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The Ethical Accountability of Organizational Leadership to Communities of Stakeholders in Healthcare

Lisa Martinelli

THE ETHICAL ACCOUNTABILITY OF ORGANIZATIONAL LEADERSHIP

TO COMMUNITIES OF STAKEHOLDERS IN HEALTHCARE

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By

Lisa A. Martinelli, JD, MA

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Approved September 25, 2020

_____
Gerard Magill, Ph.D.
Vernon F. Gallagher Chair
Professor, Center for Healthcare Ethics
(Dissertation Chair)

_____
Joris Gielen, Ph.D.
Director, Center for Healthcare Ethics
Associate Professor, Center for Healthcare Ethics

_____
Maureen O'Brien, Ph.D.
Professor, Department of Theology
(Committee Member)

_____
Joris Gielen, Ph.D.
Associate Professor, Center for Healthcare Ethics
(Committee Member)

_____
Kristine Blair, Ph.D.
Professor and Dean, McAnulty College and Graduate School of Liberal Arts

ABSTRACT

THE ETHICAL ACCOUNTABILITY OF ORGANIZATIONAL LEADERSHIP TO

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While much is written on organizational ethics in healthcare, this dissertation uniquely

links organizational ethics and stakeholder theory to the ethical accountability of leadership to

their distinct, vulnerable stakeholder communities. It does so by examining the healthcare

organization's moral agency in relation to stakeholder theory and applies those considerations to

three major stakeholder categories: confidentiality and privacy of healthcare information,

research and attention to specific pediatric populations, and ethics of care concerning the elderly

and persons with disabilities.

Comparing the complex and interdependent healthcare delivery system in the U.S. to the

anatomy and physiology of the human body, this dissertation demonstrates that maintaining

organizational homeostasis depends up ethical accountability of leadership to its constituent

stakeholder parts. The argument unfolds in a centrifugal fashion, beginning with an

understanding of organizational moral agency as illustrated through the metaphor of soul, individual and institutional agency, and stakeholder theory. Chapter 3 considers the organization's moral obligation to stakeholder privacy and confidentiality in light of the competing information age.

Returning to specific stakeholder communities, the remaining chapters outline the moral obligation and ethical accountability of healthcare organizations to create opportunities for their most vulnerable normative stakeholders across the life continuum. Specifically, it probes this duty to pediatric communities within several contexts: children with HIV, those who are maltreated, children with special cognitive needs, and those with pediatric obesity. It concludes by expanding ethical accountability to include respect for human dignity and improving the human condition for the elderly and persons with disabilities by applying ethic of care.

DEDICATION

"The family is the first essential cell of human society."   ~ Pope John XXIII

This work is dedicated to my family. My gratitude begins where it should with my late parents who, from the time I was a child, instilled in me an ethic to commit to things that matter and to finish what I start. My mother's enthusiasm for my academic pursuits was outmatched only by her pride in their completion. I am confident she was relieved and even jubilant when I completed the last sentence of this dissertation. To my sisters, Rosemary and Anita and their spouses Gary and Mike, who supported me throughout this long, long journey with words of encouragement and hope. And, to my nephew Jake, who inspired my work concerning persons with disabilities, and who continues to inspire me every day to understand what it means to flourish. And finally, to my husband David, who has only ever known me as a student – completing one degree or another - since the day we met. Thank you for putting so very much of our life on hold. Thank you for tiptoeing through the house, repeatedly explaining why invitations were declined, altered or cancelled, and for always supporting my efforts with patience and love. My Ph.D. is as much yours as it is mine.

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"Hope sees the invisible, feels the intangible, and achieves the impossible." ~ Helen Keller

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Chapter 1. – Introduction.

There is much written on organizational ethics in healthcare. The majority of the literature addresses the organization's moral duty to adhere to its mission, vision and values through ethical decision-making in light of competing interests. There is nothing in the literature, however, which directly links organizational ethics and stakeholder theory to the ethical accountability of leadership to their distinct stakeholder communities in healthcare. This dissertation confronts this gap by addressing how moral agency guides an organization's decisions and actions for the common good of constituent needs; particularly vulnerable communities of stakeholders.

Addressing this gap is important. The contemporary healthcare organization in the U.S. is complex and is comprised of intricately interdependent systems of stakeholders with varied needs and interests. Traditional stakeholder theory espouses corporate responsibility and strategy by managing for the interests of the organization's stakeholders. Because of this, stakeholder theory is a promising model for creating and maximizing value and opportunities in healthcare. Accordingly, literature on healthcare management increasingly includes applications of stakeholder theory to specific care settings.

Further, the present research and literature on ethically accountable leadership focuses on singular stakeholder concerns that are internal and external to the organization. However, healthcare is no longer binary. Ethical accountability of leadership demands that moral agency and the preservation of the organization's moral soul, is necessary not merely for its own benefit but for the benefit of the communities it serves. Respect for human dignity and enabling stakeholder communities to flourish are quintessential moral obligations of accountable leadership.

The thesis of the dissertation addresses the ethical accountability of organizational leadership to communities of stakeholders in healthcare. The analysis examines the highly complex anatomy of contemporary healthcare organizations whose constituent parts are interdependent and shaped by corporate leadership. The ethical accountability of leadership includes both individual and institutional moral agency. This combined approach to moral agency, referred to by the metaphor of an organization's moral soul, guides an organization's ethical decisions for the common good of its stakeholders. Hence, the ethical accountability of organizational leadership in healthcare highlights the moral obligations owed to its communities of stakeholders.

This dissertation focuses on these specific obligations. There is considerable literature on stakeholder confidentiality and privacy in healthcare, the needs of children, the elderly, and those stakeholders with disabilities. However there is nothing linking these entitlements and stakeholder needs to ethical leadership. Leadership in the current healthcare environment requires an awareness of multi-stakeholder needs that are unified with its own in order to sustain a morally accountable organization. Hence, this dissertation integrates moral agency and a positive ethical climate to the ethical accountability of organizational leadership to communities of stakeholders in healthcare.

This dissertation discusses moral agency in relation to stakeholder theory to explore the ethical accountability of organizational leadership. This discussion is applied to three major stakeholder categories: the confidentiality and privacy of healthcare information, research on and treatment of pediatric populations, and the ethics of care with regard to the elderly and persons with disabilities.

The thesis is presented in a centrifugal fashion, expanding outward as the chapters develop. Chapter 1 presents a general overview of the argument. Chapter 2 discusses organizational moral agency regarding its individual and institutional components, combining them in terms of the metaphor of the organization's moral soul, to explain moral agency as a cornerstone of accountable leadership through adoption of stakeholder theory. The scope of the analysis broadens in Chapter 3 to explain leadership accountability to the multi-stakeholder interests in terms of maintaining individual confidentiality and protecting privacy in the healthcare digital age. The subsequent chapters explain how the ethical accountability of organizational leadership must demonstrate respect for human dignity and the common good regarding vulnerable stakeholder communities. Chapter 4 examines the vulnerable population of pediatric stakeholders to discuss two pivotal issues in the delivery of healthcare, undertaking pediatric research and managing pediatric obesity. Chapter 5 discusses the vulnerable populations of the elderly and those with disabilities, insofar as these populations have similar healthcare needs.

1. A.   Overview of the Argument

Like the human body, a singular healthcare organization (HCO) is comprised of many affiliated pieces and parts that provide, support, and pay for some form of healthcare service and treatment to patients. The anatomy of an HCO includes physician-centered, affiliates as well as independent legal entities such as integrated professional physician organizations, facility providers; and may also include integrated payer and health insurance services. These intricately interdependent systems of providers practice medicine amidst a backdrop of environmental challenges and external influences in the form of regulators, insurance companies and most often perplexed patients who want to make their own choices.[1]

As such, the HCO cannot operate in a vacuum concentrating only on its own self-interest while remaining blind to competing ones. It is accountable and has ethical obligations to a variety of internal and external constituents whose values, needs and professional standards may be in tension with its own. Just as the human body maintains homeostasis, the HCO seeks to maintain order among its diverse stakeholders in order to achieve organizational homeostasis. One way that organizational homeostasis is measured is by how well the HCO, through its leadership, achieves its goals through rational decision-making vis-à-vis competing values and constituent interests. Its constituents include not only its patients, but the broader society it serves, those whom it employs, and even the corporate community with which it interrelates.[2] Hence, this dissertation argues that homeostasis in this sense is reflected in the ethical accountability of organizational leadership to community stakeholders in healthcare.

This argument unfolds and is developed in the following way. Chapter 2 provides the foundation for the broader discussion concerning the ethical obligation for leadership accountability to community stakeholders in healthcare by first articulating an understanding of moral agency. It bifurcates organizational moral agency into two broad components – *individual* and *institutional* agency. Individuals and institutions are expected to support the core values, culture and structure that define the organizational ethics of the HCO. And, just as the human body cannot depend solely on the *form* of anatomy to achieve health, it is also the case that it takes more than the anatomy of an HCO to survive and thrive in an era of unprecedented change. It requires the exposition of moral integrity and the virtue of its leadership. That is, it requires soul. This chapter then illustrates the unification of individual and institutional moral agents, and their ethical decision-making through appreciation of the HCO's moral soul. It will reveal, through a specific use case, how deficiencies in governance, unaccountable leadership,

stakeholder abandonment, and uncritical decision-making can permit and even cause an HCO to lose its moral soul.

Ethical decision-making, as a cornerstone of accountable leadership, requires awareness of the community of stakeholders, an understanding of those to whom the leaders serve, and the expectations of those constituents. Accordingly, this dissertation presupposes and adopts as an undercurrent, "stakeholder theory" as an approach to organizational ethics that heeds the rights and interests or groups who interact with and could be affected by the organization's decisions.[3] The potential for corporations lacking soul and moral accountability for the consequences of their actions to do real harm to people necessitates checks on their power. It also bespeaks of the need to shift the managerial mindset from the shareholder to other alternative constituents who possess a stake in the company. The birth of the stakeholder theory is the epicenter of that mindset shift, and is discussed briefly in the conclusion of Chapter 2.

Understanding what it means to have a stake in a matter is rather uncomplicated. However, determining who is entitled to such a claim, the scope of the claim, and identifying those who are responsible to the holder of those claims, particularly in an HCO, is varied and widely diffused. As the title suggests, this dissertation selects particular communities of stakeholders – pediatric, the elderly, and persons with disabilities (Chapters 4 and 5) - and argues for the ethical accountability of the HCO to those stakeholder groups. Chapter 3, however, introduces an unconventional approach to understanding this argument. By briefly delaying discussion of the specific health interests unique to the particular stakeholder communities, this dissertation first illustrates the HCO's moral accountability to a set of multi-stakeholder interests that are inherent to *all* persons. That is, leadership's accountability to protect the *confidentiality* and *privacy* of the normative stakeholders to whom the HCO has a direct moral obligation.

Many stakeholder expectations are tied to social norms, and many are fundamental expectations that are not unique to healthcare but exist as a central aspect of human dignity. Confidentiality, as an expectation and cornerstone of trust in healthcare – is one such aspect. Consisting of two distinct subchapters, Chapter 3 first dives deeply into confidentiality; the ethical obligation to preserve that which every human person has, holds sacred, and may deny having at all - their secrets. Confidentiality is embattled in an age where knowledge is power, and predictive data analytic decision-making and technology provide a crushing influence of diverse stakeholders. Many constituents compete to ingest as much secret rich health data as they can swallow in order to advance their own, or their constituents' interests. To that end, this chapter emphasizes the ethical justification for exceptions to the legal and professional obligations of the duty of confidentiality in clinical care, and the effects of those exceptions on patient and third party stakeholder expectations.

It further explores the fundamental stakeholder expectation of privacy, which is often erroneously conflated and confused with the duty of confidentiality. This chapter illustrates the differences between confidentiality and privacy through examination of the duties and rights of the confidant and confider respectively. It further illustrates the intersection of the individual stakeholder's right to privacy in their personal information, the legal and ethical justification for use of such digital information to do good, and the need for an ethical guidance to minimize threats to privacy while respecting the dignity of the person.

Amplifying respect for human dignity, this dissertation then demonstrates how ethical accountability of leadership recognizes the common good and advances stakeholder interests for the benefit of specific communities of health - especially those who are the least empowered – across the life continuum. The analysis in Chapter 4 submits that concern for disempowered

stakeholder populations is essential for ethically accountable leadership. And to that end, it examines pediatric populations; specifically demonstrating the ethical justification for involving children in medical research according to specific ethical principles, as well as exploration of ethical remediation of the psychosocial and physiological harms from childhood obesity.

Equally critical, yet at the far end of the life-continuum, are the needs of the elderly and the oldest old. Ethical accountability in healthcare requires reasonable assurance that the unmet, long-term health needs of this seemingly inaudible stakeholder population are included in attempts to improve the human condition. Chapter 5 further articulates the ethic of care that focuses on the interconnectedness of people rather than their separateness in its discussion of the needs of elderly stakeholders. In the same distinctive manner, this chapter also explores the ethical accountability of healthcare leadership to embrace and improve the human condition of disabled populations through alleviation of human suffering, and to promote human flourishing, without endeavoring to eliminate human disabilities through genetic intervention. The analysis of each chapter is set forth in greater detail in the following sections.

Chapter 2. – Organizational Moral Agency

Because persons within an HCO are not unthinking automatons operating in lockstep with nothing more than a mere code of conduct to dictate behavior, a positive ethical climate requires synergy between its moral goals, the HCO, and the competing interests of its moral agents. When they are not in sync and the leaders and stakeholders are not aligned with the critical values and norms of the HCO because of different ethical perspectives, homeostasis is threatened, distrust ensues and perpetuates a negative ethical climate.[4]

As the seemingly endless demand for compliance standards and adoption of "best practices" seize the various domains within the U.S. healthcare system, establishing values and norms that are transparent to everyone within the HCO is critical to ensure ethical cohesion. The push for cost-containment, treatment alternatives, utilization management, and quality of care are merely a few of the realities that give rise to ethical tensions.[5] Establishing a relationship with the cohorts who are called to advocate for and are charged with acting in accordance with the values and norms, is vital to creating and sustaining an ethical climate.[6]

Employees and other workforce members of organizations are its agents. They are the cells and tissues supporting the organ systems of the organization. Additionally, they are most often the face of the corporate mission, and are the embodiment of its values. They are responsible for executing on its mission and they step into the shoes of the organization every time they act within the scope of their role – and quite often even when they are not acting officially. The expectations of this principal/agent relationship, and the HCO's prescribed norms and standards are at the core of the organization's ethics program. And with that, moral expectations must be known by all of the individuals in order to ensure that the HCO doesn't "require beliefs that some of them do not have."[7]

Morality concerns the norms surrounding human behavior which are good and right and are so universally shared that they are able to cement a stable social framework. It includes measures of conduct: standards such as moral/ethical norms and beliefs, principles, rules and theories. Some aspects of morality are so embedded into our social fabric that the norms they are said to dictate are said to form a *common morality* shared and recognized by all moral persons across different cultures. These include standard ethical norms such as *do not kill* and *tell the truth*.[8]

Some moral norms prescribe rules, obligations and duties to reduce or prevent harm. Others are created to increase the good, or to provide relief to those who are harmed by a particular situation. Since the HCO is structured as a system of integrated and varied affiliated stakeholders, it needs an ethical blueprint to clearly and unambiguously identify and memorialize its mission and deeply held values by which it is defined and how it makes its decisions. When the mission and vision, and the principles espoused in the ethical blueprint are consistent with the norms, actions and moral behaviors of leadership, what results is a positive ethical climate capable of supporting a trusted and sustainable organization.[9]

2. A.   Common Morality and Moral Agency

The roles occupied by individuals within the HCO are tied to the norms and standards that define expectations – e.g. the qualities of an outstanding assistant, a respected leader, and an effective and strategic-thinking CEO. The presumed standards constitute the notion of role morality and the individuals performing in accordance with these moral standards help to establish and sustain the ethical organization, in conformance with its ethical blueprint. Actions that fail to meet these standards, as well as the persons attributed to those actions are said to be immoral.[10] To satisfy these moral standards, and in the execution of their duties, individual moral agents acting on behalf of the HCO indisputably must be persons of unwavering integrity and character who are also adept at collaboration. Honesty, integrity and truthfulness are but a few examples of moral character traits, and represent virtues indelibly engraved in common morality.

A variety of stakeholders come together to contribute to, build, and sustain a morally accountable HCO. As moral agents, nearly all of the professions represented in the delivery of healthcare are expected to adhere to prescribed professional standards and codes of conduct unique to those disciplines; while upholding the virtues of common morality. The moral agency

ascribed to the HCO requires it to cohabitate with its professional, clinical and business professionals, and integrate their normative ethical duties and values into the HCO mission.[11] This ability to cohabitate must be bi-directional. However, because individuals do not react to competing internal and external influences the same way, and given the diversity of their interests, conflicts between stakeholders within the HCO and the HCO itself can emerge, and homeostasis upset is inevitable.

Although they do not act independent of their agents, and the cannot be moral *individuals*, organizations act as moral agents when they set moral goals defined by their ethical blueprint and when the organization *acts* through the collective decision-making of its agents.[12] And while an organization cannot have motives in the same way a person does, an organization is evaluated and adjudged to be moral, as well as immoral, by its constituent stakeholders as well as other organizations within its community. An organization is adjudged according to the decisions, intentions and actions of its agents as well as by the tone and configuration of its ethical blueprint.[13]

Since it is not unusual for individuals within an organization to decide matters and act collectively, such group actions are often so inextricably intertwined that it is often impossible to distill the individually identifiable actions and separate them from the moral agency of the organization itself. Nevertheless, when an organization performs in accord with a positive ethical climate, it is deemed a moral institution. When conflict remains unresolved, the blueprint is breached, and the integrity of the organization is threatened, it may be nearly impossible to know which individual is responsible for the deviation. Anticipatory understanding of where these decision-making conflicts and deviations may occur within the institution will help preemptively mitigate the risk of disorder. A morally justified decision-making process is critical to preserve

and even restore trust and integrity in an organization experiencing discord amidst its agents and other stakeholders.

2. B.   Organizational Leadership and Ethical Decision-Making

The presence of a genuine conflict of interest may itself explain an agent's desire to circumvent the decision-making process even at the risk of loss of soul to the organization. However, even in the absence of conflict, the organization's soul can be lost when ultimate decision-making is vested, intentionally or by default, in one dominant leader. Real leadership entails more than management and decision control. Accountable leaders and their followers are responsible for enacting the organization's vision, mission and strategies in ways that are socially and morally responsible.[14] Homeostasis is at risk when leaders are dispossessed of their moral agency and propagate environments of secrecy, hidden agendas, and physical settings that isolate workforce members from leaders, and emphasize status over human concerns.[15] The Allegheny Health Education and Research Foundation (AHERF) epic story exemplifies this dispossession.

Established in 1983, AHERF morphed over time to become a behemoth organization comprised of rapidly-merged healthcare entities. By 1997, the Allegheny Health System had the distinction of being the first and largest statewide nonprofit integrated health system in the Commonwealth of Pennsylvania. In 2003, it died a $1.6 billion death and carried the paradoxical distinction of the largest non-profit HCO bankruptcy in U.S. history. The tragedy of AHERF's rise, fall and disintegration is polluted with conflicts of interests, corruption, lack of stakeholder awareness, and various forms of cooperation that went beyond losing its moral soul and suffering anatomical disorder. In a Faustian sense, in the midst of morally unjustified decision-making it sacrificed its soul, and during its indiscriminate abandonment, gave no consideration to the fact that life cannot exist apart from it.[16]

Goodpaster and Matthews hold that rational and respectful decision-makers notice and care about whether or not the consequences of their actions lead to indignities and offenses towards others.[17] The stakes are even higher for the healthcare decision-maker. Unlike other industries where the consequences of decisions most notably affect products, services and profitability, decisions within an HCO can have direct impact on the quality, and even the longevity, of human life.[18] A notable paradox for an industry which advocates for human wellness is that decisions in healthcare are often devoid of humanness; the humanness attributed to *all* of its stakeholders.

The integrity of ethical decisions can be further abraded by the reality that healthcare is morally and ethically complicated.[19] Ethical decision-making, according to Weiss, depends upon the moral majority of the people engaged in the ethical reasoning. And while there are different levels of maturity, the tightly controlled corporate environment which typically characterizes an HCO can stifle ethical decision-making.[20] Further, issues and dilemmas affecting moral decision-making result from pressures that, as Weiss advances, are exerted at personal, organizational, industrial as well as societal levels. This chapter concludes with a brief understanding of these levels and decision-making approaches as demonstrated through the lens of stakeholder considerations.

2. C.   Stakeholder Theory and Normative Constituencies

Organizational homeostasis relies upon the systematic ability of the organization to respond to unanticipated sudden or gradual, threats to its stability and health. Determining the appropriate course of action often demands making choices that benefit some to the detriment of others. R. Edward Freeman is credited with developing the stakeholder theory to underscore and draw attention to the way that managers and other individuals act and the consequences of those

actions, based upon ethical principles. The most striking feature of the stakeholder theory is that it demonstrates ways in which organizations can exercise social responsibility through moral management without contradicting the framework of a capitalistic economy.[21] Because of the complexity of the entwined and interdependent interests within an HCO and its susceptibility to disruption, stakeholder theory is a promising model for maximizing value and creating opportunities. It acknowledges moral agency and diversity of values[22] which appeals to the climate of the HCO and helps to ensure homeostasis.

Freeman holds what is widely recognized as the seminal definition, and will unless otherwise stated, be the position that this dissertation adopts. An organization's stakeholder is, "any group or individual who can affect or is affected by the achievement of the organization's objectives."[23] Methods of identifying stakeholders and determining the organization's duty to them is an exercise in moral classification. In shaping its argument, this dissertation assents to Phillips' theory of normative and derivative stakeholders; focusing specifically on specific normative stakeholder communities.

According to Phillips normative stakeholders are those individuals and groups of individuals to whom the organization has a direct moral obligation to attend to their well-being. It does not matter whether they are internal or external to the organization. What matters for Phillips and for this dissertation is that they are descriptive of their relevance and presences as customers, patients, employees, local communities, suppliers, financiers and lenders. By virtue of their humanness, normative stakeholders are afforded greater moral consideration – stakeholder fairness – in corporate decision-making than other social actors.[24]

Chapter 3. – The Ethical Challenges of Maintaining Stakeholder Confidentiality and Privacy

In applying Freeman's stakeholder definition, which looks at those who can affect or are affected by an HCO's objective successes, this chapter extensively examines the concept of confidentiality, and the right to individual privacy. In a society where knowledge is power, predictive analytics dictates decision-making, and data has become "the raw material of the information age,"[25] the time-honored respect for patient confidentiality, and the evolutionary establishment of patient privacy rights are axiomatic multi-stakeholder issues. These issues transcend all communities of care, and are in most cases agnostic to the particular patient's healthcare condition. These issues are instead intrinsically tied to humanness. Because these confidentiality and privacy interests are inseparable from their subjects, and influence decision-making across the HCO spectrum, this dissertation thoroughly explores *both* interests ahead of the subsequent normative stakeholder discussions. It does so by bifurcating both interests into two distinct sections; one setting forth the duty of confidentiality, and the other illuminating expectations of privacy.

3. A.   Confidentiality and the Ethics of Secrecy

Preserving the confidentiality of patient secrets while satisfying legitimate HCO stakeholder interests is daunting, and is not without limits.[26] To that end, this chapter illustrates the ethical justification for deviations from the legal and professional obligations of the duty of confidentiality in the delivery of care, and the effects of those deviations on patient and third party stakeholder expectations. At the core of confidentiality is the sacred status of a human person's secrets, as exhibited at the beginning of this chapter.

This section introduces the anatomy of a secret, the ethics of secrecy, and the fact that secrets are a natural part of humanness. Because there are limits to man's willingness to reveal certain truths about himself, those truths, or secrets live in the essential recesses of every person. Secrets define aspects of selfhood that intentionally remain hidden in order to preserve that which is uniquely human and different.[27] In healthcare, secrecy is a controversial matter as confidentiality is frequently abdicated to advance the interests of persons other than the patient.[28] Moral agents cloaked under the seal of confidentiality of secrets are found anywhere and everywhere humans interact, including within families, businesses, and professions. However, the somewhat contradictory reality in today's healthcare is that confidentiality is a porous obligation.

Keeping secrets about oneself demonstrates respect for the demarcation line between public and privacy life. It demonstrates respect for autonomy. This dissertation looks at the works of Sissela Bok and Anita Allen to better understand the connectivity between keeping secrets and telling the truth and their relevance in contemporary healthcare. To that end, Sissela Bok writes that secrets concerning those areas of their lives about which humans are most comfortable and know most intimately warrant the most intense attention, yet "we also experience as secrets the spaces from which we feel shut out."[29] Such is the case for the patient seeking care from a physician. Allen explores the fact that people conceal information about their health long before they see a physician, as what people learn about themselves often occur through self-encounters.[30] In addition to concealment of secrets, this section also investigates the moral imperative to tell the truth which is incumbent upon both the patient and the physician who have entered into the treating relationship.

3. B. Professional Duty and Legal Obligation

Both mental health professionals and laypersons alike advance the notion that confessing one's secrets is good for the soul, and that revealing secrets that one withholds about themselves is cathartic.[31] However, since antiquity respect for patient confidentiality has been a fundamental moral precept and professional responsibility of physicians. The promise to "not divulge, as reckoning that all such should be kept secret"[32] concerning things learned about a patient in the course of the treating relationship still resonates today. However the dynamics of modern healthcare, and the demands of civil society to adjudicate the truth serve as disruptors to many of the traditional roles of confidentiality. Thus creating ethical dilemmas for clinicians; leaving some to argue that confidentiality is dead."[33] This section concentrates on the ethical justification for exceptions to confidentiality and the tremendous uncertainty by and among physicians concerning when secrets can become public. This is explored more fully when considering the tension between the scope of privileged communications and the need for compelled disclosure of patient secrets.

3. C.   Clinical Ethics

The lines between what is protected under the duty of confidentiality, what is required to be disclosed by law, and what is necessary for the benefit of society are obfuscated at best. In sum it can be said that trust protects secrets, and "confidentiality protects trust."[34] As this chapter expands and demonstrates later, trust invokes privacy, and the law protects privacy. But the gap between what prevents breaches of trust, and departures from the rule of law, from becoming violations of privacy must be backfilled with principles of clinical ethics.

Nowhere in healthcare do ethical principles align with specific contextual needs more than in direct clinical care settings. Clinical care defines the humanness of medicine through direct physical contact and observation, and has the most notable impact on respect for human

dignity and well-being. The therapeutic relationships created within the clinical care setting are supported by the core principles of autonomy, beneficence, non-maleficence and justice.[35] Specifically, this section examines how patient secrets are obtained and shared in right relationship with the ethical principle of autonomy and its constituent principle of confidentiality; particularly when these principles are in conflict.

3. D.   Psychotherapy: Secrets Kept…Secrets Shared

Few areas of healthcare venture closer to the core of humanness than that of the psychotherapeutic practice. Psychotherapeutic practice has long respected the rule of confidentiality stating that information disclosed by the patient to the therapist in the course of the therapy may not be shared with others without the patient's express prior written consent.[36] Freud considered the promise to preserve the confidentiality of psychotherapy quintessential to successful treatment. So much so, that he encouraged patients to not reveal the fact that they were *in* treatment with *anyone* else, including intimates, spouses and other family members.[37]

The rule of confidentiality protecting psychotherapeutic secrets is an ethical principle, a professional obligation, and in many jurisdictions is supported by state law.[38] Despite these safeguards, ethical and societal conflicts unique to behavioral health and psychotherapy arise when breaching confidentiality is necessary to prevent imminent harms to other stakeholders, or to deliver justice. The tension between the principles of autonomy, beneficence and non-maleficence are vividly illustrated in this moral dilemma. Because the content of these secrets may subject the therapist to a dual allegiance; that which they have to their patient's confidentiality, and that which they may owe to society, this dissertation delves deeply into that ethical tension. The tension between protecting psychotherapy as a public good, vis-à-vis the duty to protect the public from patient-induced harm is discussed more fully in this chapter.

3. E.   The Genomic Dilemma

The moral value of confidentiality, and the duty to respect secrets is no longer confined to those belonging only to patients and research data subject. When ethical conflicts and competing obligations such as those exemplified in psychotherapy arise, principles of beneficence and non-maleficence may override confidentiality for the sake of *non-patient* third party stakeholders – thereby creating a moral dilemma.[39] Even when the third party benefit is imperative, those principles may beget a moral predicament for the physician. Such predicaments must reconcile not merely how much information to disclose to the unsuspecting and perhaps disinterested patient or non-patient, but also *what kind* of information to disclose, and perhaps most importantly, whether to disclose any information at all. These dilemmas are traversing unchartered terrain especially in the context of genomic mapping, genotyping, and genetic testing information. The duties of the physician, and the rights of patients and other stakeholders to know, and *not to know* predictive genomic information is a probing matter that defies traditional understanding of the duty of confidentiality and the practice of medicine, and rounds out the discussion of confidentiality in this chapter.

3. F.   Privacy

The challenges of maintaining confidentiality in healthcare are further exacerbated by the reality that patient information holds the key to unlocking crucial medical advances. Data is the lifeblood of the HCO. Like blood, which transports nutrients and waste, regulates balance, protects against pathogens,[40] good data not only helps to maintain homeostasis it enables growth, regeneration and even procreative transformation of the organization. As big data analytics draws from this lifeblood and innervates its body through the new age of algorithmic neural networks, personal privacy is endangered. This section explores this most controversial issue in

contemporary healthcare; how much, and to what extent must stakeholder privacy be protected, and the ethical justification for sacrificing privacy to ensure the HCO meets its obligations to deliver care for the common good.

This chapter section proceeds by briefly considering the evolution of privacy as an individual stakeholder claim, providing the foundation for current concepts articulated by contemporary theorists Alan Westin, Daniel Solove, Adam Moore, Julie Inness and Anita Allen.[41] Although it is a timeless concept, and its earliest expressions date back to antiquity and beyond,[42] it is not always clear what the word *privacy* means. It is unclear whether privacy is nothing more than a feeling evoked, or if it is to be respected as a moral, or legal claim; whether it is an individual, or collective condition. This section considers privacy's societal concepts and values as evidenced through the ponderings of the aforementioned theorists and privacy advocates.

Solove underscores the reality that "the matters we consider private change over time…because of changing attitudes, institutions, living conditions and technology[43] and are often contextual. This section shifts the dissertation focus to the right of privacy as a healthcare value. The intimate details about a patient's body, their mind, and all of their life experiences, including those surreptitious trials that may affect their health and dignity, are bathed in privacy. This dissertation is concerned specifically with the legal and moral challenges created by physical, decisional, and informational privacy; although as the subsequent sections demonstrate, the demarcation line between all three is blurring.

3. G.   Protected Health Information and the Need to Know

Healthcare is predominantly an information business. Treatment, quality measures, patient safety, efficacious clinical outcomes, clinical research, and reliance on advanced technology are merely a handful of the objectives that depend upon the acquisition and use of patient information.[44] But personal patient data has not always been the main course in the digital information feeding frenzy that is the hallmark of healthcare today. Prior to the introduction of computerized data in the 1970s, most data sets were created manually from the individuals treating the patients.[45] As recently as 20 years ago, physician notes and the mental impressions of patient encounters were still written by hand, memorialized on paper and treated with confidential reverence. All of that has changed.

This dissertation examines how the body politic of the late 1990s and the mobilization of healthcare public policy whetted appetites for what would amount to a far-reaching liberation of personal patient information. It proceeds to articulate the need for individual stakeholder legal rights to privacy in their protected health information (PHI) as promulgated through various legislative and executive pronouncements such as the HIPAA Privacy Rule (2002) and Security Rule (2005).[46] It then introduces how the proliferation of health information technologies that are dependent upon digital data is in palpable tension with the patient stakeholder privacy preferences, their exercise of control, and their expectations.[47]

Specifically, the interoperability of electronic medical records between multiple providers means that the physician-patient relationship is no longer binary[48] Nearly all information conveyed in the course of the treating relationship, presumed to be confidential, will now be accessed and used by hundreds, if not thousands of entities; many of whom will be unknown to the patient. Just as important, they will likely only know the patient as an identifiable data set, and never as a unique and distinct person. And, because of big data, the number of those

unknown end users grows exponentially. This implications from big data, and particularly the future of digital data must elevate concerns over stakeholder privacy to a place of prominence in the ethically accountable HCO.

3. H.   Big Data, Big Opportunities

"Data is not information, information is not knowledge, knowledge is not understanding, understanding is not wisdom."[49] By describing the world of information according to what it is *not,* Clifford Stoll contends that knowledge obtained from information requires a process of applied learning, continual improvement, and refinement of data. All with goal of achieving some great outcome.[50] The evolutionary progression from raw data to knowledge, and then to action is typically the purview of data scientists whose job it is to pour over and tease through terabytes of data in order to interpret and analyze presumably for some anticipated good of the organization and its stakeholders. Data drives innovation in healthcare.

Because more and more data sets are being created for and about people every second of every day, this data will continue to persist under the control of others[51] whose relationship to the HCO and patient stakeholders is increasingly distanced and attenuated. This attenuated control endangers the notion of stakeholder autonomy, and the unanticipated secondary uses of the information could call into question the validity of the consent voluntarily provided by the patient stakeholder. Weakened individual control is only one of the challenges presented by 'big data.' This chapter will probe further into the complexities of big data use in healthcare. It will consider the opportunities for profound advances in medicine and care delivery through advanced analytics and technologies. In addition it examines the ways in which big data affects how stakeholders wield power, methods of decision-making, the privacy tradeoffs, and the inadequacy of privacy laws to address those tradeoffs.

3. I.   Algorithmic Decisions

Likely the most appealing attributes of big data for business and governments are its ability to monitor human behavior individually and collectively, in addition to its predictive capabilities. It is important to recognize that the *bigness* of big data is not so much because it is massively amalgamated for anyone to remove pieces and chunks as desired. Rather, *bigness* refers to its nearly irrepressible capabilities. Capabilities which "connect disparate datasets through algorithmic analysis" that cobble together unpredictable relationships from data collected and various times and places, in various formats, drawing inferences for myriad of purposes.[52] This section of Chapter 3 takes an in-depth look at big data analytical insights in healthcare, and specifically at algorithmic decision-making as an inflection point that provides the means for decisions that were once made by data scientists, to be made by computer systems.[53]

In so doing, this section defines the roles, and illuminates the virtual detonation of artificial intelligence and machine learning in healthcare through notable examples such as Google's DeepMind. In addition it looks at the proliferation of medical devices which perform their life-saving functions according to a machine's thought process; devoid of human thinking. To that end, this section argues that algorithmic decisions, as a critical tool, provides incalculable good to healthcare. But as an unchecked weapon, it can do great harm.

Because of the intrinsic risk of data-driven discrimination, this dissertation contends that the ethical challenge for algorithmic decisions is to inculcate moral judgment – that uniquely human capability – into the big data universe. For, according to Purves, Jenkins and Strawser, "[h]uman moral judgment is not codifiable…Moral judgment requires…the ability to perceive

certain facts *as* moral considerations."[54] Such should be the impetus for accountable healthcare leaders to establish and implement ethical guidance for big data use.

3. J.   Ethical Guidance

The erosion of individual control exacerbated by artificial intelligence and robotics, facial recognition, undetectable wearable technology, augmented realities and even transhumanism threatens to invade and alter the sanctity of stakeholder privacy in healthcare. It is apparent, more so than ever, that the ethical commitment to privacy as an indivisible constituent of human dignity is a constant that, as yet, cannot be digitalized. Ethical decisions and moral judgment requires human influence. So much so, that privacy is revitalizing the field of ethics. According to Forrester Research, "ethical privacy practices will be the next consumer-driven, values-based source of differentiation"[55] As argued throughout this paper, ethical decision-making considers the humanness and dignity of the individual. This dissertation will show that accountable healthcare leaders must consider the moral rights of their stakeholders, which includes their privacy rights and interests when setting data use and strategy policies. Understanding ethical use and management of stakeholder information necessitates the creation of an ethical approach that considers what is legal, fair, and just, and has at its heart a better respect for human dignity.[56] Chapters 4 and 5 of this dissertation closely examine respect for human dignity through the lens of leadership accountability to those who are most vulnerable: pediatric, elderly and disabled populations.

