Fostering a strong relationship in Mr. Chan's case requires trust and equipping the healthcare team with the cultural knowledge required to empower the patient's autonomy when making an informed decision.

Decision-making in healthcare is one, if not the most important aspects that guide the direction of the patient's clinical care. Informed consent is an event that requires an interpretative process in the United States medical context that should build trust between the patient and the provider and helps patients gain information to make informed decisions. <sup>162</sup> Informed decision-making occurs when the patient understands their medical information and the provider informs the patient of their medical information sufficiently. Adequately informing a patient helps build a strong patient-provider relationship rooted in trust and aids the provider in crafting adequate

ways to support patient autonomy in a manner conducive for the patient. <sup>163</sup> Effective communication and culturally catered resources should ethically support patients to make informed decisions in multicultural clinical care autonomously. The physician's duty in decision-making is to provide patients with the resources to help them understand and comprehend, empowering them to make informed decisions. The goal of informed decision-making for providers is to give the patient the information that supports them to "consent" (to choose) or reject the most appropriate decision(s) for themselves. <sup>164</sup> In the North American context, the patient has a right to know their medical information. As such, treatment decisions in clinical care are solely made by the patient using the medical information presented to them by the healthcare provider.

Furthermore, from a care ethics lens, authors in the literature emphasize the importance of relational autonomy; this understanding can even be extended to informed consent. Gómez-Vírseda, Maeseneer, and Gastmans, in "Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities," propose expanding the notion of autonomy to include relational and socio-cultural components of human life. One crucial component they mention in their article is the closeness of healthcare professionals, such as nurses, with their patients, as an honorary position to support the patient and their families in the healthcare context when it comes to evaluating, informing, and conveying information. For patients in a diverse society, this could mean educating and informing patients in an equitable way that empowers them to make autonomous decisions. In *Global Applications for Cultural Competency*, Douglas et al. discuss involvements at varying levels ranging from individual, organizational, and community. These are crucial for healthcare providers to undertake when caring for Arab American immigrants in the United States. However, these elements can also be applied to and

engaged with other cross-cultural situations. These varying interventions, as presented by Douglas et al., include displaying care plans and developing resources that cater to varying and diverse culture, language, and learning/knowledge levels as well as forming community and broader collaboration relationships within the multicultural population organizations serve. Supporting Douglas et al.'s articulation, providing patients with resources to gain adequate understanding can help them make informed decisions. Ethically re-balancing autonomy in multicultural care enables patients to communicate effectively and understand their medical information to make an empowered, educated, and informed decision.

In the case of Mr. Chan, the nurse failed to uphold her ethical duty of informing Mr. Chan about his medical information. Due to Mr. Chan's limited English proficiency (LEP), she communicated and disclosed his medical information directly to his son. In this case, effective communication of private healthcare information exchange between the patient and provider did not occur because Mr. Chan's son facilitated the communication with the nurse without involving Mr. Chan. Neither the nurse nor the physician communicated with Mr. Chan to understand his cultural values and needs. Ethically obtaining informed consent requires the physician and patient to build a partnership where both adequately educate and empower each other; this should take into perspective relational dimensions such as family and social contexts. In Mr. Chan's autonomy would have been upheld by employing a translator or interpreter before his son's arrival because the doctor could have fostered strong communication with Mr. Chan first. As a result, this would have enabled Mr. Chan to build a partnership with the provider in a trusted manner that supports the ethical re-balance of the principle of autonomy. Just as empowering patient rights is a crucial characteristic of autonomy that arises out of

sensitivity to cultural diversity, similarly, the provider's duty to protect rights is a crucial characteristic of promoting social justice.

## III. Re-Balancing Justice: The Duty to Protect Rights and Promote Social Justice

Sensitivity to cultural diversity includes a duty by providers to protect the human rights of patients. In "Equity and population health: toward a broader bioethics agenda," Norman Daniels articulates, "if society is responsible for causing the initial inequality through unfair policies, it may have special obligations to give more weight to equity than maximization and to consider the speed at which it rectifies the effects of past injustice."<sup>170</sup> Daniels suggests advancing bioethical frameworks to aid in achieving harmony or insight in decision-making to ensure justice or mitigate injustices during the development of these policies.<sup>171</sup> In the informed consent process, the duty of delivering justice through fair and equal treatment can translate into the provider's responsibility to protect and promote patient welfare interests. <sup>172</sup> However, in a pluralistic society, informed consent, autonomy, justice, etc., need to be flexible enough to support the patient and provider. For instance, Asian cultures may prioritize learnings from their cultural values and norms over healthcare recommendations provided in the clinical context; Galanti gives the example of cultural profiles affecting patient care one example is that of "Asian" patients. Galanti mentions these patients may not know Western medications intake methods because of the prioritization of using herbal medications just made with water and ingested directly.<sup>173</sup> Likewise, failure to justly inform and ensure genuine consent is received in informed consent could result in negligence and even injustice on the provider's end. <sup>174</sup> Ethically re-balancing justice in multicultural clinical care should enhance the provider's duty to protect patient rights and promote social justice, meeting patients' unique needs.

Ethically re-balancing the principle of justice requires offering support to providers in upholding their duty to support equity in care delivery. Equitable care includes meeting the unique care needs of culturally diverse individuals in a manner that feels safe to them and will ensure social justice in healthcare. One method of fostering equity is delivering culturally safe care to strengthen clinical care for multicultural patients. A concrete operational method would be to collaborate with and understand the patient. This, however, requires increasing the time spent with the patient. In Mr. Chan's case, ethically re-balancing justice would have enabled equitable care delivery rooted in cultural safety and, as a result, mitigated the ethical concerns on the healthcare providing team that led to mistrust and miscommunication. An ethical re-balance of the principle of justice should involve strategies that encourage the provider to explore the patient's cultural background by performing a cross-cultural interview and taking the time to foster cultural safety.

In healthcare in a pluralistic society, cross-cultural interviews can ethically re-balance the principle of justice by assisting the provider's duty to promote social justice in care delivery. However, providers need practical methodologies to foster social justice in clinical care settings. E. Clingerman's article discusses how a social justice framework coupled with concepts underscored in cultural competency can support patients and providers when engaging in and delivering multicultural care. Ultimately, Clingerman highlights methods such as education, practice, and research that can enable providers to build a robust therapeutic relationship by understanding who the patient is as a person as key to supporting social justice. <sup>176</sup> One concrete way to build on Clingerman's discussion is by providing operationalizable strategies for providers to gain information about a patient's cultural background that can aid them in delivering equitable care according to the patient's social needs. Providers can conduct cross-

cultural interviews with their patients to understand their patients' cultural backgrounds and assess their needs.<sup>177</sup> Some questions that can be asked to foster empathy, assess patient comprehension, and understand patient preferences, beliefs, and values include:

- 1. As your clinician, what would be helpful for me to know about you, [your values], and your life?...
- 2. To ensure that I did a good job in giving you information, can you tell me what you will take away from this visit?...
- 3. How would you like decisions to be made about your health care?...
- 4. What kinds of support would be helpful to you and your family?...
- 5. As we talk about how best to care for you, what you are hoping for?...
- 6. What concerns do you have about this plan?<sup>178</sup>

For instance, Good et al. describe that getting to know a patient makes the patient-provider relationship stronger because the clinician can connect to the patient's social needs on a human-to-human level. <sup>179</sup> The tool of cross-cultural interviews in healthcare is essential because it provides a clinician with a method of delivering patient-centered care.

Cross-cultural interviews can support the provider's responsibility to protect patient rights by ethically meeting as moral strangers and promoting equity in clinical care. From Douglas et al. perspective, "social justice places the responsibility on society... to safeguard the health and well-being of the vulnerable while ensuring the protection of human rights." According to Douglas et al., equity and respect can be promoted via appreciation and compassion, which considers the need to advocate for the improvement of patient lives at community and organizational levels. As a result, cross-cultural interviews will ethically transform the current principle of justice, where patient dignity and rights are culturally considered.

In the case of Mr. Chan, the current principle of justice did not provide the healthcare team with the necessary insight, or resources, such as time, to uphold their duty in care delivery, particularly when carrying out the informed consent process for the angiogram. A cross-cultural interview (using supported linguistic autonomy) prior to the informed consent process would have provided the doctor or nurse insight to assess Mr. Chan's cultural preferences and values fully. Had the physician conducted a cross-cultural interview to converse and seek verbal consent for the procedure from Mr. Chan, he would have learned that Mr. Chan did not speak English and was just nodding out of the cultural norm for physician respect. As a result, the physician could promote social justice and trust in clinical care delivery by performing a cross-cultural interview to gain insight into Mr. Chan's cultural norms to ethically receive and give informed consent in a manner that felt safe for him.

An ethical re-balance of the principle of justice requires taking the time to foster cultural safety. Cultural safety can encourage equity and safeguard patient rights in care delivery. Curtis et al. articulate that cultural safety involves ongoing deliberation on behalf of the provider to ensure they are not being influenced by bias or assumptions of the patient's cultural background or other social determinants. The notion of cultural safety supports an ethical re-balance of the principle of justice because it is a method of delivering care that is considered safe for and by the patient. As mentioned in previous chapters, the notion of cultural safety, as a component of cultural diversity, was created by Dr. Irahapeti Ramsden and Māori nurses with the intent to deliver utmost care deemed safe by the person that was receiving the care. Cultural safety created changes in the way that culture understood to support the relationships in healthcare as a way for the provider to uphold their duty in supporting patient rights. Providers can foster cultural safety by assessing patients' perspectives on the medical information or care delivered to them.

Cultural safety supports the respectful partnership that should be formed in the informed consent process. Cultural safety helps the provider meet the patient where they are; this includes safely supporting patient rights and values despite the providers having their own cultural, or medical culture, context. 185 In healthcare practices, the resource of time is often a constraint. However, taking time to assess a patient's socio-cultural determinants of health is indispensable in a pluralistic society. From an ethical perspective, culturally safe partnerships in healthcare support re-balancing the principle of justice because the doctor is serving themselves through serving others. According to Doutrich et al., "cultural safety is informed philosophically...with an emphasis on social justice." <sup>186</sup> In clinical care, doctors can foster cultural safety by taking the time to learn who they are as a person first and a patient with a clinical condition second. Doutrich et al. state, "learn[ing] to walk alongside, refers to looking at a way forward together (quote from another participant and title of this article), standing beside or walking with the patient, family, colleague, or student, rather than 'standing over.'"187 Cultural safety is a highly effective method healthcare professionals can utilize to deliver justice in a pluralistic society. By "learn[ing] to walk alongside," healthcare professionals at large can consider approaches to deliver equitable care for the future while still upholding their duty when serving humanity. 188 Re-balancing justice ethically reinforces a doctor's duty to support person-centered care by considering the patient's perspective when fostering cultural safety.

In the case of Mr. Chan, the healthcare providing team did not participate in the informed consent process or medical information exchange process in a culturally safe way for him. In a culturally safe practice, the physician, or nurse, should take the time to understand the patient's comfort level in the healthcare context or any differing perspectives to "change the way healthcare is delivered." <sup>189</sup> In this case, that may have been accomplished by using a translator

or family member. Had the nurse or the physician taken the time to foster cultural safety (using an interpreter), they could have understood his thoughts and feelings towards the procedure and informed consent process. Luckily, there were no medical malpractices in Mr. Chan's angiogram, but this is not always the case. <sup>190</sup> For this reason, an ethical re-balance of the principle of justice is needed to support the physician, prevent unethical practices, and/or take the time to understand their patient's needs.

The informed consent process can encourage social responsibility for healthcare professionals. Chervenak and L. B. McCullough, the viewpoint of Gregory and Percival, who are physician-ethicists, on the therapeutic relationship is summarized. One of the three points of utmost importance to support sustainable practices for the future is the "preservation of medicine as a social institution or public trust that exists primarily for the benefit of present and future patients and the public health."191 Empowering patients as empowered decision-makers in the informed consent process requires consideration of social determinants of health (SDOH). N. N. Sawicki, in "Informed Consent as Societal Stewardship," points to the idea that decisions in healthcare often are made with consideration of social aspects; a concrete example they mention is that of family resources. 192 In a pluralistic society, unique socio-cultural factors require additional assessment for the clinician to deliver care to their patient safely. Meeting these patient needs can enable the provider to support their duty to deliver just and equitable care while protecting patient rights in informed consent, ultimately promoting social responsibility and social justice. In other words, an expanded process in informed consent is required to aid the provider in delivering care equitably, considering social factors such as culture, while still upholding their ethical duty to respect patient autonomy.

The informed consent process can be used as a process that helps the provider promote social justice by respecting their patient's decision per social and cultural determinants of health. R. Rhodes builds on John Rawls's justice theory; from this perspective, justice requires meeting the needs of society and ensuring that society can utilize and express freedoms effectively. <sup>193</sup> In many non-western cultures, family involvement is respected in decision-making. However, one of the challenges that come with shared decision-making is the possibility for the patient to be easily coerced to decide unaligned with their preferences and be influenced by communal interests. <sup>194</sup> A way for clinicians to prevent ethical dilemmas of coercion while still ensuring effective use of patient liberties is to build communication skills in the provider to ensure a pluralistic perspective in carrying out informed consent. Ethically re-balancing the principle of justice supports the provider by allocating additional time to plan other methods for the patient according to their cultural values, lifestyle, and preferences to ensure that culturally safe care is delivered.

In the case of Mr. Chan, ethically re-balancing the principle of justice would have enabled the healthcare providing team to serve their social responsibility ethically. The provider carrying out his duties per the current principle of justice led to a lack of understanding, reduced time taken to assess Mr. Chan's preferences, and a lack of trust in the patient-provider relationship. Social responsibility could ensure the patient would be free from paternalism from the provider and coercion from family members. Ethically re-balancing the principle of justice helps providers uphold their duty to support patient rights and deliver equitable care in a pluralistic society.

In conclusion, an ethical re-balance of the principle of autonomy and justice will aid in strengthening the relationship between patients' autonomy rights and clinicians' responsibilities

in promoting justice in a pluralistic society. This re-balance of the principle of autonomy and justice ensures equitable care delivery in cross-cultural healthcare. The case analysis of Mr. Chan highlights the importance and application of one of the ways of an ethical re-balance of the principle of autonomy and justice can mitigate ethical concerns in informed consent in care delivery. The principle of autonomy re-balanced provides the patient the resources to express, understand, and build a trusted relationship with their healthcare provider, empowering patient rights in the informed consent process. The principle of justice re-balanced provides the clinician the resources they will need to use to protect patient rights and promote social justice in clinical care processes and beyond.

In the current and near future, an ethical re-balance of the principle of autonomy and justice for cross-cultural healthcare delivery will be vital. Ethically re-balanced principles help build patient-provider relationships when meeting as moral strangers in the clinical care context. Ultimately, a robust patient-provider encounter will lead to the delivery of better-quality care. With higher quality care, creating patient uniqueness, and educating healthcare providers, ethically re-balanced principles of autonomy and justice will be a positive resource in supporting patient rights, promoting social justice, and fostering equity. In sum, sensitivity to cultural diversity as a pivotal SDOH is crucial for supporting human rights in healthcare in a pluralistic society. This sensitivity to cultural diversity also is crucial for cultivating equity in global health.

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## **Chapter 6: Cultivating Equity in Global Health**

The dissertation examines how cultural diversity as a social determinant of health, being aligned with human life, human dignity, human rights and human equity provides an ethical contribution. My explanation of the ethical contribution of cultural diversity as a social determinant of health refers to a quadrant of topics that expands the approach of the UNESCO Declaration of Bioethics and Human Rights. The UNESCO approach addresses cultural diversity in relation to human dignity and human rights. My explanation expands upon the UNESCO approach. I adopt a quadrant of topics that aligns human dignity with human life and human rights with equity. The alignment of these topics in the quadrant (dignity/life and rights/equity) explains the meaning of cultural diversity as a social determinant of health. Chapter six discusses the concept of equity in the quadrant.

## Chapter 6a. A Bioethical Perspective to Achieving Justice in Public Health Responses

Awareness of cultural diversity is indispensable for promoting health equity to achieve justice in public health responses. The literature recognizes the need for contemporary healthcare professionals to be cognizant of social factors and their impact on people navigating health and, subsequently, issues in global health. According to the policy brief, "Global equity for global health," from G-20 Insights, dated September 2021, conclusions include "[i]n a globalized era, health equity both within and between countries is a foundational pillar of global prosperity. Understanding health inequities is therefore key to preparing for future pandemics." In other words, preparing for health crises and disaster situations in a pluralistic, diverse nation, or even world, is crucial for human flourishing. The "Introduction" in *Cultural Competency for Emergency and Crisis Management Concepts, Theories and Case Studies*, articulates that culturally competent strategies for disaster planning are needed even for leaders who uphold

ethical standards around the globe because they impact social vulnerabilities.<sup>3</sup> Globally, health inequities can worsen during crises for any population but can quickly worsen for vulnerable populations. For instance, the Mayan populations near the Yucatan Peninsula can face distrust and financial struggles when navigating the healthcare arena due to many underlying factors; one of the factors that can further create distrust is that these populations hold to traditional cultural worldviews which may collide with globalized values. As such, cognizance of differing cultural values in the face of globalization is essential to support vulnerable populations.<sup>4</sup> To serve and support cultural diversity in nearly every part of the world, social vulnerabilities and health inequities need attention, especially in disasters and crises. If unaddressed, health inequities can create suffering, an ethical concern. Promoting justice in global health requires mitigating suffering and harm and enhancing one's capacity to function and, therefore, should inspire equity and improve one's quality of life.<sup>5</sup>

From a bioethical perspective, promoting justice requires preventing suffering equitably in public health responses, such as in policies and protocols. Article 14 in the UNESCO Declaration of Bioethics and Human Rights (UDBHR) refers to the social responsibility governing bodies have for health. Specifically, Article 14 states that "global health conditions at the beginning of the new century are marked by growing inequities related mostly to poverty and lack of access to health care services." These inequities can result from differing environmental, physical, and social environments and lead to suffering during global health crises. According to the World Health Organization (WHO), considerations of justice are central to ethical issues that permeate health around the globe. For instance, healthiness may be seen as a necessity for human flourishing since it is crucial for living. However, the WHO points out that opportunities for optimal health are still unavailable to most people, especially in low-resource countries or

communities where social determinants can easily influence health.<sup>8</sup> These social determinants of health (SDOH) become heightened during public health emergencies, creating vulnerabilities and a more significant gap in health disparities when health and nutrition resources are not readily available.

The following case represents ethical issues and challenges that lead to disparities in global health in a diverse society, presented in *Public Health Ethics: Cases Spanning the Globe*. In the case below, ethical issues arise due to the lack of consideration of socio-contextual factors that impact care for vulnerable populations. This case study provides one instance of public health planning that overlooks unique population needs:

Your community is a large, metropolitan city under a category 5 hurricane warning...A wide number of people widely dispersed in the city will need to be evacuated. They speak many languages, have varying levels of access to transportation, and require various levels of care. Special needs and vulnerable populations (e.g., the disabled, ill and injured, homeless, and the incarcerated) will also need help to evacuate.

As a result of emergency preparedness incident-training simulations, some agencies have developed evacuation plans. These plans are not always easily accessible to all first responders and the lack of coordination between agencies has led to confusion. Responders are unclear about who should be given priority in evacuation assistance, which resources and personnel should be devoted to evacuation efforts, and when to halt evacuation and rescue efforts and shift to recovering bodies...Worse, no central registry or database lists which community members will require help to evacuate.

In less affluent neighborhoods, some residents lack access to a car or sufficient money to transport...outside the hurricane's path. ...evacuees who cannot stay with people they know are quickly overwhelming the capacity of evacuation facilities in nearby towns. Decisions will need to be made about how to coordinate and efficiently use resources and personnel to maximize the number of people protected from the hurricane.

Officials managing the evacuation have realized that mass evacuation raises some logistical and ethical issues...They have therefore asked you, an experienced public health official, to provide input on which groups of people should be evacuated, how,

and in what order of priority. Your special concern in planning and coordinating with other agencies will be the health of the population, mitigating inequalities and the safety of the first responders. <sup>9</sup>

There are many ethical concerns in the preceding case, such as lack of prioritization, confusion amongst first responders, and no guidance on who needs help in the evacuation. All these factors highlight social vulnerabilities and disparities when care needs are unmet such as access to stable, safe, and reliable food and water sources or even the ability to evacuate safely. As a result, at-risk diverse and vulnerable populations may encounter barriers to meeting their care needs during public health emergencies. Although the case has asked a public health official, I as a bioethicist can identify and address the ethical concerns in the case to support first-responders and the people impacted by seeking methods to uphold the principle of justice. An ethics lens will consider the health needs of diverse and vulnerable populations and the resources needed to support first-responders during states of emergency globally. A bioethical perspective supports justice by inspiring considerations of SDOH to provide insight and practical strategies, ensuring equity in care delivery for underserved populations to reduce disparate outcomes. In chapter 6a, I will argue that a bioethical perspective promotes justice in public health responses to support culturally diverse and vulnerable populations as a method of cultivating global health equity.

### I. Ethical Concerns During Disaster Situations

Cognizance of cultural diversity is indispensable, especially when addressing ethical concerns during disasters by being attentive to the vulnerabilities of individuals and populations. Disasters - natural, medical, or environmental - can impact every population in any geographical area. According to Afolabi in "Public Health Disasters," disasters related to public, or population, health represents untouched areas in bioethical discourse. <sup>10</sup> For instance, resource prioritization concerning social vulnerabilities is still a budding area during public health

emergencies for underserved populations, as experienced during the Covid-19 pandemic. Afolabi points out that the unforeseen feature of disasters impacts harm, distress, and destruction. Furthermore, in national or global disasters, a vital ethical goal requires searching for a method(s) to minimize the negative consequences that can impact an individual's socio-cultural factors.<sup>11</sup> SDOH become more prominent for populations already at risk prior to disasters because frailties and vulnerabilities can worsen during or after the disaster has passed. According to Pacquiao vulnerable populations "comprise groups of people who have systematically experienced greater social or economic obstacles to health that are historically linked to discrimination or exclusion. These factors may be based on their racial or ethnic group, religion, socioeconomic status, age, gender, gender identity or sexual orientation, and migration status."12 Another barrier is poverty, which can already negatively impact individuals through discrimination and marginalization but also creates challenges to accessing healthcare services.<sup>13</sup> In addition, D.B. Waisel summarizes that vulnerable populations are those groups of people at risk of not obtaining adequate healthcare access. Waisel deems vulnerable populations as those who are "socioeconomically disadvantaged, underinsured, or those with certain medical conditions."14 Waisel also considers the ethical considerations for the LGBTQI and incarcerated populations, such as knowledge gaps when treating them and institutional gaps. <sup>15</sup> Furthermore, these populations can encounter unfair social stigmatization, impacting mental health. In other words, the literature has varying conceptualizations of vulnerable populations. However, the commonality in healthcare is that populations may encounter challenges to resources which may cause frailties due to inadequate access to care or ability to sustain health.

These healthcare conditions become amplified when the unmet needs go overlooked during emergencies. In the case study use, within the evacuation, the most affected vulnerable

populations mentioned were community members who do not speak the dominant language, who are disabled, ill, injured, homeless, or incarcerated. Because of their diversity, each of these populations could face challenges due to their unique unmet needs. However, it is evident that at a broad level, these populations face challenges of the right to safety and access to care, a gap in meeting care needs, and a lack of access to safe food and water resources, all of which can worsen current health conditions.

In the debate around human rights, health and/or healthcare, is often a central area of discussion. International human rights, as conceptualized in international documents, were birthed following World War II to foster an ethical relationship rooted in values of justice, dignity, and equity between the government and its citizens.<sup>17</sup> Over time, human rights have evolved and flourished in many disciplines to uphold inherent dignity and respect for human beings. In bioethics, human rights conceptually have normative philosophical, legal, and social roots.<sup>18</sup> Ethical concerns may arise during public health emergencies when human rights and patient rights are not equitably recognized in protocol and decision-making processes for each individual or population.

Human rights frameworks provide an all-inclusive structure applicable to countless healthcare facets. In clinical research, these human rights are vital to randomized controlled trials (RCTs) in public health studies, such as those related to populations with disabilities, to ensure sustaining legal, political, social, and cultural rights for all. On the other hand, in a pluralistic world, the unified concept of human rights accounts for the uniqueness of individuals. Human rights frameworks can ensure equitable human care is delivered within culturally diverse populations. Human rights and equality are "...advocated in terms of social protection and to safeguard entitlements" and account for the rights to access healthcare services. Therefore,

safeguarding access to healthcare is necessary to ensure one can function and participate in society to an equitable extent.

The Universal Declaration of Human Rights (UDHR) and other international human rights documents overarchingly summarize access to healthcare services. Article 14 of the UDBHR stresses the importance "social responsibility and health" and specifically on adequate nutrition and resources for well-being. In addition to being a human rights, survival resources are vital during disaster situations. Article 25 of the UDHR emphasizes the right to an adequate standard of life and well-being. The UDHR also stresses, as quoted in Douglas et al., the "right to security" in circumstances of instability such as "unemployment, sickness, disability, ... or other lack of livelihood in circumstances beyond his [or her] control. One crucial lack of livelihood circumstance includes natural disasters. In the context of the case study mentioned, deficit of access to care or adequate food, nutrition, or medications can result in an inability to attain basic livelihood needs across populations during a natural disaster. Like the preceding case, survival resources may be hard to access for populations who lack transportation or are financially unstable. The hurricane described in the case study creates gaps in care needs, resulting in challenges when upholding the human rights of vulnerable populations.