Chapter 4. – Community Stakeholders in Healthcare: Pediatric Populations

Corporate social responsibility (CSR) is concerned with the HCO's duty to respond to its stakeholders, and is a continuing commitment to look beyond its core business to the

externalities that affect all of its stakeholders and constituents. Pointedly, the morally responsible organization must realize and understand the complex interconnectedness between social and economic forces on its stakeholders. To do otherwise would, as Freeman predicts,[57] "fail to describe and predict the business world as it really is."[58] For the sake of its stakeholders, healthcare cannot afford such a miscalculation.

As this dissertation argues, providing for the common good is both a human right inured to the members of society, and a duty, for those empowered, to provide. Healthcare is a common good of a moral and civil society.[59] To that end, these next two chapters focus on the HCO's moral obligation, and social responsibility, to ensure access to clinical advances, and respect the dignity of stakeholder groups who are most vulnerable and disempowered across the life continuum.

4. A. Transcending Risks to Serve the Vulnerable

With its concentration specifically on human flourishing at the beginning of the human life continuum, Chapter 4 proffers an ethical justification for managing risk and engaging children in clinical and social research studies. Society's long-held preconceptions that women and children were weak, cloaked them under layers of protections and safeguards that historically excluded them from involvement in clinical research trials. Such exclusion resulted in a dearth of research on women and children, and a lack of clinical understanding of these groups of people. This chapter will argue for the need to avoid exploitation of children through equitable selection of participants, principles of informed consent, and concise ethical risk of harm and benefit analysis that respects human dignity. Pivotal to this argument are the roles of physician and researcher; who are most often one in the same. Throughout this chapter ethical issues specific to particular clinical, cultural, and social contexts relating to pediatric

communities will be illuminated; such as children and adolescents with HIV[60], those who suffer

from abuse and neglect, and children with special cognitive needs.

Since at least the Enlightenment period, mankind's desire to discover and uncover the

answers to life's mysteries through inquiry and scientific thought, has been fueled by the notion

that knowledge is power. In much the same way that extracting knowledge from big data

necessitates a process of repeated refinement and understanding to avoid harm, the pursuit of

knowledge of the medical world does not come without risk. While it can help and heal, the

pursuit of knowledge from human research can also bring with it infinite harms that may

disempower populations of people if obtained unethically. Specifically, ethically deficient

clinical research can exploit children on many levels.[61] This section provides a synopsis of the

dynamic history of clinical research – specifically relating to children - and the development of

the principles and processes enabling their participation in it.

4. B. Applying the Principles to Pediatric Research

Because they differ from adults, research with children is essential to understand the

pathology of disease and disorders involving them. Some diseases are unique to children, and

because they are not little adults, nor are they non-adult beings, their physiology and psychology

must be understood within the pediatric context. Although research with children is vital to child

health, this species of research remains a source of controversy.[62] The ethical challenges arising

from pediatric participation in research emanate from the presupposition that it is appropriate for

children to participate in research in the first place. This paper will not debate appropriateness

but will begin with the premise that ethical research ought to include children, provided that the

researchers first employ principles of justice and equitable selection of children. It will approach

the topic of inclusion versus exclusion through the lens of a few notable theological and philosophical theorists.

Ensuring that human research participants validly grant their consent is one of the core ethical principles of the Belmont Report; which codified the basic principles of respect for autonomy, beneficence and justice into the cornerstone principles of research ethics.[63] Consent underscores respect for persons, preserves autonomy and ensures that people maintain control over their lives – especially children. In addition, there is a legal basis for procuring consent from those who have parental responsibility over children.[64]   This section addresses this topic by highlighting the regulatory approaches to valid parental consent, the child's assent, barriers to informed consent, and the intersection of institutional review boards (IRBs) accountability for situations when consent may not be necessary.

The idea of avoiding harm, proffering benefit, and minimizing risk to children in clinical research has many dimensions. Harms are not always physiological, and are wide-ranging and dynamic – from unanticipated intrusions into privacy and embarrassment, to violations of personal dignity and self-respect.[65] Benefits are not always known and are often not detected until long after the study closes; they may not even inure to the study participants themselves.[66] Further, risk assessments look at probability and severity of harm through the lens of what is reasonably foreseeable or what is already known to have occurred.

Accordingly, this section addresses the fundamental importance of risk of harm assessments – particularly as they are influenced by the condition of the child entering the study. On the one hand, a child with a disorder may be susceptible to greater harm from a research procedure than a child who is healthy. Conversely some argue that children who are healthy

ought to remain so and are therefore entitled to greater protection. These relative positions are part of the ongoing conversation surrounding risk of harm assessments.[67]

4. C. Pediatric Vulnerability in Three Contexts

As this thesis demonstrates, ethically accountable healthcare organizations have a moral duty to address the needs of its community of stakeholders. Vulnerable populations and subpopulations of stakeholders are within the purview of an HCO; and they are dependent upon it to satisfy many of their physical and emotional needs. Children are inherently and conditionally vulnerable. Contextual vulnerability considers more than the intrinsic characteristics of the individual; it considers the contexts in which they find themselves.[68] This section explores, through the lens of pediatric research as a contingent vulnerability, the contextual backdrops to vulnerability unique to children with HIV, victims of abuse and maltreatment, and children with special intellectual and cognitive and disorders.

4. D.   Ethical and Legal Strategies for Managing Pediatric Obesity: A Moral Duty

The concept of *population health* refers to an "understanding of the epidemiology of a particular population and aligning a community's healthcare resources to not only treat illnesses…but to keep the population healthy."[69] Managing population health, particularly with respect to vulnerable populations, requires accountable leadership who possess a moral commitment to the sustained health and lifelong fulfillment of patients and communities served by the HCO.[70] Principles of stewardship, normative stakeholder theories, community-oriented health programs, and the duty to provide for the common good dictate an urgent commitment from HCOs, providers and even policymakers to disrupt this environment and act to protect this at-risk population. The remainder of this chapter addresses a specific slice of this population

health sphere. It considers with some depth, the ethical and legal strategies for accountable leaders to prevent and mitigate the psychosocial and physiological effects of pediatric obesity on children.

Even though one-third of the world's population goes to bed hungry each night, *over-nutrition* – that which occurs when too many calories and excess nutrients and food components are consumed vis-à-vis suboptimal energy expenditures – is rampant in the United States. Barring some intervening metabolic disorder, over-nutrition nearly always results in excess levels of fat tissue and bodyweight. Calculated against an individuals' height, the resulting body mass index (BMI) is the standardized yardstick used to determine whether an individual is obese. American's are among the top ten fattest people in the world, and its children are among the largest.[71]

Since 1980, childhood obesity rates have tripled to the point that close to one-third of children over age 2 are overweight or obese.[72] More than a mere descriptive word associated with BMI calculation, obesity is a multi-factor condition[73] that has wide-ranging genetic, societal and behavioral causes that begin in childhood and can continue into adulthood – rendering it a two-stage disease.[74] Obesity's impact is so diverse and dramatic that the World Health Organization Consultation on Obesity's prescient report determined it to be a highly neglected public health problem with a potential impact as great as that of smoking.[75] Since this conclusion was drawn, obesity as a public health threat has gained the same recognition as anti-tobacco and related legislation, especially with respect to its influence on children's behavior. This section examines the state of the childhood obesity as a public health crisis through the lens of societal, socio-cultural and environmental influences.

4. E. Obesogenic Vulnerability

It is widely understood and accepted that untreated obesity-related medical conditions will threaten the life of a child if they are sufficiently severe; particularly when the conditions are in the later stages of deterioration. Physical manifestations such as Type II diabetes, hypertension, asthma and sleep apnea can have devastating and debilitating effects well into adulthood. While the long-term medical consequences of pediatric obesity are well-recognized, the less obvious but highly destructive and indelible consequences of pediatric obesity, and clearly the most pervasive one in Western societies, are its psychosocial costs.[76] Because of the stigma, shame and isolation of obesity that often follow the child into adulthood, the psychosocial costs of pediatric obesity are often more chronic over their lifetime than the physiological.[77] Following a sketch of the most sinister physiological effects of obesity, this section will present the sobering psychosocial consequences and harms that threaten children; harms that can scar well into their adult lives.

4. F. *Parens Patriae* – Parenting the Community

The psychosocial consequences from being obese are socially constructed harms. As such, the social costs along with discrimination of all sorts are significant public health risks that warrant community intervention in executing remediation strategies. As an interdependent unit, it is incumbent upon the community of stakeholders, which includes the HCO, to consider the vulnerability of obese children in the face of obesogenic influences, and its duty to protect them. Somebody must account for those who cannot yet fully take care of themselves. And, the strategies employed must take into account the cultural influences and community values that affect obesity trends.[78]

Individualism and individual choice and the freedoms associated with them undergird the prevailing ideology in the United States. In conformance with societal norms and generally accepted values, a person should be able to choose what is best for them. Childhood obesity is not typically an example of personal choice, but rather a public health and societal problem. However, balancing the autonomy of the parent and their right to raise their children in their own way, according to their views and values is paramount. Parents have right to raise their children according to their perceived best interests, and interference against their will is highly controlled and limited only to the most serious cases.[79] However, where the best interest of the child is threatened, and where the choices of the parent endanger a child's life, or in the case of public health, the lives of obese children generally, community stakeholder intervention – which may include the government – can be ethically justified.

The argument for intervention requires a foundation from which the principles of the duty to do good and avoid harm, intersect with the individual rights to be left alone, and the state's responsibility to advance the community's best interests. This final section proffers a theory of principled communitarianism as that foundation. It applies the best of all three objectives. It incorporates the communitarian emphasis on the social and interdependent nature of life and what is best for the community in establishing society's moral thinking, and attributes responsibility for execution to the community.[80] This section then presents the legal doctrine of *parens patriae* to cases of persistent obesogenic environments engendering medical neglect, and argues that the state, in cooperation with the community and HCO have a moral and legal duty to protect these children.

Chapter 5. - Community Stakeholders in Healthcare: The Elderly and Persons with Disabilities

Vulnerability ensues when consequences and conditions render certain stakeholder populations susceptible to physical, economic and social harm, or disadvantage. However, people are also at risk from social biases that have less to do with their actual conditions and more to do with societal perceptions and preconceptions of them. Biases can disadvantage, discriminate and disempower. Elderly persons and persons with disabilities are often victims of such biases. For example, at some point in the life continuum, the elderly face a culture that frequently treats them differently from youth; buoyed with the presumptive undercurrent that they have lived a good life already.[81] Youth represent beauty and promise, whereas the elderly demonstrate the transient nature of life, and the death that is certain for everyone.[82]

Even though most people will experience some type of physical or mental impairment before they die, few people are willing to identify themselves as having a disability, or admit to the inevitableness of such condition. As such, persons with disabilities very often become the "other" and are dehumanized; often considered a "counterpoint to normality."[83] This chapter illustrates the ethical responsibility of accountable healthcare organizations to meet the needs of their most inaudible stakeholder populations; that is, the elderly, and those with disabilities. It explains this through an ethic of care for long-term assistance for the elderly, and through the promotion of human flourishing through respect for the human condition concerning persons with disabilities.

5. A. The Elderly Population – The Cared For and the Caregiver

Aging is an ambivalent reality. While the vast majority of emotionally healthy and well-adjusted people hope to live a long life, few relish the thought of growing old. Hardly anyone can admit a willingness to embrace and welcome the physical, emotional and even economic challenges that inevitably accompany growing old. "Even at their healthiest, the aged are

vulnerable and fragile."[84] Living a long life presents challenges to the elderly as well as to the communities within which they live. Nowhere are these challenges more visible than in the resource allocation and mechanisms that provide access to long-term healthcare services to the very old. This chapter will demonstrate the ethical justification for providing long-term and informal care to the chronically ill elderly, despite the era of age-based rationing, and ageism tendencies. This justification is articulated through policymaking initiatives that are supported by an ethic of care.

Not only is the process of aging and the attitudes surrounding it ambiguous, the meaning of the term *elderly* is equally nebulous. Any conversation addressing the needs of the elderly must emerge from an understanding of how the population is defined in the United States. In 1935, the United States determined the age of 65 to be the benchmark retirement age through its adoption of the Social Security Act;[85] patterning itself after the European nations chronological eligibility for old-age insurance. *Older* has since been defined as those aged 65 and over. According to the most recent U.S. Census, this group now represents 13 percent of the total U.S. population.[86] As of 2016, there were more than 6 million persons over the age of 85 living in the U.S. with 81, 896 of them over the age of 100. This expanding population represents some of the most acutely sick persons requiring some of the costliest and most protracted health care. This statistical profile is an essential launching point from which policy makers consider the needs of this vulnerable segment of society.

Because medical advances and technology have made it possible to prolong healthy human life, this medical progress also includes prolonging the lives of those with chronic disabling conditions and functional disabilities. Women are more likely than men to suffer from multiple chronic conditions that are not necessarily imminently life-threatening although they

generally result in limitations to mobility, physical and social activities. Men utilize more in-patient services – reimbursable by Medicare – whereas women use more prescription and custodial care services. The net result is that Medicare covers a smaller portion of women's healthcare needs. In addition, women are disproportionately impacted by healthcare access issues because they live on average 7.5 years longer than men.[87] This section unpacks the need for formal and informal long-term care for these elderly, as well as the benefits such services confer. It further argues that current policy trends and age-based rationing preferences obstruct access to these vital services; providing them only to the most dire, means-tested, financial need while denying access and assistance to those on the fringes.

5. B.   Public-Policy and Age-Based Allocation and Rationing

The purpose of policies are to articulate how governments allocate resources, influence behaviors and help to ensure the security of its constituents. They also reflect common consensus about values, and tell a story about people, history and what is important to the populace. As Holstein, Parks and Waymack aptly state, policies try to solve problems or support core beliefs.[88] Throughout the past several decades, certain core beliefs concerning the rationing of healthcare needs of the elderly have dominated policymaking thinking. Recognizing that there are various meanings ascribed to the term "rationing," this dissertation accepts the definition adopted by the Catholic Health Association as "the withholding of potentially beneficial services because policies and practices establish limits on the resources available for health care."[89] This chapter will review several predominant views of allocation and age-based rationing in order to demonstrate that an ethic of care must overwrite any consideration of such rationing and therefore support liberating constraints on the provision of long-term care services.

The belief that the elderly are a "bottomless pit of needs" and that meeting those needs will disproportionately stress already stressed financial resources, undergirds much of current public policy and forms the basis for age-based rationing.[90] This analysis looks closely at the range of thinking espoused by Callahan, Daniels, Menzel and Kilner.[91] Their thinking spans the continuum from rationing of services based on a perceived natural lifespan, to a care-oriented approach with "care" as the central principle.

As this chapter demonstrates, society's frail and elderly stakeholders have unmet needs. Policymakers must also understand better that the cultural and economic contexts coupled with the healthcare system's reimbursement payment structure, fail to provide for these needs. Current policy trends fail to consider the total-care delivery package which takes into account a comprehensive view of the elderly patient before, during and after acute care treatment. Healthcare cannot be considered independent of the social services required to support the elderly when their capabilities begin to decline.[92] This section explores further the implications of the U.S. model of needs-based claims, and considers briefly the opportunity of providing long-term care through social insurance.

5. C.   Reshaping Public Policy through Ethic of Care and Compassion

Reshaping public policy on long-term care requires redefining what is meant by *care,* the persons and communities involved, as well as their obligations and duties necessary in providing that care. The traditional medical model recognizes the interaction between the clinician and patient, and to some extent, third-party payers. However, many more persons and organizations are involved in critical ways when in-home and other community-based long-term care services are considered.[93] With the patient at the center, the delivery of appropriate, affordable and quality services depends upon the relationship between the patient and the encircling community

of stakeholders. Stakeholders include family members, professional and facility providers – including social workers and therapists - as well as government agencies, and professional associations who establish standards of care.

Accountable leadership necessarily obligates the HCO and its stakeholders to accept the need for community support for access to long-term elder care. To that end, Holstein, Parks and Waymack advocate for an ethic of interconnectedness in policymaking. They assert that the interconnectedness of individuals and groups are linked together by the values and ethics of the group. Further, they submit that policymakers and legislators must first assent to the importance of access to long-term care and the values attributed to it.[94] In short, this analysis contends that ethically justified care for the elderly must shift its focus from high-technology acute medical services to recognition of the community-based interdependent relationships. Relationships that support low-technology, informal care standards – based on the ethic of care and compassionate humanism.

This chapter explains that the healthcare delivery system in the United States is traditionally far less centered on *care* and is more precisely a health management *delivery* system. It further argues that to focus on the interconnectedness of people rather than their separateness, and to establish *care* as an organizing principle supported by norms and an ethic of care for the population, enriches the lives of the vulnerable within the community. Policies supporting long-term care for the aged and elderly must include provisions that strengthen the relationships that sustain people and bolster the interconnectivity and interdependency of humanity. Interdependency reminds everyone, including policymakers and accountable healthcare leadership, that the human lifespan encompasses a lifetime of stewardship, which just as the Catholic Church teaches, is necessary at every stage of life.[95] When policymakers imbed

this virtue into policy, the moral justification for public support of long-term care communities become self-evident. As is the case with pediatric communities described in Chapter 4, stewardship promotes the authentic good of human beings and human society, and preserves human dignity and self-respect; both for the aged and their caregivers.

While the principle goal of long-term community-based care is respect for the human dignity of the aged and chronically ill elderly, policymakers and healthcare leaders must develop and promote policy models that sustain person-focused compassion. As advanced by Tellis-Nayak and Tellis-Nayak, that entails a model that considers and advocates for the needs of all participants in care – the elderly, the family, and other caregivers.[96] The remainder of this chapter examines the issue of person-centered, collaborative and holistic care through the works of Nayak and Nayak, Nancy Fox, and Murial Gillick, and by providing examples of current models of care.

5. D. The Dignity of Disability

This dissertation's argument for ethical accountability of healthcare leaders to their communities of stakeholders, will conclude its analysis with a vivid examination of the needs of stakeholders with disabilities, and the attendant obligations of the HCO. Specifically this final section will demonstrate the healthcare profession's obligation to improve the human condition of persons with disabilities through the alleviation of human suffering and disease; hence enabling them to flourish. The alleviation of suffering and disease, however, does not presuppose the total eradication of disability. To the contrary. This analysis contends that disabilities entitle those who possess them the dignity to live with their particular disability identity in right relationship with their environments;[97] without obstacles to obfuscate them.

Consistent with this paper's emphasis on human dignity and concern for the disempowered, this section opens by exploring what it means to be human, to flourish, and to live a good life; with particular emphasis on the unique demographic of with those disabilities. It illustrates the aspects of humanity and human disability from evolutionary and theological perspectives. Understanding the various dimensions of the human condition of disability – especially the medical model - are necessarily influenced by the principles of beneficence, autonomy, non-maleficence and justice. These principles alongside genetic technology and medicine undergird the duty to improve the human condition by preventing mortality, morbidity, and even disability.[98] With that, this dissertation will also look at humankind's desire to improve the human condition from beneficent interventions, to understanding the roots, history and evolution of eugenics.

The argument for HCO leadership accountability to this vulnerable stakeholder group concludes with demonstrable justification for enabling opportunities to reverse the negative attitudes towards disability through the ethic of care. It further asserts recommendations for imparting disability ethics into decision-making, and eliminating *barriers to human flourishing* for those with disabilities, rather than the eliminating a disability, through the musings of leading theorists, including Paul Jewell, Celia Deanne-Drummond, and Tobin Siebers. In the end, it contends that accepting what are considered human disabilities requires a shift away from a culture that pursues perfection at all costs, and insists instead on recognition that the beauty found in the person with a disability is not dependent upon human perfection.[99]

Disability is pertinent to the human condition.[100] In order to fully understand the moral obligations that HCO's have towards those with disabilities, the conversation must begin with an understanding of what it means to be human. Accordingly, this section explores humanness from

the evolutionary, and theological perspectives. From the position of evolution, humans and their

embodied nature are distinguished from other animals, and are studied according to how they

live in relation to tensions in their environment; as well as in terms of human biology and

characteristics.[101] The Judeo-Christian tradition, which has influenced western thought, holds

that what makes animals human is that they are made in the image and likeness of God. And,

humans possess divinely bestowed dominion for overseeing things produced for the good of

humanity, as well as for those who produce such them.[102] This dominion presupposes the duty to

change and improve life for the rest of humanity. The complex variables that challenge and

affect human life, and inspire change are what Doerfler refers to as *conditio humana* or *the*

human condition.[103]

The human condition – the endeavor to move humanity through these challenges and

variables – is universally seen as broken and flawed. Accordingly, whether the human condition

is viewed theologically or scientifically, it strives to eliminate human limitations, alleviate

suffering and improve the quality of human life and fulfillment. Understanding the depth to

which humanity may dive as it pursues elimination of limitations – particularly those perceived

limitations associated with human disability – requires examination of the concepts of human

flourishing and the good life.[104] The remainder of this section is dedicated to that examination.

5. E. Improving the Human Condition of Disability

In its moral quest to improve the human condition, humanity wrestles with the lure of

eliminating all unacceptable characteristics, and traits not deemed typically human. To profess

that someone is disabled, or that they carry some undesirable trait, or genetic defect presupposes

that there exist criteria for what it means to be non-disabled; to be the ideal human. One widely

accepted view of ideal humanness is to possess a productive body. A body that fails to meet that societal demand is considered *disabled*.[105]

It is in society's best interest to place a high value on health and well-being, to value good health over ill-health and to reduce morbidity and improve overall health. While most people would prefer being able-bodied to being disabled, and healthy rather than unhealthy, the fact of the matter is that much of what is considered *normal* and *able* are subject to normative beliefs.[106] Because the roles occupied by HCO leaders are tied to norms and standards which set stakeholder expectations, in order to recognize the common good for these vulnerable people, the normative state of play must be understood.

To that end, a principle issue for those who seek to improve the human condition is to consider whether it is in the purview of society to decide the state of any future person by eliminating disability through genetic intervention. The connection between genetics and historical eugenic philosophies, which associated social ills with the prevalence of mental and physical defects, undergirds much of contemporary thinking concerning the way persons with disabilities are treated.[107] This chapter looks at genetic testing, prenatal testing and ethical-deselection through the expressions of several theorists including Stephen Wilkinson, Paul Ramsey and David Wasserman.

5. F. Creating Enabling Environments through Ethic of Care and Disability Ethics

This final section addresses the ethical accountability of healthcare leadership to its stakeholders with disabilities by arguing for care environments that reverse negative thinking and embrace all life as a gift. Doing so enables human flourishing, not through pursuit of genetic perfection but through enabling and acceptance of a good life worth living,[108] despite its puzzling

differences. The argument begins with the presupposition that all life is a gift, and develops that assertion according to Judeo-Christian thought leaders; for example Nancy Eisland, Hans Reinders, and William May.

It then expands to the need to impart disability ethics as part of the HCO culture of ethics in order to provide for the common good of its stakeholders. It unfolds according the social model of disability first introduced by Michael Oliver,[109] and expands to include the contemporary postures of Alicia Ouellette and Jackie Leach Scully. The social model of disability shifts attention away from the individual's traits and conditions and focuses instead on how the environment and society create obstacles for the person.[110] According to this model, those societal obstacles are themselves disabling barriers to human flourishing, not the physical or emotional manifestations of the disorder or injury.

Awareness of the barriers to healthcare that adversely affect and obstruct flourishing and enjoyment of a good life is a moral mandate for accountable healthcare leaders as they serve their stakeholders with disabilities. However, awareness without advancing affirmative measures to overcome such barriers is futile and will fail this vulnerable population. Empathy towards this population is a contingent of the moral agency ascribed to the HCO; it is an attribute imbedded within its moral soul. As such, this dissertation concludes with recommendations to create enabling environments.[111] Environments that reverse negative thinking about disability, respect the identity of disability, enhance access to care,, and ensure that respect for the dignity of the person's *abilities* directs moral decision-making.

6. **Conclusion**

Healthcare organizations are morally accountable and have ethical obligations to a wide variety of constituents, including the broad community of stakeholders that it serves. While maintaining organizational homeostasis through ethical accountability, the HCO requires a unification of individual and institutional moral agents, and adherence to its values in order to preserve its moral soul. The title of this dissertation, "Ethical Accountability of Organizational Leadership to Communities of Stakeholders" emphasizes the importance of moral decision-making and presents it through the lens of distinct stakeholder groups and concerns.

As the AHERF example demonstrates, HCOs that abandon stakeholder considerations, and engage in unchecked critical decision-making are dispossessed of accountable leadership and risk losing its moral soul. This analysis further shows that an HCO's moral soul acknowledges the diversity of stakeholder values and interests and the impact of the organization's decisions on them. The dissertation explores those communities of stakeholders and their unique interests.

Privacy rights and the respect for the confidentiality of secrets are inherently human concerns and are of particular significance to the dignity of healthcare stakeholders. This analysis dissects the legal obligations and challenges of maintaining stakeholder confidentiality at a time when healthcare in the United States practically demands and unleashes unfettered access to patient information. It then argues for an ethical justification for deviations from these obligations when accountable leaders establish guidance and practices that undergird the moral rights of their stakeholders with respect to their secrets.

Respect for human dignity and providing for the common good of society are moral imperatives of accountable healthcare leaders. This moral mandate unfolds fully in this dissertation by considering the needs of the most vulnerable and fragile stakeholder populations across the life continuum. It illustrates how ethical accountability of organizational leadership is made manifest through the HCO's moral considerations, and their contribution to the enrichment of the lives of their pediatric, elderly, and disabled populations.

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Chapter 2. – Organizational Moral Agency

2.   Introduction

The human body is organized into interdependent structural and functional levels of increasing complexity.[1] Each level of form and function builds upon and incorporates the structures and functions of the previous lower levels. Human anatomy's rich composite of chemicals, cells tissues and organs are precisely amalgamated to form organ systems that contribute to and enable particular bodily functions.[2] Anatomy and physiology represent form and function, respectively, and are the essential disciplines driving the science and the practice of medicine. When form and function are in union, a body experiences a state of good health.

Homeostasis – the body's ability to maintain stable and normal functions despite exposure to constant internal and external changes – depends upon the proper form and function of each organ and system. As such, when changes influence the order of form and function, the body must respond appropriately. Alerted to those changes, interdependent response mechanisms implicate all of the organ systems of the body, and are accountable to them to ensure proper functioning. Institutional medicine as represented by the contemporary healthcare organization, attempts the same synergy as the principles of human anatomy, physiological accountability, and homeostasis.

For purposes of this dissertation, the terms *organization/organizational and institution/institutional* and are used interchangeably, and have the same meaning. As Craig Johnson suggests, "Organizations consist of three or more people engaged in coordinated action in pursuit of a common purpose or goal."[3] As the body through which modern medicine is most commonly delivered, the healthcare organization (HCO) similarly seeks to maintain order among

its diverse stakeholders to achieve organizational homeostasis. When internal and external influences threaten order, the survival of the organization and the health of its stakeholders depend upon its ability to maintain homeostasis. As this dissertation demonstrates, maintaining order depends upon the ethical accountability of leadership to its constituent stakeholder parts. More than just anatomy, an ethically accountable HCO requires the exposition of moral integrity and the virtue of its leadership.

This chapter opens with an understanding of moral agency as the cornerstone of ethical accountability and decision-making to support a common morality. It presents a portrait of common morality and its framework including a historical snapshot of ethical norms, principles, rules and theories, and contemporary views espoused by Beauchamp and Childress, as well as Gert, Culver and Clouser. The discussion bifurcates organizational moral agency into individual and institutional components, and illustrates how their unification and ethical decision-making can innervate and preserve the HCO's moral soul. The discussion then explores the theological exposition of soul through the teachings of the Roman Catholic Church. It further develops the metaphor of soul in healthcare as that which enables the intimate relationships generated throughout the healthcare experience.[4] As a contrast, it then examines demise of an HCO when leaders are dispossessed of their moral agency, lack discernment, forfeit soul, and act with Faustian motivations that are morally irresponsible. Specifically it deeply probes the case of the Allegheny Health Education, Research Foundation's notorious bankruptcy.

Because decisions rendered by the HCOs implicate more than its bottom line, this section concludes with a brief introduction to stakeholder theory. As an approach to organizational ethics that heeds to the rights and interests of individuals or groups who interact with the HCO, this section examines the moral obligations to these groups as articulated through normative

stakeholder theory. Specifically, it presents stakeholder theory through the lens of dominant theories which are based upon stakeholder relationships; the ethics of care,[5] stakeholder fairness,[6] and stewardship.

2. A. Common Morality and Moral Agency

Morality concerns the norms surrounding human behavior which are good and right and are so universally shared that they are able to cement a stable, predictable social framework. It includes measures of conduct; standards such as moral/ethical norms and beliefs, principles, rules and theories. Some aspects of morality are so embedded into our social fabric that the norms they dictate are said to form a *common morality* shared and recognized by all moral persons across different cultures. These include, but are not limited to, standard norms such as "do not kill" and "tell the truth" as well as moral character traits such as integrity, fidelity and kindness.[7]

Some moral norms prescribe rules, obligations and duties to reduce or prevent harm, others are created to increase the good, or provide relief to those who are harmed by a particular situation or encounter. Moral principles and rules are norms of obligation; that is, they create standards of action required of all people who subscribe to common morality. According to Beauchamp and Childress, the principles of autonomy, beneficence, nonmaleficence, and justice provide the basis for specific rules and for moral reasoning and apply to all persons committed to morality.[8] Autonomy refers to the freedom to decide for oneself, beneficence imposes an action to do good, nonmaleficence calls for refraining from harmful actions, and the principle of justice refers to that which is fair, equitable and appropriate in light of what is owed to someone.[9] For Beauchamp and Childress, these principles of morality further rely upon sets of substantive, authority and procedural rules to arrive at right moral conduct.

Gert, Culver and Clouser, in contrast, dispense with principles and their cascading rules and propose instead that there are ten highly comprehensible general moral rules governing all right conduct. Five are designed to prevent direct harm: do not kill; do not cause pain; do not disable; do not deprive of freedom; and do not deprive of pleasure. And five moral rules prevent likely harm: do not deceive; keep your promise; do not cheat; obey the law; and do your duty.[10] These rules establish rights and obligations for actors and decision-makers. Gert refers to those to whom these moral rules apply as moral agents.[11] Those moral actors, and the rules and principles with which they work, must fit within a set of societal, or in the case of an HCO, its organizational beliefs and decision-making processes. Those beliefs and processes are establish a basis for common morality and associated moral action. Use of the term *ethics* throughout this dissertation will be construed as the moral beliefs and behavior of people, the rules devised to prevent conflict, to support the mores of the society and to reinforce principles of human duty.[12]

2. A. 1. Individual Agency

An institution cannot act on its own. It requires morally justified decision-makers and actors to help define its mission and purpose, and then act and perform in accordance with it, while supporting critical values and norms. These moral agents, who are both internal and external to the organization, are responsible for building and binding together a trusted organization. In short, an ethical healthcare organization is only as sound as the decisions and actions of those who create and support it, and who are also encouraged and equipped to make ethical choices according to prescribed ethical principles.[13]

The mission, values, and principles of ethics define the moral standards and illustrate the moral identity of the entity. Employees and other members of the workforce are an organization's agents and reflect that identity. They are the face of the organization's mission,

identity and culture, and are the embodiment of its values. As moral agents, they are responsible for executing on its mission and they step into the shoes of the organization every time they act within the scope of their role - and quite often, even when they are not acting officially. The roles occupied by individuals within the HCO are tied to the norms and standards that define expectations; for example, the qualities of an outstanding assistant, a respected leader, and an effective and strategic-thinking CEO. The presumed standards constitute the notion of role morality and the individuals performing in accordance with these moral standards help to establish and sustain the ethical organization. Actions that fail to meet these standards, as well as the persons attributed to those actions are said to be immoral.[14] To satisfy these moral standards, and in the execution of their duties, individual moral agents acting on behalf of the HCO indisputably must be persons of unwavering integrity and character who are also adept at collaboration. Honesty, integrity and truthfulness are but a few examples of moral character traits, and represent virtues indelibly engraved in common morality.

Although the United States has long been recognized as the source and summit of some of the finest and most advanced forms of medicine in the world, it cannot claim to be the original architect of morality in medicine. That distinction rests with the ancient Romans and Greeks from as far back as the fifth century, BCE as evidenced in the moral precepts of the Hippocratic Oath and other codes promulgated during this era.[15] These ancient codes were proclamations dedicated to achieving what was considered the end or goal of medicine – the good of the patient. And was the duty of the physician to achieve that good.[16] Medical ethics began as descriptive – someone was a physician, therefore it was known how they would act, and what they would do.[17]

The physician-centric precepts of these early codes found stickiness in Western medicine. The notion of what was ethically right relied upon the character, duty and the social ethics of the physician. *Character* addressed the inherent good qualities of one who heals; *duty* set forth the obligations of the good physician "to benefit the sick and do them no harm."[18] These were often reinforced in the form of oaths and codes, however they also existed in the moral beliefs and divine commands present in Judeo-Christian tradition. For example, the respect for life imposes a moral duty not to end a life. Finally, *social ethics* is the idea that the physician assumes responsibility for the entire profession through their behavior in the community. The American Medical Association, for more than a century, modeled the code of medical ethics as synonymous for rules of professional conduct, physician integrity, and social responsibility.[19]

From the early twentieth century, solo practitioners were the model of medical integrity. The notion of what they ought to do was baked into them from professors, colleagues and trusted mentors. Rarely was their judgment of their own ethical duties called into question. But, as science and medical technologies redefined and reshaped the clarity with which the medical doctor's conscience once operated, the patient-centered mindset of what constituted the good became distorted. Medical interventions provided by or directed by machines challenged the concepts of physician duty. The physician who once saw her healing art inextricably tied to the good of her patient, and their relationship, was forced to share her relationship with science and technology.[20] The transformation of medicine, and the evolution of the contemporary healthcare organization influenced the shift away from descriptive nature of ethics to more of a normative approach. And since an HCO is more than an accumulation of physicians, these transformations influenced a broad swath of moral agents.

Aside from the standards attributed to their roles, individuals also have personal values, which act as guiding principles in their lives.[21] They typically subscribe to their own unique beliefs and standards. Personal values are reflected in individual attitudes and are most often rooted in experiential as well as cultural influences. For the most part, an organization's values are similarly shaped by its tradition, culture and the amalgamated personalities of its leaders, and may not be identical to the personal values of its individual agents. However, good leadership must be able to articulate those values and strive to ensure a degree of congruence with individual values.[22] Dissonance between individual stakeholder and organizational values, however, is oftentimes inevitable.

A variety of individuals come together to build and sustain a morally accountable HCO. As moral agents, nearly all of the professions represented are expected to adhere to prescribed professional standards and codes of conduct unique to those disciplines; while upholding the virtues of common morality. The moral agency ascribed to the HCO requires it to cohabitate with its professional, clinical and business professionals and integrate their normative ethical duties and values into the HCO mission.[23] This ability to cohabitate must be bi-directional.

Because persons within an HCO are not unthinking automatons operating in lockstep with nothing more than a mere code of conduct to dictate behavior, a positive ethical climate requires synergy between its moral goals, the HCO and the competing interests of its moral agents. When they are not in sync, and moral agents are not aligned with the critical values of norms of the HCO, homeostasis is upset. Diversity of interests, and divergent methods for reacting to competing internal and external influences further enable conflicts to emerge, distrust to ensue, and the perpetuation of a negative ethical climate.[24]

2. A. 2.   Institutional Agency and Decision-Making

Since an organization cannot *act* as individuals do, it is the HCO's ethics program which represents a memorialized and formalized mission and vision statement. It sets forth the principles of ethics adopted by the organization which guide behaviors and actions. Although it does not act independent of its agents, and an organization cannot be considered a moral *individual*, it does act through the collective decision-making of its moral agents. And while it cannot have a motive in the same way a person does, an institution is evaluated and adjudged to be moral or immoral by its constituents as well as other organizations according to the decisions, intentions and actions of its moral agents.[25]

"Organizational ethics applies moral standards and principles to the organizational context."[26] Organizational ethics provides the framework for a code of conduct, or ethical program of core values, culture and structure that undergird an organization and illustrate its optimal normative mission. In building its ethical character, the governing board of directors must unambiguously identify and make public the mission and values that are deeply held by the organization and are associated with its identity. They must also establish the ethical standards with which members of the board as well as management and frontline employees will comply.[27] The board's actions in developing the mission and vision statements establish the parameters of its ethics program – setting the tone for a culture of ethics.[28] But a framework alone is insufficient to ensure a culture of ethics within an HCO.

The notion of culture implies that certain norms, habits and beliefs are shared identities which reflect an organization's most important values, and its good governance and character. An organization's culture includes rituals, narratives and assumptions, and even power struggles that constitute a way of life for constituents formed of shared behaviors and norms.[29]

Organizations with robust cultures are able to transfer their identities onto new members in order to acculturate them into the values system of the organization. Culture and organizational identity are most often demonstrated through an organization's programs, policies and procedures. Additionally, leaders within the organization are the most important antecedent of ethical organizational identity.[30]

Group decision-making is an integral part of an organization's operations. Group actions are often so inextricable intertwined that it is may be impossible to distill the individually identifiable actions and separate them from the moral agency of the organization itself. It may be the case where a decision is made individually, but executed collectively as a group. Nevertheless, when an organization renders decisions, and performs as part of a positive ethical climate, self-interest is minimized, trust is imbedded internally and externally, and it is deemed to be a moral institution.[31]

To that end, moral and political philosopher Alasdair MacIntyre argued that good management and good judgement is based in part on *practices* – the collective human activity of seeking of moral excellence – that relies upon moral reasoning, not merely emotivism. *Emotivism*, according to MacIntyre, is the notion that moral judgments are mere expressions preferences, feelings or emotions and because preferences are subjective and can be manipulated, they breed moral uncertainty.[32] Moral agents who act collectively in furtherance of the missions and values must be cautioned against organizational emotivism, and should instead rely on sound moral reasoning. G. Moore contends that emotivism can be minimized when organizations establish a power-balance method of decision-making oversight to ensure that views and desires of some are not privileged and preferred over the preferences of others.[33]

Reliance on unique facts and circumstances that are often intermingled with emotions and other conflicting, life-altering factors is one of the complicating hallmarks of decision-making in contemporary healthcare. The amorphous and frequently ad hoc nature of healthcare decisions underscore the need for methods of systematic and morally justified decision-making. Without a systematic framework, decisions, particularly those which, on their face violate a moral rule, are subject to allegations of arbitrariness. Balancing these preferences in decision-making is an organizational challenge. For example, physicians endeavor to first do no harm to their patients while secondarily complying with medical necessity proscriptions and insurance coverage constraints. Nursing staff advocate on behalf of the patient's best interest face moral choices when those perceived interests conflict with physician orders. And HCO leadership seeking to fill demographic gaps in care by increasing market penetration through potentially anti-competitive means all represent conflicts of commitment and interests, which present challenges to moral agency.[34] Reconciling these conflicts requires a moral decision-making process that recognizes the values and virtues espoused in the constituents' ethical positions and creates opportunities to include those positions in appropriate places within the organization.

2. A. 3. Virtue and Moral Soul

The ethical decisions of its moral agents ought to be in harmony with the organization's moral identity and remain synonymous with its character and collection of virtues. Although secular and theological references to virtue and the state of being virtuous differ in terms of their origins and ultimate goals,[35] their commonly understood meanings, reflective of the desire for good, are not dissimilar. For simplicity and continuity, this dissertation adopts the meanings promulgated by the Roman Catholic Church.

Human virtues are attitudes and dispositions that guide conduct and actions according to sound reasoning and make it possible to live a good and moral life. A virtuous person seeks to perform only good actions and to use reason to achieve good.[36] Virtues such as prudence and practical wisdom provide direction for the moral agent to know what is good. And similarly, an organization's virtuous character, which ought to be the core of the organization's self-concept, allow it to recognize the good when it is present.[37] Virtuosity requires human effort and disposition to maintain what is good. And the human body and mind, in concert, deliberating what is good rely upon its *soul* to animate and bring to life the decision-making. In the same way that virtues rely upon deliberation and thought to fuel the good, the *body* of the ethical healthcare organization unifies with its moral soul and relies upon it to be virtuous. It can be said that virtue – affection for that which is good - is the armor that safeguards the soul.

Because much of human reasoning often confronts abstract and indiscrete information, good reasoning typically requires the imposition of artificial boundaries and illustrations to help make sense of human experiences. It is often easier to comprehend what something is like or unlike, than to understand what it is. As such, human thought seeks clarify from *ontological* metaphors – images that associate human experience in terms of familiar nonhuman entities or things.[38] For example, a deviant actor may be labeled a bad apple, while a top performer compared to a rising star. Frequently, ontological metaphors will characterize a nonhuman object as a person or as having human traits. Difficult concepts such as motivations, characteristics and emotions are often described through *personification* which imputes human qualities and traits to nonhuman things.[39] To illustrate, the right set of facts can help and investigator get to the *heart* of a case, while a successfully marketed computer program could be the *brain* of an organization.

Historically, industrial-age ontological metaphors were used to describe organizations: promoting the image of a successful enterprise as a well-oiled machine, or a finely-tuned watch. Today however, the contemporary digital information age would make little sense of the machine metaphor. Instead the soul is a more illustrative and contemporary representation of the unifying and holistic web of connectedness in an organization.[40]

In both the secular and the spiritual sense, the *soul* depicts the core essence of a person – it is the energy which gives life and manifests virtuous character and is the spirit of human reasoning. Moral agents are fueled by their soul. The soul is the union of spirit and body and reflects that two-fold constitution of humans. Since the integrated HCO is a unified system of people, things, and processes that function like a human body, the soul of an HCO is the spirit that seeks to preserve cohesion of its mission, values and virtuous character.[41] It can be said that just as the human body is united to its spirit and virtues through its soul, the ethically accountable organization is united to its mission and values through *its* soul.

As a human characteristic, understanding the theological union of body and soul is essential to understanding the soul of an HCO, and the gravity of the negative consequences when the soul is compromised. According to the Roman Catholic Church, the spirit and body together form one unique human possessing a soul that is individual, immortal and created by God alone.[42] The soul animates the body and is the subject of its consciousness, and although the immortal soul does not die with the physical body[43], the body that loses its soul is eternally dead.

The Church further teaches that the theological virtues of faith, hope and charity are the foundations of Christian morality, and are divinely infused into human souls enabling the person to live virtuously. They are so fundamental that they undergird all other moral virtues that live deeply inside the human soul. Theological virtues describe belief in the Divine, the desire for

eternal life, and the love of God above all things.[44] Moral virtues such as justice, prudence, fortitude and temperance guide human conduct and govern acts. When rooted into action with the soul, they result in good works and moral decisions.[45]

The soul is a unique attribute of humanness and is the lived manifestation of spirituality in an individual, and represents the good in an organization through the actions of its moral agents.[46] Just as the mortal soul is a unity with the body, so is the soul of its moral agents a unity with the organization. The leaders and governance bodies of organizations must look deep within their own souls and reflect upon and activate their moral virtues in order to make just and prudent decisions. William O'Brien aptly contends that maintaining soul and managing morally is difficult for most organizations because moral excellence requires commitments that often contrast with society's inclinations and habits. It demands more than mere compliance with law and conformance with principles; it requires a vigorous and authentic commitment to moral truths. Leadership desires such as instant gratification about lifetime satisfaction, technological fixes in lieu of advancement of the human spirit, and an emphasis on looking good over and above *being good* jeopardize the soul of the HCO.[47] Such tendencies, which treat the soul as fungible, will separate it from the organization and threaten both of their survival.

2. B.   Organizational Leadership and Ethical Decision-Making

The Roman Catholic Church teaches that evil and sin, which are inextricably tied to Adam's fall, amount to death of the soul and eternal condemnation.[48] Just as the German protagonist Faust knew that his decision to trade his immortal soul for earthly pleasures would forever separate him from that which was good, organizations can knowingly compromise their moral soul. Faust's willful failure to recognize the consequences of his decision, his failed consciences, and his denial of his own fallibility, nearly cost him his eternal soul. Organizations

can lose their moral soul through Faustian bargains, imprudent decision-making and actions of leadership that fail to discern the consequences of their choices.

The Christian practice of discernment – a decision-making process that engages the spirituality, imagination and beliefs of those involved in the matter – although still relatively rare, is used in organizational decisions.[49] Ascension Healthcare, the world's largest Catholic healthcare system in the world, and the largest non-profit system in the United States practices a highly structured mission discernment process as part of its business culture.[50] Ascension concedes, however, that not all situations are ripe for the discernment process. Instances where precedent has been set by prior decisions, and cases that need to be decided quickly may not fit well within this highly deliberate process. Nevertheless, in the majority of cases where it is applicable, Ascension's model adopts a multi-step approach. It includes, *inter alia,* identifying the central problem or question to be answered, considering the stakeholders who are affected most directly, consideration of the salient values and moral concerns, and any alternatives that may be considered, including what other organizations and prudent persons in similar situations,[51] have done.

Corporate discernment is a reflective process that involves sifting through individual and collective experiences in order to know which choices will best support the ethical mission of an organization.[52] According to Margaret Benefiels' work on spiritual leadership in organizations, *mission discernment* is a reflective decision-making process designed to stimulate discussion abound decision-makers enabling them to identify and report reasons for or against a particular course of action in relation to corporate values and mission. This continual process ensures that appropriate business and clinical analyses are elevated and prioritized in light of the mission and core values.

Discernment does not merely help determine what to do; rather, mission discernment embraces the core values of what matters to the organization in every decision. It requires trust and openness among the organization's moral agents and presupposes that decision-makers and leaders hold the mission and values of the organization at the center of their leadership. Discernment demands the avoidance of temptation to make important decisions too quickly, or with underdeveloped information. When leadership is called to make decisions on behalf of the organization, the expectation is that they will provide strategic solutions to a variety of different problems. In so doing, they often must wrestle with conflicting values among stakeholders as well as find courage to render unpopular decisions. They are called to examine the collective conscience of the organization.[53] Discernment is the process of deliberating what is good and allowing the moral agents' soul to guide the ethical decision. However, when the soul is lost to conflict or vice, then the process of ethical decision-making, like the body that is separated from the soul, is already dead.

2. B. 1.   Enabling Conflicts of Interest, Complicity, and Principles of Cooperation.

Standards of role morality apply throughout an HCO. However, moral agents who sit in leadership and management roles, particularly members of boards of directors, are held to a higher level of fiduciary duty.[54] Conflicts arise when decision-makers are confronted with incentives – personal or financial – to act in ways that breach the fiduciary duty and normative standards of their moral role. Acting on these incentives compromises their best judgment, integrity and soul. Most notable conflicts of interest in healthcare are attributed to physicians[55] however high-level decision-makers such as executive management and board participants are often targets of external influence.[56] Conflicts of interest can be eliminated by removing the incentive or inducement to abandon soul, however, conflict of conscience originates from the

ontological wiring of the actor and is impossible to eliminate unless the offending situation is materially altered.

Conflicts of conscience result from the inability to act in ways that are faithful to an individual's conscience and moral convictions. Since healthcare organizations have moral identities, and since their morality is adjudged according to the actions of its agents, the process of moral reasoning and discernment can be impacted by agents' individual consciences. Moreover, the organization's collective conscience is inextricably tied to its mission and vision and cannot be separated from its moral agency. Conflicts between various agents and stakeholders within the healthcare organizations are nearly inevitable and render collective moral choices particularly challenging. Reconciling conflicts of conscience requires a moral decision-making process that provides a systematic approach to ethical problem solving acknowledging moral sensitivity, judgment, motivation and character.[57] The process must recognize the values espoused by the constituents' ethical positions and create opportunities to discern the value of those positions vis-à-vis the organization's ethical identity.

Suboptimal decision-making is a barrier to reconciling the conflicted conscience with the moral identity of the organization. Decision-making is obstructed and moral reasoning is threatened when conflicted moral agents compartmentalize decisions and issues such that they are isolated from the rest of the organization. Insulating individual conflicts from the rest of the organization eclipses discernment, collective reflection, and moral agency; thus minimizing accountability and enabling loss of soul.[58]

The motivation or desire to compartmentalize conflicts may also make mission discernment – that is, evaluating decisions in light of the mission and core values of the organization impossible. Without the ability to identify and report reasons for or against a

particular course of actions, the rational decision-making process is woefully incomplete.[59] The

presence of a genuine conflict of interest, or conscience may themselves explain an agent's

desire to circumvent the decision-making process, even at the risk of loss of organizational soul.

However, an organization can also lose its soul when ultimate decision-making is vested,

intentionally or by default, in one dominant leader.

Role transference frequently occurs whenever there is a tightness binding the behavior

and desires of top-management to the ultimate decisions of the organization. The actor, who is

most frequently (but not exclusively) the CEO, represents the organization's public face and is

assumed to also reflect its moral identity, and to exercise moral authority on behalf of all of the

organization. The danger of transference is that lower-level managers and frontline employees

abdicate their moral duties – by default – and begin to think and act as if moral agency is not

their responsibility. It is as if members of the workforce engage in a form of follow-the-

leader.[60]This phenomenon can affect the organization's external reputation and public image

such that the image of the agent is the perceived image of the organization; in essence, the soul

and spirit driving the agent, drives the organization. In its most extreme, the mission and values

of the organization are surreptitiously replaced with the values and virtues of one dominant

leader – which may be in conflict with the moral identity of the organization. Role transference

may further endanger the organization's soul if narcissistic behavior pervades decision-making.

Since organizations are assemblages of individuals, they adopt an organizational self-

esteem often imparted from senior leadership. Senior leadership personalities that exhibit

extreme love of self, Faustian inclinations, compartmentalization and disclaiming awareness of

their faults are considered narcissistic. Grant and McGhee in their work on organizational

narcissism contend that narcissistic tendencies found in organizational culture are determined

primarily by the effectiveness of corporate governance. Since the board is responsible for the moral or immoral identity of the organization, they aptly hold that the character of the directors and the manner in which they exercise judgement in choosing the CEO is directly linked to the organizational culture of narcissism.[61] Extreme narcissism prevents an organization from acting properly because it lacks a moral identity; it cannot act virtuously. It is morally flawed and is soulless. As a result, organizations can project a narcissistic rather than moral identity.[62] They can react and even respond to issues with ego-defense mechanisms just as people do – in order to protect and preserve the organization's image rather than its moral soul. Narcissistic leadership creates a fertile environment for scandal, corruption and complicity.

When an organization, through its agents, succumbs to conflicts of conscience, behaves objectionably and breaches its fiduciary duty to promote its mission and values, it often involves cooperation with someone or something else.[63] However, not all acts of cooperation involve wrongdoing or objectionable conduct. Consider the image offered by Linda and James Henry of the high-flying geese who fly in perfect v-formation following the lead geese – a position that regularly changes. They share a vision, trust, support of one another and a shared leadership to achieve a common end.[64] Cooperation involves compromise. The image of the geese invokes compromise of the rotating role lead geese – each taking their turn. Christopher Kutz similarly describes group cooperation as individuals who are suitably combined acting upon participatory intentions to achieve jointly intentional actions.[65] According to Kutz, participation in an act renders an actor accountable for the outcome, and acts attributable to the group as a whole, as well as to the other participating members. Just like high-flying geese, group identity is explained in terms of individual participatory intentions.[66]

Cooperation can also involve the compromise of morality when person or institutions cooperate in the wrongdoing of another for the purpose of achieving some end. The consequences of cooperation are Januslike – the identical act will either result in llicit/material cooperation, or it will result in illicit/formal cooperation with culpability as the determinative factor in both instances.[67] Both the principle of cooperation, and the complicity principle advanced by Kutz teach that accountability for what others do, and the harm associated with wrongdoings turn on the intentions of the participant.[68] Plainly, anyone who knowingly participates in a bad act, or influences the particular outcome, is accountable for their role in that act. This is so even if their contribution to the outcome is slight relative to the collective involvement of the group.

The scope of individual accountability to complicit actions looks at whether or not the individuals are provided with reason to avoid and respond to harmful acts, as well as their distance or proximity from the act. As such, it is necessary to determine whether or not their intent to achieve a particular goal included the ensuing evil, or harm. Participatory intentions are essential elements in assessing accountability and culpability. But just as knowledge can implicate a participant, ignorance of the probability of harm does not fully exculpate an actor.[69]

Those with a straightforward and purposeful intent to promote a particular action are accountable to a different degree than those who participate in an action with different motives. Consider the board member who votes affirmatively on a resolution to transfer corporate funds to camouflage cash shortfalls from accounting disparities. And another who is persuaded to vote affirmatively on the same resolution, but believes the cash transfer will fund the purchase of a new ambulatory care center. Or, consider the board member who supports the resolution but does not understand the nature of the transaction, the movement of the money and the history of the

funds. She voted by proxy without sufficient opportunity to make a fully informed decision. All of the aforementioned members are complicit and acted in cooperation with one another because they voted on resolution that will result in a bad act – enabling the theft of funds. But, notwithstanding their fiduciary duties, the former board member is the most culpable, while the last member to vote is the least.[70]

In addition, actor accountability can be further characterized according to a spatial metaphor. That is, the stronger the link between the actor and the collective act, the less weight is given to the actor's ignorance of its nature. Those agents who intend a particular result are said to be at the core of the activity and those who don't are considered at the periphery. The distance from the core to the periphery is measured through functional assessment of the facts and circumstances. Notwithstanding any duty imposed upon the second and third board members to fully understand the purpose of the funds transfer in the aforementioned scenario, the agent who conjured up the funds transfer is at the core of the activity. The agent with the least insight would likely be justified as having engaged in legitimate or licit cooperation.[71]

The distance from immorality in decision-making is significant for the theological metaphor of moral soul. For Fernandez Lynch, the proximity from the wrongdoing is the essential distinction between licit (moral), and illicit (immoral) cooperation. In addition to having a good reason for cooperating, the peripheral proximity helps to mitigate the unintended wrongdoer's culpability.[72]

The Roman Catholic Church's teaching on sin provides an appropriate window looking out onto the notions of how morally licit and illicit cooperation parallels catechetical teachings on moral and venial sin. Moral sin is an offense against God, reason, and truth.[73] A moral sin is a grave violation of God's law and destroys the theological virtues of charity ensouled in a

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person's heart. It is a guarantee of eternal damnation, and eternal hell. Commission of a moral

sin requires full knowledge of and complete consent to the sinfulness of the act, and presupposes

that the offender chooses to participate in the wrongdoing with the intent to sin, resulting in

death of the soul.[74] The characteristics of mortal sin are parallel to those associated with illicit

cooperation. As such, the existence of illicit cooperation among moral agents and other

organizational decision-makers translates into loss of an organization's soul.

While a venial sin may impede the human soul's progress in exercising the human virtues

of the moral good[75] it does not break the covenant with God and result in mortal sin. Venial sins

lack the requisite knowledge and complete consent that moral sin possesses. Associated with

licit cooperation, venial sins are *light* moral infractions which do not separate the person from

their soul.[76] However, the Church teaches its faithful that light infractions are like drops in the

ocean – their increased volume creates a great mass. Repeated acts of licit cooperation assaults

the soul of the organization. The act of sin creates the proclivity to sin, and sin again. When

moral and venial sin occurs repeatedly within a group of moral agents acting individually as well

as collectively on behalf of and HCO, its ubiquity can undermine its moral identity, moral

authority, and moral soul. The epic bankruptcy of the Allegheny Health Education and Research

Foundation demonstrates how wrongdoing can become so tightly woven into the fabric of

organizational conduct that it can be hidden from governance or ignored entirely.

2. B. 2.   The Sold Soul: The Allegheny Health Education and Research Foundation.

Established in 1983, the Allegheny Health Education and Research Foundation (AHERF)

morphed over time to become an HCO comprised of rapidly-merged healthcare entities.

Hahnemann University of the Health Sciences and the Medical College of Pennsylvania in

Philadelphia merged with Allegheny General Hospital (AGH), a research and teaching hospital

in Pittsburgh.[77] Under the leadership of its president and CEO, Sherif Abdelhak, who was

appointed in 1986, the period between 1990 and 1997 marked unprecedented expansion and

organizational growth. By 1997, the Allegheny Health System had the distinction of being the

first and largest statewide nonprofit integrated health system in the Commonwealth of

Pennsylvania.

The HCO was initially inspired by a mission to expand its alliance with medical schools

to enhance medical education in Pennsylvania. This included preserving the richness of medical

education legacy in the Philadelphia region of Pennsylvania. However, AHERF's original

mission proclaimed widely throughout internal and external publications, "to learn, to teach, to

heal the sick, and to conserve health"[78] was more akin to a mission of divide and conquer

through unprecedented mergers and consolidations. Almost immediately after Abdelhak took

the reins, the HCO was goaded into expansion by the prominence and dominance of its rival

competitor – The University of Pittsburgh Medical Center Health System (UPMC). It's refusal

to partner with AHERF in 1983 sparked jilted emotions that fueled AHERF's longstanding

desire to increase the size of its market footprint.[79] In response to that desire coupled with

Abelhak's Faustian professional ambitions, the organization embarked on a hospital shopping

spree of questionable acquisitions.

Abdelhak single-handedly spearheaded and orchestrated rapid and expansive hospital and

ambulatory care acquisitions. By 1997, the HCO swelled to include 14 hospitals, 310 primary

care physicians in the Philadelphia region, and 136 in Pittsburgh. They were purchased at very

high prices during a bidding war with competitors in order to enlarge its physician network.

These physicians and their practices were acquired without adequate negotiation, due diligence

and prudent assessment of the value and worth of the entities. Abdelhak set forth what he touted

as inviolable mandates to AHERF's chief operating officer; ordering that he put together deals as fast as possible.[80]

Induced into luring and buying up as many physician practices as possible, the chief operating officer was offered an incentive commission of $15,000 for every physician contract signed, and for every deal that was closed quickly; stoking numerous conflicts of interest. Physicians and their practices were essentially devoured by accepting compensation packages that included salary, percentage of revenues generated through care delivery, and grossly inflated asset purchase prices. The total compensation package for each physician was often in the millions of dollars. Those deals were made without any long and short-range projections for performance or return on investment. Moreover the physicians' employment contracts did not provide AHERF with post-acquisition oversight rights to monitor productivity and did not anticipate that physicians might refer patients outside of AHERF's geographic proximity. The absence of mission discernment, due diligence and poorly calculated assumptions created financial distress amidst AGH and other merge entities; entities that were, for the most part, once financially healthy. Or, at the very least, they were not on the precipice of dying at the time they were merged.[81]

Losses mounted. Hospitals and physician practices purchased without adequate due diligence, asset valuation, or planning eventually drained cash and reserves from the healthy parent entity. AHERF purchased some hospitals that had little to no cash flow, and it was forced to service the debt it literally bought with cash transfers between healthy facilities to compensate for underperforming professional and facility providers. To make conditions worse, secretive cash transfers between entities violated bond agreements, and raids on hospital endowments and enormous debt amassed from the acquisitions. Debts were created and cancelled without any

consideration to the creditor. Losses became astronomical – ballooning from $41 million in 1996 to $61 million in 1997.[82]

Clinicians and research faculty were lured by large salaries but were also baited with the promise of new labs and staff – incentives that are considered delicacies among physicians who are engaged in research. Additionally, associating with clinical and research faculty was a necessity for AHERF to compete with UPMC. But also, and possibly more important, it meant funding from the National Institute of Health (NIH); an avenue for enriching the cash-strapped organization. Anxiety and discontent slowly bubbled up from these physicians and their practices, as many of the promises made during their recruitment and affiliation were broken. These promises were made by AHERF executives; many of whom knew at the time they were made that the growing financial problems would most likely preclude fulfilling them. Physicians, however, accepted the offers and promises without full knowledge of the impending financial implosion.[83]

AHERF's governance structure provided a very week undercurrent to support and oversee the explosive growth, mounting debt, and other decision-making activity within the organization. The organization was notable for having an enormous parent board consisting of between 20-25 members. It also had ten different boards responsible for oversight of 55 different subsidiaries and diversified businesses. The board compositions did not provide any director overlap such that directors on one board had little or no understanding or insight into what was occurring elsewhere in the enterprise.[84] This resulted in silo-decisions made in a vacuum without transparency into the overall impact of one businesses' decision on another.

Because HCO's are interdependent, the ability to achieve efficiencies, eliminate redundancies and provide access to quality, cost-effective health care requires insight into the

horizontal *and* vertical dimensions of each entity within the integrated structure. AHERF did not

respect this interdependency; rather it operated under the command and control of one

individual.[85] As economic shortfalls spread throughout each of the merged facilities, mere

survival became a priority, and depended upon the ability to subsidize one another rather than

achieve efficiencies of scale. Instead of enjoying market dominance, which was one of its

intended goals, AHERF's hospitals were unable to make capital expenditures and improvements

and placed themselves at a competitive disadvantage in Philadelphia and Pittsburgh markets.

Eventually, AHERF's auditors, Coopers and Lybrand produced a detailed report for the

AHERF audit committee reporting on the magnitude of the corporate debt. The debt was

calculated at $1.06 billion – a figure that was twice the size of AHERF's unrestricted assets.

However, the full AHERF board never saw the report. Nevertheless, significant budget and

expenditure cuts ensued in October 1997. More than 1200 employees lost their jobs. Faculty and

staff were forced to take a 20% salary reduction, and care delivery budgets were slashed.

Budgets were so thin, that antiquated and deteriorating equipment was not replaced. Patient

safety concerns abounded. Access to critical medical supplies dwindled. Some operating rooms

did not even have intravenous tubing.[86] During this same period of dire cutbacks and substandard

care, Abdelhak and his top five senior executives received salary increases.

The corporate bylaws gave AHERF authority to engage in intra-company transfers of

money without parent/donor consent, which meant that money could be moved around by senior

management without consent of the board. This hole in the bylaws and the absence of oversight

checks and balances enabled and facilitated financial conflicts of interest and illicit cooperation.

For example, five members of the AHERF board were executives of Mellon Bank – a creditor of

AHERF. In 1998, crumbling under the weight of suffocating debts, Abdelhak unilaterally

ordered the repayment of an $89 million loan to Mellon Bank without board discussion, or board approval.[87]

Infected with conflicts of interests, corruption, and various forms of cooperation, AHERF went beyond losing its moral soul. In the end, Sherif Abdelhak's reign as CEO was unceremoniously terminated on June 5, 1998, and AHERF subsequently filed for Chapter 11 bankruptcy protection on July 21. At the time that the final decree and settlement was reached in 2003, the $1.6 billion dollar death of AHERF represented the largest not-for-profit health care bankruptcy in the United States.[88] Like Faust, AHERF sacrificed its soul, and during its indiscriminate abandonment, it gave no consideration to the fact that its life could not exist apart from it.

2. B. 3.   A Soul Restored: A Post-Mortem Analysis

Faust eventually saw the error of his ways after spending nearly 25 years in diabolical complicity and in pursuit of self-indulgent desires with Mephistopheles. Eventually he yearned to reclaim the essence of what it means to be human and to preserve the subject of consciousness and freedom – his soul. He wanted redemption.[89] AHERF's leadership did not seek such deliverance.

Sherif Abdelhak sold his professional soul, and AHERF's moral soul, through imprudent decision-making and immoral actions that failed to consider and discern consequences and experiences that help to decide and support the ethical mission of the organization. Not a vestige of AHERF's original mission to learn, to teach, and to heal the sick could be found in its decisions. Conflicts of interest eclipsed moral agency, and complicity circumvented virtuous behavior. Additionally, AHERF's system of governance was so adulterated that its original

valued and mission statement were subsumed in the individual mission and motives of Abdelhak. The annals of AHERF and the Allegheny Health System reflect an organization so rotted by complicity that the possibility of redemption and restoration of such a decomposed soul seemed helpless. Yet, redemption can reunite the soul with the body,[90] and in the case of AHERF it is necessary to retrospectively explore missed opportunities for redemption while considering the future of an HCO and its reunited soul.

The notorious collapse and decimation of the AHERF HCO set into motion a series of investigations, civil suits, settlements and criminal indictments spanning the five year period between 1998 and 2003. The Security and Exchange Commission (SEC) investigated the tangled web of financial dealings. Moody's Investors Service questioned the integrity of AHERF's audited financial statements. The U.S. attorney for the Western District of Pennsylvania began gathering information for a grand jury review. Pennsylvania's Attorney General investigated AHERF's charitable assets, and *Philadelphia Inquirer, Pittsburgh Post-Gazette* and a number of other national media outlets began researching the epic tale of corruption and self-dealing.[91] The cumulative results of various investigations revealed a host of individual and institutional moral deficiencies. Deficiencies which, had they been identified, communicated and remedied could have not only saved the HCO, but allowed its moral soul and body to remain intact.

The AHERF debacle demonstrates a breakdown at each level of organizational accountability. And the question of who was guarding the henhouse becomes a pivotal concern when examining the conflicts of interest and cooperation that choked the blood supply from the HCO's values and virtues. Reflecting the interdependency of the constituent parts of an HCO, the community relied upon the trustees of the foundation to guard its charitable assets. The trustees relied upon the auditors to validate the finances, and the auditors relied upon AHERF's

executives, including the CEO, chief financial officers and lawyers. Whether through direct proximate acts or failures to act, illicit cooperation was metastatic. Within Abdelhak's ruling clique, conflict of interest and alliances between the actors not only resulted in acts of illicit cooperation, it encouraged the sale of its own moral soul.[92]

The SEC investigation of Coopers & Lybrand revealed the auditor's direct participation in a fraudulent scheme to help AHERF management arrange for duplicitous transfers of restricted funds and then cover the fraud, and their involvement.[93] Management knowingly and recklessly caused Coopers and Lybrand to release false statements to enhance and enrich the credibility of the financial statements to the board. Some may argue that of all of the culpable actors, the board ought not to be held accountable as it relied upon the veracity of the information provided, and was not privy to the recesses of Abdelhak's dealings.

However, key responsibilities of the board are adherence to principles of organizational ethics and the preservation of moral soul, in addition to fiduciary duties. Board responsibility requires access to information, even if it entails probing further and more deeply than usual to learn what goes on behind its veil.[94] As such many of the AHERF board members may have lacked the intent to participate in wrongdoing when they voted affirmatively on deleterious actions for which they had little or no information. The lack of openness and flow of information, and the dearth of information generally was certainly a barrier to discernment; an indispensable element of moral decision-making.[95] And they may even have been far enough from the act to justify mitigating culpability. However at a minimum, they are accountable for failing to uphold their fiduciary duty to the community and the organization by not demanding additional information or requesting substantiation of major acquisitions and expenditures. In the absence of discernment, no heed was paid to the needs of AHERF's internal and external

stakeholders. Discernment and other affirmative board actions would have helped to ensure that AHERF's moral soul was intact and not at risk for liquidation along with its other assets.

Moreover, because the relationship between the board and the CEO is so critical to preserving moral soul, [96]it is reasonable to question the board's rationale for appointing him CEO in the first instance, given what was known of Abdelhak's executive character. Abdelhak was perceived as autocratic and controlling. He exercised top-down management which was non-participatory and entombed in secrecy. His warfare style of management inspired fear and emasculated others to the extent that insiders and leaders within the organization were fearful and hesitant to express anything except high praise for him. He was described by those within the organization as an empire builder who took high risks.[97]

Complicity and illicit cooperation where the hallmarks of Abdelhak's reign. Those characterizations were largely attributed to his complete domination over all board decisions. Board meetings were scripted affairs with decision-making relying solely and completely upon his assessments and judgments. Abdelhak and the board chairman discouraged questions and dismissed anyone who challenged actions and decisions. Abdelhak held himself out as having full authority over the board.[98]

Narcissism was his professional trademark. According to knowledgeable insiders, he never admitted fault, blamed others for everything, and self-aggrandizement and demonstrable self-love were the hallmarks of his professional persona.[99] He was wryly referred to as "the maximum leader" and sacrilegiously as "the great I am."[100] His identity became synonymous with AHERF's, and the two identities were so tightly aligned that it was difficult to distinguish whether he was a person representing an organization, or an organization living through him. Role transference enabled people to conflate Abdelhak with the organization. AHERF adopted

his professional narcissistic personality, rather than promoting the face of the corporate mission and values.

While the board cannot be responsible for his dysfunctional and disordered personality, they can be held to in dereliction of their duty for appointing Abdelhak, and more importantly, for retaining him. The board is also obligated to follow and monitor the conduct of its executive management. As the author of the ethics model, and as the custodian for its mission and values, the board breached its ethical and fiduciary duty when it consciously failed to take action against Abdelhak and oust him once his destructive symptoms and characteristics surfaced.[101] The board cannot use ignorance as an excuse to mitigate its culpability and responsibility.[102] It is culpable for contributing to the loss of moral soul.[103]

This sentiment was underscored by Judge M. Bruce McCullough during the bankruptcy proceedings. He questioned the AHERF board in order to ascertain their roles and reporting lines to determine what they were doing, and who was executing. To no one's surprise, there were findings of incompetence and gross mismanagement. He held that the trustees were tainted by irreconcilable conflicts of interest culminating ineptitude and egregious disregard of their fiduciary duties.[104] Everyone was enriched, except the wide swath of stakeholders who were harmed. This includes but is in no way limited to the patients who suffered from a crippled delivery model, and the practitioners, clinicians and other members of the AHERF workforce who were financially impacted and ignored. While the AHERF bankruptcy discharged debt and nominally recognized creditors, it was impossible to make whole again all impacted by this moral and financial cataclysm. Nevertheless, like the human soul, if any vestige of the HCO remains, its soul may be rekindled with virtue, and reunited with its body through moral agency an a culture of ethics.

The Roman Catholic Church teaches that hope for the sinner is confession and forgiveness. By restoring the venial offender's moral progress, and reuniting the mortal offender with Christ through reconciliation, the souls of the penitent are refreshed, renewed an reunited again with human virtues to guide its moral reasoning. The soul and the body are made whole again.[105] Reconciliation with God requires moral accountability through reflection and examination of conscience, contrition,[106] and penance.[107] The cohesion of the soul with the body enables moral reasoning and discernment. Virtues cannot flow and permit good works without unity with the soul.

Forgiveness is a necessary part of reconciliation, and so it is with an organizations redemption and moral restoration. Since an organization cannot act on its own, it must rely on the collective actions of its moral agents to demonstrate the intent to be reconciled with the communities it may have harmed when it was soulless. This contrition must be reflected in the exemplary conduct and integrity of its moral agents serving as organizational ambassadors within the community.[108] Since role transference can tightly link an actor to the organization's persona such that the organization adopts any dysfunctional characteristics, it can also adopt and project positive ones; importantly, those that represent missions of healing and virtue.[109] Moral agents are visible and tangible representatives of the HCO's values and purpose. Hence, role transference can be used to the positive advantage of the organization that seeks redemption

Further, moral agents can reunite with the HCO's soul through establishment of a morally rational and systematic decision-making process. In this way, moral agents will place the best interest of the HCO and its stakeholders ahead of their own self-interest and preferences.[110] Rational and systematic decision-making builds trust and restored integrity between and amongst its agents and stakeholders.[111] The process of moral decision-making includes listening to the

needs of the communities of stakeholders served by the organization. It ought not to entertain narcissistic propensities. In fact, moral decision-making imbeds the trust of internal and external constituents within the organization.[112]

In the case of AHERF, if mission discernment advancing education, healing the sick and conserving health had guided expenditure and acquisition decisions, instead of Abdelhak's professional narcissism, prudent due diligence would have prevailed. In that way, the soul would not have been easily separated from decisions; rather, it would have become an inextricable part of the solution.[113] Nevertheless, the lure and slipperiness of conflicts of interest and conflicts of conscience can never be fully eliminated because persons, in their humanity, think, act and share space in a world that is influenced by good as well as evil. As such, restoring soul also necessitates a need to return to the principles of professionalism and compliance with normative standards of conduct that guide organizational ethics and moral agency.[114] Professional codes of conduct allow for self-regulation and assessment. This provides moral agents throughout the HCO from the boardroom to the mail room, the opportunity to ask "how well are we doing"[115] and to react and respond accordingly. Self-performance assessments, metrics tracking goals and professional standards keep moral agents in-check with the HCO's vision and mission, and helps to insulate and protect its moral soul.