Disparities in health status amongst different populations are an ethical issue because they positively impact the well-being of some and negatively on others, creating unfairness. According to Douglas et al., health disparities are the gaps or consequences on specific populations' physical and mental health that cause social inequalities, such as poor healthcare outcomes.<sup>27</sup> Social inequities are an ethical concern; they can disadvantage in human flourishing such as suffering and unequal opportunities to achieve optimal health. Douglas et al. state that "...health promotion should be grounded on the principles of social justice and protection of

basic human rights" that aims to support well-being equitably.<sup>28</sup> For example, overlooked care needs during public health emergencies contribute to social inequities, creating a growing gap in health disparities for vulnerable populations. This gap can be bridged using practical strategies to help vulnerable populations with the intent to support their human flourishing or at least mitigate any further harm.

A typical public health response strategy during natural disasters like hurricanes includes mass evacuation. Barrett et al. purported mass evacuations raise ethical issues because they can potentially unfairly affect vulnerable and marginalized populations.<sup>29</sup> In other words, decisions to implement mass evacuations raise ethical concerns primarily in the realm of justice. Barrett et al. state that public health officials need to consider social determinants of health (SDOH) or ill health, such as socioeconomic disparities, that can create disadvantages for community members and hinder their ability to comply with evacuation orders. An example is lacking access to transportation and financial resources that may prevent many people who encounter these challenges in evacuating; as experienced by people during the 2005 Hurricane Katrina in New Orleans, Louisiana.<sup>30</sup>

From a bioethics perspective, I propose that achieving justice in public health response strategies requires taking a community or duty-based approach. In *Public Health Ethics and Practice* Peckham et al. state that the ethical contributions of the health of the public "will depend upon culture and history and will be – at least to some extent – path dependent; that is, what it is possible to do or achieve depends upon the structures and cultures already in existence." For mass evacuations and public health responses, this could involve taking actions to mitigate and prepare for emergencies using a population-based approach. One method is to craft culturally comprehensive policies and protocols to ensure that the consideration of diverse

community's needs are accounted for. Furthermore, Peckham et al. argued that healthcare should be considered from a social stage because the needs must be based on the actual lived experiences of people, not just healthcare policy, law, or ethical principles.<sup>32</sup> To build on Peckham et al.'s discussion, shaping policies and public health responses requires accounting for the current or past reality and real-lived experiences of populations within a community, nation, or geographical location to prepare for future natural disasters.

In the preceding case, real-lived experiences were acknowledged but not practically accounted for; there was no database or registry to help emergency responders understand the populations' needs.<sup>33</sup> From a bioethical lens, public health officials can work to implement a community database or registry that is easily accessible to first responders for humanitarian assistance. The database or registry can include information on the community demographic, care needs, and contributing circumstances to help provide first responders with a resource that guides their care delivery. For instance, in this case, the community database could include information on the spoken languages of the community members; this could enable first responders to deliver care in a way that can help community members understand evacuation orders.<sup>34</sup> However, this would require patient and community partnership, compliance, and consent to provide information to local public health officials to help support the creation of a personalized community-based resource to assist first responders. One method to move towards meeting care needs, such as safe and reliable food and water sources during a state of emergency, is to craft prevention measures aimed at supporting unique, diverse, and vulnerable populations.

Food and water are basic survival needs but can become challenging to access during public health emergencies. Affected populations of public health crises may experience a lack of safe and reliable food and water sources during public health emergencies.<sup>35</sup> According to Wetter

et al. in "Ethical Allocation of Scarce Food Resources During Public Health Emergencies," the impacts of scarcities in the face of public health emergencies, such as pandemics, encompasses more than just medical and healthcare resources.<sup>36</sup> Wetter summarizes a vital point from Georgetown University Center on Education and the Workforce website that millions of Americans faced unemployment, including declines in business, which impacted health insurance and financial stability and thus affected SDOH. These two factors ultimately impacted people's ability to maintain and obtain survival needs, such as food and nutrition, due to the Covid-19 pandemic.<sup>37</sup> The Covid-19 pandemic impacted all populations. However, due to fluctuating social determinants of health (SDOH) such as socioeconomic status, geographical location, etc., vulnerable populations may face a greater risk for sustaining their livelihood and even health during disaster situations, such as the Covid-19 pandemic. During public health emergencies, access to safe and reliable food and water resources becomes a challenge and is equally important to address, specifically for vulnerable populations.

SDOH can impact one's quality of life positively or negatively throughout the lifespan. When SDOH impact quality of life negatively, they may be an area of ethical concern especially during public health emergencies. According to Goldberg, operationalizing the SDOH into public health practice, or interventions, can be done through the notion of prevention.<sup>38</sup> Goldberg provides three methods of prevention that are primarily applicable to the context of health professions: "primary, secondary and tertiary."<sup>39</sup> The primary level highlights lessening risk, the secondary level highlights early discovery of disease, and the tertiary level highlights mitigating the impacts of the disease after diagnosis. While the notion of prevention certainly contributes a vital role in health professions, in public health emergencies, prevention can be operationalized in response crafting. For instance, understanding community needs when crafting public health

responses can be crucial to preventing the lack of livelihood of those most vulnerable. The impacts discussed in Wetter's point on the consequences of Covid-19 impact people in the United States and around the globe. Insecurities in essential survival resources, such as food and water, become heightened during public health emergencies and are an ethical concern, especially for the most vulnerable, due to existing challenges that impact their ability to obtain survival resources.

Furthermore, ethical concerns of finding safe and reliable food and water resources differ amongst populations, such as those who struggle financially, the elderly, the youth, and those with pre-existing conditions. Wetter mentioned a vital point that when families tried to "stretch budgets to provide basic food needs," it also constrained other necessities such as medications or stable housing and could further impact the health outcomes of populations. Financial instability can lead to creating a broader gap in health disparities. For instance, older adults with pre-existing conditions such as diabetes or heart disease who face financial difficulties are impacted by a more significant risk with unmet nutritional needs or go without care. Social determinants of health or ill health can create a more significant challenge for specific populations to access food and nutritional resources, making them more vulnerable in emergencies.

In the case study, there was a note of the resident's lack of access to transportation or financial resources to be able to evacuate outside of the range of the hurricane.<sup>44</sup> In less affluent neighborhoods, community members may struggle financially not just to evacuate but also to obtain essential survival resources such as food and water if evacuation is not possible or feasible. To mitigate adverse impacts and suffering on affected vulnerable populations, public health officials can craft response efforts to combat these issues. For example, public health

officials can allocate emergency funds to support vulnerable populations financially during times of natural disaster to help meet gaps in food, water, and basic care needs ethically. Preparing for and mitigating harmful health impacts requires crafting public health responses equitably, ensuring justice for vulnerable populations.

## **II. Equitably Crafting Public Health Responses**

Attentiveness to cultural diversity promotes equitable responses to public health. Ethical concerns related to justice in healthcare may arise when individual health (or respect for autonomy) is compromised because of the prioritization of the health of populations (or the greater good). The *Oxford Handbook of Public Health Ethics* recognizes that public health approaches are typically utilitarian, but "there are today prominent calls for social justice in the field."<sup>45</sup> In other words, utilitarian approaches to public health can overlook individual needs, but a social justice approach can ensure the human flourishing of all. Upholding justice equitably in a pluralistic society requires meeting the unique care needs of people, taking into consideration SDOH.

According to the *Oxford Handbook of Public Health Ethics*, emergency preparedness in public health is a four-phased approach: "mitigation, preparedness, response, and recovery." In chapter 6a, since the focus is on the response step, the two steps prior (mitigation and preparedness) will also be briefly considered as they are crucial building blocks to ensuring proper implementation of response strategies. Mitigation happens before the public health emergency event occurs and considers potential threats and damages that can be prevented; preparedness involves various entities such as the "governments, institutions, and communities" ability to handle the emergency when it is happening; and response focuses on steps that are taken during the actual state of emergency to ensure protection. Recognizing SDOH as an

ethical asset in these three steps is crucial for sustaining a bioethical perspective. Ethics answers are not clear and always easy to assess, which is needed during public health emergencies; however bioethical awareness can help guide the creation of a balanced and equipoised approach when conflicting values arise.<sup>48</sup>

Culture is a crucial SDOH when caring for populations in a pluralistic society. More evidence to include culture as a foundational SDOH can be found in the *Encyclopedia of Medical Anthropology: Health and Illness in the World's Cultures*, which states that "moral values are shaped by socio-cultural values and beliefs." Culture not only provides insight into one's traditions and values but can also provide insight into individual lifestyle choices, communication methods, and differing values amongst populations. Culture is one's way(s) of life. Furthermore, the ability to achieve optimal health and human flourishing is intertwined with various SDOH, broadly labeled as culture. In order to foster effective public health responses, understanding the socio-cultural context of a population is imperative to support needs equitably.

Social factors (housing, transportation, food and nutrition, and social and economic mobility, amongst others) have proven to impact the rate and severity of illness for populations varyingly.<sup>51</sup> Bravemen and Gottlieb note that over time social factors such as environment, geographical location, or socio-economic status can contribute to an influential role in shaping the health of populations and communities.<sup>52</sup> These social factors can become heightened during states of emergency. Likewise, Gray concluded that "[e]mergency planners need to widen the current conceptualisation of vulnerability."<sup>53</sup> For instance, widening planning efforts could mean including meticulous and practical strategies to support vulnerable populations, those who are currently ill or injured, etc., in humanitarian assistance efforts. In the case study mentioned, widening the scope of planning would require updated assistance considering the needs of ill,

injured, homeless, and even incarcerated populations.<sup>54</sup> Public health responses need to account for vulnerabilities to ensure responses mitigate future risks of worsening living conditions and cultivating health equity.

Cultivating health equity calls for looking at health as holistic; for instance, looking to medical factors as well as identifying social factors to mitigate and prepare for risks. Health equity requires consideration of social determinants of health. SDOH "are very broad and range from unemployment, unsafe workplaces, urban slums, lack of education, gender discrimination, food insecurity, and air quality through to degraded natural environments."55 Good et al. articulated about the clinical context of psychiatry that even though there have been advances in medicine and technology that improve the lives of patients in a positive way but "...the profession is challenged by a growing 'disparities' movement pushing for psychiatry to be more responsive to the needs of diverse racial, ethnic, cultural, religious, and socioeconomic groups...<sup>56</sup> This challenge is equally present during emergencies and applicable to the profession of emergency responders. Equity refers to being responsive to unique needs and providing people with the resources they need to thrive. It "requires practitioners to engage more fully in evaluating and understanding the unique needs of high-risk, high-vulnerability community members."57 Understanding the care needs of vulnerable populations can serve as a source of support for emergency responders to foster effective assistance strategies. When responders understand the needs of the people they serve, they can create adaptable approaches to distributing resources.

However, humanitarian efforts to understand their population and potential vulnerabilities need resources and support. A vulnerability analysis or risk assessment can be conducted to recognize vulnerabilities and understand social and cultural factors. In *Disaster Nursing and* 

Emergency Preparedness: "Essentials to Disaster Planning," Tener et al. stated that the disaster team must identify those at risk of vulnerabilities to understand potential risks; strategies include vulnerability analysis and a risk assessment. Utilizing a vulnerability analysis and/or risk assessment can provide first responders with data on SDOH. In addition, the field of data science can provide data or insights into areas that create risks and enable actionable decision-making resources during states of emergencies. As a result, vulnerability analysis and risk assessments enable the identification of vulnerabilities; SDOH identification brings first responders one step closer to fostering health equity.

Data identification and collection are vital to conducting a practical vulnerability analysis or risk assessment. Tener et al. state:

[h]azard identification is used to determine which events are most likely to affect a community and to make decisions about whom or what to protect as the basis of establishing measures for prevention, mitigation, and response. Historical data and data from other sources are collected to identify previous and potential hazards.<sup>60</sup>

Tener et al. discuss data identification, collection, and usage in the context of all hazards; similar notions can be echoed and specified to natural disasters. For instance, in the context of the United States, census data that can be easily acquired without further consent from the US Census Bureau can be used as a starting source to collect SDOH information about age, race, residence, and even phone numbers. Some expansions to the Census include the addition of other SDOH such as native or preferred languages spoken. Operationalizing census information can include using phone numbers to communicate digitally with impacted populations. However, communicating via phone may require additional consent, especially concerning restrictions and guidance on which health information is allowed to be digitally communicated upholding to guidelines such as HIPAA (if in the United States). An ethicist can provide insight into ways to

develop an agreement to ethically obtain consent or ethically communicate with users without breach of confidential information.<sup>62</sup> This SDOH information can assist first responders in identifying risks and analysts when performing an analysis.