2. C.   Stakeholder Theory and Normative Constituencies

Goodpaster and Matthews hold that rational and respectful decision-makers notice and care about whether or not the consequences of their actions lead to indignities and offenses towards others.[116] The stakes are even higher for the healthcare decision-maker. Unlike other industries where the consequences of decisions most notably affect products, services and profitability, decisions within an HCO can have direct impact on the length and quality of human

life.[117] A notable paradox for an industry that advocates for human wellness is that decisions in healthcare often appear to be devoid of humanness.

The integrity of ethical decisions can be further abraded by the fact that health care is morally and ethically complicated.[118] Ethical decision-making, according to Weiss, also depends upon the moral maturity of the people engaged in the reasoning. And while there are different levels of maturity, the tightly controlled corporate environment which typically characterizes an HCO, can stifle ethical decision-making.[119] In addition, issues and dilemmas affecting moral decision-making result from pressures that, as Weiss advances, are exerted at personal, organizational, industrial as well as social levels. To that end, the remainder of this chapter illustrates an understanding of these levels of decision-making through the lens of stakeholder theory, and its reliance on morality and ethical principles.

2. C. 1.   Normative Stakeholder Theory

Organizational homeostasis relies upon the systematic ability of the organization to respond to unanticipated sudden or gradual threats to its stability and health. Determining the appropriate course of action often demands making choices that benefit some to the determinant of others. The traditional capitalistic view of corporate decision-making placed shareholder interests at the center of such decision-making, with the managerial mind set of placing profit and returns ahead of all other considerations. This all too ubiquitous mindset fueled the perception that the corporation was a corrupt and shameless construct lacking in good will and gratitude. Possessing unchecked power and resilient to shame or punishment, it was soulless.[120]

Historically, the potential for corporations that lacked soul and moral accountability for the consequences of their actions to do real harm to people necessitated checks on their power. It

also bespoke of the need to shift the managerial mindset from the shareholder to other alternative constituents possessing a stake in the company. The birth of stakeholder theory was the epicenter of that shift. Broadly stated, stakeholder theory is an approach to organizational ethics that heeds the rights and interests of individuals or groups who interact with, and could be affected by the organization's decisions.[121] R .Edward Freeman is credited with developing stakeholder theory to underscore and draw attention to the way that managers and other individuals act and the consequences of those actions, based upon ethical principles. The most striking feature of stakeholder theory is that it demonstrates ways in which organizations can exercise social responsibility through moral management without contradicting the framework of a moral capitalistic economy.[122] Like the discernment process for ethical decision-making that reflects upon those who may be affected by particular decisions, stakeholder theory applies moral theory and considerations of right behavior to management decisions.

As described earlier, the structural and functional levels of anatomy come together to sustain the human body. These levels include all of the organ systems that form the human person; functioning together as interdependent components. For example, cells need nutrients that are procured through the digestive system and distributed via the circulatory system.[123] These systems cohabitate alongside large populations of bacteria and microorganisms that exist within the body to either enhance or disrupt homeostasis; depending upon their inherent purpose. It can be said that these system functions and microbiota have a *stake* in the homeostasis of the body. This stake is analogous to the interest or claim that a group or individual has in the outcome of an HCO's decisions or actions towards other.[124]

Over the past thirty years since Freeman unleashed his groundbreaking theory, a variety of modified stakeholder theories have emerged: each with its own set of assumptions and claims.

Despite its appeal, the consequences of its popularity as well as the vigorous critiques of it have, in many ways, muddled and obfuscated its utility. For example, with at least fifty-five recognized definitions, there is much theoretical debate simply surrounding the definition of *stakeholder* itself.[125]

Understanding what it means to have a stake in a matter is rather uncomplicated. Determining who is entitled to such a claim and identifying those who are responsible to the holder of those claims is a varied as the microbiota in the human body, or as diverse as the stakeholders within an HCO. Freedman holds what is widely recognized as the seminal definition of stakeholder, and will unless otherwise stated, be the position adopted throughout this dissertation. An organization's stakeholder is, "any group or individual who can affect or is affected by the achievement of the organization's objectives."[126] Methods of identifying stakeholders and determining the organization's duty to them is often an exercise in moral classification. In advancing the argument for ethical obligations for accountability of leaders to stakeholders, this discussion illustrates the moral classification of stakeholder's according to Phillips' theory of normative and derivative stakeholders.

According to Phillips, the organizational universe is not constructed and bisected by legitimate stakeholders and non-stakeholders. It is, however, partitioned in the first instance by normative stakeholders. Despite traditional problems with definitions of *normative*, this concept is considered to be the heart or core of stakeholder theory.[127] In its broadest sense, normative stakeholder theories seek to alter corporate behavior, either directly or through management, leadership or governance bodies acting according to what *ought* to be done to achieve good. It considers what *should* be done to meet the needs, interests and claims of the organization's individual or group stakeholders according to certain moral norms.

Normative stakeholders are those individuals and groups of individuals to whom the organization has a direct moral obligation to attend to their well-being.[128] They are the beneficiaries and objects for which the organization is managed – they give the organization purpose. They are not recognized according to their proximity and situs to the organization. They are not uniquely internal or external to the company. Rather, they are descriptive of their relevance and presence as customers, patients, employees, local communities, suppliers, or financiers and lenders.[129]

By virtue of their humanness, normative stakeholders are afforded greater moral consideration; that is to say, stakeholder fairness, in corporate decision-making, than other social actors.[130] That is not intended to suggest that non-normative stakeholders are morally disregarded or diminished. But rather, there is a stakeholder-based moral obligation for fairness that is layered on top, enriching the condition of the normative stakeholder. To further elucidate, normative stakeholders do not misappropriate entitlements away from derivative stakeholders. Rather, they are merely entitled to more.

Just as the human body is affected by external influencers that create disruption as well as equipoise, so it is that an HCO can be influenced by derivative stakeholders. Derivative stakeholders are groups who can sow seeds of detriment, or create benefit to the company by virtue of their passions; such as activists, the media, and competitors.[131] Although the organization has no direct moral obligation to advance the interests of the derivative stakeholder, Phillips advocates that management acknowledge and pay them heed for the sake of normative stakeholders.[132]

Even though derivative stakeholders do not directly derive benefit from the moral obligations of the organization, they obtain their legitimacy as stakeholders nonetheless from

their ability to affect and impact the normative constituent. While many may act in ways that are salutary to the organization; for example: a journalist who reports a favorable story about the company concerning their labor strike, they are contrasted by the derogatory news article instigated by a company's rival competitor. Powerful derivative stakeholders can effectuate seismic influence and authority, and justify the moral decisions made by organization in support of the normative stakeholder.[133]

Because of the complexity of the entwined and interdependent interests with an HCO and its susceptibility to disruption, stakeholder theory is a promising model for maximizing value creation opportunities. It acknowledges moral agency and diversity of values[134] which appeals to the climate of the HCO and help to ensure homeostasis. This discussion illustrates and contrasts two of the dominant normative stakeholder concepts – the ethic of care, and principle of stakeholder fairness as advanced by their most notable theorists. It includes each theorist's respective interpretation of what characterizes a stakeholder, as well as a recognition of the role of stewardship in reconciling need with limited resources. In subsequent chapters, this discussion expands to include a specific cross-section of internal and external HCO stakeholders, vis-à-vis these concepts; evaluating their claims against the organization's normative obligations to them.

2. C. 2.   Feminist Theory and Ethics of Care

In contrast to traditional economics-based views of management that are presumed to protect the interests of the corporation and its shareholders primarily, "stakeholder theory can be viewed as a *feminine* normative counterpart, whereby corporations seek to promote stakeholder satisfaction through a more cooperative, caring relationship."[135] This reconstitution of normative stakeholder theory is supported by the feminist ethics of care proposing that stakeholders are viewed as connected sets of relationships with each other, not merely with the organization.[136] In

contrast to social contract theories, feminist moral theory looks beyond legalistic, right-based considerations of stakeholder interests and elevates the value of relationship to ensure that those interests are brought to the forefront of managerial thought. Despite the feminist characterization, research indicates that preference for ethics of care over justice is identified with men as well as women.[137]

The discussion presented here and developed more fully throughout several subsequent chapters illustrates five variations of feminine ethics of care, stakeholder theory and analysis through the lens of distinct, but aligned theorists. Care ethics is traced to Carol Gilligan's work. She undergirds her critique of masculine economics-based management by suggesting that stages of moral maturity transform inward assessments of the right course of action, into outward considerations of those which whom we are in relation. Relationship requires connectedness with others, while differentiating the other from the self. This results in care for others.[138] Nel Noddings asserts that it is not merely those with whom we are in relation that should be the object of our caring, but rather, caring ought to be a universal attitude that we demonstrate to our wider shared society.[139] Ruth Groenhout considers ethics of care by exploring the connection to human nature as a method for moral decision-making.

And, although highly recognized for their individual attitudes advancing stakeholder theory and its application, this discussion unifies Andrew Wicks, Daniel Gilbert and R. Edward Freeman's conversations on the feminist theory and presents them as a single theory. They collectively incorporate the ethics of care into the dominant masculine bias metaphors that are the hallmark of traditional stakeholder theory.[140] Finally, Brian Burton and Craig Dunn similarly present a unified theory incorporating care for the least advantaged stakeholder while ensuring that some privilege is afforded to those who enjoy close relationships with the decision-maker.[141]

Obligations between stakeholders and the idea of accountability are bi-directional and multi-dimensional. On the one hand, stakeholder relationships occur between persons or groups of persons. Accordingly, there is a fundamental moral duty to treat people with respect and recognize their unique human dignity, treat them fairly, and avoid harm. On the other hand, the relationships often entail additional obligations stemming from the role-based relationship between the HCO and its stakeholder. For example, an HCO executive is morally accountable to its employees because of their humanness, *and* because of their status as employee/normative stakeholders.[142] Accountable leaders act in deference to their multi-dimensional stakeholder obligations through demonstrable commitments to fairness.

2. C. 3.   Stakeholder Fairness, Social Contract, and Stewardship

Integrity, fairness, and trust are ethical concepts that comprise the moral principles that should be applied in practical business settings.[143] The culture of ethical accountability within each HCO determines the degree to which these concepts become rooted in the moral principles of the organization. As Wallenhorst contends, the key marker of an ethically sound organization is the tone set by its executive leaders.[144] And, with normative stakeholders at the center of their minds, their business needs must be based on ideas of fairness. The shear breadth of normative stakeholders to whom HCO executives are accountable makes employing fairness one of the most ambitious demands placed upon leadership. Applying fairness requires that the needs, interests, and concerns of particular stakeholders be considered in relationship to others.[145]

Managing for HCO stakeholders seeks win-win outcomes through collaborative and caring relationships. Complex situations, however, can result in zero-sum games where the gain of one individual or group is necessarily lost by another.[146] This seemingly inevitable reality is not intended to foretell that stakeholder theory is inherently uncompromising and self-

concerning. On the contrary, Robert Phillips' notable principle of stakeholder fairness argues

that the obligations of fairness by and among stakeholders are *created* when benefits resulting

from cooperative efforts are accepted by a group of stakeholders.[147] Rather than attempting to

treat all stakeholders equally, which he believes is impossible, Phillips recommends the principle

of equity to determine which normative stakeholder should receive more.[148] Phillips confesses

that his work is based on John Rawls's principle of fair play which, according to Phillips, is the

moral foundation of stakeholder theory. [149]

This notion of fairness, according to Freeman, presupposes basic equality among

stakeholders in terms of their moral rights. He addresses how the inequalities that might arise

may be resolved through his doctrine of fair contracts. [150] Of the six fair contract ground rules

espoused by Freeman, the agency principle postulates that all agents participating in the contract

must serve the interests of all stakeholders.[151] This principle squares entirely with the moral

obligations of the ethically accountable HCO and its constituent interdependencies.

In contrast, the concept of integrated social contract theory espouses, according to

Thomas Donaldson and Thomas Dunfee, a foundation for stakeholder theory that suggests

management take into consideration stakeholder norms rather than interests.[152] Donaldson and

Dunfee's model is communitarian in that it considers the normative voice of the relevant

stakeholder communities. Determining who is a stakeholder, and who or what is not depends

upon a number of factors and precise analysis of the facts and circumstances confronting the

organization and its constituents.

Principles of fairness must also nourish policy and decision-making with respect to

distribution of scarce resources; especially in healthcare. Justice and equity are key concerns[153]

and are frequently central in the minds of management. However, morally accountable

leadership is concerned with more than ensuring that resources are distributed with justice and equity. They are called to remain faithful to the ethic of stewardship in the management of stakeholders.

Stewardship in healthcare is an understanding that all of the resources of the HCO, including real and intangible ones, are held in trust by the organization and its leadership for the good of others.[154] It is not merely an aspiration of good leadership. Stewardship is a fiduciary duty and a commitment to the organization. It is an ethic that transcends healthcare and is integral to nearly every discipline, including theology, information management,[155] environmental management, and economics. The principle difference in the value of stewardship within other disciplines lies in the origin of the resources at issue. That is, Catholic social teaching provides that stewardship is the command of God for humankind to use the world's resources He gifted to them responsibly for the benefit of all.[156] For the non-religious HCO, the value of stewardship requires that the care delivery system monitor and use its resources – varied as they are – wisely.[157]

Because the range of stakeholders in healthcare delivery is diverse, the ability of an HCO to achieve its mission, survive as a viable business and provide for the good of others without breeding ethical tensions is dubious at best.[158] Adding to this tension is the fact that members of management are normative stakeholders themselves. Although as stewards, their duty to safeguard the welfare of the company requires a balancing of multiple claims which include competing and conflicting stakeholders that could threaten their own self-interest.[159] Despite this conflict, it is possible for the soul of its leaders, projected onto and through the HCO, to maintain homeostasis for the organization and its communities of stakeholders. Methods for accountable

management of specific stakeholder interests and communities of health are explored more deeply in the remaining chapters of this dissertation.

2. D.   Conclusion

The anatomy of the contemporary healthcare organization (HCO), like the human body, is an interdependent system of form and function responding to internal and external environmental influences in order to survive and maintain homeostasis. The business model of the HCO is highly complex as it is comprised of a series of unending interacting and coexisting touchpoints and relationships; each with their own unique self-interests and objectives. Maintaining healthy order within such a heterogeneous system depends upon the ethical accountability of HCO leadership to its constituent parts; specifically to its normative stakeholders.

Moral agency, as the cornerstone of ethical leadership, is the ability to discern, decide and act according to what is right, and to be accountable for those actions. Moral soul is the distinguishing characteristic of accountable leadership. Individual and institutional moral agents, possessing distinctive qualities and moral obligations act on behalf of the HCO, and are the embodiment of its moral soul. An organization is adjudged by those individuals and communities it serves according to the decisions, intentions and actions of its agents; as well as by the values and principles it espouses.

Conversely, the absence of moral soul is recognized in such things as conflicts of interest, conflicts of conscience and all too often deficiencies in moral judgment that result in stakeholder abandonment. When leaders are dispossessed of their moral agency and act in morally irresponsible ways, the soul of the HCO dies, as demonstrated through the AHERF case study.

Stakeholder theory, which takes into account considerations beyond mere economic, is an approach to organizational ethics that heeds to the rights and interests of individuals who interact with and could be affected by the HCO's decisions. It is concerned with the HCO's direct moral obligations to its constituents. The ethics of care, and the principle of stakeholder fairness are two dominant stakeholder concepts which appeal to the climate of the contemporary HCO to help ensure homeostasis. They look, respectively to the relational quality of moral human interaction, and to the principles of fairness as an undercurrent of policy and decision-making, as well as stewardship as a fiduciary duty and commitment to the HCO and its community of stakeholders. Stakeholder value and values are the foundation of ethical accountability and organizational leadership and underscore the HCO's moral duty to its interdependent stakeholder communities.

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Chapter 3 – Ethical Challenges of Maintaining Stakeholder Confidentiality and Privacy

3.   Introduction

Contrary to intuitive assumptions, not all healthcare interests are purely corporal. Obtaining wellness of the human body, mind, and even spirit are patent concerns of most healthcare stakeholders, regardless of their specific relationship to the healthcare organization (HCO). However, human flourishing and respect for human dignity also includes recognition of the patient's right and interest in preserving that which is most unique and personal to them – the confidentiality and privacy of their most intimate thoughts and facts - their information. This chapter thoroughly explores this stakeholder interest by bifurcating them into distinct sections; one setting forth the duty of confidentiality, and the other illuminating expectations of privacy.

The timeless concept of confidentiality is embattled in an age where knowledge is power, predictive analytics dictates decision making, and data has become "the raw material of the information age."[1] Confidentiality – the cornerstone of trust in healthcare – is further weakened under the crushing influence of diverse stakeholders competing to ingest as much health data as can be consumed in order to advance their own interests, or those of their constituents. Yet, patient data holds the key to unlocking crucial medical advances. Patient data has become the lifeblood of the contemporary HCO, and as Big Data analytics innervates its body through the new age of algorithmic neural networks, personal privacy is endangered. Undetectable and camouflaged amongst the digital data elements of this feeding frenzy, are the things which every human person has, holds sacred, and may even deny having at all – their secrets.

Preserving the confidentiality of patient secrets while satisfying legitimate competing stakeholder interests is daunting and is never absolute. Accordingly, this chapter dissects the

concept of confidentiality as a multi-stakeholder interest in contemporary HCOs. It will demonstrate the ethical justification for exceptions to the legal and professional obligations of the duty of confidentiality in clinical care, and the effects of those exceptions on patient and third party expectations. It will then illustrate the intersection of the individual's right to privacy in their personal information, the legal and ethical justification for use of such digital information to do good, and the need for ethical guidelines and principles to minimize threats to privacy while respecting the dignity of the person.

This chapter begins with an examination of the anatomy of a secret, the ethics of secrecy, and the fact that secrets are a natural part of humanness, according to the works of Sissela Bok, and Anita Allen. It then illustrates how the revelation of patient secrets in the course of the physician-patient relationship, forms the seal of confidentiality, triggering the ethical principles, and the professional and legal strictures protecting them. Despite these obligations, this paper explores the disruptors that justify disclosures of protected secrets in the clinical setting and the contradictions and ambiguous situations that besiege the ethics of physician-patient confidentiality.[2]

Concerning the duty of confidentiality as a constituent of the principle of respect for autonomy, this chapter proceeds to discuss the role of autonomy and informed consent as a means for patients to exercise control over the disposition of their secrets. It discusses the need for physicians to avail themselves to their patient's autonomous voice when considering the scope of information necessary for a fully informed consent. It then shifts to the ethical dilemmas confronted by clinicians as they are called to be confidants and guardians of secrets.

Specifically this chapter examines challenges to confidentiality that result from the clinicians' duty to protect secrets learned in the course of the psychotherapeutic practice.

Adopting the assertion that mental health is a public good, it presents alternatives to absolute

confidentiality in the form of duty to warn third parties. This dual allegiance between protecting

the patient, and securing her secrets, and consideration for the welfare of others, presents a

dilemma that implicates both legal duties and ethical principles.

It then explores the duality of duty and the ethical dilemmas engendered through

advances in genomic medicine. Genomic medicine, which for purposes of this dissertation

includes references to genetic testing and whole genome sequencing, is pioneering promising

and unprecedented advances in human health that will help to better understand the qualities of

diseases.[3] At the same time, its findings incidentally expand the common understanding of

secrets to include that which may never be known to anyone – including the patient. In addition,

this chapter illustrates how genomic medicine multiplies the breadth of third party stakeholders

who may or may not have an interest in obtaining these secrets, and the ethical justification for

disclosing them, or protecting and respecting their secrecy.

The focus of this chapter then shifts to the stakeholder expectation of privacy. It proceeds

by briefly exploring the evolution of privacy as an individual claim, providing the foundation for

current concepts articulated by several contemporary theorists Alan Westin, Daniel Solove,

Adam Moore, Julie Inness and Anita Allen. The sanctity of privacy as both an inviolable right

and a moral duty to respect intimacy, as manifest in contemporary healthcare, is also discussed;

in addition to the effects on patient privacy from the emergence of diverse stakeholders, the

transformation of American medicine, and technology. All of which implicate individual

privacy.

In consideration of the healthcare industry's appetite for protected health information,

this chapter explores the relatively recent legislative and regulatory activities enabling the access,

use and disclosure of individuals' information. Protecting the privacy of patient stakeholders, ensuring that they are able to maintain control over their sensitive information while emancipating data through health information technologies is also discussed. Specifically, this chapter explores interoperability of electronic medical records and the implications to the historically binary relationship between the physician and patient.

The proliferation of digital information, the ubiquity of the Big Data phenomenon, and the emergence of artificial intelligence, machine learning, and algorithmic decision-making not only drive healthcare innovation, they weaken the control of the patient; endangering autonomy. This chapter probes the opportunities and ethical complexities of Big Data and health data dependent technologies. In demonstrating how accountable healthcare leaders must consider the moral rights of their stakeholders, the chapter concludes with an exposition of an ethical framework for data use that has at its heart a better respect for human dignity.[4]

3. A.   Confidentiality and the Ethics of Secrecy

"Ask me no secrets, and I'll tell you no lies: is a sardonic idiom that has been used by poets and cynics alike to express the limits of man's willingness to reveal certain truths about himself. These truths, or secrets, live in the essential recesses of every person, and define aspects of selfhood that intentionally remain hidden in order to preserve that which is uniquely human and different.[5] Much of human behavior is driven by the need to wall of others from access to secrets that define human aspirations, experiences and desires. Fear of public disclosure of private truths is a strong, but not exclusive, motivator for concealment and even deception. In that vein, however, lying is not the only way to avoid undesirable consequences of disclosing of secrets. Rather, the antidote for fear of public revelation is trust.

Trust in others is a human value that enables intimacy. It is most needed when one is no longer in control.[6] Surrendering control to a trusted other allows for the release of inhibitions that can obstruct human growth and flourishing. It creates a tie that binds the one who reveals an unknown to the recipient who now conceals, through the presumed inviolable bond of confidentiality. In such confidential relations, the confidant assumes the obligation not to use what has been revealed to harm the confider, or to share it with third parties, without the consent of the confider.[7] The trust imbued in such confidential relations is what seals the commitment of the various agents who have moral obligations and duties to preserve entrusted secrets.

Moral agents cloaked under the seal of confidentiality are found anywhere and everywhere humans interact, including within families, businesses, friendships, and professions. Particularly in the healthcare setting, the principle of confidentiality and the moral and legal obligations emerging from it can be thought of as a kind of security blanket protecting the secrets of a variety of stakeholders. However confidentiality in healthcare today is a porous obligation, and it can be argued that the blanket is threadbare in many places. Medical secrecy in healthcare is a controversial matter as confidentiality is frequently abdicated to advance the interests of persons other than the patient.[8] Exploration into the ethical makeup of a secret and the moral agency affecting its vitality is essential to justify the porosity of confidentiality.

3. A.1 Keeping Secrets

Insinuating that humans are incapable of committing to an unbreakable confidence, Benjamin Franklin wittily warned that, "[t]hree may keep a secret, if two of them are dead."[9] Franklin might be surprised to learn that according to some, if two of the three are dead, there are no secrets at all. Because traditional conceptions of secrecy hold that without a person from whom information is withheld, secrecy cannot occur. In essence, there is no secrecy at all when

one is alone.[10] However, this paper adopts the perspectives advanced by Slepian, Chun and Mason that "an individual has a secret from the moment he or she decides to withhold information" often long before they are in the presence of the person from whom they are concealing.[11] As such, respect for the virtue of secrets - those facts or things that people intend to be "kept from the knowledge of others or shared only confidentially with a few"[12] is a quintessential quality of humanness, because humans keep secrets.

Even though giving up control *can* be emancipating, collective and individual dignity is enriched by the awareness that one can control their secrets. One's thoughts, and the details about their most intimate self that are not outwardly and openly expressed, are secrets. And it is important to note that while all deception requires secrecy, all secrecy is not meant to deceive.[13] Someone may keep secrets by omission – that is, intentionally withholding something about themselves - in an attempt to avoid unpleasant or painful memories, without actively lying about the subject.

For example, the intentional failure of a professional man to discuss, with his fiancé, the firing from his job at a fast food restaurant when he was in high school because he is embarrassed to discuss the underlying reason – his immature conduct - is not, *prima facie,* deception. As Kelly suggests, "secrecy is a nearly universal phenomenon, and being able to keep personal secrets may even be seen as a sign of maturation."[14] It is self-control in the most literal sense. Keeping secrets about oneself demonstrates respect for the demarcation line between public and private life. It demonstrates respect for individual autonomy.

Sissela Bok's concept of the ethics of secrecy points to the importance of secrets in healthcare. She writes that humans are most comfortable and assured when they confront areas of life that they know intimately, or belong to, and "within that area, what we keep secret

requires our most intense and active attention."[15] In contrast she contends that even amidst the many areas of life about which we know little, "we also experience as secrets the spaces from which we feel shut out."[16] Such is the case for the patient seeking care from a physician. The patient knows her body and her thoughts better than anyone, and has elected to keep certain intimacies concealed; entrusting them to her physician. She similarly holds as secret that which she does not know, but will soon be discovered and revealed by her physician.

Bok underscores that the sacred and the secret have been related through Latin etymology since antiquity.[17] The *secretum,* as something set apart and hidden, and the *arcanum* as that which is spiritually mysterious and secret are vestiges preserved in contemporary secret keeping. Keeping secrets is particularly sacrosanct in the physician-patient relationship. The confidentiality of secrets disclosed to physicians, either through direct communication or through physical revelation, is a fundamental presupposition of every medical encounter.[18]

Quality care depends upon mutual transparency and trust. This is relevant as it is widely recognized that patients who lack trust in particular physicians, or healthcare generally, are less likely to seek care or be compliant with treatment protocols.[19] As such, the willing patient imparts the information to her physician in confidence and trust[20] and once a secret is revealed, the physician's duty of confidentiality – that is, the duty to keep her secret – is invoked. In this regard, keeping secrets within the confines of the physician patient relationship has been long considered binary. Since secrets involve the revelation of information, presumably known only to the patient – at least initially - so too is the truth of the revelation.

3. A .2.   To Tell the Truth

People typically choose to conceal information about their health long before they see a provider. Aches, pains, moods, and changes in a person's body may all be things that people keep secret; perhaps out of fear, indifference, independence, invincible ignorance, denial, or some combination thereof. Remaining true to themselves however, the intimate relationship that people enjoy with their own body and mind, according to Anita Allen, means that many diseases and injuries are invisible to other people. Because health conditions often remain hidden, most of what people learn about themselves and their conditions occur extra-professionally, through self-encounters.[21] For all that, in order for the clinician to serve the patient's best interests, patients must realize some sacrifices to secrecy, and willingness to tell the truth.

To that end, many norms of social interaction are interrupted in the clinical setting. Questions are asked, and narratives are revealed in the course of care that do not typically transpire in polite company. Discussing one's body and its conditions transparently, and revealing one's experiences and emotions taps into the fragility of a patient's self-esteem and vulnerability; which "follow individuals into their doctors' offices.[22] Considering all that is exposed through the clinical encounter, and in recognition of the fact that information is the most versatile resource in the healthcare setting,[23] the need for truthful disclosures is incontrovertible. Both the clinician and the patient are keepers of secrets in a trust-based relationship that is strictly dependent upon the moral imperative of veracity.[24]

But, people lie in an effort to manage information.[25] Of the many domains of human life where lying appears to be the most prevalent, the health care delivery setting calls for special attention.[26] It is widely acknowledged that most patients lie to their doctors to avoid negative consequences, to escape embarrassment, and to be presented in a more favorable light. The most

common are lies about diet, smoking and alcohol habits, as well as sexual activities and preferences.[27] Some lies are also rooted in the patient's desire to achieve some economic gain such as public welfare benefits, or other attempts to defraud the healthcare system. Regardless of the motive, it is also understood within the context of secrecy in healthcare, that "lying is an expression of a power relationship, whether it is used as a tactic to impose ones' power, or, on the contrary, to resist the other's power."[28]

The moral imperative to tell the truth is incumbent upon both the patient and the physician who have entered into a treating relationship.[29] In addition, truthful conveyance of information provides the greatest opportunity for successful care delivery and outcomes. Intentionally providing inaccurate or untrustworthy facts that may skew the physician's assessment and diagnosis. At its extreme, people with factitious disorders, who deliberately conjure up illnesses or act as if they have illnesses or symptoms, produce unique, though not uncommon trials for the physician.[30] Although there is little formal guidance on the nature of the physician's duty to treat if the patient is knowingly untruthful, the physician-patient relationship "is a reciprocal one, and if patients don't meet their duty to be truthful, then doctors do not have a responsibility to continue to care for them."[31] Withholding the truth is dangerous. It is harmful to the patient, and may justify the physician's decision to discharge the patient from his care.[32]

However, telling the truth has discordant meaning for the physician. Situations may compel the physician to withhold certain truths from the patient.[33] Hence the failure to tell the patient something about a particular aspect of their health, including a true statement of fact, may be perceived as intentional deception, or lying. Later sections of this paper examine those circumstances more fully. Nevertheless, the physician's duty of confidentiality, while fraught

with moral dilemmas, is derived from the ethical principle of patient autonomy as well as legal obligations respecting the patient's right of privacy.[34]

3. B.   **Professional Duty and Legal Obligation**

Both mental health professionals and laypersons alike advance the notion that confessing one's secrets is good for the soul, and that revealing secrets that one withholds about themselves is cathartic.[35] In fact, relieving oneself of the burdens of their secrets is reported to have actual health benefits. Ridding oneself of secrets has been shown to improve immunological functioning, relieve stress, and even reduce the number of physician office visits.[36] While most of the research on secrets has focused on secrets about the self, little work has been done on the willingness and ability of those to whom secrets have been revealed to keep them confidential.[37] The effect of the secret on the confidant's conscience and promise to keep the secret is fodder for future research and further analysis.

However, since antiquity, respect for patient confidentiality has been a fundamental moral precept and professional responsibility of physicians. The promise to "not divulge, as reckoning that all such should be kept secret"[38] concerning things learned about a patient in the course of the treating relationship resonates today. It can be argued that society's confidence in the sanctity of physician-patient communications is as essential as the confidence held by the individual patient. However, the dynamics of modern healthcare, and the demands of civil society to adjudicate the truth are disruptors to many of the traditional rules of confidentiality. Thus creating ethical dilemmas for clinicians; leaving some to argue that confidentiality is dead.[39] Challenged by advanced data analytics, complex care management, patient data-dependent technologies, clinical collaboration, as well as the rules of civil and criminal

procedure, the mantle of confidentiality under which patient secrets are revealed to the physician is ambiguous.

3. B. 1. The Duty of Confidentiality

A pledge of confidentiality not to divulge secrets that are made either implicitly or explicitly,[40] and a patient's expectations of privacy, are often erroneously conflated and confused. Their meanings are as distinct as they are similar. To understand the difference between confidentiality and privacy requires a focus on the duties and rights of the confidant and confider respectively. The physician's duty of confidentiality is supported by collateral and corresponding obligations to the patient. With the patient's interest at the forefront of his decisions, the physician has a duty to uphold the confidence in the physician/patient relationship generally, and the patient's legal right to privacy, specifically.[41]

The legal right to privacy, which is in essence an expectation of confidentiality that is enforceable by and rooted in law, is a preeminent concern in contemporary healthcare. The intricacies and debates relating to the legal right to privacy are addressed later in this chapter. It is enough for now to acknowledge that patients forfeit some, but not all, of their privacy rights when they enter into treating relationships and share secrets with their physician. However, the physician's *prima facie* duty of confidentiality, rooted in principles of ethics, and codified in professional codes, laws, and model rules of conduct, is what binds the physician to the "warranty of silence."[42]

Nevertheless, in some cases, confidentiality can be open-ended and must yield for the greater good. However, departures from the expectation of confidentiality that is the hallmark of the physician-patient relationship, should only occur in particular instances - when the severity of

not disclosing, and the life and health of third parties would outmuscle patient confidentiality.[43] Additionally, it may be necessary for the sake of the patient that physicians share medical secrets with other clinicians on the treatment team, or even unaffiliated physicians in furtherance of population health, patient safety, or quality of care initiatives. Alas, because the duty of confidentiality is no longer absolute, indiscretions and imprudent practices can also result in breaches of patient confidentiality. Although this chapter concentrates on the *ethical* justification for exceptions to confidentiality, a thorough discussion must include at least a brief recognition of the inappropriate breaches of confidentiality that occur within clinical settings. Such inappropriate incidents threaten to erode stakeholder trust, as well as corrode the integrity of the healthcare system.

The intimacy of the physician-patient relationship enables physicians and other healthcare professionals involved in patient care to form subjective impressions of the patient, their habits, lifestyles and other tangential activities. When sensitive information becomes part of these impressions and is shared with and expressed to others beyond the patient treatment relationship, these disclosures can cause irreparable harm to patients, their reputations, and to their personal dignity.[44] Medicine today is often practiced in teams comprised of more than just the medical personnel involved in a patient's care. As these teams interact, largely innocent yet inappropriate disclosures of patient secrets as well as subjective impressions increasingly occur in public areas of the hospital such as corridors, elevators, stairwells, and cafeterias. Research demonstrates that breaches of confidentiality within the hospital care setting are a major problem – occurring as frequently as once every 62 hours.[45] It concludes that physicians do not always know how to reconcile the need to share information with the need for breach avoidance.[46]

There is tremendous uncertainty among physicians concerning when secrets can become public. This is evident when considering the scope of privileged communications.

3. B. 2.   The Evidentiary Privilege

Justice, according to principles of jurisprudence, refers to the restoration of balance by ensuring that which is morally due is delivered. A just decision seeks to treat like cases alike, and different cases differently. Principles of natural justice in America ensure that there are "guarantees of impartiality or objectivity."[47] For justice to be served, full and transparent discovery and disclosure of relevant facts of a dispute are paramount. The failure to reveal that which may influence the restoration of balance in society, either through lack of awareness, or even perjury, can defile the delivery of justice. All too often, the need to discover and reveal secrets through truthful testimony is the pivot point between justice and injustice. When necessary facts are secrets that are shrouded in impenetrable confidentiality, the confidential relationship can make for a precarious foundation where secrecy and legal equity collide.

Not all truthful evidence concerning a case or controversy is discoverable. The evidentiary privilege – the right of one to refuse to testify about matters, or the right to prevent another from doing so – permits the suppression of evidence obtained through certain confidential relationships.[48] The physician-patient privilege, recognized alongside the attorney-client and priest-penitent privileges, accompanies and sustains patient secrecy. This evidentiary privilege protects the communications made by both the patient *and* the physician.

Statements made by the patient are protected from compelled disclosure in a legal proceeding. As the holder of the privilege, she may waive the privilege and allow for testimony that would make public the secrets she shared with her physician. However, the physician is not

permitted to waive *his* privilege without her consent. With few exceptions, statements made by the physician to the patient are also protected as privileged. The evidentiary privilege is critical. It enshrouds and insulates the sacredness of physician-patient exchanges beyond the bounds of mere confidentiality. It asserts that there can be a greater societal interest in protecting trust and preserving secrecy than in revealing the information.[49] Reverence for the fiduciary relationship between the physician and the patient can, and frequently does, outweigh the need to provide testimony.

But the need for compelled disclosure of patient information to a third party -what is in effect a breach of confidentiality - can override the fiduciary relationship. Many breaches of the expectation of confidentiality are not unlawful or inappropriate at all but are essential to public health and policy, despite the impact on patient privacy.[50] Health oversight activities such as disclosures to public health authorities for infectious disease control, workers' compensation claims, and certain national priority disclosure are a few examples. In addition, physicians may disclose patient secrets when defending themselves in a lawsuit brought by the patient. Other mandated duties to disclose confidential patient information to third parties are outlined later in this paper. But it must be noted that the lines between what is protected under the duty of confidentiality, what is required to be disclosed by law, and what is necessary for the benefit of society are obfuscated at best. In sum it can be said that trust protects secrets, and "confidentiality protects trust."[51] Trust invokes privacy, and the law protects privacy. But the gap between what prevents breaches of trust from being violations privacy must be backfilled with principles of ethics.

3. C.   Clinical Ethics

Filling the gap between ethical principles and sound judgements in order to guide moral decision making, demands that the principles be "specific to the needs of the particular contexts."[52] Nowhere in healthcare do ethical principles align with specific contextual needs more than in direct clinical care settings. That is not to say that laboratory and theoretical medical advances are devoid of ethical considerations. In fact, despite the widespread medical ethics mandate requiring full disclosure of medical errors, very few pathologists personally disclose pathology or lab errors to patients; often because they believe doing so would disrupt the patient's direct relationship with the physician.[53] As a further matter, patients are rarely even aware of the role of the pathologist, and there is almost never a personal relationship with the pathologist.[54] However, *clinical care* defines the humanness of medicine through direct physical contact and observation, and has the most notable impact on respect for human dignity and well-being. The therapeutic relationships created within the clinical setting are supported by the core principles of autonomy, beneficence, non-maleficence and justice.[55]

Post, Bluestein and Dubler maintain that these core ethical principles cannot provide sufficient moral analysis if they are merely applied mechanically, or in a vacuum, as they are reliant on context and narrative. The clinical context is fertile with ethical influencers such as power imbalances, access to care, decisions to forego treatment, and informed consent, to name just a few.[56] As an instrument for moral reasoning, core ethical principles inform and guide those matters that resonate most profoundly with the gravitas of patient health. Specifically, this section examines how patient secrets are obtained and shared in right relationship with ethical principle of autonomy and its constituent principle of confidentiality; particularly when these principles are in conflict.

3. C. 1.   Autonomy: The Patient's Voice

The duty of confidentiality, and the patient's expectation of privacy in healthcare are constituents of the respect for the principle of autonomy.[57] While a number of theories of autonomy exist, individual autonomy is generally accepted to mean the freedom to make choices without coercive and controlling influences. Those choices also include the patient's right to decide what, and to whom, personal information about them is to be used, disclosed and stored. It also includes the patient's right to refuse access to information they otherwise do not know about themselves. Autonomy empowers patients with the tools to control decisions about their own health and well-being generally. It allows the patient to have an active hand in their care. Respect for patient autonomy is respect for the patient's voice.

Autonomy is not enjoyed in a vacuum and is not a unilateral right. For it to sustain its dignity as a principle of common morality, respect for the principle of autonomy imposes obligations on those with a duty to protect the patient's interests. The patient's right to expect freedom from constraints, coercion and influences impose what Beauchamp and Childress refer to as "negative obligations" on the actions of physicians and other moral agents. Avoiding paternalism, or the intentional countermanding of patient preferences by the physician because he believes his judgement of what benefits or harms the patient[58] is best, is an example of a negative obligation. Complementary positive obligations are also imposed on physicians and other healthcare professionals. These prescribe that health care professionals provide sufficient information and facts to enable the patient to make informed decisions about themselves and their health.[59]

Eliminating constraints, and enabling transparency helps to achieve positive patient outcomes, and reinforces the dignity preserved through unencumbered choice and unimpeded human flourishing. Beauchamp and Childress maintain that these positive and negative

obligations attributed to respect for autonomy are seminal for the moral principles of veracity/truth-telling as well as informed consent - which insulates patient autonomy."[60] Actualized respect for autonomy acknowledged through informed consent helps to ensure that the patient's voice is heard.

However, as this dissertation demonstrates, harmonizing autonomy, informed consent and confidentiality is an endeavor that is rife with contradictions that can muffle the patient's voice. The patient's voice, with respect to how her secrets are shared, competes with the voices and concerns of other stakeholders including the physician, the community's interest in the health and safety of the population writ large, and the concern for justice.[61] It is often the case that patient's autonomous voice is drowned out, even when the contradictions are resolved through ethical decision-making.

To that end Petronio, DiCorcia, and Duggan focus on enhancing the communication process between physicians and patients in an attempt to reconcile the different assumptions each have about the other, and help to magnify the autonomous voice. They posit that improved communications between physicians and patients ought to be memorialized through what they refer to as a *confidentiality pledge*. The pledge articulates the patient's expectations, while describing how confidential information may be disclosed and shared in the face of contradictions and conflicts confronted by physician.[62] The pledge concept advocates open discussion between the physician and patient about how secrets are treated. It represents a meeting of the minds and additional support for effective and empowering informed consent.

3. C. 2.   Informed Consent: Telling It Like It Is?

The original meaning of *inform*, from the Latin *informare*, meant to give form to something, to give it shape or to modify it; and eventually came to be used more narrowly to mean "instruct" or "educate."[63] The concept of informed consent as applied to clinical ethics is, in essence, an amalgamated byproduct of both the former and the latter meanings. As a consequence of clinical care, patient secrets shared with physicians are reconstituted according to the clinician's understanding, clinical observations, and overall assessments. The secrets are further morphed into personal health information that, along with data from collateral sources such as lab and diagnostic information, consultative and other relevant longitudinal information, become part of the patient's medical record. For effective instruction and education to occur enabling the patient to be fully informed, the information must be successfully communicated.[64]

Informed consent for treatment, which also includes informed *refusal*, speaks to the right to self-determination, and the power to exercise control over oneself, avoiding exploitation, and especially making choices about how secrets are kept, shared and used.[65]   Originally a legal doctrine associated with any unwelcomed touching or battery, informed consent currently enjoys standing as a critical expression of patient autonomy, and occupies a dominant role in healthcare. As consumers of health services, which for most patients represents a blind item, meaningful informed consent emboldens patients to unmask the unknown. Yet, despite its preeminence, the physician's ethical obligation to respect patient self-governance through informed consent is not absolute. It competes with the principles of beneficence, non-maleficence and justice.

The intersection of these principles with informed consent raises questions relating to the scope of the information provided to patients to adequately support their independent decision making. Sawicki writes that legal and ethically-focused proponents choose concepts like materiality and relevance of the information to define the scope of disclosure, despite the

subjectivity of the measurements.[66] She further contends that patient's consider factors beyond

medical efficacy when contemplating care decisions. Consideration for the burdens potentially

imposed on caregivers and other third parties, costs, and impacts to the quality of life also drive

patient decisions. Ultimately, however, it is the physician who decides the type of information

and the spectrum of issues disclosed during the informed consent conversation with the patient.

The extent to which this decision making authority over patient secrets is ethically justified,

implicates physician paternalism, violates confidentiality, or in the most extreme cases, creates

potential abuses of power[67] is a matter for further ethical discourse within specific clinical

settings.

Dissecting the legal elements of the duty of disclosure under informed consent law in the

United States is beyond the scope of this paper. However, it is important to call attention to the

inherent limitations of the legal doctrine which Thaddeus Pope maintains impede patient

empowerment. Most relevant to its relationship to confidentiality, Pope asserts the physician's

duty to disclose is too narrow in that considerations about the information disclosed to the patient

are measured only by what objective hypothetical patients would need to know, not his particular

patient.[68] This hypothetical assumption fails to give credit to the patient's ability to consider

other factors when contemplating treatment. As such, patient self-determination is compromised

when subjective considerations are not respected.

HCOs share in the ethical responsibility for providing sufficient information to patients.

To that end, policies and procedures addressing informed consent ought to be revisited and

strategically reconsidered with the patient's voice in mind. Traditional views of informed

consent must shift from check-box procedures to systemic approaches designed to include

disclosures of patient quality measures, population health outcomes, health disparities, as well as

the types of data used to arrive at these measures. Providing this information along with participation in meaningful communication with physicians will redefine the physician-patient dyad in order that patients can make *truly* informed decisions.[69]

3. D. Psychotherapy: Secrets Kept…Secrets Shared

Few areas of healthcare venture closer to the core of humanness than that of the psychotherapeutic practice. Barriers to secrecy are whittled away as the patient reveals the mosaic of her life; intimate pieces and parts of her past that may never otherwise be shared, except for the therapeutic encounter with the mental health provider. Psychotherapeutic practice has long respected the rule of confidentiality stating that information disclosed by the patient to the therapist in the course of the therapy may not be shared with others without the patient's prior express written consent.[70] Freud considered the need to preserve confidentiality of psychotherapy quintessential to successful treatment. So much so, that he encouraged patients not to even reveal the fact that they were *in* treatment with anyone else, including intimates, spouses and other family members.[71]

Not surprisingly, concealing and even denying that one was in therapy in Freud's time did not require much persuasion. The centuries-old stigma associated with behavioral health and mental illness descends from a dark time when ignorance about people with behavioral issues was the norm. Mental illness has long been attributed to sin and the work of the devil, and those who suffered from it were often deemed insane, and were locked away in asylums or madhouses.[72] The stigma of mental illness remains a problem today, and persons with such conditions have encountered discrimination, even after laws were passed banning such activities.[73] To that end, the fear that privacy will be lost in psychotherapy is often a compelling

reason why people forego treatment at all. The fear of laying bare the secrets of one's infallibility remains profound.

The rule of confidentiality protecting these secrets is an ethical principle, professional obligation, and in many jurisdictions is supported by state law.[74] Despite these safeguards, ethical and societal conflicts unique to behavioral health and psychotherapy arise when breaching confidentiality is necessary to prevent imminent harms to others, or to deliver justice. The tension between the principles of autonomy, beneficence and non-maleficence are vividly illustrated in this moral dilemma.

3. D. 1.   Protecting a Public Good

United States Supreme Court associate justice John Paul Stevens, in his seminal opinion *Jaffee v. Redmond*, opined that mental health for the citizenry was "a public good of transcendent importance."[75] It is indeed. It is widely acknowledged that good health is an integral part of a good life, which includes, according to the World Health Organization, "a state of complete physical, mental and social well-being…"[76] Mental health for the citizenry presupposes that all who need it will receive it.

Underscoring the gravity of the psychotherapist privilege, Stevens distinguished it from the physician privilege according to the ability to obtain, and the need for personal information. His insight noted that physicians are, in most cases, able to treat patients through physical examination alone, or from limited objective information. This is most often the nature of emergency care, when many patients are unable to speak, or to aid the physician in evaluating symptoms. It must be noted, however, that despite the absence of oral communications between the patient and physician, the information procured is still protected by federal privacy law.[77]

Nonetheless, although treating a nonverbal patient may result in redundant or avoidable diagnostic testing and procedures, many diseases and conditions are treatable without the patient speaking a word.

However, that is not the case in most areas of behavioral health. Psychotherapy requires the disclosure of secrets that most often are not observable or discoverable unless and until they are unleashed by the patient in probing exchanges with the therapist. People who keep secrets from themselves without realizing their own censorship are said to be experiencing repression. In contrast, self-concealment occurs when one knowingly keeps things that they consider distressing or negative from others.[78] In both instances, successful treatment depends upon transparency, which is enabled by ensuring that these secrets, many of which invoke feelings of shame and guilt, are cloaked in privilege. Thus, the psychotherapist privilege, according to Justice Stevens, serves the public good[79] by enabling paths to treatment for infirmities that would otherwise remain hidden and unrealized.

Informed consent, as a path to treatment, is stringently upheld in the psychotherapeutic setting. Derived from the mental health professional code of ethics as well as respect for autonomy, informed consent is the patient's right to voluntarily agree to participate in counseling and other mental health services. Consent can only be granted after the scope of services and counseling processes are described in terms sufficiently comprehensible to the patient.[80] However, an inherent irony concerning the efficacy of informed consent in the psychotherapeutic setting is that much of what the patient agrees to disclose may not even be known by the patient until the process of therapeutic self-discovery unleashes such inner secrets.[81] Successful therapy reveals the unconscious. Therefore, according to Lear, confidentiality is constitutive of the psychoanalytic process itself, and is not merely a value to consider. When the patient no longer

keeps secrets from *themselves*, they transform their interests from being a secret-keeper to holder of privacy rights.[82] The contents of those secrets also may subject the therapist to a dual allegiance; that which they have to their patient, and that which they may now owe to society.

3. D. 2. Protecting the Public

The moral dilemma, hardened out of that duality of allegiance which often forces the therapist to become a double agent[83], is distinctively omnipresent in psychotherapy. And the consequences from violations confidentiality are similarly distinct. Notwithstanding impacts to the trust relationship that occur in the purely clinical setting, when a physician breaches the confidentiality of her patient's protected health information, the underlying medical condition generally is not affected. That is to say, inadvertent disclosure of an image of a malignant organ to an unauthorized third party is not likely to impact the cancer prognosis or the efficacy of the treatment. That is not the case in psychoanalysis.

Consider for example, what happens when the patient who has been sexually abused tells her story. Doing so is an exercise of her freedom, and an expression of her willingness to surrender control to another whose judgement and discretion she trusts. The psychotherapist or other behavioral health professional takes possession of her story.[84] And if, unbeknownst to the patient, he uses her story to advance some purpose other than her treatment, the psychic harm to the patient and the fragility of her emotional health could be compromised, and the future efficacy of her therapy very likely compromised. In an extreme but very real example, Kantrowitz richly describes the psychological trauma recorded by American author and novelist Philip Roth. Roth famously wrote about his torment, describing "the anger…the hurt about being viewed as a specimen, and reduced to a syndrome"[85] after learning his therapist had plagiarized his sessions by publishing a 30-page article about their relationship.

Notwithstanding such misappropriation, if the abuse patient, in telling her story, expresses violence towards her offender, or confesses that she wishes to engage in actions harmful to herself or others as a result, moral and legal obligations may change the undercurrent of her narrative. The therapist must confront the moral dilemma that Moser and Berman warn of when "unlocking one secret may require the creation of another."[86] Those secondary secrets and ancillary allegiances demonstrate that confidentiality is never absolute,[87] and that the therapist is obligated by principles of beneficence, and non-maleficence to fulfill his duty to necessary third parties as well.

The psychotherapeutic privilege – that which the *Jaffee* Court deemed worthy of protecting the public good – is not an absolute privilege. Courts have decided and generated volumes of precedent to support instances when the public is served at the sacrifice of patient confidentiality through evidentiary disclosure and testimony. However, the case of *Tarasoff v. Regents of the University of California* explored one of the most remarkable incidents in psychotherapy.[88] It examined the duty of a psychiatrist who learned, through outpatient counseling, that his client intended to, and eventually did, kill an unnamed, yet readily identifiable girl. The Court in *Tarasoff*[89] decreed that therapists incur obligations to protect third parties when the patient expresses a serious intent to harm themselves or an identifiable other, and that harm is likely to occur in the present, or future.

This "duty to warn" obligation is an exception to the duty of confidentiality even when, under common law, there is no legal duty to prevent one person from harming another.[90] It bespeaks of the awareness of, and ethical justification for revealing patient secrets for the public good – a good that is antithetical to the interests of the patient. This public beneficence which

seeks to "pursue and secure public benefits and minimize personal and public harm"[91] is also at the heart of debates surrounding genomic determinism and the disclosure of genomic secrets.

3. E. The Genomic Dilemma

The moral value of confidentiality, and the duty to respect secrets is no longer confined to those belonging only to patients and research data subjects. When ethical conflicts and competing obligations such as those exemplified in psychotherapy arise, principles of beneficence and non-maleficence may override confidentiality for the sake of a *non-patient* third party – thereby creating a moral dilemma.[92] Even when the third party benefit is imperative, those principles may beget a moral predicament for the physician. Such predicaments must reconcile not merely how much information to disclose to the unsuspecting and perhaps disinterested patient or non-patient, but also *what kind* of information to disclose, and perhaps most importantly, whether to disclose information at all. These dilemmas are traversing unchartered terrain especially in the context of genomic mapping, genotyping, and genetic testing information.

Secrets released from whole genome sequences provide "important insights into the medical and related life prospects of individuals as well as their relatives - who most likely did not consent to the sequencing procedure."[93] Whole genomic sequencing unleashes a person's entire genome along with all of its genetic variations or changes in the DNA sequence. These variants provide information about genetic traits, as well as disease carrier status, and susceptibility to diseases including, but certainly not limited to diabetes, some cancers and late onset diseases such as Alzheimer's.[94]

The expansive and predictive power of genomic medicine creates an infinite constellation of health secrets belonging to identifiable patients, patients' family, as well as indeterminate groups of people. Even without the full sequence, many of these secrets are formed and discovered from information obtained in the ordinary course of the delivery of care itself – not from the patient *herself*. Discrete genetic tests examine specific genes among the more than 20,000 known human genes, in order to identify a particular disease variant; all without the patient uttering a single word to her doctor. Consequently, the physician then holds the power to disclose - to her patient or the patient's family and relatives – information she has learned through linked genomic information as well, even "when the individual has not shared any of his or her genetic information directly."[95] The duties of the physician and the rights of patients and others to know, *and* not to know, predictive genomic information is a probing matter that defies traditional understanding of the duty of confidentiality and the practice of medicine.

3. E. 1. The Right to Know Oneself

Currently there are a variety of methods and justifications for knowing and understanding one's genomic information. It is widely held that patients can derive much benefit and personalized health advice from their genomic information. Pharmacogenomics, for example, can predict an individual's drug responses merely from the appearance of certain genetic factors, and nutrigenomics can determine potential adverse effects from food and specific food ingredients. Both discoveries have the potential to result in optimal health.[96] While only indirectly relevant to one's health, obtaining genetic-based ancestry information through direct-to-consumer testing services can have far-reaching effects on the test taker's sense-of-self and identity.

In addition, people are entitled to know their own genetic information obtained from tests administered in the clinical setting; typically involving a physician. This is the traditional venue for those who present with a medical indication, or symptom of a disease where genetic factors have been shown to play an important role.[97] Initially concerned with disease pathology alone, the idea of genomic information carries with it the preconception that it forecasts and foretells of doom-filled preconditions, impending maladies, and dreadful life and death predictions. However, Siddhartha Mukherjee reveals that "genetics has crossed over from the strand of pathology to the strand of normalcy."[98] That is to say that this new science can be applied in order to better understand culture, history, language, memory and other characteristics of human life and human destiny;[99] essentially evolving towards a science of normalcy from which humankind can benefit.

In that vein, Prainsack aptly points out that advances in clinical genetic analyses often disclose incidental findings of information relating to conditions beyond what was intended by the test.[100] It is presumed, however, that the testing and the desire to extract important information from the genetic fingerprint is an expression of the person's autonomy and free-will, is validated by informed consent, and it serves the best interest of the test taker to receive the unlocked secrets about themselves. When that information potentially concerns the health of others such as monozygote siblings or other filial relationships, or when it reveals information concerning paternity or ancestry, the ethical, social and psychological effects of knowing that information on such stakeholders are not trivial.[101] Whether one's autonomous right to obtain their own genetic secrets should include preventing disclosures to family members who may share that genetic link is at the center of the ethical dilemma. To that end, relational autonomy or feminist ethics suggests people also have moral responsibilities to each other because they stand

in relationship with each other; they have an interest in maintaining family and community relations. In short, one person's choices affect another person's autonomy.[102]

Consider how the duty to warn, which exempts hardline confidentiality in order to protect third parties, is dependent upon the patient's voluntary disclosure of her secrets and consent to subsequent re-disclosure. This duty to warn balances the patient's expectations of confidentiality against harm to third parties. However, genomic analytic techniques provide insight into unanticipated findings concerning potential health conditions that could affect and harm third parties and family members; particularly if the predisposition to the condition remained unrealized and unmanaged.[103] The moral predicament for the physician is exacerbated when the patient refuses to share information concerning the risky hereditary condition.

While knowledge of the unanticipated predisposition to disease or disability may prevent eventual harm to the third party or their offspring if acted upon, unsolicited disclosure of disease susceptibility may also create more psychological harm to them than benefit.[104] Clearly, there are legitimate beneficent reasons for disclosing such information to third parties. However, what demands equal attention, in terms of assessing arguments from beneficence and non-maleficence, is the family member who, because of the information learned, has been unwittingly placed in a precarious state of mind. The bell cannot be un-rung.

3. E. 2. The Right to Be Forgotten

To that end, in a world where wearable devices and the Internet of Things gather and store digital information on everyone, the increased aggregation of "the quantified self" portends that people will know things about themselves that were never before contemplated.[105] The ubiquity of the digital data environment means that a person's genomic information may also be

accessible outside of the HCO as well. Moreover, the commercialization of genomics, and the explosive fetish for personal ancestry and do-it-yourself genomic testing information, suggests that an unmet need to know more about one's genomic profile, may have been satisfied.[106] It may be argued, however, that persons may obtain information about themselves that they would prefer not knowing, particularly if certain of their genetic factors produce characteristics associated with unexpected groups of people.[107] Ross suggests that even though most of this commercial genomic testing information provides a mere snapshot, and not the full genomic sequencing, there is great potential for false worry and misinformation.[108]

This potential for false worry is ever present with genetic analysis performed within clinical settings as well. Consciously avoiding harms from worry and anxiety is the preeminent ethical justification for a physician to withhold the truth from their patients. While veracity and truth-telling are essential to respect autonomy, the matter of disclosing genomic information brings to bear the distinction between telling the truth, and the right to the truth. And while the right to be told the truth is a core component of informed consent, clinicians are confronted with the moral dilemma to determine when it is right and just to be told something less.[109]

Selective non-disclosure of certain information that, in the physician's professional judgment, may be detrimental to her patient, is not new. But Lunshof and Chadwick point out that the therapeutic privilege may not be justified in an age of participatory healthcare where stakeholders' voices are encouraged.[110] Moreover, the therapeutic privilege does not address the detriment to the non-patient; especially when they are a family member.

Much of the moral dilemma confronting the physician who straddles the duty of confidentiality and the duty and obligation to disclose, or not to disclose genomic information, lies in the fact that medicine has changed. Sheila Jasanoff contends that the primary mission of

medicine, to make sick people well and to enable the apparently well, but at-risk, to remain healthy is vexed by genetic science. "Knowing bodies in a new way, through a person's genetic code, opens up the prospects for unprecedented intrusions on cherished rights of liberty, equality and privacy"[111] which the physician, and even the HCO leader, must now factor into their decisions. The physician not only must consider these consequences as they relate to his patient, but also through the lens of someone he may not know.

Frequently cited justifications for disclosing genetic information to family members include the importance of conveying reproductive risks of inheritable conditions in order to enable timely reproductive decisions.[112] In addition, it has been argued that genetic information is familial rather than personal and therefore is communal in nature and, and to not share it with at-risk family members would be selfish.[113] In either case, it is widely recognized that, at the very least, the physician has an ethical obligation to attempt to persuade the patient to discuss the hereditary risk with the affected family members.[114] The success of these persuasive attempts, while difficult to assess, underscore the critical role that the physician plays in respecting the ethics of secrecy hidden within the patient's family tree; the roots of which encroach upon the privacy of all of those identified.

3. F.   Privacy

Privacy is a timeless concept. Judith Decrew asserts that the earliest expressions of privacy date back to antiquity, and beyond.[115] Shame and its association with good and evil has been a consequence of privacy invasions since Adam and Eve took to wearing fig leaves.[116] Noah further exhibited shame, anger and a preference for decency over his bodily privacy, when he discovered how his sons treated his unanticipated nakedness.[117] Even the political divide between the public and private spheres of life, espoused by Aristotle, bespeaks of a desire to

shield citizens from unwarranted intrusions. And, of course, humans have been whispering what they don't want others to hear since they began communicating with words and sounds. Notwithstanding its persistence for thousands of years, and despite the eager willingness of people to decry violations to their individual privacy today, it is not a concept that is well defined or understood.[118]

As demonstrated through history, privacy evokes feeling, and is often defined by that feeling; in the same way that 'freedom' and 'peace' are more emotive than precise in their meanings. This contributes to the disarray that Solove contends is the state of play for privacy today.[119] There are as many definitions of privacy as there are occasions to evoke its feeling. Considered the founding father of contemporary privacy, Alan Westin taught that privacy is an "…[i]ndividual's claim to determine what information about himself or herself should be known to others…when such information will be communicated or obtained, and what uses will be made of it by others."[120] Despite this widely accepted meaning, what besets those who think about privacy is the need to understand what is at its core, as sensitivities to privacy often go beyond the act of communicating information. Whether respect for privacy is a moral claim, or legal one; whether it is an individual, or collective condition, and even the degree to which it is a societal issue are the ponderings of theorists and advocates.

3. F. 1. Concepts and Values

Westin argued that privacy is a set of expectations created from social values that are defined by culture. And that it is both a psychological and physical condition originating from choices and preferences, as well as a right that one has to assert an expectation for legal protection.[121] He believed that privacy debates are infinite, as they are tied to societal norms supporting human conduct that is acceptable, neutral or advancing the public good.[122] Much of

the disarray espoused by Solove is fueled by cultural variances driving privacy values and expectations. Adam Moore takes culture's influences on privacy a step beyond. He supports the notion that culture exerts significant influence on privacy, but sees privacy itself as a cultural universal that drives his compelling theory that privacy is about control.

According to Moore, as a societal value, privacy is a fundamental moral claim that washes over the various privacy interests and concerns which are innately human, and provides a necessary equilibrium to the examination of those interests.[123] He calls attention to the fact that privacy interests speak necessarily to the human need to control one's world. This includes the right of control over property and one's physical world, control over one's body and its capacities, the right to control decisions - often referred to as decisional privacy – as well as control over informational privacy.[124]

For Moore, "privacy…is a core human value – the right to control access to oneself is an essential part of human well-being or flourishing."[125] Control over what others know about oneself does not necessarily presuppose an intent to deceive. To the contrary, privacy validates the innately human need to protect those unique facts that help to construct uniquely human lives. Moore's theory is especially appealing in healthcare as its central mission is complimentary to it - to promote human welfare. The intersection of Moore's claim of control, and the acknowledgement of respect for humans is the launching point for Julie Inness's intimacy theory of the concept and value of privacy.

Inness posits a non-consequentialist argument that the value of privacy is found in the moral duty to respect individuals as loving, liking and caring, autonomous and rational beings with the capacity to freely choose, and to form and develop close relationships.[126] She accepts the notion that claims to privacy are moral claims to control aspects of life, as well as to separate

oneself from certain life conditions. But she suggests that merely exercising control over access to information, to oneself, or the intimate decisions of the person, are individually too narrow, and collectively too broad.[127] Instead, she refines the moral claim to control over aspects of life that involve "decisions about *intimate* information, *intimate* access and *intimate* action (emphasis added)."[128]

Intimacy claims, for Inness, are the core of privacy. Whether something is intimate depends upon the role that the particular aspect of life plays for the individual in furtherance of that which they love, like, or care about.[129] For example, a patient sharing private aspects of her life with her physician in the course of treatment is intimate, according to Inness's theory, in that she wishes to exercise control while advancing that which she likes – her health – with someone she has engaged in a caring relationship. The value of intimacy cannot be overstated, and is but one installment in Anita Allen's claim for self-directed accountability vis-à-vis personal privacy.

"Privacy," admits Allen, "is purposely personal."[130] Yet, privacy is also a foundational good of our society that is required of freedom, dignity and the preservation of individual and collective good character. This fundamental good demands of people, in addition to the moral obligation to respect others' privacy, "a moral or ethical obligation to protect their own privacy."[131] That is to say that while moral duties are typically other-oriented, Allen's accountability theory argues that a duty to self, while a second order duty, is necessary to support the duty to others.[132] Bi-directional privacy accountability is especially cogent in healthcare as the failure of someone to reasonably protect his own health information from unauthorized use could foreseeably cause downstream harm to his intimates, or other close associations within his community. This conflation of other and self-oriented moral agency reflects the importance of stakeholder accountability in matters of personal privacy.

3. F. 2. **Privacy as a Healthcare Value**

Whether the idea of privacy generates an emotional response, or a collective reaction to specific legal doctrines – or the absence of any such doctrines - privacy remains an amorphous concept.[133] There are, however, applications of personal privacy that are clearly valued for the ends they achieve.[134] Privacy for the sake of ensuring that people are protected from unwarranted intrusions into their home, or to their physical person is rooted in the tenets of civilized society. However, Solove underscores the reality that "the matters we consider private change over time…because of changing attitudes, institutions, living conditions and technology"[135] and are often contextual. Yet, few examples of the value of privacy are as controversial as in contemporary healthcare. How much, and to what extent must stakeholder privacy be protected, or even sacrificed to ensure that the healthcare organization (HCO) meets its obligations to deliver care for the common good is an evolving moral dilemma.

Intimate details about a patient's body, their mind, and all of their life experiences, including those surreptitious trials that may affect their health and dignity, are bathed in privacy. In healthcare, physical privacy is understandably limited, though not without reasonable protections against unwarranted contact or exposure, as are aspects of decisional privacy, which generally fall within the purview of informed consent.[136] Informational privacy is concerned with the discipline around preventing unauthorized access, use and disclosure of a person's protected health information (PHI). This chapter is concerned with the legal and moral challenges created by physical, decisional, and informational privacy; although as demonstrated throughout this writing, the demarcation line between all three is blurring.

There is great irony in the idea that individual privacy in healthcare is controversial. On its face, the physician-patient encounter is steeped in privacy protections stemming from the duty of confidentiality. Presumably, the physical environment also bespeaks of secrecy. As evidenced by curtains separating patients in the emergency department, imbedded computer monitors rendered unreadable by snoopers, and increased preference for private inpatient rooms. "Patients' privacy in hospital settings is widely recognized as important for patients' well-being and satisfaction"[137] In addition, healthcare privacy is heavily regulated in the United States, and is subject to a wide array of state and federal laws and regulations restricting data use.[138] Nevertheless, the law cannot protect against all of the unintended consequences emanating from use of health data, nor can compliance with it alone resolve the privacy challenges.

Technology and medical advances, and the insatiable hunger for more data, better data, and faster access to it nearly always conflict with decades-old laws governing their use. Yet, nothing can happen without access to data. Every aspect of the transformation of American healthcare described hereunder is dependent upon better access to patient health information. The introduction of evidenced-based medicine at the turn of 21st century medicine, whereby clinical decisions relied upon research evidence rather than clinician judgement alone, virtually demanded access to aggregate and unmasked patient information. Eventually evidenced-based alone gave way to value-based medicine. Value-based medicine is "the integration of best research evidence with clinical expertise and patient values."[139] As with the concept of privacy, value in this sense is a relative term, and has evolved to mean decisions that yield increased life expectancy and quality of life.[140] The transformation translates to an increased need for more and more patient data. Accordingly, the shift in focus to a value-based enterprise means that health

information is, all the more, dominating the list of organizational concerns from the boardrooms to the operating rooms.[141]

3. G.   Protected Health Information and the Need to Know

Healthcare is predominantly an information business. Treatment, quality measures, patient safety, efficacious clinical outcomes, clinical research, and reliance on advanced technology are merely a handful of the healthcare objectives that depend upon the acquisition and use of patient information.[142] But personal patient data has not always been the main course in the information feeding frenzy that is the hallmark of healthcare today. Prior to the introduction of computerized data in the 1970s, most data sets were created manually from the individuals treating the patients.[143] As recently as twenty years ago, physician notes and the mental impressions of his patient encounters were still written by hand, memorialized on paper and treated with confidential reverence. All of that has changed.

Regardless of its form, patient healthcare information is rich with data that can serve many purposes. Aside from its clinical attributes, it contains demographic insights, can provide economic forecasts for the HCO, exposes a financial snapshot of the patient, and can even include information about U.S. government agencies such as the Departments of Health and Human Services, and Veteran's Affairs. Many organizations not in the business of healthcare collect and use health information from their customers as part of doing business with them; insurance, financial institutions, education and real estate, to name a few.[144] To that end, the body politic during the late 1990s, the mobilization of public policy wishing to insulate health insurance for unwell employees, and even the motivations of the criminal element, whetted appetites for what would amount to a far-reaching liberation of personal patient information.

3. G. 1.   Access, Use and Disclosure: Stakeholder Expectations

HIPAA started it all. The Health Insurance Portability and Accountability Act of 1996,[145] was introduced as part of the Clinton Administration's attempt to socialize healthcare in the United States. It brought to light the need to ensure that workers would not lose their health insurance if they changed jobs, or had pre-existing health conditions. Among the portability provisions, HIPAA established administrative simplification requirements enabling insurance claims and payments to process more efficiently between providers and insurance companies. Establishment of uniform electronic transmittals of transaction code sets provided for greater ease of sharing patient information.[146]

Today, the acronym HIPAA is synonymous with healthcare privacy, yet the Act is not a per se privacy regulation. In fact, establishing a privacy right was never part of the original legislative intent. Rather, concern for the privacy of individual medical information was a regulatory after-thought. As compliance with HIPAA required that volumes of medical information be converted to rapid-pace electronic transmittals, Congress became increasingly concerned with the privacy and security of the PHI. Through a series of legislative and executive missteps, and political posturing, the Department of Health and Human Services promulgated the HIPAA Privacy Rule (2002) and Security Rule (2005) to address the need for, and create the individual's codified right to privacy in their PHI.[147]

Since then, controlling how protected health information is accessed, used, stored and disclosed has become an imperative in contemporary healthcare. The HIPAA Privacy Rule provides federally protected patient privacy rights to access, amend, restrict and account for disclosures of their personal health information.[148] Many states also enacted statutes providing civil and criminal protection against misuse of medical information; as well as laws that afford

greater privacy protection for certain sensitive medical information such as HIV/AIDS, mental health, and substance abuse treatment.[149] But policies and regulations don't protect patient privacy, or ensure that decisions rendered from data use are also fair and just, people do. Despite the snarl of privacy regulations, healthcare as a politically-infused industry appears to have emancipated volumes of patient information.

Although it is a restrictive regulation requiring patient authorization and consent for most disclosures of PHI to third parties, the HIPAA Privacy Rule allows for a number of exceptions. Health plans, most providers, and healthcare clearinghouses ("Covered Entities"), are permitted to access, use and disclose the *minimum necessary*[150] amount of their patient's PHI without the patient's authorization. Specifically, if the disclosure of PHI is for treatment, payment, or any one of a number of health care operations activities, there is no need to obtain any patient consent at all.[151] The absence of consent does not itself mean that private information is shared indiscriminately or without patient awareness, however. Patients are provided notice, have a right to certain accountings, and in some limited instances may opt-out of the disclosure altogether.[152]   Nevertheless, the exceptions to the need for a patient consent in many ways have swallowed the Rule entirely, thereby unleashing what often appears as an unconstrained flood of personal health information into the wild. As such, the role of health information, the case for expanded physician access, and the proliferation of technology that is dependent upon digital data, are in palpable tension with patient stakeholder privacy preferences, their exercise of control, and their expectations.[153]

3. G. 2.   Health Information Technologies

In 2004, the Bush Administration pronounced through Executive Order, that every American would have an electronic health record by 2014. This Executive Order was motivated

by the need to improve quality of care and reduce healthcare costs through enhanced clinical decision making made possible by expanded access to information. In addition it recognized the need to reduce errors of omission and commission from illegible and poorly handwritten physician notes and prescription drug orders. All of these digital data sparks ignited and fueled the world of the electronic health record.[154]

The Office of the National Coordinator for Health Information Technology (ONC) was spawned from this Executive Order, and was formally mandated in 2009 through the Health Information Technology for Economic and Clinical Health Act (HITECH). HITECH was enacted as part of the Obama Administration's American Recovery and Reinvestment Act (ARRA). Under the direction of the Department of Health and Human Services, the ONC has been charged with constructing and implementing a nationwide health information system comprised of a variety of information and communication technologies (ICTs). The ONC's goal is to have an interoperable health information ecosystem stood up by 2024.[155]

ICTs focusing on healthcare including patient registries, adverse-event databases and data-mining tools[156] are being designed, tested and implemented at a pace that is nearly impossible to accurately gauge in real-time. Personal health records (PHRs), patient portals, telemedicine delivery channels, and health information exchanges (HIEs) are a few of the most recognized technologies that rely on acquiring, aggregating and analyzing patient health data to extract value for a diverse set of stakeholders. The eHealth Exchange™ is an example of a private sector HIE which transitioned from the ONC in 2012. It is a network of hospitals, pharmacies, federal agencies, medical groups and dialysis centers spanning all 50 states that links health data belonging to approximately 100 million patients.[157] Except for the patients, whose information is automatically pushed to HIE unless they opt-out, all participants mutually

agree to certain data sharing standards and specifications. The intent is to send and access patient information in order to reduce costs and improve clinical outcomes, improve patient safety and facilitate business planning.