In the preceding case, equity is needed to support underserved populations when ethically crafting public health responses. In the case study, emergency responders were unclear about which populations to prioritize in their response efforts. Risk analysis or assessment would have provided insight into which populations needed to be prioritized to help them successfully participate in mass evacuations or follow public health protocols without facing adverse impacts. Prioritization in this case includes the vulnerable populations mentioned, such as those with language barriers and without transportation or financial resources. Health equity would have ensured meeting people's care needs with consideration of SDOH.

The ethical implications that SDOH sheds light on raise exigency for diverse, pluralistic societies. SDOH provide a deepened understanding of factors that can support human health in emergency preparation by understanding unique care needs. In conjunction with SDOH, bioethics can be used as a critical tool to promote respect, dignity, and interdependence for the fundamental human virtues in global issues.<sup>65</sup> Health disparities among racially (or culturally) diverse and marginalized populations result from environmental and social determinants of health, as discussed in "Robert Wood Johnson Foundation's Commission to Build a Healthier America."<sup>66</sup> Health disparities ultimately represent unmet or overlooked care needs in another dimension of an individual's life.

In Cultural Competency for Emergency and Crisis Management: Concepts, Theories and Case Studies: "Chapter 6," the authors summarize that evacuation has vital challenges for at-risk, vulnerable populations such as immigrants, undocumented immigrants, and minority

populations. Evacuation is complicated "because it can require a significant time and financial investment. For example, families must pay for gas; account for increased traffic, which increases drive times; and be able to either arrive at a state-operated shelter, stay with relatives/family, or pay for lodging. This is simply not feasible for many families."<sup>67</sup> In other words, the authors conclude that social determinants impact populations varyingly and can explain individual challenges during states of emergencies. Ethically, SDOH can be used to identify a person's needs to improve and develop a deeper understanding to support their care needs during public health emergencies.

In a pluralistic society, SDOH, including culture, are indispensable for addressing disparities during public health emergencies. If disparities are not addressed, distrust amongst the population can create gaps in communication efforts. The *Dictionary of Global Bioethics* recognizes that medicine, healthcare, and even research should be conducted with the intent to foster and sustain public "trust." During natural disaster situations, communication is vital in ensuring the public can take adequate safety measures. However, for communication to be effective, trust is vital. Honest and transparent communication is necessary to build trust with the public; further, if people cannot trust what local, community, national, or global public health leaders convey regarding safety, the messages will have little to no value. As a result, the public and the people will be unable to understand the severity of the risk(s) involved in the natural disaster situation to follow measures such as evacuation.

In the preceding case study, ethical concerns are raised in the event of a hurricane. The populations mentioned included people who were linguistically diverse, incarcerated, disabled, etc.<sup>70</sup> Knowing the diversity amongst the affected populations is vital to provide first responders with a deepened understanding of how to provide aid to community members effectively.

Meeting care needs, therefore, requires special attention to the SDOH of diversity about the health needs of these populations during mass evacuations. One ethical concern in the case was that there were no central database(s) of which populations or people needed aid. A lack of a central database is a source of concern because it fails to ensure that first responders have the resources necessary to aid everyone. A database using data that is ethically sourced should be implemented to overcome this issue and empower emergency responders. Ethically sourced data can include data that is consensually obtained and maintained from the populations with disclosure of its utilization. Serving underserved populations requires empowering humanitarian assistance efforts - in this case the first responders - by providing the right tools and resources.

Serving humanity at the public health level should require meeting the care needs of diverse individuals and be a core component of public health response efforts. A foundational pillar of social establishments is carrying out duties for the greater social good or fulfilling social responsibility. One way of upholding institutional social responsibility is to care for the needs of the community. Using the risk analysis and assessment data, one can reflect on the community's needs. Technology offers new methods for management of health information and new techniques for global healthcare service delivery. Technology as a reflective practice can enable serving the needs of underserved populations and by doing so, one is not only serving themselves in their profession but also serving humanity.

Ethically, providing service to humanity can be observed in personhood. From the perspective of personalism theories, the doctor is seen as serving their own humanity through serving other humans.<sup>75</sup> In the public health sector, personalism can be operationalized when policymakers undertake methods to stand with and support the unique and diverse communities

in a multicultural society (which can be a very high form of justice). As mentioned in chapter 5, "learning to walk alongside" can be a way to serve humanity in the future, especially in public health responses.<sup>76</sup> Ethically serving humanity to support vulnerable populations' fundamental rights and needs in a pluralistic society requires reflection, collaboration, and empathy.

Another method to uphold social duties is in policy development. Douglas et al. articulated that "health policy can affect culturally diverse groups, particularly those who are economically disadvantaged, vulnerable, and/or underserved."<sup>77</sup> Therefore, policy development can enable individuals to seek the care they need at the time they need it via equitable access to care and financial resources (i.e., payment models). From this perspective, serving humanity means serving the unique human needs that result from a pluralistic society. Sensitivity to cultural diversity means that equity during public health emergencies ultimately involves serving the unique needs of humanity in a culturally, racially, and socially diverse society.

In the preceding case, there was a lack of technology, i.e., no central database.<sup>78</sup>

Technology would have enabled a better understanding of the needs of the populations and mitigated further risks or vulnerabilities. Health policies could be outlined for the guidelines for the ethical usage of technology to empower first responders when serving underserved populations. Using technology such as cell phone communication to send out information about evacuation protocols could have been sourced using a central database. Cell phones could have been used to provide helpful information showing the safety status amongst community members. In the mentioned case, the first responders could have used one of the preceding options to communicate with community responders via sending out a notification to understand an individual's ability to obtain transportation. In the future, these response strategies will aid

first responders in understanding the community members to provide equitable care during natural disasters.

### III. Methods to Support Equity for Future Populations

Awareness of cultural diversity also provides critical guidance about equity for future populations. Promoting justice in a pluralistic society requires supporting future populations in emergency responses. In *Global Issues in Healthcare: Issues and Policies*, Carol Holtz argues that human rights globally should be protected, particularly for groups who are most vulnerable, such as Aboriginal populations in Canada, due to social exclusion and other structural components that hinder autonomy or even mobility.<sup>79</sup> From this perspective, protection is an aspect of social responsibility shared amongst healthcare providers, policymakers, and other social institutions to ensure the equity and well-being of underserved populations. Achieving health equity and social justice then requires the reassessment of unique care needs to elevate those who do not have the opportunity to achieve optimal health due to underlying SDOH.<sup>80</sup>

From a bioethical perspective, justice is a core principle to consider. In public health responses, justice may require different approaches because, like each person, each professional has different knowledge, understanding, and resources. Echoing these notions, one of the policies that "Envisioning a Better U.S. Health Care System for All: Reducing Barriers to Care and Addressing Social Determinants of Health," recommended is "greater resources must be devoted to addressing environmental health, and that strategies are needed to address, prevent, mitigate, and adapt to the health consequences of climate change." The preceding notion can be applied to public health responses. One practical measure is to allot resources, such as technology, dedicated for assistance efforts to mitigate health consequences for vulnerable or marginalized populations. Barret et al. state that because mass evacuations are often carried out by different

levels of government and local responders, to preserve public autonomy, there needs to be an excellent level(s) of organization and coordination between entities.<sup>82</sup> In other words, during public health emergencies, agencies need synergy, and should not work in silos. Responses need methods to mitigate any future suffering and with the intent to provide optimal care and safety.

In the face of mass evacuations, a prerequisite for responders to successfully help people is to understand the needs of the populations they are aiding. As such, awareness of continuously changing needs and vulnerabilities is one way to craft effective responses for future populations' needs. To put it another way, helping the people who help the people is essential to carry out response efforts successfully. Three methods to foster awareness in future response planning efforts include field exposure, education, and advocacy. In the preceding case, supporting the equity of future populations requires coordinated effort amongst local and national agencies.

Field/site work in communities can aid in raising awareness and exposure to the real-lived experiences of people. Healthcare professionals at large participate in social responsibility towards humanity when caring for people directly and indirectly, such as in the case of natural disasters. From a bioethics perspective, social responsibility supports human flourishing and social development. According to "Article 1" of the UN Universal Declaration of Human Rights (UDHR), human beings "...should act towards one another in a spirit of brotherhood," and encourages a responsibility towards one another. Active 14" of the UDBHR supports the sharing of duties among members of society as vital to "social responsibility and health." As a result, duty-based approaches support social responsibility such as undertaking efforts to understand SDOH insofar as they impact real-lived experiences before, during, and even after natural disasters.

Fieldwork can create trusted relationships in healthcare by recognizing the unity of people with the first responders and healthcare providers. The relationality in caring professions or "caring science" should enable patients to be seen as dignified people; this entails understanding their needs and serving populations well. Schotsmans articulates that human beings are continuously developing, multi-dimensional, and constantly evolving with their sociocultural surroundings, and that is what formulates who they are as a person. Personalism supports the promotion of multidimensionality of human beings. Furthermore, Schotsmans points out that human beings always live in societal relation to others. Multidimensionality is one component that should aid in building trusted relationships with community members. Ethicists can partner with humanitarian assisters to gain field insight into different populations' challenges before or after a disaster.

In caring professions, the doctor or health professional is always in relation to the individual they are serving. Empathy can support the caregiver in delivering "dignity enhancing care" by considering health holistically on a "...historical, social, and spiritual" level. <sup>88</sup> In other words, dignifying their humanity in relation to the patient or the other. Thus, building trust in the community and fostering deep knowledge of the socio-cultural context is critical for public engagement. <sup>89</sup> For professionals who practice in community settings, strategies to continuously develop a focus on population health for culturally diverse individuals can serve a positive function.

In the preceding case, fieldwork would have enabled first responders, public health professionals, and protocol makers to understand the real-life circumstances of the community members to build trust and serve them effectively. Ethicists could have a partner in field exposure efforts to understand community needs and even provide ethical insight to technical

members in humanitarian efforts. Technical members can be utilized in gathering data and implementing technical creation efforts; ethicists can aid them in mitigating bias and injustices and ethically sourcing and utilizing data. In addition to fieldwork, or in instances where fieldwork is not possible, education can supplement learning about community needs.

Continuing education can be a positive resource for future emergency preparedness and responses in a globalized and continuously changing society and environment. Healthcare ethics committees within a healthcare organization encounter being perceived to "...only addresses clinical issues and therefore would not be useful to leaders trying to address or reflect on organizational or business ethics issues." Serving a role in emergency preparedness can mend this issue of healthcare ethics committees and expand their traditional expertise of education that fits with the changing public health landscape. Ethicists or ethics committees can facilitate public health preparedness strategies courses using the previously discussed field work. A practical methodology would be to expand their focus on issues affecting the organization's business model, such as mass evacuations. Ethics committees can use policy development skills to aid organizational leaders in mass evacuation efforts. Ethicists and ethics committees can also help identify the care needs of the populations the organization serves and provide resource allocation insight to humanitarian assisters.

Furthermore, healthcare ethics committees are composed of multidisciplinary members; they can bring together their diverse knowledge to create educational resources for future organization preparedness tailored for professionals at different levels (nurses, doctors, administrators, etc.). In "Lifelong Learning for Public Health Practice Education: A Model Curriculum for Bioterrorism and Emergency Readiness," Olson et al. mention that competency is a component of "knowledge, skills, and attitudes," and it should be a continuous lifelong process

that includes reflections from practice and experience. <sup>91</sup> Olson et al. also purport there is a lack of access to training and education materials, that makes it difficult for healthcare systems to react during public health crises. <sup>92</sup> One method to combat this challenge is to offer level specific education and training from fieldwork learnings. Olson et al. discuss the need for competency-based core capabilities to prepare public health professionals in the face of "bioterrorism and emergency readiness." <sup>93</sup> Healthcare ethics committees are in a pivotal position within the organization to create and deliver competency-based continuing education, trainings, and learning experiences for staff.

One of the expertise and function of bioethicists, including ethicists in ethics committees, is to educate by pointing out differing moral perspectives and values. <sup>94</sup> Healthcare ethics committees can work to put together trainings, create classes, and foster experiences that help staff and clinicians advance their competency skills without having to take time off to attend conferences outside the organization. In the preceding case, education in using risk assessment analysis and patient or member databases could have provided support for the first responders and public health leaders on resource distribution and prioritization of those individuals in most need. Educational approaches can even serve as one form of advocating for those with imminent care needs.

Health advocacy is crucial to supporting SDOH in public health emergencies. Douglas et al. state that "[a]dvocacy is also founded on the principle of justice and fairness by ensuring that each person is given his or her due." Further, health advocates can be found on many levels in the healthcare system ranging from clinical care to the broader public sector in the form of representational, case, cause, etc. advocates helping to improve health. Moreover, advocating for community health should start at the community level. For instance, "hosting community

health fairs with ethnic community organizations that support vulnerable populations adds value to the organization's mission." Health advocacy should aid in building competencies that achieve equity by advocating for the needs of diverse populations and communities.

Advocating for community needs through education can serve as a foundational component or a new responsibility that ethicists can utilize at the community level. In "The responsibilities of the engaged bioethicist: Scholar, advocate, activist," Scully articulates the notion that bioethicists have unique responsibilities from professional and academic standpoints. Professionally, bioethicists play an active role in mitigating "moral trouble;" academically, bioethicist scholars have a vital role in seeking the truth. 98 Vulnerabilities during public health emergencies create issues for communities and populations facing gaps in care needs. Scully identifies "a continuum of responsibilities" for a bioethicist who is engaged in responsibilities that includes:

- (a) to get the facts right
- (b) to avoid epistemic distortion
- (c) to avoid exploitation of the situation and those directly affected
- (d) to ensure proper representation
- (e) to be aware of, and respond appropriately to, hierarchies of authority at play <sup>99</sup>

Bioethicists can practically apply these responsibilities at the community level by a) getting the factually correct information on what is needed for their population, b/c) ensuring to avoid distorting the situation and needs of the people affected, d) ensuring accurate and factually correct representation of the situation at hand, e) as well as being able to respond effectively to authoritative figures such as local, state, and national authorities. As a result, ethicists can serve as educators and truth seekers in the advocacy of promoting and supporting diverse community health needs to promote the health of future populations.

Advocating for the needs of communities can take a variety of forms. In "Health Advocacy," Hubinette et al. articulate that according to the vertical axis, advocacy can take form through agency and activism. Agency includes ways of navigating systems such as healthcare by providing information and education and connecting to community resources. In contrast, activism includes undertaking action that brings about different forms of change, such as political and social. <sup>100</sup> Ethicists are in a great position to act as community agents providing education and information to the community and health professionals. At the community level, ethicists can educate public health professionals about the specific needs and resource distributions during public health emergencies. As a result, ethicists can serve as agents who build trust between the community and health professionals at large. In the preceding case, an ethicist could have been utilized to educate healthcare professionals on community needs or engage with community members to understand their resource challenges first-hand.

Conclusively, current public health strategies lack effective methods to address public health emergencies. This can lead to ethics issues such as unintendedly infringing human rights, creating gaps in care needs, and creating barriers to accessing food and water resources. These issues can cause suffering for vulnerable populations at risk. Bioethicists provide a unique lens to help healthcare professionals address issues related to justice, especially regarding vulnerable populations. Implementing strategies for field exposure, education, and advocacy are a starting point for positive change that bioethicists can support in crafting public health responses equitably in the future. Insofar as awareness of cultural diversity is indispensable for promoting health equity to achieve justice in public health responses, this awareness must be prominent in the emerging role of public health ethics, such as during pandemics.

# <u>Chapter 6b. The Emerging Role of National Bioethics Committees During Public Health</u> <u>Crises: Addressing Cultural Equity During the Covid-19 Pandemic</u>

The rapid growth of new scientific medicine and emerging technologies in the 21st century brings new questions of morality. 101 Healthcare ethics committees originated in the 1960s and, over time, have evolved into a primary component that facilitates ethics issues and dilemmas within a healthcare organization. 102 Ethical dilemmas arise due to differing viewpoints, values, and sometimes care needs between two entities. With the growing demography and gap in health disparities in the United States, it will be vital to incorporate equity into the facets of healthcare. For instance, increased data collection, measurement, and tracking; increased workforce diversity; implementing effective interventions; and personalized medicine can all provide opportunities for reshaping care delivery. 103 The future of bioethics will need to incorporate ethics into public health delivery methods to sustain the unique care needs of diverse patient populations. To evaluate the values of the medical culture and that of the public in a multicultural society, healthcare ethics committees serve as facilitating bodies of moral dialogue via education, policy development, and consultation. 104 As a result, healthcare ethics committees play a crucial role within healthcare organizations in supporting and evaluating dilemmas that reflect the best interests of the context and people involved.

Global health crises are an emerging area for healthcare ethics committees to flourish nationally. Ethics committees serve as leaders giving distinct perspectives to try to equipoise in institutional and social values via guidance in policy formation; however, lack of policy proficiency creates challenges. Furthermore, global public health crises in the 21st century, "raise concerns about access to resources and their equitable use. The ethical consequences of these developments can lead to social and societal tensions – especially in an unequal world

undergoing rapid demographic change."<sup>106</sup> Global health crises can create unintended impacts and even ethical concerns due to differing values in care and expectations between the patient, healthcare-providing team, and national leaders. For example, a patient's view on their disease could impact their self-management behaviors.<sup>107</sup> In a study conducted by Paul et al., they found that during the Covid-19 pandemic in India, statistics around perception, attitudes, and behaviors were similar among healthcare professionals and the public.<sup>108</sup> These findings could be because of the lack of uncertainty around the Covid-19 illness and disease. Healthcare ethics committees can expand their role, which should involve ethically crafting and implementing communication methods during crises by ensuring trust and transparency in protocol and risk factor communication within the public.

One of the struggles healthcare ethics committees face is the aptitude to survive within healthcare organizations. <sup>109</sup> To reach sustainability, an ethics committee needs the support of the healthcare leaders as well as individual staff members, but this requires understanding "how what you do can enhance what they do." <sup>110</sup> One methodology for creating sustainable healthcare ethics committees is to seek ways to provide value outside of the organization; in an emerging role, bioethicists can serve as national stewards in response to 21<sup>st</sup>-century global health crises. By expanding their traditional function, national bioethics committees can create an ethos during global health crises and make a positive impact in multicultural societies for the future.

#### I. Healthcare Ethics Committees

Attentiveness to cultural diversity must be prominent in the emerging role of public health ethics, such as during pandemics. In particular, competence in cultural diversity is crucial for bioethics committees whose involvement in pandemics is crucial. Healthcare ethics committees are mediating entities that facilitate ethics within an organization. The Joint

Commission on the Accreditation of Healthcare Organizations (JCAHO) passed a directive in the early 90s that required all of its accredited hospitals to have methods for attending to ethics issues in the clinical context. <sup>111</sup> JCAHO mandated the need for healthcare ethics within the organization, which can manifest in varying forms, such as ethics departments, ethicists, or ethics committees.

The traditional value healthcare ethics committees bring is to educate, develop policies, and provide advice through case consultations within healthcare institutions. Healthcare ethics committees' size, members' expertise, and impact vary among healthcare organizations and patient populations. Committees can improve their chances of survival and add to their success by supporting the ethical practice of healthcare at their institution during global health crises. Fluidity among healthcare ethics committees can aid them in the organizational impact in response to current national events such as public health crises. For instance, ethics committees can reassess needs, goals, and impacts to effectively serve institutions and national governments during pandemics by promoting trust, ensuring optimal consent, and transparently communicating in research trials for vaccinees. They can expand their traditional functions as policymakers, mediators, and educators towards an emerging and needed role as national bioethics stewards during global health crises.

National bioethics committees can contribute to a vital role during global public health crises. In "A survey of national ethics and bioethics committees" Köhler et al. state that "establishing national ethics committees is merely the first step – the greater challenge is to increase their capacity to be independent, pluralistic, enquiring bodies able to give sustainable advice to governments and the public." During global health crises, committees can provide guidance on mitigating health misinformation. During the Covid-19 pandemic, bioethics

committees could provide methods for researchers to "[p]rioritize understanding how people are exposed to and affected by misinformation, and how this may vary for different subpopulations." Nationally, ethics committees can work to undertake urgent needs during crises, such as transparent communication and shaping research governance protocols. For instance, in Latin America, a national ethics committee was organized to regulate oversights when gathering research, by UNESCO. However, Kohler et al. state the challenge of gaining resources as much of the literature does. 116 Furthermore, pandemic-associated provider and policy-maker priorities will shift and need to balance bioethical principles of care, equity, and moral equality to guide institutional patient care decisions clinically. As a result, bioethics committees can outline guidance for institutional and national-level healthcare leaders by creating resources such as educational materials, decision-making tools, or even communication plans to foster equitable responses in multicultural societies.

Ethics committees are composed of members from multidisciplinary backgrounds, such as chaplains, nurses, doctors, lawyers, and ethicists, which inform a holistic perspective of the ethical case/dilemma. A holistic perspective is vital in ethical issues in healthcare because it provides different views when assessing a particular situation. Nationally, ethics committees are diverse from country to country. In Hajibabaee et al.'s article, European countries have more established committees while many Western Pacific regions are still developing. In the Eastern Mediterranean region of Iran, committees are there but need to be more robust. On the contrary, in the United States, healthcare ethics committees are widely recognized and tasked with guiding organizational policy, managing ethical issues, making recommendations, and providing education. Ethics committees gather to discuss and evaluate these goals within the organization. The committees should meet monthly or quarterly to review literature, policies, and

other organizational protocols.<sup>121</sup> As a result, in the US ethics committees serve as organizational members who help improve and advance ethics.

According to the *ASBH Core Competencies*, each member delivering ethics services should develop core competencies, skills, and knowledge for ethics consultations to offer support and value to the organization. These core skills and knowledge range from basic to advanced and aim to enable a strong foundation for the consultation. These capabilities help when facilitating meetings, identifying ethics issues and methods to resolve them, evaluating and quality improvement, and reasoning through moral dilemmas. As a result, an ethics committee has a broad range of skills and competencies that help holistically assess ethical dilemmas within healthcare organizations.

In addition, healthcare ethics committees' function to support organizational leadership. Healthcare ethics committees are responsible for guiding decision-making, such as making recommendations for ethics cases or offering educational support. 124 Ethics committees also provide support in policy development. Policy development can either be crafting new or revising old policies such as informed consent rules, do not resuscitate orders, or artificial nutrition and hydration guidelines. 125 Another function of ethics committees is to provide organizational ethics insight. In this respect, healthcare ethics committees have a broad role within healthcare organizations that supports many functionalities, such as quality of care delivery. Healthcare ethics committees, even outside of hospital settings, can play a prominent role in cases where there are dual loyalty conflicts, such as those encountered in managed care organizations (MCOs), between reducing financial costs and sustaining quality of care delivery. 126 For instance, during a pandemic, this could require healthcare ethics committees to extend their expertise to resource allocation in care delivery. Their skillset to support varying

organizational functionalities can be expanded and applied to serve the needs of emerging issues in an evolving role.

Traditionally, as the literature purported, the focus of healthcare ethics committees has been on performing clinical cases/rounds, creating educational resources and programs, and policy formulation on ethical issues within clinical care. These broad functionality areas ultimately help connect the two perspectives of medical culture and the culture of the public or patient. For instance, in an ethics case consultation, issues around the principle of autonomy could arise to the differing perspectives of the medical and patient culture(s). An ethicist should help mediate the social values and guide the provider and the patient toward a solution that upholds the best interest in the situation. As a result, ethicists may act as mediating entities who help give clarifying perspectives on the emerging issues at hand. To do this, healthcare ethics committees need to be actively dependent on the organization to have the means to support patients but also independent to sustain broader societal values such as social justice, human rights, and dignity. 128

However, one of the challenges with healthcare ethics committees is establishing a stable foundation. Post et al.'s literature mentions that new ways to support organizations is needed for committees to achieve stability because some ethics committees survive while others struggle to achieve sustainability over time.<sup>129</sup> One methodology that can help ethics committees establish a strong foundation, and sustainability is to support local, state, federal, or global systems. For instance, sustainability can include incorporating the ethics committee within the broader healthcare organization or state governance structure by moving from a patient-provider-centered responsibility to a wider community, population, and stakeholder responsibility in the organization.<sup>130</sup> Expanding beyond the organizational level can enable the ethics committee to

provide a meaningful impact in the broader global public health sphere. Doing this can help create accountability, visibility, and a more holistic systems approach nationally. Furthermore, securing an interwoven foundation outside the healthcare organization would even bring awareness to healthcare ethics committees outside of the traditional role into a national bioethics role.

Moreover, the unique role that ethics committees hold in organizations can allow its members, specifically ethicists, to be in leadership positions from a business or systems perspective providing value to the local and national organizational level. Traditionally, bioethics is a vital source of support and guidance for institutional staff and faculty in upholding their institutional social missions of serving people and ensuring ethical, legal, and scientific implications (ELSI) would be operationalized conscientiously. 131 Healthcare organizations, from a business systems perspective, are professional entities. For ethics committees to gain the appropriate resources, time, and financial funding, they must highlight their goals, impacts, and values. Healthcare ethics committees' goal is to supply training that will enable providers to take what they learn from consultations and apply it independently in their practice. Once professionals can independently work through ethics issues, they can deliver more efficient and timely care which upholds the institution's social mission to provide optimal care. <sup>132</sup> By highlighting the goals, healthcare ethics committees can be held responsible for their work. The ethics committee can propose future financial resources by showing their impact on emerging issues. By delivering value in the form of ethics services to patients, the healthcare ethics committee can make meaningful relationships with colleagues within the organization, allowing their work to continue and prosper. 133 Further, by expanding these roles, healthcare ethics committees can provide value within a national organization to supply optimal ethics support for

future ELSI issues with the rise of global health crises. Thus, healthcare ethics committees can establish strong rapport for their emerging role, enabling the committee to thrive nationally.