The most ubiquitous ICT by far, and the darling of several presidential administrations is the electronic health record, or EHR. EHRs are anticipated to be longitudinal, comprehensive and interoperable. That is, they contain PHI attributed to identifiable individuals from cradle to grave, they include all clinical encounters with wide ranges of providers, and are accessible electronically by any EHR user to whom access is granted.[158] While each objective of the EHR carries privacy concerns, the interoperability of technology sought by the ONC, presents the greatest opportunity for threats to privacy values.

Interoperable technology allows providers who use different electronic health records to communicate with each other directly through an integrated single EHR.[159] The interoperability of medical records means that the physician-patient relationship is no longer binary. Nearly all information conveyed in the course of the treating relationship, presumed to be confidential, will now be accessed and used by hundreds, if not thousands of entities; many of whom will be unknown to the patient. Just as important, they will likely only know the patient as an identifiable data set, and never as a unique and distinct person. And, because of Big Data, the number of those unknown end users grows exponentially. This should elevate concerns over stakeholder privacy to a place of prominence within the ethically accountable HCO.

3. H.   Big Data, Big Opportunities

Evidence and value-based approaches to healthcare management, and provider payment incentives made on the basis of good health outcomes rather than merely the volume of services

provided, necessitates analysis of considerable volumes of stakeholder clinical data. Preventive

medicine, public health initiatives, and innovations in biomedical technology similarly rely upon

analysis of health information. Accordingly, Big Data is, in measurable ways, an instrumental

disruptor in healthcare today.[160] It exerts tremendous influence on advances in medicine and care

delivery, how healthcare stakeholders wield power, the unavoidable privacy tradeoffs, and the

limitations of existing laws to address those tradeoffs. Big Data is widely understood to mean

"large, diverse, complex, longitudinal and/or distributed data sets" that are generated from a wide

variety of digital sources such as email, Internet transactions, sensors and connected devices.[161]

However, what really matters about Big Data is not so much what it is, but rather how it is

used.[162] The panoply of uses are limited only by the innovations of the human mind.

Very few, if any, of the downstream uses of healthcare Big Data are contemplated or

understood at the time the patient grants her informed consent for treatment. Assume for the sake

of argument that the patient sufficiently understood the cornucopia of purported Big Data health

benefits and attendant uses of her information. To be *fully* informed, she must also understand

that her data could potentially reside in a repository that can be accessed, ingested, interpreted

and even identified by any researcher anywhere in the world, for any number of downstream

uses.[163] Moreover, even data that is publicly available through social media and other Big Data

digital environments can reveal personal traits that patients may not have intended to be public

when sophisticated computational techniques are applied to it.[164] Yet, these menaces to privacy

cannot eclipse the reality that Big Data use can benefit important facets of human life in

innumerable ways.

3. H. 1.   Big Data: Defined, Connected, and Exposed

Big Data is often defined contextually according to how it is used. In such instances the term is used synonymously with 'Big Data analytics' to describe the *practice* of combining "volumes of diversely sourced information" which are then analyzed using algorithms to assist decision making.[165] And, there is virtually no limit to the diversity of the data that populates the Big Data environment; and it is not all attributed to natural persons. That is, sensors that track the weather, the timing of streetlights, and home security systems share a commingled data community with information from EHRs, smartphones, and motor vehicle global positioning systems, to name just a very few.

Nearly everything about the way that we acquire data, and the knowledge produced from it in the 21st century has changed. The Internet of Things (IoT), the relatively familiar term used to describe, "…[t]he ability of devices to communicate with each other using embedded sensors that are linked through wired and wireless networks"[166] further increased the exponential explosion of digitized data. According to Alec Ross, approximately ninety percent of the world's digital data has been created in just the few years since 2014.[167] Being connected is ubiquitous, and getting connected has never been easier. The Internet, social media, tens of thousands of mobile applications, commercial and government databases, and nearly every modern convenience is Internet-enabled – from coffee pots to condoms - and dumps digital information into to the universe of Big Data. Big Data is obese; and it is gaining weight by the nanosecond.

According to European Data Protection Supervisor, Giovanni Buttarelli, "By 2020 connectivity is predicted to become a standard feature, with 25 billion connected objects…They will be able to detect blood clots and monitor fitness and wound healing"[168] among other things. The permeation of healthcare data into the Internet connected universe, in tandem with

government's appetite for "interoperative and electronic access to data across a myriad of information systems"[169] offers societal benefits unmatched through any other means. By amassing large quantities of data, valuable health insights will be gained from granular data points. In other words, by having a haystack, data scientists can find the needle they seek.[170] Yet, without a framework for balancing Big Data's societal benefits against the individual and community stakeholder, and societal harms from misguided and malevolent use,[171] the Big Data haystack could function more like a hornet's nest.

For example, the ubiquity of cloud computing – storing data on connected networks via the Internet – is appealing to the HCO. However, the fact that many cloud providers provide multitenancy data storage, that is, many clients sharing data space on the same pieces of hardware (public cloud), rather than solely occupied (private) storage[172] is hardly if ever, understood by the patient. Cloud providers frequently store patient data in countries outside the United States, where they can be further accessed by sources unknown to the patient.

In addition, big datasets stored on mobile computing devices are susceptible to accidental loss or theft.[173] As Verizon unveiled in its 2017 report, healthcare was distinguished as a top industry for data loss in 2016.[174] The risk of loss of aggregated and identifiable patient data from Big Data sources adversely affects more than the HCO and the impacted patients directly. It impacts the physician-patient relationship particularly, and the integrity of healthcare's reputation generally. The mere threat of a loss is sufficient to reshape the patient's willingness to share sensitive information with their physician.[175]

3. H. 2.   The Big Data Haystack

Recording data about the world is nothing new. Since earliest man painted his experiences on cave walls, humans have kept records. But never before has recorded information been thrust upon humankind with such unprecedented volume, with such a diverse variety, and with such velocity as in the present digital information age.[176] The nearly continuous generation of data from limitless connected sources offers society theory-free objective sources of knowledge largely because "data can offer connections that radiate in all directions."[177] As the availability of clinical data connections expand, clinical decisions can be made based upon inferential connections, as well as the experiences reported by colleagues with similarly situated patients in real-time.[178] The direct and indirect health benefits to patients from this new way of creating knowledge are unquantifiable. And, in many ways, so are the harms.

Not all health information is subject to protection from unauthorized disclosure under the HIPAA Privacy Rule. HIPAA only protects PHI created, used and disclosed by and between Covered Entities. Medical information websites, health chat rooms, medical apps and online genetic testing sites may be subject to Federal Trade Commission (FTC) consumer protection, but are not necessarily subject to use restrictions.[179] What this means is that health and wellness data sets that were uploaded from personal connected devices, that were not intended to be used to make inferential medical decisions, are vulnerable to such uses.

Maintaining good health means more than disease management. More than ever it includes a focus on preventive health and disease avoidance, which looks to personal lifestyle choices and preferences, family ancestry and other social determinants, to predict and address health issues and outcomes.[180] As such, data from Internet-enabled activity trackers that measure how much a person walks, eats, sleeps, and sits idle can be aggregated and accessible to that person's physician. He can then make wellness-related assumptions about his patient, even when

she is not seeking treatment from him. In addition, Internet-enabled household items, such as the 'smart' refrigerator, can alert a person when they are out of a particular item such as their favorite ice cream, or triple-cheese pizza. With access to accurate data logs, health insurance companies may be able to assess the healthiness of their members' diets and perhaps correlate the size of their grocery list to the size of their insurance premiums.[181]

Although nearly all privacy laws require some form of individual notice and consent, or authorization when those who acquire data seek to use it for a particular purpose, the sheer number of data users renders consent impracticable and unmanageable in the Big Data context.[182] The Big Data universe is not an individual-centered environment. Moreover, individual data subjects who consent to having their data digitally connected through their Internet-enabled 'smart' devices typically are not afforded the opportunity to question the secondary or tertiary third-party uses of their data once they are connected.

Nor would they necessarily contemplate how much of their personal identity, and their closely held secrets could be revealed through manipulation of their unstructured and even anonymized data. Cynthia Dwork illustrates the power of linkage attacks – the ability to connect auxiliary information from one privately connected source, to data from other databases – in order to identify individuals and their sensitive information; including their personal health records.[183] In short, current privacy laws are not likely to resolve the phenomenon of Big Data vis-à-vis the patient expectation of privacy dilemma.[184] The laws and ethical practices must first be recalibrated in order to coexist with algorithmic decision making and artificial intelligence.

3. I.   **Algorithmic Decisions**

What are likely the most appealing attributes of Big Data for business and governments are its ability to monitor human behavior individually and collectively, in addition to its predictive capability. It is important to recognize that the bigness of Big Data is not so much that data is massively amalgamated for anyone to remove pieces and chunks as desired. Rather, the bigness refers to its nearly irrepressible capabilities. Capabilities which "connect disparate datasets through algorithmic analysis" that cobble together unpredictable relationships from data collected at various times and places, in various forms and formats, drawing inferences for a myriad of purposes.[185]

Algorithms draw from and feed off of an ever-expanding universe of data about persons and weigh them against prescribed metrics, in order to arrive at computer-generated, rather than human-contemplated decision making. Within healthcare, predictive algorithms provide decision-support tools for physicians whenever they face uncertainty or clinical ambiguity. There are unlimited algorithmic possibilities. For example, algorithms can predict the risk of patient readmission in patients with heart failure. They can also predict the risk of neonatal infection which could influence the physician's decision whether or not to prescribe costly and potentially unnecessary antibiotics.[186] Predictive algorithms are also highly effective in expediting research and development of new drugs and related clinical treatment pathways by eliminating time constraints, and human-induced delays. These results can run through a database, and algorithms will identify relevant trials for cancer patients with particular types of tumors.[187] As more and more mathematical algorithms replace human discernment and contemplation, humans will move away from making their own decisions, and move towards "tools that make decisions without a person in the loop."[188]

3. I. 1.   Real Data…Artificial Intelligence

"Data is not information, information is not knowledge, knowledge is not understanding, and understanding is not wisdom."[189] By describing the world of information according to what it is *not*, Clifford Stoll illustrates that knowledge obtained from information requires a process of applied learning and continual improvement, and refinement of data. All with the goal of achieving some great outcome.[190] The evolutionary progression from raw data to knowledge and then to action is typically the purview of the data scientists whose job it is to pour over and tease through terabytes of data in order to interpret and analyze presumably for some anticipated good of the organization and its stakeholders. Today, algorithmic decision making is an inflection point in information processing and provides the means for decisions that were once made by data scientists to be made by computer systems.[191]

An algorithm, in computer science, refers to a well-defined set of facts or rules that are to be followed in order to accomplish a particular goal or calculation. The rules themselves are resident within a system's source code which provide the fuel for what is recognized today as machine learning,[192] or the ability to perform activities based solely on recognition of data patterns. Although the terms are often used interchangeably, machine learning (ML) and artificial intelligence (AI) are not the same.

Artificial intelligence is a broad concept that describes the ability for a device to act 'smart' or intelligently, as a human would.[193] It is an area of computer science that seemingly gives machines the ability to mimic cognitive functions normally attributed only to the human mind; essentially imitating human intelligence. [194] *Generalized artificial intelligence* is a type of AI that includes ML. Machine learning gets its education from continually correcting and improving upon the accuracy of the probabilities and predictions it makes, thereby refining its decision making capabilities. For example, smartphone technology becomes obsolete almost

immediately as its decision making and task-performing functionality becomes refined through enhanced ML. *Applied artificial intelligence* refers to the application of machine learning to perform specific acts, such as autonomous driving vehicles or drone navigation, to name only a few.[195] As more information about physical interactions and private facts are digitized, digital records of these facts and whereabouts procreate and propagate, and artificial intelligence tells humans what do and how to do it, humans will make decisions according to direction provided by a machine. Not only will machines make decisions, they will also perform activities that were once solely within the province of humans.

Artificial intelligence is the single most important tool in the delivery of healthcare today. Unleashing algorithms to identify patterns within haystacks of data is accelerating the science and practice of medicine. By accelerating delivery times beyond that which human intervention alone demands, machine learning and artificial intelligence have revolutionized healthcare. Consider how the now notorious collaboration between Google's artificial intelligence subsidiary DeepMind and the Royal Free London National Health Service Trust, defined a "national algorithm" to detect acute kidney injury (AKI) and transmit suspected AKI to a clinician's mobile device.[196] In addition, one of the most ballyhooed artificial intelligence tools to enter the physician's world was IBM's signature brand – Watson.

Through its collaborative partnerships with medical laboratories, oncologists, hospitals and elite cancer institutes, IBM amassed and procured massive amounts of data for ingestion into its Watson supercomputer. Watson's artificial intelligence was initially a boon to healthcare. It was purportedly designed to offer genomic sequencing and diagnostic analysis to oncologists in order to make advanced diagnosis, precision medicine and treatments accessible to patients who may not otherwise have access to such exclusive care.[197] In reported test cases on 1000 cancer

diagnosis, Watson's treatment plans matched those of the oncologists. In cases where Watson recommended treatments that physicians missed, it was because Watson had ingested research papers that the oncologists had not yet read.[198] As a critical tool, artificial intelligence provides incalculable good to healthcare. As an unchecked weapon, it can do great harm.

3. I. 2.   Ceding Control…Enabling Discrimination

Throughout the history and evolution of humankind, the authority to choose for oneself, and the respect for free will has been cherished as the most revered source of human authority.[199] Such humanism also undergirds healthcare, as autonomy and the control over one's body, as well as the private information about oneself is inextricably attributed to respect for human dignity. Yet, as Schneier asserts, civil society often requires that people cede power and control over themselves to others, despite the inherent risk in doing so.[200]

As dataism, which sees the world and its decision making power as a series of data flows, dominates the universe, it argues that humans will no longer be able to see clear of all of the information available to make decisions. Dataists argue that at some point, the algorithms will know a person better than they know themselves. Therefore control over decision making will be ceded to artificial intelligence.[201] While this insurgent view has not been fully actualized, it is fair to say that in healthcare, a large part of decision making control has been ceded to algorithmic analysis; but such relinquishment is not necessarily done at the will of the patient.

With the advent of the interoperable electronic health record, many HCOs use risk engines to apply algorithms across all forms of medical information about their patients. Health information is combined internally with other data points. Data points, commonly referred to as social determinants of health, include environmental and lifestyle factors that can be used to

determine health outcomes for individuals and populations.[202] When coupled with data from medical interventions, they create a neatly packaged predictive profiles of the probable diseases and other maladies that could affect the patient based on the algorithmic output. There is also a lucrative commercial market for ancestry related data that is similarly reconstituted and sold to physicians who then use the predictive dashboards to help their patients.[203] Big Data analytics can not only open predictive doors that can help people live longer and flourish, it can discriminate.

Paul Ohm contends that "Although we have banned discrimination based on race, Big Data helps companies find a reasonable proxy for race."[204] There are enough unregulated data elements available today that even if a data source did not specifically contain protected information about a person, sufficient quantities of unregulated data elements about that person can make it possible to derive the protected information. Moreover, despite its near-perfect machine translation, the algorithmic thought process is subject to spurious correlations that could have adverse consequences for the patient.[205] As such, algorithmic inferences can incite the weaponization of data. Unchecked inferences and unsubstantiated data insights can be powerfully and permanently destructive to the human being who exists on the other side of the algorithm.

These big-data inspired inferences fuel decision-making from which actions are taken that may help as well as harm the person. Barocas and Nissenbaum aptly argue that Big Data analytical insights from tracked and recorded details of human behavior present threats to fundamental values such as, fairness, due process, and perhaps most importantly, privacy.[206] Ironically, those values, the very ones compromised by certain analytical insights, are the precise

principles that will ensure that collectively, data can benefit society while protecting individuality.

When considering data-driven discrimination, what is conspicuous by its absence from the Big Data haystack, algorithmically driven innovation and machine inspired decisions is human moral judgment. The ethical challenge for algorithmic decisions is to inculcate moral judgment – that uniquely human capability - into the Big Data universe. For according to Purves, Jenkins and Strawser, "[h]uman moral judgment is not codifiable, i.e., it cannot be captured by a set of rules. Moral judgment requires…the ability to perceive certain facts *as* moral considerations."[207]   Such is the impetus for establishing and implementing an ethical framework for Big Data use generally, and healthcare information particularly.

3. J.   Ethical Guidance

The fear of intrusive technology and the nosiness of the press plagued the minds of Samuel Warren and Louis Brandeis little more than a century ago. Their prescient paranoia argued for one of the most fundamentally human rights in American jurisprudence – the right to be let alone.[208] Intrusive and invasive technology, and the nosiness of governments, scientists, clinicians, hospital executives, marketers, and actuaries ought to invoke similar healthy paranoia in stakeholders of today. The future of privacy in healthcare is being transformed from the maturation of a legal right, to the respect for human flourishing in a digitally networked world.

The erosion of individual control exacerbated by artificial intelligence and robotics, facial recognition, undetected wearable technology, augmented realities and even transhumanism threatens to invade and alter the sanctity of privacy. It is apparent, more so than ever, that the ethical commitment to privacy as an indivisible constituent of human dignity is a constant that,

as yet, cannot be digitalized. Ethical decisions and moral judgment requires human influence. So much so, that privacy is revitalizing the field of ethics. According to Forrester Research, "ethical privacy practices will be the next consumer-driven, values-based source of differentiation"[209] between HCOs and other derivative stakeholders or competitors.

There is an acute and urgent demand for a practical and comprehensive ethical framework for accountable leaders to follow in order to harmonize the voracious hunger to understand infinite points of healthcare data, with patient autonomy, dignity and personhood. Yet, there is currently little consensus on how to approach applied ethics in this new age. What is clear, however, is that this data-driven world that is devoid of moral judgment must regain human accountability. To do that, according to Martin Abrams, "it will be necessary to depend on people to build ethics into the objectives for the systems through accountable data governance…that ensures the outcomes are legal, fair and just to the various stakeholders."[210]

3. J. 1. Accountability and Data Ethics

The data that is created for and about patients every second of every day will continue to persist under the control of others[211] whose relationship to the HCO and to its patient stakeholders is increasingly distanced and attenuated. This attenuated control threatens patient stakeholder autonomy; a central principle of privacy, as well as of common morality illustrated through healthcare ethics. The threat to patient autonomy is but one of the ethical dilemmas that accountable HCO leadership must solve for when they seek to harness the power of Big Data for the benefit of many stakeholder interests.

As illustrated, the ethical justification for recognizing individual privacy as a moral duty, a social value espoused for the common good, and a core human desire to control access to

oneself in order to catalyze human flourishing rests upon respect for individual dignity. As such, ensuring that data is used and managed ethically on behalf of stakeholder interests necessitates the creation of an ethical framework that considers what is legal, fair, and just. In support of this assertion, Buttarelli contends that objectification – using a person or their information as a tool to serve someone else's purposes – which is the undercurrent of Big Data analytics - is a violation of privacy and human dignity.[212] His position, of course, is representative of the view espoused by the European Union, and numerous other countries, which considers privacy a fundamental right of all humans, in contrast to the United States' patchwork of privacy laws. Nevertheless, Big Data analytics and algorithmic decision making is a global phenomenon. And as such, the appreciation for principles of fairness and justice must transcend jurisdictional and geographic limitations thereby encouraging an international commitment to ethical principles of accountable data stewardship.

Despite the inherent limitations of regulations as a mechanism for protecting privacy, there is a basis in law, both domestically and internationally, for principles of fairness and justice. Originally promulgated in 1973 by the Department of Health, Education and Welfare (now the Department of Health and Human Services – DHHS) the Fair Information Practice Principles (FIPPS) became the cornerstone set of principles for personal data collection and creation of record keeping systems.[213] Concerned with individual rights, the FIPPs evolved and became the prime influencer of a number of standards adopted by the ONC, the Organization for Economic Cooperation and Development (OECD) the ONC, and the FTC, to name just a few. However, the FIPPS were designed to empower consumers with the limited ability to control information through notice and choice, but do little to ensure information disclosed is not used in unfair or harmful ways.[214]

What is fair or unfair is often as difficult to define as any of the other concepts advanced throughout this chapter thus far. For behavior to be unfair according the FTC, the practice must cause substantial injury that cannot be reasonably avoided by the individual and is not outweighed by the benefits.[215] Proving legal injury in Big Data misuse is tenuous at best, as the customary litmus test is most often economic harm. In other contexts, fairness also presupposes that the benefits inured are outweighed by the risks and do not create biases that disadvantage the benefactor or beneficiary.

However, in the Big Data space, Solove argues that the harm from unfair data use is a dehumanizing effect on people. Because data emanating from aggregated databases "fails to capture the texture of our lives. Rather than provide a nuanced portrait of our personalities, they capture the stereotypes and the brute facts without the reasons."[216] Accordingly, to preserve the cherished texture of their patients' lives and to ensure fairness in the use of their data, accountable healthcare leaders must consider the privacy rights and interests of this stakeholder group when setting data use and strategy policies. Such reflective consideration must include any adverse consequences that are readily foreseeable, as well as those less so. Ethical principles respecting autonomy, fairness and justice, as well as assimilation of the norms driving these principles, must be baked into data policies that afford such consequential reflection.

One way accountable HCOs can transform their ethical approach to using patient data in the digital information age is to reframe their overall data strategy through implementation of an enterprise-wide code of data ethics. Adherence to ethical codes is a marker of accountability in many professions, and is most profoundly present in healthcare. Accordingly, a code of data ethics would create a "forum to translate identified ethical principles into defined ethical actions and practices in their organizations as part of their information governance model."[217] As

illustrated in earlier chapters, the ethical character and culture of an HCO reflects its most

significant norms and values. Similarly, according to O'Keefe and O'Brien, "[a]n ethical

framework in the context of modern information management will need to consider

organizational values, processes and development of technology in the context of fundamental

ethical principles such as human rights and dignity."[218] This presupposes that such code would

provision ethical reviews and consultations of particular data uses, processes, and activities.

Ethical data reviews may result particular uses deemed necessarily off limits[219] for the sake of

patient dignity, and alignment with institutional norms and values.

3. J. 2 Recalibration: Reshaping Our Norms

Westin wrote that the norms of privacy in society depend upon political, sociocultural

and personal settings.[220] Schneier's perspective similarly contends that norms of personal privacy

are cultural and situational – changing across generations.[221] This observation is well-grounded

and validated as witnessed by society's undaunted reliance on and ubiquity of the smartphone

camera today, in contrast to Warren and Brandeis' virulent distrust of the Kodak 'snap camera'

in 1890. This dissertation suggests that privacy norms are contextual, too. As such, the privacy

offenses in healthcare data are likely to have a greater gravitational pull on one's senses than

exposure to political thoughts, online shopping habits, and vacation spots might. The

vulnerability and fragility of human dignity that is constituent of the healthcare experience

context is sufficient to ignite deep emotional responses to violations of that dignity.

Nevertheless, the constellation of digital data footprints that are left everywhere, by

virtually everyone, seems to suggest that few people are likely to ponder, or even consider where

their data is, where it is going, or how it is used today. As a consequence, expectations of privacy

have been reoriented such that most people believe they have less privacy today, instead of

more.[222] What matters most about this reorientation, aside from the danger of privacy apathy, is the need to recalibrate today's privacy norms, rather than dismiss them as meaningless. We may, in fact, have less privacy today, but there has hardly been a time in in history when we need it more than now.

Inviolate respect for privacy engenders patient trust in the HCO, and its leadership. At the heart of trust generally is the act of surrendering control to another. In addition to surrender, Malhotra's view that it is the willingness to be "vulnerable to the discretionary behavior of others…based upon the positive expectations regarding the other person's motivations and/or behavior."[223] Human beings trust with their hearts and their heads, and that is particularly important as privacy is both a feeling as well as a right. Patient trust also relies mightily up the hearts and heads of the clinicians and executive leadership. However, algorithms, which are emerging as dominant decision makers, and machine learning tools, predict and inform without human feeling or thinking.

Going forward in an age of Big Data, artificial and machine-driven decision-making, and continuously innovative advanced analytics means that normative conceptions of privacy and trust, must change. Patient stakeholders may eventually be expected to accept that they are vulnerable to the discretions and indiscretions of algorithmic-generated intelligence. And while surrendering control to an algorithm cannot replace trust in another human being, patients ought to begin to recognize that machine learning is, at the very least, a derivative stakeholder to the contemporary HCO. Realistically, artificial intelligence and machine learning are not going to replace physicians, but they will most definitely modify what a physician needs to know, as well as what will occupy their time.[224]

Humankind's necessary coexistence with Big Data vis-à-vis those aspects of life which are entitled to privacy protection will necessarily entail a shift in norms. Alec Ross boldly warns that as information about our fallibilities, flaws, fantasies and foibles becomes accessible and indelibly preserved in Big Data, the greater the likelihood that the things we prize as novel or even scandalous will eventually be neither.[225] Nothing is likely to surprise anyone anymore – including those unique aspects of being human which are most cherished. He further observes that even "serendipity fades with everything we hand over to algorithms."[226] Cohabitation in harmony with Big Data will mean that humans must fill the moral gaps left by algorithmic decision making. Decision makers must realize the need to exercise their moral judgments in place of that which artificial and machine interventions cannot do. When that happens, patient privacy will embrace a world of artificial intelligence that affords humankind the opportunity to be more authentically human.

3. K. Conclusion

Keeping secrets is innately human. Secrets afford individuals the opportunity to control aspects of their life and to establish necessary boundaries between themselves and society.[227] If Franklin's cynical observations were true, the unconditional inability to keep secrets would pervert trust and confidence in healthcare, and would create an impenetrable barrier to necessary transparency. Such a barrier would degrade if not destroy the quality of the relationship between the physician and patient and the resulting care.

Nevertheless, many secrets are no longer binary between the patient and her physician. Many features of modern medicine present challenges to patient confidentiality. Among those features, the contemporary healthcare environment is both enriched *and* complicated by a data-

driven hunger supported by advances in digital technology such that, "secrets get exposed sooner than they used to…making them harder to keep."[228]

Of the many challenges that the information age imposes on healthcare stakeholders, the ability to maintain the seal of confidentiality concerning patient secrets is paramount. It is supported, in many cases, by law, ethical principles, and by the seal of privileged communications which protect against arbitrary disclosure. The universal principles of respect for autonomy, beneficence, and non-maleficence are the primary justification for confidentiality based upon what is best of the person[229] and considered in concert with the specific contexts of the clinical setting.

With few exceptions, most stakeholders are autonomous, and they require sufficient information to make sound decisions.[230] Informed consent necessitates that the physician understand the autonomous voice of his patient when determining what she needs to know in order to consent to treatment, *and* to the sharing of her secrets. For the most part, the duty of confidentiality, the expectation of the patient, and the sufficiency of information necessary to confer informed consent, are formulated and executed on behalf of the patient. However, third party stakeholder interests often present compelling and legitimate threats to the principle of confidentiality.

From its earliest days, the secrets shared in the psychotherapeutic setting were sacrosanct. Many of the truths revealed through the therapist/patient relationship may not even have been recognized or known by the patient at the time that informed consent was given, as psychotherapy is in many ways a deliberate process of mining for secrets. The duty to protect these secrets are derived from professional codes, ethical principles, as well as by sources of law. The duty to warn – resulting from the seminal *Tarasoff rule* – considers public beneficence as

compelling justification sufficient to override patient confidentiality; imposing a mental health professional's duty to potentially unknown third parties, in addition to that which he owes to his patient.

As such, the tension between the clinician's allegiance to his patient, and the third-party interests of other stakeholders, is central to the ethical justification for sharing genomic secrets.[231] Advances in genomic medicine present another set of ethical dilemmas for the healthcare stakeholder – specifically the physician – with respect to the duty of confidentiality. For the all the good that genomic medicine promises, the secrets discovered and disclosed place the physician and the patient in an unprecedented predicament. A predicament that must rely upon the ethical principles of beneficence and non-maleficence to determine who has a right to know those secrets, how much should they know, and to what extent they may elect to forego knowing the secrets at all. Healthcare is barely approaching the threshold of this new frontier in medicine and the ethical considerations relating to the confidentiality afforded to these secrets will emerge along with the science. The ethical obligations to these varied stakeholders will rely upon deliberate moral decision making; which includes respect for the ethics of secrecy.

The relationship between the patient and her doctor is crowded. They are no longer a pair. Rather, their encounters are part of a complex constellation of data sharing potentially exposing the secrets exchanged that were once presumed sacred. Impugning the presumption that the law and common morality alone would prevent such intrusion into a patient's most intimate matters, privacy as an inviolable legal as well as moral claim in healthcare is close to extinction.

There is a powerful push for interoperable everything, and ubiquitous digital technologies that force patient data into environments that are not individual-centered and lack the capacity to

respect the patient need for autonomy and individual control. Flooded with Big Data from incalculable sources, healthcare decisions that once were the province of human beings are subordinated to technologies powered by algorithms, artificial intelligence, and machine learned tools. Thus, there is a rapid erosion of the time-held demarcation lines between a patient's physical, decisional and informational privacy rights and entitlements. The absence of clear boundaries presents moral challenges and conflicts for the healthcare professional, the HCO, and stakeholders who entrust their secrets to them.

The ethically accountable HCO has a moral duty to its stakeholders to invest in a data strategy that advances, at its core, principles of data ethics to reflect respect for the human rights and dignity of its normative stakeholders. These principles of data ethics are to be embedded within and throughout the HCO to undergird ethical review and analysis of data uses across the enterprise. This code of data ethics ought to represent the norms and values of the HCO, as well as those belonging to its stakeholders. As norms, values and expectations surrounding privacy in healthcare continue to evolve, ethically accountable leaders must reconcile the tension between technology and algorithmic decision-making with the recognition that moral judgement is the province of humans, not machines.

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Chapter 4 – Community Stakeholders in Healthcare: Pediatric Populations

4.   **Introduction**

Corporate social responsibility (CSR) is concerned with the HCO's duty to respond to its stakeholders and is a continuing commitment to look beyond its core business to the externalities that affect all its stakeholders and constituents. Pointedly, the morally responsible organization must realize, understand, and harmonize its decisions amidst the complex interconnectedness between social and economic forces pressing on its stakeholders. To do otherwise would, as Freeman predicts, "fail to describe and predict the business world as it really is."[1] For the sake of its stakeholders, the HCO cannot afford such a miscalculation.

As such, ethical accountability to stakeholders in healthcare requires a moral commitment from HCOs to the sustained well-being of the communities they serve. To do so, they must create opportunities for their normative stakeholders, and most especially the most vulnerable amongst them, to flourish. As this dissertation argues, providing for the common good is both a human right inured to the members of society, and a duty to provide for those so empowered. Since healthcare is a common good of a moral and civil society,[2] principles of stewardship and the duty to provide for the common good requires a commitment from HCOs to disrupt the status quo and mobilize change for the good of at-risk stakeholders. To that end, the remainder of this dissertation explores the HCO's ethical accountability to ensure access to clinical advances, and respect for the dignity of stakeholder groups who are the most vulnerable and disempowered across the life continuum. This chapter is dedicated to the second of the three dissertation stakeholder categories: the treatment of pediatric populations.

With a focus specifically at the beginning of the life continuum, this chapter centers its attention on children and their attendant vulnerability. It commences with an ethical justification for transcending risk and upholding the moral obligation to promote the engagement of children in clinical and social research studies. To undergird the ethical arguments advanced, it opens with an explication of the concept of vulnerability as a condition of humanity[3] as interpreted by several moral theorists, including Mackenzie, Rogers and Dodds. Expanding upon its moral significance, it then provides a view into the grim history of exploitation surrounding human subject research, and its evolution into modern day clinical research. It then proceeds through the development of ethical principles, and regulatory codes and guidelines as they apply to human subject research generally, and then to children specifically.

Within the context of clinical research, physicians and researchers are often the same person. They confront moral predicaments when their commitments as treating physicians run counter to those expected of researchers engaged in scientific inquiry. To illustrate, when referring to those who participate in research as "subjects," there is the risk that they will be become dehumanized somehow; causing researchers to forget humanity and impose less than ethical procedures.[4] In addition, as moral agents, they must navigate ethical challenges specific to the clinical, cultural, social, and contextual considerations that are unique to their patients and subjects, and influence their decisions. These specific research considerations and risks, as well as an examination of the moral duty of HCOs and their agents to expand opportunities for ethical research participation[5] are explored throughout this chapter. Particularly, it aligns its focus on the most vulnerable pediatric communities: children and adolescents with HIV, abused and maltreated children, and those with cognitive disabilities.

Recognizing that none of these risks can be completely eliminated, this chapter concludes that the risks to these children as participants in HIV, child abuse, and cognitive disability research can be managed and even mitigated. Adoption of the goodness-of-fit model espoused by leading theorists, including Cecilia Fisher,[6] underscores the moral obligation of the ethically accountable HCO and its clinician leaders to advocate inclusion and research that respects human dignity and promotes empowerment. The goodness-of-fit model and ethical commitment to this community of stakeholders is further explored throughout the remainder of this chapter. It considers the ethical challenges of pediatric HIV status, as well as strategies for accountable leaders to mitigate and even prevent the life-threatening adverse effects of abuse, and pediatric obesity on children.

As a multi-factor condition, pediatric obesity is a public health threat. The second half of this chapter examines this population through the lens of societal, socio-cultural and environmental influences. It addresses the ethical and legal strategies for managing pediatric obesity by describing the problems and societal impacts of the disease generally. It then considers the various obesogenic environments and community influences that support, enable and propagate these environments, and the resulting obesity-related medical conditions that can threaten the life of a child.

While the long-term medical consequences of pediatric obesity are incontrovertible, this chapter delves deeply into the psychosocial as well as physiological effects of this condition; particularly in light of Western culture's obsession with thinness. For many children, being labeled obese often subjects them to humiliating stigma, prejudice and suffering – coupled with their medical conditions.[7] These psychosocial consequences most often persist throughout the child's life; traversing into adulthood. Since they are socially constructed, these psychosocial

harms result in social costs that warrant community intervention in executing remediation strategies.

Because the HCO's ethical accountability extends beyond its internal stakeholders, it oftentimes has a moral duty to protect those who cannot yet fully protect themselves. As such, this dissertation develops and sets forth an argument for principled communitarianism combining the principles of the duty to do what is good, and to avoid harm, with the individual's right to be left alone, and the community's duty to advance its best interests. To that end, this dissertation introduces the legal theory of *parens patriae* to cases of persistent obesogenic environments engendering medical neglect. It further argues that, as a social parent,[8] the HCO's moral duty to protect its pediatric stakeholders involves intervention, and cooperation with its full community.

4. A.   Transcending Risks to Serve the Vulnerable

Centuries before the Information Age, the Enlightenment period triggered humankind's desire to discover and uncover the answers to life's mysteries through inquiry and scientific thought. One of hallmarks of this historic time was the notion that knowledge is power. It was believed that knowledge and understanding endowed people with power and control over their own lives. It was in thinking about the world that humankind recognized its humanness.[9] The more knowledge humankind acquired and the more it learned about its world, the more apparent it became that the *absence* of knowledge precipitated vulnerability, disadvantage, and disempowerment. Control, manifested through self-determination and autonomy, permitted enlightened people to rise above oppressive rulers to take dominion over their own lives and destinies.   In many ways, knowledge and power defeated death, and translated into survival.