An emerging role healthcare ethics committees can undertake is supporting up-and-coming areas of ethical concerns nationally. One of the budding considerations that are most prominent in 21st-century healthcare are social and cultural factors during global health crises, especially in a pluralistic society. Healthcare ethics committees can facilitate ethical considerations on a national level during global health crises. Douglas et al. point out the workforce diversity such as multidisciplinary staff and faculty are just as vital for delivering culturally proficient care. Systems and processes for culturally proficient care can provide a foundation for global health crises. With this foundation, committees would be in a superior position to undertake broader healthcare system-wide ethics issues, such as being underinsured or uninsured because of job insecurity or loss due to global crises. An emerging role for bioethics committees includes providing support nationally by utilizing healthcare ethics committee's traditional skills of education, policy development, and clarifying values.

During global public health crises, national ethics committees can be crucial to helping address the values of the impacted people. In managing infectious disease outbreaks, health authorities, including government leaders, have a critical responsibility to communicate with the public to effectively relay health information and prevent the spread of health misinformation. <sup>137</sup> Health misinformation is a vital ethical concern because it can prevent people from taking safe actions to protect themselves during public health crises. According to the US surgeon general's report, *Confronting Health Misinformation: The U.S. Surgeon General's Advisory on Building a Healthy Information Environment*, providers can help account for health misinformation by implementing ethical practices such as active listening, understanding patient worldviews,

values, and beliefs.<sup>138</sup> Accounting for health misinformation can quickly be done by including an ethicist in consultation or by having national bioethics guidance at a community engaging health professionals at large. Countries and government leaders also have the duty and responsibility to protect the citizens within their borders and the international community because viral diseases, such as SARS-COV-2, are so easily transmissible. Some approaches include adequate national public health laws, global tracking, and preparedness, and providing resources for assistance.<sup>139</sup> Another integral approach is implementing a national bioethics committee to assist with the preceding approaches and provide education, decision-making support, and resource allocation guidance.

Furthermore, bioethical issues need to be addressed from a scientific and ethical standpoint. The interdisciplinary members of ethics can be leveraged to provide diverse perspectives to policymakers and government health authorities on ethical methods to illustrate national values and priorities in managing pandemics or crises. Healthcare ethics committees should play a key role in developing the necessary resources and tools to help drive global health crises nationally, ensuring the sustainability of ethical standards. National bioethics committees can aid in drafting policies and educational resources for culturally diverse populations.

As bioethics committees develop into emerging roles, traditional skillsets can be used to develop resources at a national level, working to serve the moral needs of a pluralistic society. In *Guidance for Managing Ethical Issues in Infectious Disease Outbreaks*, the World Health Organization (WHO) states additional guidelines, some of which are: "involving the local community," "situations of particular vulnerability," and "allocating scarce resources." Furthermore, in "A survey of national ethics committees," Kohler et al. articulated that national ethics/bioethics committees can provide vital ethics guidance during crises situations rooted in

ethical considerations. However, to achieve sustainability, ethics committees need support, such as "legally mandated, independent, diverse in membership, transparent and sufficiently funded to be effective and visible." <sup>142</sup> In other words, by creating a foundation supported by the preceding social responsibility, healthcare ethics committees can create lasting change and evolve into national ethics (or bioethics) committees. Further, by participating in creating equitable guidance during global health crises, a sustainable foundation for the ethics committee can be established. Sustainability results in a national bioethics committee that will serve as a valuable resource for years. Insofar as awareness of cultural diversity needs to be prominent in the emerging role of public health ethics, such as in pandemics, creating an ethos around cultural diversity is indispensable.

## II. Creating an Ethos around Cultural Diversity During Global Health Crises

The ethicist contributes an imperative role during global health crises. According to the Institute of Medicine (IOM), ethicists play a vital role in pandemic preparation and planning by recognizing and raising awareness of the ethical values needed to support public health decisions, communication, and transparency. A national bioethics committee composed of ethicists, policymakers, and federal leaders can help provide guidance, creating an ethos of ethically sound and feasible responses during pandemic outbreaks. In the "Epilogue" of the 2021 version of the *Handbook for Health Care Ethics Committees*, Post recognizes that the challenges faced during pandemics are ethical at "heart:" however, "ethical analysis must examine how different sub-groups of the population fare relative to one another with respect to their access to and utilization of public health measures." When individual sub-group needs are overlooked, injustices can unintentionally occur. During global pandemics, the "heart" of ethics includes clear dialogue, fostering trust in public responses, and avoiding significant knowledge gaps,

misperceptions, or miscommunications between public health officials and a multicultural society. Nationally, bioethicists should provide support to prepare for pandemics, such as strategies for containing spread.<sup>145</sup>

In the United States a bioethics commission was chartered and intended to guide ethics on new and emerging issues in science, research, and technology. According to the US Department of Health and Human Services, a "Presidential Commission for the Study of Bioethical Issues" was created between 2009 and 2010 under President Obama's administration. However, it is unclear if the US still has a bioethics commission, as the work mentioned on the webpage is only documented from 2009-2017.<sup>146</sup> Accordingly, national bioethics committees are needed to aid and alleviate forthcoming bioethics issues and serve as a source of professional and national ethical guidance. Article 19 of the UNESCO Universal Declaration of Bioethics and Human Rights (UDBHR) illuminates the significance of an ethics committee. Article 19 recognizes the need to establish independent, interdisciplinary committees that can address, engage, and assess ethics issues on numerous levels. Article 20 of the UDBHR similarly recognizes the importance of guidance for risk assessment and management issues promoting human welfare. 147 These articles play a vital role in forming a national bioethics committee and the risk assessment and management value they can provide in light of new bioethics issues. Huxtable, in "COVID-19: where is the national ethical guidance?," argues that "[t]he task will not be easy, and guidance will need to ensure that it hears and heeds the voices of stakeholders, including health and social care professionals, as well as patients."148 In other words, in a multicultural society, national bieothics committees will have to consider many individuals' perspectives to create an ethical ethos during global health crises. To create an ethical ethos,

national bioethics committees can make policy recommendations, foster human-centered responses, and create ethical guidance rooted in trust, fostering cultural equity.

Globally, every country wanted to find proper insight during the Covid-19 pandemic. Due to a culturally diverse demographic, each population's needs, values, and beliefs will be different, and unique policies can create approaches to health equity for providers. He Rhodes articulates that outlining clinical policy measures of triage care can provide ethical guidance in challenging clinical decisions of determining resource allocation. In a public health crises, outlining clinical policy prioritization measures such as vaccine shortage(s) alleviates the decision-making burden on providers. This would also mean not only considering the success of the maximum number of lives saved but also the failures of unused resources. Furthermore, pandemic response policies and prioritization processes must be ethically sound. Yimer et al. argue that in pandemics, ethics issues in policies can occur in three areas: measures (such as isolation), practices (such as school closures), and responses (such as resource distribution) which include implications on protection of the individual versus the greater good. National bioethics committees should aid institutional leaders with ethically detailed policy recommendations to meet the needs of a pluralistic society.

National ethical guidance should assist public health responses, particularly practices related to physical safety. Yimer et al. state that in guiding safe physical practices, "the relative weight given to each harm and benefit depends...on the moral context and cultural beliefs." Beneficence and non-maleficence should be ethically assessed to ensure that just national principles are upheld within public health safety practices. During the Covid-19 pandemic, one of the protocols employed included shutting down schools to practice social and physical distancing to protect children. However, this protocol could also conflict with notions of justice.

For instance, for some children, educational institutions are supportive environments, and without the right to access them, the youth population may be at greater risk.<sup>153</sup> While school closures may seem like the safest option initially during a global pandemic, there requires more deliberation to understand the underlying ethical consequences and community needs. As such, ethical guidance can aid in assessing the underlying factors to ensure populations are treated fairly per benefic and non-malefic principles in a culturally and socially diverse community.

Ethical oversight should also help outline responses for resources for emergency pandemic crises. Yimer et al. purport that the Covid-19 pandemic revealed the unequal access to resources across geographically, culturally, and socially diverse populations. For instance, they pointed out that disparities existed globally in the distributions of vaccines, medications, lab testing capacity, hospital bed capacity, and ventilators. Ethically viable policy criteria should be incorporated as a national and global effort to create methods of just circulating of scarce supplies. Policy recommendations, such as allocating resources based on diverse and non-Covid patients' needs, including supplying masks, providing training on protocols, and creating accessible testing sites, are some areas to incorporate culturally equitable guidelines. Thus, national bioethics committees can provide insight during global health crises to assist in ethical deliberation in policy recommendations for practice and response, fostering human-centered measures.

Human-centered measures during global health crises support bioethics in promoting cultural equity. Personal responsibility can be created to promote human-centered responses by supporting and building trust with the public to meet the needs of diverse communities. IOM's forum discusses the distribution of antimicrobial drugs, hand sanitizers, and countermeasures in the case of harmful events through the MedKit program fostered human-centric safety measures

and community engagement.<sup>156</sup> Similar distributions of masks, antiviral drugs, etc., can be implemented to guide crises, such as the Covid-19 pandemic.

National bioethics committees should direct strong community engagement to understand the real-lived challenges of unique populations. Furthermore, the IOM's forum articulated that transparency, as well as principles of civilian participation, are two aspects that are key to building trust between government efforts and the public. 157 National bioethics committees should help create ethical decision-making procedures incorporating public engagement and deliberation. These procedures should include ethical implementation and communication of protocols and interventions that are understood, accepted, and acknowledged by the public. 158 As a result, national bioethical approaches should include strategies to engage the voices of the communities impacted to foster human-centered evidence-based measures.

Community engagement includes and employs the perspective of the individual populations impacted by crises and can be a primary source of cultural equity. The community can provide a valuable human centered lens through which health professionals can become aware of multifaceted health issues where the concern of priorities from a social lens can also be fostered. Furthermore, when the Covid-19 pandemic manifested, community engagement included a broad concern for knowledge, practices, and procedures to be followed to protect each other's well-being. For instance, mask mandates were a broadly implemented practice during the Covid-19 pandemic. McGuire et al. formulate that robust community engagement strategies should include clarifying the need for a protocol(s) and contexts informed by real-lived experiences. These approaches employ ethical principles of respect for autonomy, trust, and social responsibility between communities and healthcare experts, which can mitigate misinformation (one of the consequences of Covid-19). However, trust and social

responsibility may only be created if knowledge about the crisis among citizens is fairly and equitably communicated. As such, national bioethics committees should engage in releasing trusted information in collaboration with local healthcare entities to promote shared responsibility among all people equitably.

Furthermore, analyzing the Covid-19 pandemic measures from an ethics of care lens highlights the strengths and weaknesses of ethical responses from bioethical perspectives. In "A Mind of Care," Hellsten notes that an ethics of care framework could aid in sustaining core human values such as relationality, well-being, and thriving as essential aspects for consideration during the Covid-19 pandemic. The ethics of care considers individual human life in relationship to other lives and can foster human-centeredness. Hellsten further purports that the Finnish government echoed ethics of care in measures and responses by stating that food and medicine would be provided, fresh and clean natural environments would be sustained so that communities could engage in meaningful physical and spiritual activities, and an emphasis would be placed on creating connection and community while ensuring distancing. An ethics of care framework can provide inspiration for national bioethics committees to create equitable human-centered measures to sustain core human values during crises, such as the Covid-19 pandemic.

Just and fair ethical guidance is one of the global challenges related to Covid-19. In "Fairness, Ethnicity, and COVID-19 Ethics," Paton argues that fairness does not always equal equity in healthcare and in pandemics can unfortunately disproportionately impact populations leading to more suffering for those in low resource situations. One approach that national bioethics committees can undertake is strengthening fair, ethical guidance with equity during global health crises to meet the needs of culturally diverse populations. Patton suggests using

interdisciplinary approaches such as sociology to relate health to ethnicity and social relationships as key during pandemics. <sup>164</sup> Cultural, racial, or ethnic worldviews and values impact health behaviors and outcomes. Although there are many universal cultural factors, many aspects vastly differ between individuals, which may cause miscommunication and misinterpretation among individuals from culturally different backgrounds. <sup>165</sup> As a result, national bioethics committees should aid in developing guidance per social determinants of health (SDOH), such as culture, to create equity in global health crises.

National bioethics committee members can serve as educators in pandemic planning efforts to fill knowledge gaps and reduce health inequities. For instance, as educators, committee members can identify the importance and impacts of cultural health equity to improve trust and respect of the patient community-level policies and to develop cultural and linguistic competence. 166 Patton argues that there has been little work done around mitigating health inequalities in the public health realm, but "the need for new guidance in the pandemic provides an opportunity to reorient policy and public health measures." <sup>167</sup> In other words, reorienting policy measures must consider concepts of fairness and incorporate strategies to promote equity. For instance, an equitable approach would need to consider the social science considerations, such as SDOH, of ethnicity and cultural background to determine an equitable approach that promotes and provides education on protocol measures.<sup>168</sup> A national bieothics committee can provide a methodology for crises like Covid-19, where insights can inform preserving the lives and well-being of individuals equitably in a pluralistic society would be of utmost importance. Therefore, bioethics innovators are in a vital position to lead national leaders, staff, and citizens toward creating ethical guidance based on the social science foundations, more widely recognized as SDOH, to improve health equity.

Globally and nationally, looking at existing guidelines and incorporating strategies to mitigate challenges such as health disparities in past crises can help guide equitable responses during the Covid-19 pandemic and future crises. One example of an organization that looked to historical insights to guide its Covid-19 planning efforts that Paton used was the Royal College of Physicians. They looked at existing ethical guidance from the SARS and H1N1 pandemics and used these findings and challenges as a starting point for an empirical bioethics approach for clinical guidance rooted in social science analyses. The Royal College of Physicians then developed an equitable ethical framework for decision-making based on concepts such as social responsibility, inclusivity, and transparency. As a result, the empirical work provided cultural perspectives and contexts to guide pandemic responses. It helped develop advice for doctors on the importance of considering a patient's background and cultural context when making decisions about delivering care. 169 Ultimately, national bioethics committees can use similar social sciences foundations that the Royal College of Physicians used to foster equitability when developing ethical guidance to reflect the socio-cultural context within which the guidance will be implemented.

## III. Impact of National Ethics Committees in Multicultural Societies

Fostering an ethos around cultural diversity in global health crises, such as in pandemics, provides an opportunity for national ethics (or bioethics) committees to have a robust, positive impact in the future. Culture as an SDOH brings with it differences in coping styles, behaviors, and social norms which create the need for varying methods to fulfilling care requirements.<sup>170</sup> The Covid-19 pandemic is shedding light on the gaps and barriers in approaches to crises and for vulnerable populations especially for people who are unable to physically socially distance, isolate, or are unable to understand the importance of following protocols. Healthcare inequities

have become a central concern in the national and global dialogue about Covid-19 in the United States and beyond.<sup>171</sup> Addressing health inequities is one step towards cultural equity. National bioethics committees can contribute to long-term sustainable changes by using past learnings to reduce suffering caused by disproportionate health outcomes and seek methods for mitigation in future pandemics, disasters, and crises.

Cultural equity is vital to sustain human dignity in multicultural societies during global health crises. Doulas et al. mention that culturally competent care can help achieve health equity by considerations of social justice and human rights in healthcare and can sustain dignity for the vulnerable populations.<sup>172</sup> Equity, however, should shed light on socio-cultural contexts that formulate an individual's real-lived experiences. Chowkwanyun and Reed articulate that providing culturally equitable public health responses requires analyzing data of SDOH, such as socio-economic status (SES) to make approaches individualized. If SDOH data does not provide strong insights into disparities, the authors mention pivoting approaches to examine other stress related impacts on populations and resource accessibility to protect the health of diverse, minority patients.<sup>173</sup> National bioethics committees can help modify current or past approaches to create culturally equitable responses to mitigate healthcare disparities, guide public health decisions, and create just allocation of resources during global health crises for the future.

Culturally competent communication methods can be fostered by national bioethics committees to fill knowledge gaps in public health protocols to mitigate healthcare disparities. A normative lens rooted in cultural competency can guide leadership on methods to strengthen community engagement.<sup>174</sup> Communication that engages the needs of the community can be foundational to protecting individual human dignity. The US surgeon general's report on misinformation, they suggests that healthcare professionals at large can "[p]artner with

community groups and other local organizations to prevent and address health misinformation."<sup>175</sup> One specific strategy bioethicists can undertake at an institutional level is to ensure communications for safety protocols are community centered. Therefore, national bioethical guidance should help ethically enhance communication methods to respect human dignity in multicultural societies.

Nationally, bioethicists can engage with government leaders and public health officials to ensure cultural competency is engaged as a social responsibility. One of the challenges during the Covid-19 pandemic was stigmatization and blame for those who did fall ill due to inappropriate following of protocols, such as not sheltering in place. Sometimes, sheltering in place may not even always be effective especially for people who live in physically crowded areas. Understanding cultural competency in global health crises is a social responsibility.

Roberto et al. state public health officials have a responsibility toward cultural competency. A method to address the lack of cultural competency can be through conversing about cultural humility or cultural intelligence to mitigate stigmatization and cultural disinformation. National bioethics committees can bring cultural equity to leadership conversations. Committee members can work with leaders to create equity by implementing communication resources to reduce stigmatization and misinformation.

Cultural equity can mitigate healthcare disparities by shedding light on the unique care needs of multicultural societies to advocate for marginalized populations. For instance, geographic location can create varying access to healthcare services in the United States. During the Covid-19 pandemic, risks and deficits in access to healthcare resources due to geographical location might explain the issues related to the distribution of healthcare services among diverse populations.<sup>178</sup> Much of the literature mentions issues such as access to testing sites, hospitals, or

even vaccination sign-ups which all contribute to resource deficits that may create disparities in healthcare outcomes. Ultimately, there is a need to mitigate healthcare disparities and reimagine the current health system to foster equitable care for future health crises.

Bioethicists can reimagine the health system by incorporating social responsibility to create sustainable approaches considering the cultural values of multicultural societies. Tiako et al. states methods in which a more socially responsible and equitable healthcare system consists of:

- (1) remain vigilant in addressing bias and its effects on patient care;
- (2) implement strategies to mitigate structural bias and use data to rapidly mitigate disparities in quality of care and transitions in care; and (3) address inequities, diversity, and inclusion across the entire healthcare workforce.<sup>179</sup>

National ethics committee members can work with leaders and healthcare providers to use the approaches that Tiako et al. mention to mitigate health disparities at a community and national level. Nationally, ethics committee members can work with providers to ensure that they address mistrust by acknowledging a patient's experiences and upholding their individuality or human dignity. Next, national ethics committees can aid in implementing strategies to help address financial shortcomings or unmet care needs to enhance the quality of care delivered. Addressing care needs can be the required norm to enhance the quality of care to meet patients' cultural and social needs to uphold social responsibility respectfully. Lastly, healthcare leaders can help incorporate real-lived experiences to promote diversity and inclusion within the committee. One way of doing so is by getting to know the patients and their cultural background. Larkins et al. in their article used case studies to understand strategies to improve quality of primary care delivery for the Aboriginal and Torres Strait Islander populations. By understanding cultural background, the struggles, challenges, and strengths of various groups of people can be brought

to the surface.<sup>183</sup> Similarly, culturally catered communication and equitable policy development with consideration of real-lived experiences provides an ethical lens for guiding public health decisions.

Ethics leaders have a social responsibility to ensure that public health decisions uphold human rights ethically and morally. A common public health measures made around the world during the Covid-19 pandemic was the decision to undertake isolation and physical human to human distancing; these were implemented to minimize the death spread of disease and mitigate stress on the healthcare system to maximize safety for the entire population. However, isolation can create constraints on individual autonomy or human rights. Further, as pointed out by Jeffrey, many ethical challenges originated due to social distancing, solidarity, and isolation. One of the challenges that resulted from the pandemic was the unintended consequences on mental health due to isolation, fear of the illness, among others.

A multidisciplinary national bioethics committee can explore the relational ethical dimensions of isolation. An ethical lens sheds light on ways to mitigate unintended consequences on mental health especially for the culture of the youth population. For example, isolating during a health crises might benefit the greater good but it does not account for the individual's well-being in the long-run; a relational theoretical foundation would foster equitable care as a core component of sustaining autonomy and individual human values. <sup>187</sup> In "Relational ethical approaches to the Covid-19 pandemic," Jeffrey states that responding to public health crises requires loosening utilitarian lenses that are intended to meet the needs of large, diverse populations to help highlight individual human-centered values such as "... duty, equity, relational autonomy, [and] trust..." Relational ethical methods can sustain vital human rights and dignity to safeguard the health of society but still look to ways to consider relational

dimensions to support mental health. For instance, for the youth population, school closures inhibited crucial social interactions. One way to combat the negative impacts of not having social interactions is through relational dimensions of technology, such as virtual activities and events. Considering individual ethical components, such as SDOH, is the start of how equitable healthcare outcomes can be achieved, and unintentional harm can be minimized. For example, solidarity is a good solution for providing support for vulnerable or marginalized groups that were impacted by these unknown and unintended consequences and even other factors such as recognizing the outcomes that affect the homeless. Ethical human-centered approaches to public health measures can be a core focus of national bioethics committees to mitigate unintended consequences of isolation on mental health.

From a relational ethics lens, the ethics of isolation and social distancing become a situation where individual measures should be outlined uniquely in a multicultural society. There is a need to ensure the social distancing and isolation measures are on par with the rights of humans to ensure their well-being is upheld justly. This means accounting for the social and cultural norms and behaviors of the community as done in "Does culture matter social distancing under the COVID-19 pandemic?" by Huynh. Furthermore, in a culturally diverse society "coping and resilience" strategies and impacts may differ on mental health stressors and isolation may have further varying effects on collective versus individualistic cultures. Emphasis on isolation can place an unfair burden on varying populations in a multicultural society. For instance, Gopalan and Misra discuss the socio-cultural challenges related to isolation in India. They point out that,

[t]he social fabric of India thrives on interdependence, both emotional and economic, within families, relatives and friends. Close physical interactions like living in crowded housing and other places... Despite the lockdown, crowding has been observed in religious places, during travel (e.g. 'herds' of migrants on buses)... While 'vertical distancing' is the cause of inequalities in India, the 'horizontal distancing' put in place in the wake of COVID19 has further exacerbated these inequalities.

The more troubling aspect is the lack of proper provision of safety nets (e.g. food safety) for those hit the hardest by lockdown...As a result of the lockdown, there is increased possibility of malnutrition among the low SES.<sup>192</sup>

One method to ensure the unfair burden is alleviated for vulnerable populations is to consider SDOH in the decision making of public health measures. National bioethical guidance can provide insight into relational and socio-cultural significance in protocol formation to sustain human rights and dignity in a multicultural society. By considering SDOH, the appropriate allocation of resources can be deliberated, thereby mitigating unintended consequences on well-being.

In areas where physical isolation and distancing are difficult, protective resources such as masks, sanitizers, and food allowances should be provided as supportive or protective measures for people. However, during the Covid-19 pandemic, another great challenge was allocating scarce resources. Allocation of scarce resources can impact culturally diverse individuals in a pluralistic society varyingly. Schoch-Spana et al. state that alongside in-nation differences, culture is also seen as a force shaping a nations or entire region's pandemic approach. The notion of a one-size-fits-all plan for ethically allocating scarce medical resources butts up against divergent sociocultural conditions. In other words, culture plays a vital role in healthcare, particularly the outcomes of the allocation of medical resources. Schoch-Spana et al. purport that when state, federal, and local authorities are aware of these diverse cultural needs, they can better communicate about resource allocation through all phases of a crisis and that too with greater compassion. An ethics-based approach could help healthcare authorities equitably help populations, or in other words, equitably serve those who are serving the people. National

bioethical guidance can assist in and outlining a code of ethics highlighting human values, decision making methods, and determining prioritization standards to guide policymakers, leadership, and clinicians to meet the needs of a multicultural society.

Ethical values to guide the rationing of scarce resources during global health crises are crucial to promoting equity in healthcare. The Covid-19 pandemic has disproportionately affected culturally diverse minority groups in developed first-world nations as well. Allocating scarce resources to meet unique care needs is crucial to ensuring equity in multicultural societies. In "Mitigating ethnic disparities in covid-19 and beyond" Razai et al. discuss that ethnic minorities in the United Kingdom (UK) have poorer access and experiences in healthcare, and they are less likely to voice concerns about access to testing and personal protective equipment due to previous negative experiences. Working with state and local officials can be an expanded function of national ethics members to understand areas of barriers and take action to ensure allocation and distribution of vital protective and safety resources such as masks, gloves, and other protective equipment.