Towards the end of this era, survival began to mean more than prevailing against domination. The same motivation to control and take dominion over human life sparked the quest to understand the cause and prevention of disease; and "to stamp out or radically limit death or disease."[10] Because of its success as a scientific endeavor, the use of human subjects in clinical and social research initially garnered tremendous enthusiasm and public support. However, the pursuit of knowledge of the world does not come without risks. While it can help and heal, the pursuit of knowledge from human research can also bring with it infinite harms that may *disempower* specific populations if not obtained ethically. This is particularly true when the research subjects are members of a highly vulnerable class such as children, and doubly-so when the children have special needs, diseases, or are victims of abuse.

In addition, society's long-held preconception that women and children were weak cloaked them under layers of protections and safeguards that excluded them from involvement in clinical research trials. Such exclusions resulted in an overall dearth of research on women and children, and a general lack of clinical understanding of these stakeholder groups; thereby exposing them to health risks from the absence of meaningful prevention and treatment. Over-inclusive protectionist policies also have the effect of expanding determinations of vulnerability to entire populations of people with such granularity that few potential research candidates *are not* classified as vulnerable. Such broad labeling risks rendering the notion of vulnerability meaningless, or worse, exacerbating the negative consequences of stereotyping and discrimination.[11] Balancing the rights of vulnerable children to participate in research, providing sufficient information to them, and protecting them from unreasonable risks and harms are the principle challenges for conducting this kind of research ethically.[12] This is the charge of morally accountable leadership.

4. A. 1.   Understanding Vulnerability and Moral Duty

First appearing in the late 17th century, the etymology of 'vulnerable' stems from the Latin *vulnerare* meaning 'to wound', and *vulnus* meaning 'wound.' *Vulnerability* then, is having the ability or capability to be wounded, and is the meaning adopted throughout this dissertation. From this perspective, it can be argued that all HCO stakeholders are vulnerable given the nature of healthcare generally and the power imbalances inherent in its relational contexts. Yet, the *concept* of vulnerability in bioethics, and particularly research ethics, has been, and remains the object of great moral debate.[13] As Ganguli-Mitra and Biller-Andorno point out, "With the changing face of healthcare and biomedical research in a globalized world, the term 'vulnerable' as well as an adequate definition and scope have increasingly come under close scrutiny."[14] Despite the debate, for purposes of ethical discourse, the concept of vulnerability must appeal to the protection of all human life broadly, and not just a concern for the human condition.

According to Mackenzie, Rogers and Dodds, as embodied, social beings with material and physical dependencies that are both susceptible to and dependent upon environmental and internal influences, vulnerability is a condition of human life. As such, "within bioethics vulnerability is variably viewed as an ontological condition of all human existence and as a marker to identify those who require extra care, where the especially vulnerable are those whose autonomy, or dignity or integrity are capable of being threatened."[15] Although humans are ontologically susceptible to vulnerability, there are contextual considerations that shape various other theories and characteristics of human vulnerability that extend beyond the aforementioned threats.

Contingent susceptibility theory suggests that vulnerability is relational. That is to say that "[i]nequalities of power, dependency, capacity or need render some agents vulnerable to

exploitation by others."[16] Such exploitation is enabled precisely because humans are inherently dependent upon others for care and support in satisfying those needs, and largely exist within interdependent, relational communities. According to Mullin, "It is our needs that make us vulnerable...We are therefore, vulnerable to others not only because they may attack or wound us, but also because our neediness and limited ability to meet our own needs makes us dependent on others for care…"[17] Children are supreme examples of a population predisposed to contingent vulnerability theory in this context.

Rogers similarly argues that vulnerability involves two concepts. She contends that the first concept of *universal vulnerability* is inherent and inevitable as part of the human condition. And the second concept of *contextual vulnerability* "is associated with contextual factors, which signifies precariousness or greater risks of harms for particular individuals."[18] Much of what is understood as vulnerability within healthcare today contemplates this precariousness and looks at "the social, cultural or economic context the individual finds themselves in, rather than a stringent categorization measured against the ability to give consent or to make an autonomous choice."[19] As Mackenzie, Rogers and Dodds suggest, both concepts of vulnerability ought to be incorporated into ethics of vulnerability discussions. The remainder of this dissertation, through its arguments for ethical accountability of HCO leadership to its stakeholders, adopts and advances this blended perspective of vulnerability.

A predominant challenge with contextual vulnerability is that it establishes and attempts to understand an almost infinite number of characteristics and conditions that comprise and are unique to vulnerable subgroups. To illustrate, the Belmont Report, the Declaration of Helsinki, and the Council for International Organizations of Medical Science, all described more fully hereunder, identify as many as 19 specific populations deemed particularly vulnerable because of

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contingent forms of vulnerability.[20] From the conspicuous continuum of populations such as children, the elderly, and patients with incurable diseases, to less visible groups of poor people, nomads or displaced persons, and subordinate members of hierarchical groups, suggests that there is a layering of conditions. Solbakk suggests that such layered conditions overlap each other and are both persistent (universal) and variable (accidental or 'fallen victim') conditions of vulnerability; the differentiation signaling the kinds of protection or remediation necessary, and the rights to which the vulnerable are entitled.[21] Providing for the vulnerable necessitates identifying the appropriate parties who bear responsibility for them.

Mackenzie, Rogers and Dodds contend that two theories undergird the moral obligations engendered by vulnerability. The first suggests that the vulnerability itself is the source of a moral obligation, while the second perspective argues that the vulnerability is more akin to a signal pointing to other moral obligations such as providing for an unmet need, or mitigating or avoiding harm.[22] Accordingly, it is both the inherent nature of human vulnerability as well as the situational conditions that give rise to the moral obligation and ethical duty to mitigate threats and protect the vulnerable. By illuminating Goodlin's proposition, Mackenzie, Rogers and Dodds maintain that this duty inures to "anyone who is in a position to assist but most especially on those to whom a person is most vulnerable. Thus persons who are in positions of power and authority have special responsibilities…"[23] To understand this within the context of vulnerable pediatric populations – particularly pediatric research - it is necessary to look at the effects of all authoritative relationships on the child; primarily HCO leadership which includes clinicians, researchers, and institutional review boards (IRBs). The remainder of this dissertation appropriates this theory of moral duty to ethically accountable HCO leadership.

4. A. 2.   Expanding Medicine through Research, or Exploitation?

In preserving the ancient principle that medicine should do no harm, the practice of medicine has historically been a patient-centric endeavor supporting the physician's commitment to promote health and protect – one patient at a time. The quest for knowledge per se, was rarely the objective of good medicine. It was a relational and largely paternalistic endeavor. It was the physician, who in seeking to the protect life and the dignity of her patient, often made decisions for her on the basis of the best individualized therapy.[24] As the practice of medicine sought to cure the sick and relieve pain and suffering, research looked to expand knowledge in an effort eliminate disease globally, understand treatment, and delay or even prevent death.[25] The need for biomedical research emerged since progress and survival necessitated a broader and more utilitarian understanding of disease.

Biomedical research came to be defined as those interactions which tested hypotheses and sought generalizable knowledge about diseases to sustain and enhance the good of society and humanity by improving the practice of medicine.[26] Although the terms biomedical research and clinical research are often used interchangeably, the majority of biomedical research is conducted on animals and their tissue; not human subjects. The outputs of biomedical research typically support medicine generally. Clinical research, on the other hand, involves humans and is designed to enhance therapeutic interventions.[27]   As such, medical advancements are often realized from the knowledge obtained from clinical research on human subjects. Unless otherwise stated, all references to research throughout this chapter shall mean clinical research. This history of clinical research illustrates how disencumbered desires for such advancements often created unintended adverse consequences.

Much of the quest for research-based knowledge throughout the 19th and 20th centuries, and the medical discoveries made during this period were the collateral effects of wars, military conflicts, and attempts to understand the casualties associated with them. Although understanding therapeutic interventions and disease management was indispensable during military conflict, it was significant in the postwar period as well. Despite the valuable contributions to medicine that emerged during this time, the crimes against humanity from unspeakable human experiences occurring behind the front lines remain the hallmark of this period. Incalculable numbers of human beings were involuntarily selected and exposed to physical and emotional experimentation designed to test the limits of human tolerance and biology. Prisoners of war were involuntarily immersed in tanks of ice water to observe the boundaries of hypothermia, and pressure-chamber experiments were performed on children to induce epileptic seizures.[28] Dissection and organ extraction of live persons, and the intentional wounding of women prisoners' legs in order to understand the efficacy of injected sulphonamide were but a few of the ghastly and macabre tortures performed in the name of research during World War II.[29] These inceptive days of human subject research drew attention to and illuminated the fundamental truth that respect for human life could not be forfeited by treating participants as a means to an end.[30]

These fundamental truths provided the backdrop for the groundbreaking Nuremberg Code, promulgated by U.S. judges following the Nazi trials of World War II. As a foundational document, it is based upon natural law and human rights, and sets forth basic moral, ethical and legal concepts undergirding research involving human subjects.[31] A 10-point statement of principles outlining professional ethics for medical researchers, the Code influenced all

subsequent standards of conduct for human participant research.[32] A central, and most celebrated tenant of the Code punctuated the need for participants' voluntary informed consent.

Notwithstanding the positive influence of the Code, exploitation of humans participating in research proliferated for decades under the guise of ethical research. As late as the 1970s, many of these inhumane experiments were discovered and disclosed; revealing questionable procedures surrounding selection of participants and volunteers as well as deficient or nonexistent informed consent processes. For example, the Tuskegee Syphilis Experiment remains an example of an indelible moral failing within the United States. Treatment to an identified population of American black men infected with advanced syphilis was intentionally withheld in order to gauge progression of the untreated disease.[33] National and international codes were developed in an attempt to supplement the full and universal adoption of the Code. Regulations and codified principles defining ethical research, justice in selection, and protocols to ensure bi-directional flow of information between the researcher and the vulnerable research subject ensued.[34]

4. A. 3.   Rules, Regulations, and Rights

The paternalistic presumption that women and children were vulnerable and therefore required greater protections, historically excluded them from participation in human research trials.[35] While the desire to protect was laudable on its face, the consequences of exclusion were that women and healthy children were under-researched and therefore little was known about them medically. Since the view of ethical human research was largely concerned with distributing the risk to the sturdiest and most resilient, opportunities to provide needed services were often missed, as were prospects to avoid harmful ones. Effective treatments, understanding drug reactions and interactions, the pathology of disease, and safe dosages of medications for

women and children were virtually unknown[36] while men between the ages of 16-60 were the most tested. The dearth of information and understanding left them to become therapeutic orphans.[37]

However, children who were institutionalized or otherwise deemed defective were not always orphaned in this way. To the contrary, they were often so dehumanized as to be considered expendable resources, and victimized as subjects for over-utilization of nontherapeutic research; research which is not likely to have any direct benefit to the participant child.[38] The horror discovered within the walls of the Willowbrook State School for persons with intellectual disabilities is an example of the most atrocious abuse of non-therapeutic research on children since World War II. Resident children were intentionally given the hepatitis virus in order to understand the effects of gamma globulin on them.[39] Defenders claimed that because the hepatitis virus was already present throughout the institution, the virus was likely to infect the children anyway. In many ways, the children *became* the human experiment. From this flagrant disregard for human dignity, nontherapeutic research brought to light the notion that a person could be wronged without necessarily being harmed. Rising public awareness of the exploitation of these vulnerable children and the sentiments at that time, induced debate and a push for legislation and guidelines. Such pronouncements shifted the mindset from excluding children from research as a *risk* avoidance tool, to one that permitted research but sought fairness in the distribution of the *benefit*.[40]

Following the Nuremberg Code were a series of promulgations which sought to respect autonomy and human rights while balancing the harm and benefit to protect human research participants; including children.[41] For example, the Belmont Report, published in 1979 by the National Commission for the Protection of Human Subjects Biomedical and Behavioral

Research, codified the moral principles of respect for persons through autonomy, beneficence and justice, into the bedrock principles of research ethics.[42] This principled approach established strict criteria for ethical human subject research. For its time, the Report powered a moral stir by illuminating the practice of selecting children for nontherapeutic research which had no relation to the child's own health. This lead to the National Institute of Health and other agencies' push for regulations. Acknowledging the need for research with children, but cognizant of their vulnerability and history of exploitation, these regulations landed within the purview of the Department of Health, Education and Welfare. That agency – which is now the Department of Health and Human Services – addressed the acceptability of research involving children in the form of the Federal Policy for the protection of Human Subjects; specifically Subpart D of the Common Rule."[43]

Published in 1991 and effectively revised in 2017, The Common Rule amplified the Belmont Report and further set forth ethical provisions and parameters. These included the establishment of the institutional review Board, or IRB. The IRB ensured that research protocols and plans were sufficiently vetted, risks to research subjects were minimized, and that they received the protections they were owed. IRBs continue to occupy a central role in human subject research.[44]

Subpart D of the Common Rule sanctions research with all children according to nine statutory provisions which parallel the principles of the Belmont Report. Subpart D provisions range from the assessment of risk and prospect of benefit to the role of the IRBs, the requirement of parental consent and child's assent, protections for highly vulnerable children, as well as processes for conducting unapproved research with children.[45] In 1998 the National Institutes of Health published policies and guidelines supporting inclusion of children as research

participants, and in 2002 Congress adopted legislation promoting increased drug trials involving children.[46]

4. B.　　　　　Applying the Principles to Pediatric Research

Because they differ from adults, research with children is essential to understand the pathology of disease and disorders involving them. Some diseases are unique to children and because they are not little adults, nor are they non-adult beings, their physiology and psychology must be understood within the pediatric context. Although including children in clinical research is critically essential to understanding child health, this species of research remains a source of controversy.[47]

Respecting the humanness of children demands first that they be accepted as fully human. Early 19th century biology and philosophy viewed children as *human becoming* who were pre-competent and although they were developing into full humans, they were essentially biology-in-progress. Because they were considered incomplete, their completeness was thought to impair the quality of the research data, and their developmental level was considered short of the requisite capacity necessary to consent to research.[48] Their completeness and competence was measured against an adult world rather than the everyday world of a child.

Research with children, and particularly research involving those who are contextually vulnerable, discussed more fully hereunder, often involves reliance on knowledge obtained from children's subjective experiences in natural contexts, which is fraught with potential misinterpretations and misunderstandings of their experiences. Even the meaning of the word *children* is subjective in that it includes a broad spectrum of meanings. It includes infants and teenagers; girls and boys; and varied social, ethnic and religious backgrounds; including able-

bodies and those with physical and sensory impairments.[49] The Belmont Report provides a widely accepted definition of the term *children*. It holds that children are persons who have not attained the age of legal consent to medical care according to the law of the jurisdiction in which the research is conducted.[50] But children are more than their defined legal status. They are inherently and conditionally vulnerable, as they cohabitate with others in a world of complex relationships, cultural contexts and unique experiences.

Accepting and understanding children's experiences as they understand them and their world, will help to reinforce the notion that they are competent human beings, rather than deficient adults with no opinion, expressions and thoughts.[51] However, it is the differentiated quality of children, rather than their perceived incompleteness, which challenges the ability to consistently apply the ethical principles espoused by the Belmont Report and related guidance. Notwithstanding the degree to which they are perceived complete or incomplete, the matter of vulnerability and defenselessness against harm undergirds the ethics of pediatric research and drives the debate surrounding this species of research and the associated risk of harm. Despite the challenges, execution of clinical research demands a moral commitment to adhere to fundamental ethical principles.

4. B. 1.   Foundations of Ethical Research: Inclusion and Choosing Justly

Understanding which children should participate in research is essential to understanding how to serve all children sufficiently and fairly so that every child, including those belonging to highly vulnerable subpopulations, can *benefit* from the outcomes, or at least not be *harmed*. Highly vulnerable children, such as those with special cognitive needs, have been the object and subject of unethical and unjust research practices since the 18th century, but it was the Willowbrook State School case which stirred worldwide controversy.[52] The aftermath of

Willowbrook marked, once again, a movement away from including children in research in an effort to protect them from harmful experimentation.

Becoming therapeutic orphans by default, statistics from the post-Willowbrook period demonstrate that children were disempowered and vulnerable as both research subjects and patients; particularly in the area of drug safety. Infant deaths from diethylene glycol poisoning, and birth defects from exposure to thalidomide during pregnancy are a few tragic examples. At that time, most drugs prescribed for children were not tested in children; only about 20 percent of FDA-approved drugs were cleared for pediatric use.[53] In fact, it was not until the Food and Drug Administration Modernization Act of 1997 that pediatric clinical trial infrastructure began to take shape.[54] Henceforth, legislation such as the Pediatric Research Equity Act of 2003 (PREA) and the Best Pharmaceuticals for Children Act if 2002 (BPCA) helped facilitate pediatric drug studies as well as the approval of more than 730 labeling changes for drugs prescribed to children.[55] Similarly in Europe during this time, most drugs prescribed for children were done so off label due to insufficient safety, and efficacy information. Beyond drug studies, the burden of proof for pediatric researchers today has shifted from the need to demonstrate *why* children should be included in research to whether or not there are ethical reasons why they should *not* be included. The welfare of children in pediatric research must be balanced against the need to protect them from harm. In pursuit of that balance, it is necessary to examine whether justice in the participation process implies a moral duty to participate in research in the first instance.

As a principle of morality, Rosamond Rhodes submits that to the extent humankind demands more out of science "we should each see the need to participate in studies by contributing and sacrificing some of our time, energy, comfort, blood, bodies, and privacy."[56] To that end she argues that research amounts to a collaborative necessity to include people of every

sort from infants and adolescents to pregnant women, the elderly and persons with diseases and conditions of every type. This collaborative necessity is a moral duty, according to Rhodes, that is fair and just since biomedical science is for the common good, and the benefits of research inure to the broader society. It is further dramatically amplified to impose duties on clinicians, researchers, and IRB protocol reviewers to consider their own willingness to enroll in studies when reviewing potential study participants.[57]

In contrast, Yarborough asserts that supporting common good of healthcare through participation in clinical research, either tacitly or expressly, is not a moral duty even though the societal benefits of research can inure to anyone who has occasion to access the fruits of healthcare.[58] His sentiments suggest that those who do not participate in or advocate for support of clinical trials are not guilty of a moral failing because much of clinical research is itself a failure. Citing that much of research is wasteful, he points to the statistically high fail rate of many forms of clinical research to rebut the obligation of individuals "to take on risks for the sake of clinical research." [59] According to Yarborough, approximately half of completed trials never get published in full, and that many of the drug trials published in high-impact journals appear to have been designed for marketing purpose.[60] He further contends that much of pre-clinical research is fraught with software coding error, mislabeled cell lines, and inaccurate data that adversely affect quality and safety of the finalized clinical trial. For Yarborough, such inaccuracies diminish the societal benefits and increase the likelihood of adverse consequences, and risks of harm.

With respect to children, Fleishman and Collagan contend that placing some children at risk for the sake of all is acceptable on condition that there are necessary and sufficient methods in place to protect the children enrolled in the research. These safeguards are important to ensure

that they are not exposed to undue risk, without any direct benefit.[61] This seemingly

straightforward solution to inclusion has not been met with universal acceptance. The debate

surrounding pediatric research is fueled nationally and internationally by divisive theological and

philosophical opinions; from staunch conservative to radically liberal.

Protestant theologian, Paul Ramsey, argued against research involving children

contending that doing so was only justified if it furthered the medical interests of the child. He

further posited that nontherapeutic research ought never to be performed without the consent of

the child subject. For Ramsey, the argument that the children who do not benefit directly from

research would develop moral character from the altruistic act of participation was fallacious.

According to Ramsey, the child could not develop moral character from performing acts that

were unwilled by them.[62]

On the other hand, Roman Catholic theologian Richard McCormick, argued that research

with children was necessary to improve the health and well-being of this population collectively.

As such, parental consent would sufficiently protect their interests since parents know their

children best, and are perfectly suited to make sound decisions on their behalf. He further

asserted, with a rather broad assumption, that most children if they were able to consent, would

want to participate in experiments that contribute to generalizable knowledge for the common

good.[63] Throughout the world, policies and political undercurrents concerning pediatric research

experience similarly divergent views.

Both the U.S. and international communities attempted to harmonize the perspectives

within their policy positions and related codes/regulations, to justify research with children.

Despite the effort, it is not surprising that there is not a clear, universally adopted position. The

Belmont Report recognized that research involving children is justified to cure childhood

diseases and to improve well-being provided that their vulnerabilities were recognized, and protections for them prevailed.[64] The Report underscored that the concept of equitable selection, as a matter of social justice, established an order of preference in the selection of certain classes of research subjects; ensuring that protections prevailed. To that end, research ought to take place first on animals, then on adults, and then on older children, prior to infants.[65]

The Declaration of Helsinki contains two preconditions supporting research with children. The research must be indispensable to promote pediatric health, and it cannot otherwise be conducted on populations who are able to give their own consent. Refining the Declaration's position, the Convention on Human Rights and Biomedicine set parameters around research with vulnerable persons, but did not expressly advocate research with children. However, the Council for International Organizations of Medical Science (CIOMS) does support children in research in order to avoid dangerous reliance on drugs and treatments that have only been tested on adults. Accordingly, it supports pediatric research only in those instances where the knowledge sought cannot be obtained by research carried out on adults.[66]

The European Union recognizes the need to protect children in pediatric research. To maintain consistency throughout the EU, it published a number of directives outlining good clinical practices. The primary objective of these directives is to provide guidance on the use of informed consent involving parents and guardians, as well as on procuring assent of the child. Understanding which children should participate in research is critical to understanding how to comprehensively and fairly serve children so that every child, especially those belonging to vulnerable subpopulations, can benefit from the outcomes. Harmonizing regulations and practices relating to ethical clinical research for vulnerable populations is a global aspiration.[67]

The pursuit of knowledge of children through pediatric research has pendulously evolved. From periods marked by exploitation, to over-protection and orphaning, reverting back to exploitation, to what is now a presumption that research with children is conditionally desirable. This escalates the significance of informed consent, the assent and competency of the child, and the assessment of risks and benefits as vital ethical considerations. Respect for the autonomy of the person requires that legally competent, as well as legally incompetent persons be given the chance to choose whether or not to participate in research; to the extent they are able.[68]

4. B. 2.   Foundations of Ethical Research: Respect for Autonomy and Informed Consent

The Belmont Report's conviction that respect for persons entails respect for their autonomy is what drives informed consent. Ensuring that human research subjects validly grant their consent prior to commencing participation helps to preserve autonomy; the respect for the person's ability to make informed decisions about their health that is free from interference and limitations that may obstruct their decision-making.[69] Truly informed decision-making is predicated on the notion that sufficient information is available. To promote self-determination, the 2017 revised Common Rule (effective in 2019) approached informed decisions through the enactment of a key provisions invoking the reasonable person standard.[70] Prospective participants, or their legal representatives must receive "information that a reasonable person would want to have in order to make an informed decision about whether to participate, and an opportunity to discuss that information.[71]

The reasonable person standard exists in the common law to determine what is fair and just when determining and measuring the legal responsibility and accountability of a party to a particular matter. Its application to medical disclosure law vis-à-vis the revised Common Rule reflects for the first time an explicit need for investigators, and physicians, to be aware of and

address what information a reasonable person would need to know; not merely what the researchers and IRBs consider relevant.[72] This further helps to ensure that research subjects or their surrogate, especially children who may have diminished autonomy and special needs, have adequate understanding of the circumstances and conditions in order to maintain control over their lives.[73] Respect for autonomy and informed consent does not guarantee the safety of the therapy or procedure, but it does help to provide reasonable assurance that people participating in human research are able to exercise their free-will. The ability to sufficiently and validly exercise control and free-will, including the ability to assent to take part in a research study, requires that people be fully informed of the facts necessary to give consent.

As such, the principle of informed consent consists of three primary considerations. Consent requires firstly, the competence of the of the research participant to make a rational decision; secondly, whether the participant is able to comprehend the relevant information provided as well as the consequences of their decision, and finally the extent to which that individual's consent decisions are voluntary.[74] Voluntariness necessitates that the decisions are free from significant or undue controlling influences of coercion, persuasion, and manipulation.[75] Dynamic variables can also legitimately influence and impact the informed consent process without invalidating the consent. These influences are most notably observed in vulnerable, pediatric populations.

While the legal and ethical underpinnings of valid consent are critical components of research, the *intrinsic* value of consent in the pediatric context is what enables children to project their voices and views throughout the research experience. Valid informed consent helps to empower the vulnerable. It gives them a voice. Respect for the autonomy of a child and her ability to make decisions for herself necessitates that the researcher endeavor to understand the

child's voice, viewpoint, perspective and wishes. Given that children organize their thoughts differently than adults and do not always express their viewpoints in ways that adult investigators instinctively understand, a child's true intent may not be known.[76] Moreover, the child may not even comprehend the information provided, or may be influenced by factors that are unknown to the investigator. Balancing the respect for autonomy and these ambiguities against the need to procure legally valid consent supports the need for parental or other third-party intercession and consent.[77]

Accordingly, "informed consent in pediatric research means the permission of parents, (biological or adoptive) or other legal representatives or 'guardians' (individuals authorized under state or federal law to consent on behalf of the child)."[78] The rudiments of informed consent are not controversial; rather, it is the administration and effectiveness that present ethical issues. If there is a direct benefit to the child, or there is minimal risk to them from participation in the research study, then an IRB may determine that consent of only one parent is sufficient. In the case of non-therapeutic research that involves more than minimal risk, both parents must consent. However, parental permission and assent of the child may be waived entirely if the minimal risk research could not be carried out without the waiver, the child subjects will be provided with relevant information following the research, and the waiver itself does not impact the rights or well-being of the subjects. In addition, unless an IRB determines that the capacity of the child is so limited that they cannot be consulted concerning the research, the Common Rule provides that the assent of the child, or affirmative agreement to participate ought to be solicited.[79] It is worth noting the important distinction between capacity and competence. The terms capacity and impaired capacity refer to results of clinical evaluation, while competence and incompetence refer to the legal status of someone to make their own decisions.[80]

Competency, capacity to understand, voluntariness, and having enough information are so interdependent upon one another that they should not be uncoupled and treated as independent from one another. Informed consent should be assessed and valued as an indivisible continuum of processes to uphold the autonomy and dignity of the research subject, rather than a compliance checkbox item that more closely resembles an exchange of executed permission slips.[81] Arnason, Li, and Cong defend the idea that informed consent is a communicative process involving mutual listening, sharing and timely response.[82] Underscoring the importance of communication, Nancy E. Kass, of Johns Hopkins Berman Institute of Bioethics contends that informed consent documentation and the process for procuring it ought to prompt and guide further conversation about the research. To that end, "looking someone in the eye, getting sense of whether they're with you, and even asking them to repeat back what they understand is the most likely strategy to achieve meaningful understanding."[83] The sufficiency of this process is subjective and largely stakeholder specific, beginning with an assessment of the quality of information, an examination of the likelihood that it has been understood, and ensuring that coercion or unreasonable external manipulations were not exerted to influence consent. This subjectivity is exceedingly important when examining the sufficiency of and processes for obtaining informed consent when the research subject is a child.

4. B. 3.   Foundations of Ethical Research: Benefit, Harm, and Assessing Risk

In addition to respect for autonomy through informed consent and justice through equitable selection, the Belmont Report obligates the researchers to adhere to the principle of beneficence by maximizing benefits, while minimizing harms to the research subjects.[84] For purposes of this discussion, a *benefit* is defined as something of positive value related to health and welfare. *Harms* can be physical, psychological, legal, social or financial injuries, and must

be evaluated from the perspective of the research subject. In the case of a child, the harm must be evaluated from their perspective and perception; not the adult researcher or parent. The concept of *risk* considers the potential harm to the research subject as well as their family, or community.[85] In short, beneficence obligates researchers and all involved in human research to acknowledge and support the best interest of the child subject, and help to ensure that their well-being is promoted wherever possible.

As set forth in Subpart D of the Common Rule, research involving children is permissible if it offers the prospect of direct benefit to the child, and is aligned with appropriate risk stratifications. The regulation, however, does not define what is meant by *direct benefit*, and there is little agreement on the ambitious definitions offered by a variety of researchers. The concepts of direct and indirect benefits were introduced by the National Commission to bolster protections for those who could not provide their own, independent informed consent. Because it feared exposing vulnerable groups of people to heightened risks in pursuit of benefits that may be speculative, or realized in the distant future, the National Commission espoused the position that direct benefits must be "fairly immediate."[86] Others like Keyserlingk, Glass and Gauthier argue that research must afford vulnerable research subjects benefits of *significant* magnitude.[87] And other views consider the degree of 'tangible positive outcome' such as pain relief and increased mobility.[88]

Useful for this discussion, Nancy King proffers three types of benefits. Direct benefits, according to King, are therapeutic benefits that inure to the child directly from the intervention or experiment. Collateral benefits are those arising merely from being a research subject even if the child did not receive the intervention or participate in the study. Examples of collateral benefits include receiving a free medical exam, or the altruistic benefit resulting from involvement with

the study. And, aspirational benefits provide social value, and are benefits that inure to the broader society, as well as future patients.[89]

The consequences of such inconsistent and even conflicting perspectives on what constitutes a direct benefit can subvert confidence in the protections necessary for those who cannot exercise their autonomy and informed consent.[90] Particularly for children who are unable to assess and appreciate the gravity of risk and benefit to themselves, and especially for those who serve as their surrogate decision-maker, risk benefit calculations are difficult. To that end, Friedman, Robbins and Wendler suggest that when considering the degree of accompanying risks vis-à-vis the potential direct benefits, not all benefits are created equal.[91] Notably, in cases of nontherapeutic research – or research with no prospect of direct benefit - it is necessary to assess the risk of harm according to a thorough balancing, and non-arbitrary analysis,[92] prior to seeking informed consent.

In establishing the strict criteria for research involving children, the National Commission classified risk into three categories according to its probability: minimal risk, a minor increase over minimal risk, and more than a minor increase over minimal risk.[93] Accordingly, with respect to children, it defined minimal risk, as "the probability and magnitude of physical or psychological harm that is normally encountered in the daily lives, or in the routine medical or psychological examination of healthy children."[94] It is important to note that the Common Rule definition of minimal risk, which does not appear in Subpart D involving children, but rather Subpart A, makes no reference to healthy children. Rather, it considers the daily lives of the general population. For the sake of particularly vulnerable children, some argue that the risk standard ought to be relative to the individual child who is the subject of the proposed research – not the healthy child. Probability and severity of harm can be influenced by the condition of the

child entering the study. That is to say that a child with a disorder may be vulnerable to greater harm from a research procedure than a child who is healthy. Conversely, some argue that children who are healthy out to remain so and are therefore entitled to greater protection. These relative positions are part of the ongoing conversation surrounding risk of harm assessments.[95]

The idea of avoiding harm, proffering benefit, and minimizing risk to children in clinical research has many dimensions. Harms are wide-ranging and dynamic. They range from the physiological, to unanticipated intrusions into privacy and embarrassment, to offenses to personal dignity and self-respect. All of which must be balanced against the interests of active participants, and those who may benefit in the future.[96] Benefits are not always known and are often not detected until long after the study closes, and may not even inure to the study participants themselves. Further, they may be misinterpreted altogether if the informed consent process failed to counter a therapeutic misconception, or if any potential benefits were misconstrued as cures or something more than collateral.[97] Risk assessments look at probability and severity of harm through the lens of what is reasonably foreseeable or what is already known to have occurred. Evaluating the likelihood of harm to a child requires unique insight into the experiential as well as conjectural understanding of what it means to be a child; which, in the absence of meaningful clinical research, remains unknown. Despite this conundrum, understanding the vulnerability of children relies upon knowledge obtained through ethical clinical research.

4. C.   Pediatric Vulnerability in Three Contexts

This thesis demonstrates that ethically accountable healthcare organizations have a moral duty to address the needs of its community of stakeholders. Vulnerable populations and subpopulations of stakeholders are within the purview of an HCO, and they are dependent upon

it to satisfy many of their physical and emotional needs. Since vulnerability is both a source of moral obligation, and an indicator of conditions that give rise to such obligations, HCOs have an incontrovertible duty to its vulnerable stakeholders. Power and authority demand moral responsibility, and the HCO is a wellspring of both. Children are inherently and conditionally vulnerable. "They need care not only to survive but also to develop their basic physical, intellectual and emotional capacities,"[98] and are entirely dependent, albeit often temporally, upon the authority and power of others to decide most matters for them.

The most common metric of vulnerability within healthcare is the autonomy of the individual; specifically, assessing the competence and capacity to give informed consent.[99] However, an autonomy-based understanding of vulnerability alone is too limiting because vulnerability is contextual. The taxonomy of contextual vulnerability looks to the types of vulnerability according to the circumstances, surroundings, environments and other related factors affecting the individual. Representative factors include institutional vulnerabilities, such as those experienced by prisoners. Deferential vulnerability, which considers gender, race or socioeconomic contexts, as well as medical, cognitive and communicative vulnerability.[100] Contextual vulnerability considers more than the intrinsic characteristics of the individual; it considers the contexts in which they find themselves.[101] This section explores, through the lens of pediatric research as a contingent vulnerability, the contextual vulnerability unique to children with HIV, victims of abuse and maltreatment, and children with special cognitive and developmental disorders. Because healthcare and clinical research are relational, the significance of interpersonal and social relationships and the influences of authority figures such physicians, researchers and IRBs, legal proxies and other caregivers, underscore the need for relational ethics.

4. C. 1.   Children with HIV

Human immunodeficiency virus (HIV) is a virus spread through the exchange of certain body fluids that attack CD4 cells, also known as T-cells, which support the body's immune system and help it to fight off infections. Unlike other viruses, the human body cannot fully rid itself of HIV; therefore, once a person acquires the virus, they have it for life. Over time, if left untreated, HIV outnumbers and destroys the CD4 cells, rendering the body susceptible to other infections; particularly opportunistic infection-based cancers. When these infections overpower the immune system, it is an indication of their progression towards the final stage of HIV, or acquired immunodeficiency syndrome – AIDS.[102]

Although there is no cure, antiretroviral therapy (ART) can significantly reduce the viral load – amount of HIV present in the body's blood – to amounts that are virtually undetectable thereby preventing further transmission of HIV. Although ART has greatly reduced HIV prevention and management and has contributed to a 48% reduction in AIDS-related deaths, it "does not remove replicative HIV from the body and is not a cure"[103] In order to maintain the reduction in viral load and transmission prevention, ART must be administered for the life of the patient with HIV. In the absence of cure, HIV remains a chronic disease carrying a devastating prognosis in its active stages.

Approximately 37.9 million people worldwide live with HIV;[104] including 1.8 million children under 15 years-of-age. Children and youth can acquire HIV through perinatal, or mother-to-child transmission (MTCT), through sexual contact, or through other non-vertical/nonsexual encounters such as unsafe intravenous drug use,[105] and blood transfusions. Ninety-percent of pediatric HIV cases occur from MTCT either in utero, during labor and delivery, or postnatally through breast-feeding.[106] ART administered during pregnancy has

resulted in significant reductions in rates of perinatal transmissions, and has improved morbidity and mortality rates. Despite the significance of ART, HIV is a chronic infectious disease in need of a cure. HIV cure research seeks therapeutic interventions to control or eliminate HIV such that further medical interventions are unnecessary to maintain health.[107]

HIV-infected children are contextually vulnerable. At one time, they were not expected to live past childhood. However, with longer lifespans today, children and young people growing up with HIV face considerable challenges to their physical and mental health as well as developmental processes.[108] Although adolescence is a time of high risk generally, those with HIV can be particularly susceptible to psychosocial challenges as they face not only developmental vulnerability, also HIV-related stressors.[109] Whether HIV was acquired prenatally or behaviorally, distinctive features characterize the experience of learning to make sense of and live with a communicable and highly stigmatized infection during childhood and adolescence."[110] The stigma associated with HIV infection also raises one of the most controversial matters in pediatric HIV; that is, determining if and when to disclose the HIV status to the affected child.