Amongst the just allocation of resources, ethical guidance can foster robust decision-making methods. An ethics framework can provide decision-making guidelines for allocating resources that aid providers in cross-cultural clinical care. Schoch-Sapna et al. argue that states can develop a framework to standardize allocation decisions, which would aid health authorities and clinicians when providing care to the broader community. Schoch-Sapna et al.'s study concluded that a culturally competent method for scarce resource allocation requires engaging with the public and knowing their population's needs and values. <sup>198</sup> As a result, national bioethics members can provide methods to community health authorities that engage culturally

catered decision guides to enable providers to deliver resources based on population needs during global health crises.

Culturally competent care can be created by allocating resources among multicultural societies equitably. Schoch-Sapna et al.'s state that "[p]andemic ethicists invoke principles such as transparency, inclusivity, and education and information, citing multiple benefits." Culturally catered ethics approaches can be implemented by national ethics committee members to ensure diverse groups who are (or have been) at risk of not receiving equitable care are given the consideration needed to provide them with the best care. Interweaving ethics in public health crises can put equitability at the core of planning to consider the culture and context of populations. A national bioethics committee can help guide the ethics of equitability, allocating resources among diverse populations cultivating health equity.

In sum, the expanded traditional function of healthcare ethics committees into national bioethics committees creates an ethos during global health crises and makes a positive impact in multicultural societies currently and for the future. Committees can provide value during pandemics by engaging in national bioethical issues where ethics value, impact, and effectiveness become vital during global health crises. Differing cultural values and healthcare needs arise during global health outbreaks for populations varyingly. Expanding the critical components of healthcare ethics committees of education, policies, and mediating differing goals into an emerging role that involves being bioethics stewards for global health crises can help create a viable establishment nationally. The impact of a robust national ethics committee can create cultural equity by mitigating healthcare disparities, guiding public health decisions ethically, and equitably allocating resources. Therefore, a practical ethics committee must be established to achieve ethically sound public health responses such as those required in

managing the Covid-19 pandemic. As a result, national ethics (or bioethics) committees are vital sources of ethics support during global health crises for creating equity in a multicultural society.

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<sup>&</sup>lt;sup>3</sup> Knox Claire Connolly and Haupt Brittany "Brie, Cultural Competency for Emergency and Crisis Management: Concepts, Theories and Case Studies (New York, NY: Routledge, 2020), Book. Pg.: 25

<sup>&</sup>lt;sup>4</sup> Sotomayor and Barrero-Castillero, "Globalization and vulnerable populations in times of a pandemic: a Mayan perspective." Pgs.: 1-2

<sup>&</sup>lt;sup>5</sup> Stapleton et al., "Global health ethics: an introduction to prominent theories and relevant topics." Pg.:2

<sup>&</sup>lt;sup>6</sup> Have and Jean, The UNESCO Universal Declaration on Bioethics and Human Rights: Background, Principles and Application. Pg.: 219

<sup>&</sup>lt;sup>7</sup> Centres for Bioethics Global Network of WHO Collaborating, *Global Health Ethics Key Issues* (Switzerland: World Health Organization, 2015). https://books.google.com/books?id=XbzosgEACAAJ. Pg.: 19

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<sup>&</sup>lt;sup>9</sup> Barrett et al., Public Health Ethics: Cases Spanning the Globe. Pg.: 134

<sup>&</sup>lt;sup>10</sup> Afolabi, "Public Health Disasters." Pg.: 1

<sup>&</sup>lt;sup>11</sup> Afolabi, "Public Health Disasters." Pg.: 3

<sup>&</sup>lt;sup>12</sup> Douglas, Pacquiao, and Purnell, Global Applications of Culturally Competent Health Care: Guidelines for Practice. Pg.: 5.

<sup>&</sup>lt;sup>13</sup> Douglas, Pacquiao, and Purnell, Global Applications of Culturally Competent Health Care: Guidelines for Practice. Pgs.: 5-6

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 Waisel, "Vulnerable populations in healthcare." Pgs.: 188, 190

<sup>&</sup>lt;sup>16</sup> Barrett et al., Public Health Ethics: Cases Spanning the Globe. Pg.: 134

<sup>&</sup>lt;sup>17</sup> Have and Gordijn, *Handbook of Global Bioethics*. Pg.: 467

<sup>&</sup>lt;sup>18</sup> Have and Gordijn, *Handbook of Global Bioethics*. Pgs.: 468-469

<sup>&</sup>lt;sup>19</sup>Berghs et al., "Rights to social determinants of flourishing? A paradigm for disability and public health research and policy." Pg.: 3.

<sup>&</sup>lt;sup>20</sup> Berghs et al., "Rights to social determinants of flourishing? A paradigm for disability and public health research and policy." Pg.: 4

<sup>&</sup>lt;sup>21</sup> Have and Gordijn, *Handbook of Global Bioethics*. Pg.: 467

<sup>&</sup>lt;sup>22</sup> Have and Jean, The UNESCO Universal Declaration on Bioethics and Human Rights: Background. Principles and Application. Pg.: 219

<sup>&</sup>lt;sup>23</sup> "Universal Declaration of Human Rights."

<sup>&</sup>lt;sup>24</sup> Douglas, Pacquiao, and Purnell, Global Applications of Culturally Competent Health Care: Guidelines for Practice. Pg.: 15

<sup>&</sup>lt;sup>25</sup> Barrett et al., Public Health Ethics: Cases Spanning the Globe. Pg.: 134

<sup>&</sup>lt;sup>26</sup> Barrett et al., Public Health Ethics: Cases Spanning the Globe. Pg.: 134

<sup>&</sup>lt;sup>27</sup> Douglas, Pacquiao, and Purnell, Global Applications of Culturally Competent Health Care: Guidelines for Practice. Pg.: v

<sup>&</sup>lt;sup>28</sup> Douglas, Pacquiao, and Purnell, Global Applications of Culturally Competent Health Care: Guidelines for Practice. Pg.: v

<sup>&</sup>lt;sup>29</sup> Barrett et al., *Public Health Ethics: Cases Spanning the Globe*. Pg.: 133

<sup>&</sup>lt;sup>30</sup> Barrett et al., *Public Health Ethics: Cases Spanning the Globe*. Pg.: 133

<sup>&</sup>lt;sup>31</sup> Peckham and Hann, *Public health ethics and practice*. Pg.: 27.

<sup>&</sup>lt;sup>32</sup> Peckham and Hann, *Public health ethics and practice*. Pg.: 28

<sup>&</sup>lt;sup>33</sup> Barrett et al., Public Health Ethics: Cases Spanning the Globe. Pg.:134

<sup>&</sup>lt;sup>34</sup> Barrett et al., Public Health Ethics: Cases Spanning the Globe, Pg.:134

<sup>35</sup> Leslie Meltzer Henry, "766767An Overview of Public Health Ethics in Emergency Preparedness and Response," in The Oxford Handbook of Public Health Ethics, ed. Anna C. Mastroianni, Jeffrey P. Kahn, and Nancy E. Kass (Oxford University Press, 2019). Pg.: 767

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## **Chapter 7: Conclusion**

This dissertation has examined how cultural diversity as a social determinant of health, being aligned with human life, human dignity, human rights, and human equity, provides an ethical contribution. My explanation of the ethical contribution of cultural diversity as a social determinant of health refers to a quadrant of topics that expands the approach of the UNESCO Declaration of Bioethics and Human Rights. The UNESCO approach addresses cultural diversity in relation to human dignity and human rights. My explanation has expanded upon the UNESCO approach. I adopted a quadrant of topics that aligns human dignity with human life and human rights with equity. The alignment of these topics in the quadrant (dignity/life and rights/equity) explained the meaning of cultural diversity as a social determinant of health. Chapter seven provides a brief conclusion of this dissertation.

Chapter 1 paved the way for the dissertation, articulated the need for the ethical contribution of cultural diversity as a social determinant of health, and provided summaries of the subsequent chapters.

Chapter 2 highlighted the significance of cultural diversity in healthcare in the 21<sup>st</sup> century. Chapter 2a discussed cultural diversity as a foundational part of healthcare that accompanies the expansion of globalization and budding diversity globally and in the United States. Incorporating cultural diversity in healthcare processes ensures human dignity and rights are upheld and works towards providing person-focused care delivery. Cultural diversity as a component of cultural competency permeates various facets of healthcare, including but not limited to public health, clinical care, global bioethics/health, and much more. Sustainably supporting cultural diversity requires considering culture as a social and environmental determinant of health.

Chapter 2b analyzed culture as a vital determinant of human and environmental health; they are reciprocally related. Respect for cultural diversity in healthcare is a component of sustainability and is crucial to protecting the planet for future generations. Operationalizing global bioethics fosters empathetic approaches between utilizing and conserving the Earth's diverse natural resources to create sustainability for current and future generations. Cultural diversity also includes considerations of social factors in all stages of life.

Chapter 3 discussed valuing human life at the start and end of life. Chapter 3a explored cultural diversity as a component of religious considerations in the value of beginning of life. Scientific, secular, and religious approaches provide varying cultural perspectives on the beginning of life issues, but ultimately, all point to crucial aspects of life's intrinsic value. These varying socio-cultural considerations are also echoed in decision-making at the end of life.

Chapter 3b delved into cultural diversity as a component of religious considerations in the value of end of life. Similar to the start of life, scientific, secular, and religious approaches provide varying cultural perspectives on end-of-life approaches to palliative care. Ultimately, all point to crucial aspects of the value of dignity and respect as vital to end-of-life decisions when upholding standards in culturally diverse forms of care delivery. Decision-making is a prominent aspect of end-of-life care as well as clinical care in general.

Chapter 4 highlighted the significance of upholding human dignity in multicultural clinical care. Chapter 4a discussed how the growing diversity in the United States and worldwide requires the healthcare field to make shifts and adjustments to uphold dignity in clinical care. These shifts need to support patient-provider relationships, promote positive care outcomes, and ensure high-quality standards of care are delivered equitably. Ethics case consultations can support patients and providers in clinical care when faced with cross-cultural differences in

values, beliefs, and decision-making approaches. Ethics consultations and ethicists are vital in ensuring culturally catered care is delivered under the guidance of various ethics theories, such as ethics of care.

Chapter 4b examined the ethics of care approach to support cross cultural care. In particular, the theory recognizes the significance of social components of human dignity and life which are vital to supporting cultural diversity. Relational autonomy is prominent from an ethics of care perspective because they acknowledge the impact and importance of social dimensions of life, especially regarding healthcare decision-making. SDOH can provide providers with deeper insight into patients' social and contextual features to deliver equitable care and uphold dignity.

Chapter 5 explored supporting human rights in healthcare in a pluralistic society. Chapter 5a illustrated SDOH as fundamental to healthcare rights by analyzing a case; when SDOH are overlooked, they have the potential to create risks in patient outcomes and health. To ensure culturally component care delivery for the growing multicultural population, SDOH need to be considered and actively engaged in healthcare. SDOH in clinical care delivery can help the provider understand the real-lived experience of their patient. Ethicists also play a vital role in supporting the growing diverse population by providing education to the workforce.

Chapter 5b provided a concrete method to operationalize cultural diversity as a SDOH to uphold rights in a pluralistic society: establishing the re-balance of widely accepted principles of autonomy and justice demonstrated using a case study. Re-balancing autonomy in the patient-provider relationship requires methods to support and meet the patient where they are regarding socio-cultural factors. Re-balancing justice in healthcare requires providing practical methods, time, and resources to help healthcare professionals at large promote social justice and uphold their social responsibility in their day-to-day work.

Chapter 6 analyzed cultivating equity in global health. Chapter 6a considered a bioethical perspective to achieving justice in public health responses. This included using a case study supporting the significant role that professionals at large play in public health emergencies such as natural disasters. A bioethics perspective aids in expanding standards already in place to support SDOH and make it easier to advance methods further to meet care needs during public health crises. For instance, one way justice can be achieved in public health responses is by supporting first responders with practical resources to effectively help people during disasters.

Chapter 6b reflected on a real-lived concrete example of a crises, the Covid-19 pandemic, to further equitable sources of support during public health crises. One support is developing and utilizing a robust national bioethics committee that already traditionally support other organizations in clinical settings. With the growing bioethics issues creating an ethos around cultural diversity during global health crises is vital for cultivating equity. National ethics committees can impact multicultural societies in decision-making, resource allocation, and serving as a voice for underserved populations. Bioethical insight sheds light on health equity for culturally diverse populations.

Chapter 7 concluded this dissertation with a summary of the preceding chapters. Expanding on UNESCO's approach gives a robust underpinning for the ethical contribution of cultural diversity as a social determinant of health considering life, dignity, rights, and equity. Although the case studies analyzed in this dissertation were found in the literature, they illustrate the realities that culturally diverse, underserved, or vulnerable populations face today and are foundational in learning to care for the whole human being. In the current, and near future, of the 21st century, ethical contributions of cultural diversity as a social determinant of health are vital for sustaining the well-being of the individual and, subsequently, the population.

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