The presence of HIV is most often attributed to stigmatized behavior such as high-risk sexual activity, intravenous drug use, and same-sex sexual behavior. Because the majority of HIV-infected children acquire the virus through MTCT, disclosing the infection often unveils other family secrets such as paternity, socioeconomic status, patterns of parental sexual behavior, and drug use.[111] These consequences compete with the public health risks of non-disclosure. Children who are unaware of their HIV serostatus can unwittingly engage in behaviors that create risks. Risks from non-compliance with medication – the purpose of which they don't understand, to risky sexual behavior and substance use, to the potential for transmitting ART-

resistance strains of the virus as a result of such behavior. Notably for this dissertation, children who do not know they are infected are unable to participate in HIV cure research studies.

Failing to disclose their perinatal HIV infection to them exacerbates the child's vulnerability. Currently there is very little published research to evaluate the most appropriate time and the psychosocial effects of HIV disclosure or non-disclosure on the child. However, practitioners confront disclosure issues with great frequency, and there is some clinical consensus on recommended guidelines.[112] Although, Sabharwal, Mitchell and Fan contend that recommendations alone are not enough to encourage disclosure. Considering their emotional, psychological and cognitive development, HIV-infected youth must be aware of their serostatus, regardless of parental desire to delay disclosure.[113]

To that end, HIV-infected children are subordinate to the authority, power, and competing interests of caregivers upon whom they are dependent. Their power, and this dependency mandates that parents, caregivers and providers have a moral duty to provide physically and emotionally supportive environments for children and adolescents with HIV. Such duty entails comprehensive consideration of the dynamic cultural, social, familial and emotional contexts these children experience, as well as the context of their relationships with these authority figures. Accordingly, Marhefku, Turner, and Chenneville advocate for research to better understand "[t]he antecedents, processes and outcomes of disclosure to children.[114] Ethically enabling all appropriate species of research on these contextually vulnerable children must be reconciled within their unique environments. Relational ethics recognizes the interpersonal contexts; its application is essential to addressing the contingent vulnerability of this distinct pediatric population, and the research involving them.

According to the goodness-of-fit (GFE) model of relational ethics, the vulnerability of the child is considered beyond just her age and capacity. Ethical procedures assess the goodness-of-fit between clinical context of treatment and research, and the child's development, which includes caregiver and parental comprehension, their personal values, and cultural norms.[115] The GFE model focuses on collaboration between the clinician, the investigator, the families and the child, and is relevant to all aspect of clinical treatment and research, including informed consent and considerations of capacity to understand. GFE shifts the judgement "[a]way from an exclusive focus on assumed child or guardian vulnerabilities to an examination of the clinical or experimental setting that can reduce or facilitate informed choice."[116] It requires an awareness of cultural values, as well as "[h]ow HIV stigma is differentially distributed across social groups."[117]

Because of dearth of available research on HIV-infected children, the goodness-of-fit framework necessitates an independent effort on the part of the ethically accountable physician and researcher to understand the relational dynamics of this vulnerable stakeholder group. Rahill, Joshi and Lescano prescribe professional and cultural training and education to help the healthcare professional understand the impact of culture and personal values on the child and their caregivers. In addition, "Education and training can also help clinicians and researchers develop a clearer understanding of their own cultural beliefs and values in relation to the multiple identities that a racial, religious, ethnic, disabled or sexual minority youth who is also HIV positive may be experiencing."[118] Such cultural humility is an essential component of moral accountability vis-à-vis the needs of vulnerable children, as further illustrated by those who are victims of abuse.

4. C. 2.   Child Maltreatment

Intentional harm to children is not a modern day phenomenon. Evidence of infanticide, abandonment, beatings, terrorization, and child sexual abuse is seen as far back as the 9th century B.C. Children typically occupied the lowest social strata in ancient times, and their maltreatment was considered rather unremarkable. The perception that children were impediments whose existence placed strains on society extended into Elizabethan England. Social policies were designed to protect society from vagrancy, idleness and other delinquencies attributed to children.[119]

It wasn't until the late 19th century that the consequential story of Mary Ellen Wilson brought the reality of child abuse into the public arena. Because there were no relevant laws protecting children, 8-year-old Mary was rescued, according to animal cruelty laws, from horrendous physical abuse at the hands of her foster parents. Her suffering helped illuminate the need for public attention and legislation.[120] Over the next several decades, child abuse centers as well as state and federal child abuse advisory boards emerged, establishing the basis for a child protection system in the U.S.[121] Albeit imperfect, the system established civil and criminal protections for maltreated children. As the evolution of child abuse protection efforts intersected with the expansion of medical research, hyper-protective concerns for children isolated them from meaningful research. Despite the general dearth of research, studies that were conducted introduced compelling evidence of the short- and long-term effects of maltreatment on children.

Although legal definitions of *child maltreatment* and abuse generally align with the specific provisions of individual state penal codes and statutes, this dissertation adopts the definition provided by The Centers for Disease Control and Prevention (CDC); because it is comprehensive and universally recognized. Throughout this dissertation it is used

interchangeably with the term *child abuse*. The CDC defines child maltreatment as "[a]ny act or series of acts of commission or omission by a parent or other caregiver that results in harm, potential for harm, or threat of harm to a child."[122] Child maltreatment recognizes four main types of abusive acts: physical abuse, sexual abuse, emotional or psychological abuse, and neglect.[123] Each type identifies specific harms such as beating, shaking, abusive head trauma, scalding and poisoning, sexual contact and exploitation, blaming, intimidating, degrading and isolating, and failure to provide for or supervise a child – to name just a few.[124] According to the CDC definition, and consistent with most statutory frameworks, only a caregiver can perpetrate maltreatment. Acts and injuries by all others are considered criminal assaults and/or batteries.[125]

Findings from early research on child and adolescent development revealed that girls who were sexually abused reported having more instances of gynecological problems, persistent sleep issues, obesity, cognitive challenges, HIV risk, and early puberty, than non-maltreated girls.[126] "Neglect, the most prevalent type of child maltreatment, is associated with restricted growth of the corpus callosum, dental disease, failure to thrive, and a variety of mental, emotional and behavioral impairments among children."[127] "Adults who were mistreated in childhood are at significantly greater risk of experiencing serious illness and premature mortality from a variety of conditions, including drug/alcohol addiction, cancer, lung disease, severe obesity, heart disease, asthma and liver disease."[128] The consequences of child maltreatment trauma can develop across the child's lifespan. However, not all children who experience maltreatment necessarily develop physiological and mental health problems. A child's resiliency to such problems can be enriched through protective factors such as familial and social support mechanisms.[129]

Child maltreatment is a serious public health matter, and "[t]he consequences…are pervasive, spanning multiple domains of functioning.[130] According to CDC reporting, in 2015 there were 4 million reports of child maltreatment involving 7.2 million children in the United States. As this rate increases, its prevalence and recognition as a childhood illness requires research to improve its diagnosis, treatment and prevention.[131] To that end, Guttman, Shouldice and Levin aptly contend that "there is a moral duty for researchers to be active in this area."[132] The ethical and legal considerations, however, associated with child maltreatment research, are challenging, arduous and present multiple unique dimensions because of the nature of the *illness*. The depth of ethical issues ascribed to child maltreatment research is well beyond the scope and limits of this chapter. Rather, it calls attention to the moral duty of the HCO, through its accountable physicians and other professionals to recognize the necessity and value of child maltreatment research as multi-stakeholder concern, and the methods to address the challenges. Most of the research in child abuse will result in a benefit to the common good of society, rather than to the child participant. In fact, the mere disclosure of the abuse could result in more harm to the child. Therefore, not unlike risks from disclosure of HIV-infected children, moral accountability requires that "studies be designed to protect against and avoid further harm and trauma" from the disclosure of abuse.[133]

Ethical research practices preclude intentionally inducing injury or illness without valid consent, and generally require examining the illness in its naturally occurring setting. The nature of child maltreatment research, which is in effect injury research involving children who are contextually vulnerable, presents risks that are per se sufficiently high. Although injury research typically involves children who have been identified through case reports, studies on prevention and intervention strategies may reveal undetected incidents of prior, current or imminent

abuse.[134] Child maltreatment is trauma that is unique because it is non-accidental. The intentionality of the parent or caregiver perpetrator, who is most often the logical proxy for informed consent based on the presumption that they have the best interest of the child in mind despite abusive evidence to the contrary, is an ethical paradox.[135]

Even if the informed consent requirement is waived in an attempt to protect the maltreated child from additional trauma, child maltreatment research presents ethical challenges to the researcher and clinician. The risk of causing distress to a child during an interview process, appropriately handling the discovery of abuse that was never reported, and identification of perpetrators[136] are just a few of the unique challenges of this species of research. The relational ethics model of pediatric research may palliate these challenges. One way is for healthcare professionals to recognize the centrality of culture, cultural influences and rights to cultural autonomy in their work with this vulnerable population.[137]

Just as it applies to the goodness-of-fit approach to HIV research, culture is important in all aspects of detection, prevention, intervention and treatment of child maltreatment.[138] Because culture influences all dimensions of child-rearing as well as child development, and maturation into adolescence and adulthood, it is an essential component of relational ethics in child maltreatment research. Cultural considerations will help to determine how resilient the child is to potential harm, how the child's family setting may influence the abuse as well as the interventions employed, and the extent to which culturally influenced social systems may protect, or expose the child to greater vulnerability."[139] Thus, researchers and clinicians working with abused children must possess cultural competence as well as cultural literacy – an understanding of the perspectives and experiences of the victims and their parents/caregivers - in order to adapt the research and practices accordingly."[140] An ethically accountable HCO is duty

bound to provide methods for understanding the role of culture within the child's ecosystemic framework to its researchers, clinicians, caregivers and children. The moral duty of the HCO to mitigate risks to vulnerable children in research is further examined through the lens of those with special cognitive needs.

4. C. 3.   Children with Intellectual and Cognitive Disabilities

Developmental disability is a term that broadly describes intellectual, or physical impairment, or a combination of the two that generally manifests before the individual reaches age 22. A developmental disability likely continues indefinitely and results in substantial limitation of life activities such as self-care, receptive-expressive language, self-direction, learning, and capacity for independent living.[141] "Intellectual disability (ID) encompasses the "cognitive" part of this definition, that is, a disability that is broadly related to thought processes…It is characterized by significant limitations in intellectual functioning (reasoning, learning and problem-solving), and in adaptive behavior."[142]

Intellectual disability includes those congenital cognitive disorders that are likely to be diagnosed in early childhood such as Down syndrome, Fragile X syndrome, and autism.[143] Today, the term intellectual disability is often used independent from the other disorders to replace the condition previously known as mental retardation. Nevertheless, unless otherwise specified, references to intellectual disability used throughout this chapter will mean cognitive disabilities and related impairments.

As Leslie Francis aptly asserts, intellectual disabilities are complex and multi-faceted and their attendant impairments vary significantly from person to person.[144] Some children with intellectual disabilities may have difficulty with abstract reasoning and impulse control.

Intellectual disability challenges the child's ability to make right judgment. They often experience problems with social adaptation rendering them gullible and naïve, placing them at risk for victimization, and increasing their dependency on others.[145] Because many intellectual disabilities lack physical manifestations, the child's vulnerability may be invisible. The presumption of 'normalness' can compound the risk of victimization.

According to the Centers for Disease Control and Prevention, the prevalence of children diagnosed with any form of developmental disability increased between 2014 and 2016 from 5.76% to 6.99% [146] respectively; ranging from mild speech and language impairment to more severe intellectual disability and autism. Specifically, diagnoses of autism, or autism spectrum disorder (ASD), have appreciably increased since 2000; such that today, 1 in 59 children will be diagnosed with one or more of autism's spectrum of pervasive disorders.[147] "The most recent Global Burden of Disease data estimate that in 2015, there were 3.6 million children aged 1-9 years living with autism and more than 15 million living with idiopathic developmental intellectual disability."[148] In addition to learning the reasons why more children than ever are being diagnosed with ASD, there is much more to discover about this complicated disorder specifically, and intellectual disabilities generally. Aside from understanding the causes and risk factors, early and accurate identification and diagnosis of a child's impairment can help to mitigate adverse effects to the child as well as those experienced by family and caregiver stakeholders.

In the wake of Willowbrook, much attention has been paid to protecting children with intellectual disabilities because of their vulnerability.[149] However, bioethicists, researchers, and disability advocates, have argued that excluding persons with intellectual disabilities from research is unfair, may be too stringent, and may be equally harmful to them. For instance, it is

widely understood that early detection and evidence-based interventions provide the best opportunities for children with ASD to develop and flourish.[150] Interventions such as speech and occupational therapy, as well as emotional adaptation training allow the plasticity of the young child's brain to change and have a better chance of developing enhanced potential. Denying evidenced-based research opportunities designed to discover effective and customized interventional therapies can thwart these chances. Also, precluding children with intellectual disabilities from participation in research denies family members and caregivers, broader insight and understanding into treatments and interventions that provide assistance to them, and aid to the child.[151]

Children with cognitive disabilities are contingently vulnerable in that they are dependent upon the authority and control of others. They are also contextually vulnerable to the environment, conditions, and relational experiences unique to them vis-à-vis their disorder. Understanding the contextual world of a child with a cognitive disability is frequently obfuscated by communication and other sensory barriers. As such, ethical research entails enlisting the perspectives of the child in understanding their world, and the influences which shape it. According to Cuskelly, most research literature is devoid of the child's perspective. Participatory research, however, goes beyond merely including children. It contends that to fully understand the contextual nature of a child's vulnerability, the child ought to participate in the actual design and execution of the research. There is growing evidence and acceptance of the participatory approach to research with children with intellectual disabilities.[152]

Unpacking this further, participatory research illuminates the goodness-of-fit model of relational ethics. Through collaboration and engagement with the child and their authority figures, healthcare professionals can identify and acknowledge how the child's perspectives are

tied to and shaped by their relationship with others. For example, although expectations of reciprocity and dependence are important in nearly all human interactions, those expectations are indispensable cornerstones in the life and experiences of a person with an intellectual disability.[153] Moreover, unlike children with HIV, or those who are maltreated, the dependencies of the child with intellectual disability do not evolve gradually from the onset of the disorder. Rather, most children with intellectual disability, especially autism, have never experienced any other way of being,[154] or understanding of themselves. Therefore, the way these children see the world and themselves in relation to it, are attitudes and frames of reference that must be understood and appreciated in order to effectuate ethical research on them. In addition, it will help to ensure necessary clinical advances exist to address the population health of this stakeholder community.

4. D.   Ethical and Legal Strategies for Managing Pediatric Obesity: A Moral Duty

The concept of *population health* refers to an "understanding of the epidemiology of a particular population and aligning a community's healthcare resources to not only treat illnesses …but to keep the population healthy."[155] Managing population health, particularly with respect to vulnerable populations, requires accountable leadership who possess a moral commitment to the sustained health and lifelong fulfillment of patients and communities served by the HCO.[156] Principles of stewardship, normative stakeholder theories, community-oriented health programs, and the duty to provide for the common good dictate an urgent commitment from HCOs, providers and even policymakers to disrupt this environment and act to protect this at-risk population. The remainder of this chapter addresses a specific slice of this population health sphere. It considers with some depth, the ethical and legal strategies for accountable leaders to prevent and mitigate the psychosocial and physiological effects of pediatric obesity on children.

Fifty years ago, the sentiment that *big girls don't cry* was intended to depict the fortitude and mettle associated with strong, resilient women.[157] This image of indefatigable women who were too big in spirit to be injured or reduced to tears is rarely uttered in polite society today. Reason being, that today big girls *do* cry, and so do big boys particularly when they are obese. The 21st century is shaped by its cultural obsession with obesity. For that reason and a number of others, children cannot sustain a relationship with obesity. Rendering them vulnerable, obesity affects a child's emotional, social, physical, academic and psychological functioning; providing them every justified reason to cry.

These factors uphold childhood obesity as a critical public health threat. It is positioned between the need for regulated behavior modification, and the respect for the child's individual self-determination. It also sits amidst the competing interests of government and physician intervention, and respect for parental sovereignty in determining what is best for their child physically and psychologically. When obesity creates a degree of harm to a child that is disproportionate to the benefit conferred by the competing interests, and actions or inactions exacerbate and negative consequences of obesity, ethical concerns arise.[158] Something or someone must intercede on the child's behalf. This chapter addresses the moral duty of the ethically accountable HCO to this public health threat and its vulnerable stakeholder group. It outlines the ethical justification for HCO intervention to address the disproportionate psychosocial and physiological harms of childhood obesity through care ethics, and the invocation of a modified common law doctrine of *parens patriae*.

4. D. 1.   Pediatric Obesity as a Public Health Threat

Even though one-third of the world's population goes to bed hungry each night, *over-nutrition* – that which occurs when too many calories and excess nutrients and food components

are consumed vis-à-vis suboptimal energy expenditures – is rampant in the United States. Barring some intervening metabolic disorder, over-nutrition nearly always results in excess levels of fat tissue and bodyweight. Calculated against an individuals' height, the resulting body mass index (BMI) is the standardized yardstick used to determine whether an individual is obese. American's are among the top ten fattest people in the world, and its children are among the largest.[159] Although there is some dispute as to the outer limits of bodyweight or BMI necessary to constitute obesity, it recognized that childhood obesity is a biological reality that has wide-ranging societal implications.[160]

The current state of the obesity crisis in the United States is most obviously measured in raw statistics. Since 1980, childhood obesity rates have tripled to the point that close to one-third of children over age 2 are overweight or are obese.[161] Approximately 4% of U.S. children are considered extremely obese; a figure which outpaces the number of children with cancer, HIV, cystic fibrosis and juvenile diabetes combined.[162] Even though the numbers associated with childhood obesity can be calculated in various ways, all available data shows a dramatic and accelerated rise. More than a mere descriptive word associated with a BMI calculation, obesity is a multi-factoral disease.[163] It has wide-ranging genetic, societal and behavioral causes that begin in childhood and left unabated can continue into adulthood. This characteristic renders it a two-stage disease.[164]

One of the most pressing, and least obvious concerns of this very visible disease to emerge is the impact that continual rises in childhood obesity will have on the adult disease rate going forward. U.S. statistics show that a child who was obese during the first and second year of life stands an 8% chance of becoming and obese adult, while a child who is obese between the ages of 10 and 14 has a 70% chance. The rates are even higher if the child has at least one obese

parent.[165] Because it is a two-stage disease, not only does the physicality of obesity accompany the adult, the adverse medical and psychosocial health outcomes also negatively impact adult lives.

All of this presupposes that the child can even expect to live to adulthood. For the first time since the 1900s, when public health initiatives first began to make significant and measurable improvements in pediatric health, life expectancy for children is eroding because of obesity. According to recent statistics, children can no longer expect to live longer than their parents, due to the effects of adult diseases such as Type II diabetes and other diseases that are tied to childhood obesity.[166] Childhood obesity has been shown to lead to higher death rates in middle age due to, for example, the 3 to 4 time increase in risk of heart attack, doubling the risk rate from cancer, and 2.5 times the risk of death from respiratory disease.[167] Moreover, roughly 36 percent of adults in the United States who are twenty years or older are obese, and 6.3 percent of them are considered extremely obese. It is estimated that 300,000 deaths annually are linked to obesity.[168]

The societal costs of this obesity explosion are both real *and* indirect. The real costs are often the most startling and attract wider audience interest because they represent comprehensible dollars and cents. Lifetime medical costs attributed to normal weight children are approximately $12,900 per child however they are reported to exceed $19,000 in the case of an *obese* child.[169] Many of the direct medical costs are associated with excessive doctor's visits and medication. According to recent study estimates, lifetime medical costs can exceed $14 billion when they are multiplied by the present number of obese 10-year-olds in the United States. A number of these additional real costs won't be realized until much later when the child begins to experience health and behavioral conditions that are tied to childhood obesity.

Although more inexact in its calculation than direct costs, indirect costs can also have far-reaching impacts in terms of child absenteeism. Children who experience increased absenteeism from school due to obesity related medical conditions can also disrupt the parent's life through their own absenteeism from, and lost productivity while at work.[170] As such, obesity's impact is so diverse and dramatic that the World Health Organization Consultation on Obesity's prescient report in 1997 determined it to be a highly neglected public health problem with a potential impact as great as that of smoking.[171] Since this conclusion was drawn, obesity as a public health threat has gained the same recognition as anti-tobacco and related legislation, especially with respect to its influence on children's behavior. These ground-breaking interventions were fueled by, among other things, vocal appeals to change the influences that sustained such harmful behavior.[172]

4. D. 2.   Children Are What They Eat?

There are at least 200 genes known to factor into a person's weight, and although genetics do play a limited role in obesity, researchers and experts adhere to the position that obesity is largely controlled through behavior. With the exception of certain known metabolic conditions for which obesity is a consequence, along with certain inheritable statures and body shapes, the fundamental causes for the obesity epidemic are behaviors and lifestyles, especially diets.[173] Current research suggests that as much as 80% of children in the United States have diets that are considered poor or in drastic need of improvement, amplified by behaviors which are strongly dominated by negative societal influences.[174] As a behavior-induced disease, there are also a number of environmental factors that influence not only the behaviors, but the environmental changes within which those behaviors thrive.

One demonstrable way in which negative behaviors thrive in response to their environment is in the super-sizing and over-consumption of unhealthy processed foods. Up to a certain age, children will only eat what they are given, and the growing phenomenon of *food deserts* – places where healthy food options are not readily available – leave little if any healthy, obesity-resistant alternatives.[175] In addition to food deserts, Western culture is programmed to consume unhealthy food quickly, cheaply and in mega quantities with scale-shattering consequences.[176]

Further, Warren and Smalley aptly suggest that decreased levels of physical activity have led to a 'lazy-fication' of children. Studies have shown that nearly three-quarters of children have a sedentary lifestyle and do not get the recommended daily amount of exercise. Lazy-fication is amplified by the fact that physical education in public school systems – once an important component of learning – is no longer valued as such.[177]As an obesogenic influence, an inactive child's basic caloric needs have gotten lower without offsetting a corresponding decrease in caloric *intake*.[178] Notwithstanding the tie to obesity, such inactivity is also linked to many other chronic health conditions.

Technology and new societal concerns have fortified the lazy-fication and fattening of children. Nielson recently reported that children aged 2 to 5 spend an average of 32 hours per week – the equivalent of a work week – watching television or playing video games. Children are essentially plugged-into inactivity.[179] Prolonged television viewing impacts numerous health outcomes through its cumulative impact on diet and exercise including obesity and diabetes. For every extra 2 hours of television watching per day, there are 176 more cases of Type 2 diabetes.[180] Simply put, most children don't move around much anymore. They live in a society that largely does everything for them.

Childhood recreation has shifted from that which used to include sustained physical activity, to sedentary computerized technology and social media providing instant gratification. Add to this the fact that, as a means to protect children from predatory threats, abduction and other forms of neighborhood violence, parents no longer encourage unsupervised outside play. Eating used to be a way for children to recharge their batteries. Today however, children no longer have to *spend* calories to *get* them.[181] To promote movement away from lazy-fication, it is first necessary to understand whether these influences are due to environmental factors, individual choices, or a combination of the two.

4. D. 3.   **Obesogenic Influences**

It is well understood that the socio-cultural environment influences body-size preferences, as well as eating and activity patterns. In the United States in particular, much emphasis is placed on possessing an attractive body. An attractive body in that particular societal context equates to thinness. As such, the role that culture and social values assume with respect to childhood obesity cannot be overstated. Cultural influences shape food-related practices in families and broader community settings. Not only is the notion of a well-nurtured body a notion that is culturally shaped, children are exposed to a wide continuum of values and expectations from parents and their sibling/peer groups that effect their ideal of body-size as well as appropriate eating and activity practices.[182] These cultural groups and their values undergird the eating choices that result from individual and environmental constructs.

The causal network of factors leading to obesity is complex and spans many sectors of society including the family, the education system, the food industry, the media, the transport sector, and of course, the government.[183] The presence of multiple factors encourages the dangerous temptation to find fault with one or many of these factors and to assign blame to either

the individual and their choices, or the environment in which these factors reside. Because of their complexity, or perhaps in spite of it, it is not possible to correctly assign blame to any single causal factor to the pediatric obesity problem.

Eating is a social behavior which most often takes place where people spend the most amount of time. At least for children, that place is traditionally the home. And especially for children, who are particularly susceptible to behavioral influences, observing the eating habits of others within the home is a powerful influence on their own preferences and behavior. It is well-established that the home and the activities that take place within it and the family unit, tend to define the child and his or her behaviors and their preferences. Children learn what they live. Therefore, it is not surprising that the nutrition behaviors and preferences of children and adolescents are closely associated with those of their parents and others within the family unit.[184] Statistics demonstrate that half of the children with at least one obese parent will become obese themselves, and if both parents are obese, there is an 80% chance that the child will be obese.[185]

With respect to the family, the emotional climate of the home and the family unit, regardless of its composition, is typically measured by levels of conflict and cohesion. Research indicates that children who experience a family-centered and emotionally supportive home life tend to engage in healthier behaviors and eating habits. "A common family value is a shared meal time."[186] Children who experience structured mealtimes tend to consume a healthier diet and are less-likely to be overweight. Mealtime becomes a family-centered activity where eating choices and portion sizes are predetermined, controlled and supported.[187]

In contrast, there is some evidence that parents of overweight children were more likely to use maladaptive control strategies and less-supportive behaviors than those who parent non-overweight children. Admittedly there is, however, relatively little documented information

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concerning parenting practices of overweight children. And it is difficult to know whether the parental behavior or the obesity came first. Nevertheless, family conflict and lower levels of parental warmth and engagement are often associated with poorer adherence to treatments for other pediatric chronic medical conditions; therefore it is not unreasonable to draw a nexus to childhood obesity.[188] Still, additional environmental, societal, and individual factors bear directly upon obesity in children.

For example, "The timeline for the accelerated rates of childhood obesity coincides with increased numbers of both, or single parents, participating in the workforce."[189] Two-thirds of children under the age of 6 in the United States spend some time in child care and are likely to experience some if not most of their daily calorie consumption and expenditure in that setting.[190] Child care centers influence nutrition and eating practices. But as a regulated industry, child care services are the purview of the state, and recommendations to create positive nutritional environments are largely a matter for the legislators. Nevertheless day care centers and schools are responsible for children outside of the home and family, and represent another place where children spend a significant portion of their time.

Peer influences emerge as another factor in the prevalence and prevention of obesity, "and the school setting is where children learn many social behaviors."[191] What is taught and offered to children in these venues plays a demonstrable role in influencing obesity and can similarly champion an anti-obesity environment. It is critical that obesogenic environments continue to be identified and attempts to create and sustain such anti-obese environments, and the promotion of healthy behavioral influences push on. Such attempts must be fueled by a comprehensive understanding of the long-term consequences of pediatric obesity.

4. E.   Obesogenic Vulnerability

It is widely understood and accepted that untreated obesity-related medical conditions will threaten the life of a child if they are sufficiently severe; particularly when the conditions are in the later stages of deterioration. Physical manifestations such as Type II diabetes, hypertension, asthma and sleep apnea can have devastating and debilitating effects well into adulthood. It is important to note that even if the child's physical health is never directly in danger, the restrictions on mobility and other normal childhood activities may negatively impact the child's psyche. As such, while long-term medical consequences of pediatric obesity are well-recognized, the less obvious but highly destructive and indelible consequences of pediatric obesity, and clearly the most pervasive ones in Western societies, are its psychosocial costs.[192] Because of the stigma, shame and isolation of obesity that often follow the child into adulthood the psychosocial costs of pediatric obesity are more chronic over a child's lifetime than the physiological.[193] Still, the physiological effects of childhood obesity are often irreversible and can, not only shorten a child's life expectancy, but interfere with their ability to flourish; thereby punctuating the significance of contingent vulnerability, and underscoring the moral duty of the HCO to intervene.

4. E. 1.   Physiological Harms

With the possible exception of Type I diabetes mellitus, children are presenting with many obesity-related adult diseases that have never been seen in children before. Because of a paucity of pediatric research generally, adult diseases present in children are difficult to manage and equally difficult to detract from accompanying the child to adulthood. Moreover, many pediatricians are not adequately trained nor prepared to treat children for some of these adult-

oriented conditions such as cardiovascular disease, sleep apnea, and hypertension.[194] Type II diabetes mellitus – which is often referred to as *adult onset* – presents another such example.

There is no known cure for Type I, or *juvenile diabetes*. It is an autoimmune disease in which the body no longer produces insulin, and survival depends upon a lifetime commitment to strict diet control and insulin dependence. Causes have been attributed to genetic predisposition as well as exposure to certain viruses, and while a child with Type I diabetes may become overweight during the course of the disease, obesity is not typically a precursor to the disease. On the other hand, there are many factors that contribute to and increase someone's risk for Type II diabetes, with obesity representing such a significant factor that they have been described as "twin epidemics."[195]

The more fatty tissue a person has, the more resistant the person's cells are to the sugar controlling effects of insulin.[196] A team of researchers from the Institute of Molecular and Cell Biology recently revealed that an important protein responsible for regulating insulin in the cells is lacking in obese individuals. The gene code for the NUKE protein is inactive in individuals who have high-fat, calorie dense diets. The absence of NUKE leads to insulin resistance which impedes the body's ability to regulate glucose effectively which increases blood sugar levels and leads to diabetes. The NUKE protein reappears when high-fat diets are eliminated.[197]

Because of the high rates of obese children, many children are being diagnosed with Type II diabetes rather than Type I. Because Type II diabetes will often go into remission when body weight is brought into normal range, and losing weight can completely prevent its onset, Type II diabetes is most often both curable and preventable. To that end, with an emphasis on diet and exercise, many pediatricians must adopt new treatment protocols for their young patients with diabetes.[198]

Similarly, obese children often experience *cardiovascular adaptation*, which means that the heart has to adjust to the differences in body weight, oftentimes by working harder, thereby impacting the way it functions. Pericardial fat can build up around the heart. As such, overweight adolescents have reported decreased heart function because their increased body mass places so much strain on their heart.[199] As the heart is pushed to function harder, high blood pressure places compounding strain on the circulatory system which forces *it* to work harder thereby adding strain to the body's blood vessels. Plaque builds up in the arteries of overweight children by the time they reach their 20s. The body gradually accumulates all of the exposure to the harmful cardiac influences which then sets into motion a cascade of bodily processes and reactions that lead to the development of cardiovascular disease.[200] Because of the omnipresence of these trigger points, being an overweight child with an overburdened cardiovascular system is practically a guarantee of irreversible cardiac disease. As science examines the reasons why more than a half million people in the United States die each year from heart disease, it is necessary to examine what was behind the curtain that *really* killed them. Losing weight and perhaps more importantly, preventing obesity in the first place, is shown to dramatically reverse conditions such as Type II diabetes, hypertension and certain heart malfunctions.

Given the emphasis on weight loss, requests for weight-loss surgeries for children are increasing. And since the average age of a typical bariatric surgery patient is 40-years, these physicians face the same dilemmas as the pediatrician. "Physicians trust that morbidly obese adult patients can put all known risks and complications into perspective before agreeing to a bariatric operation. It is not clear that pediatric patients and their families have the same perspective."[201] Bariatric surgeons are not always trained and adequately prepared for the pediatric patient. Additionally, the long-term consequences of bariatric surgery on young

children, such as the need for postoperative lifelong compliance with diet and behavioral modifications, are not well understood.

Understanding the linkage between obesogenic influences and behaviors that are quite literally killing children and imposing changes to those factors is the charge of parents and other sources of authority who are able to mandate change through control of the environments. This charge gives them unprecedented power to reverse or prevent illnesses that could impact the child for the rest of their life. These changes can not only prevent obesity-related illness but can help the child's mind consciously or unconsciously adapt, in a healthy way, its body to its social environment. This psychosocial balance is often threatened by obesity-related consequences such as bullying, victimization, damaged self-esteem and even depression. To successfully change these environments, these psychosocial factors must be understood first within the family and peer environments and then more closely within the individual's settings.[202]

4. E. 2.   Psychosocial Harms

Peer relations are central to a child's healthy social and emotional development. Most everyone wants to be liked by those within their social circle. Peer acceptance and popularity are more often than not the litmus tests for a child's healthy self-perception. Children who are a typical weight and body size are most often the most popular. Therefore, all children, regardless of their weight and size, are abundantly aware of the importance of bodyweight and are introduced to that preference practically from the moment peer socialization begins; as early as age 5. They see it, discuss it, and ridicule it. They may try to hide their own body if they are at all overweight, and draw attention to the size of others' if they are not. But obesity, unlike many other diseases, is impossible to hide. Size is one of the most salient features of a person and is often the basis for premature judgment and dislike.[203]

Not unlike their adult counterparts, non-obese children often view overweight peers as less-disciplined, lazy, self-indulgent and inherently less popular. Research reveals that one of the most immediate consequences of being overweight is the differential treatment overweight children report receiving from their peers *and* society at large.[204] These consequences are the result of *weight bias,* or "the inclination to form unreasonable judgements based on a person's weight…and stem from negative attitudes and beliefs."[205] Simply stated, the peer environment is not accepting of obesity.[206] Problematic peer interactions are one of the most notable hallmarks of the psychosocial correlate of pediatric obesity. Name-calling, teasing, bullying and other forms of victimization are significant social problems affecting obese children. They rarely concern non-obese children or adolescents. Differential treatment is both damaging and devastating to a child's self-perception. However bullying can be the cruelest and most tragic obesity-related consequence.

The act of bullying is associated with the intentional harassment, aggression or threats towards someone perceived to be weak, vulnerable or defenseless. There are as many forms of bullying as there are bullies. And the incidences of bullying range from physical abuse to assaultive verbal humiliation to detrimental gossip.[207] Cyberbullying and social networking provide a practically infinite audience that exponentially expands the reach of a bully ensuring that the brutality is unending.[208] Regardless of its form, all bullying evokes overwhelming and often paralyzing fear and intimidation.

Nearly 25% of boys and 17% of girls are bullied. These statistics have been tied to increases in victim substance abuse and suicide. In fact a recent meta-analysis demonstrated that children who are bulled are more than twice as likely to have suicidal ideations and to make suicide attempts as their peers who are not bullied.[209] The most common motivator for bullying

is physical appearance – dominated by body size. Overweight children are 50% more likely to be bullied than typical-weight children. Sadly, many children report being harassed about their weight from their own families.

Bullying generally is a long-term and consistent issue. If a child is bullied once, their chance of continual bullying increases, and the damaging consequences of bullying are compounded and intensified. This unrelenting harm to a child helps to explain why victims of bullying have higher rates of anxiety, bed-wetting, depression, psychosomatic symptoms, eating disorders, lower academic achievement,[210] and of course, fewer friends and more relationship issues.[211] Withdrawal and disassociation are common traits of a bullying victim. As such, children who have been bullied because they are obese suffer harm from the general effects of being overweight compounded by the humiliation of being bullied. Because of its two-staged characteristic, the duality of consequences associated with persistent obesity-related bullying can lead to life-long struggles with mental illness.

In response to this pervasive treatment, and in the absence of contrary evidence, many, if not all overweight children begin to believe the differential descriptors and preconceptions about themselves. And, although longitudinal studies are necessary, evidence shows that the negative attitudes that obese children hold about themselves and their physical appearance cyclically invite further stigmatization and rejection.[212] The obese child who is bullied perceives themselves as diminished and unworthy, thereby reinforcing the preconception that they are weak and unworthy, which invites and encourages more abuse. Cumulatively, this lays the groundwork for pediatric psychological disorders, and further increases the risk for additional psychological challenges into adulthood.

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4. E. 3.   Perception Becomes Reality: Internalizing the External

Health-related quality of life ratings, or HRQOL, are assigned to the physical, emotional and social well-being of a person based on their own internal perspectives. Largely because they come to believe and accept the stigma attributed to them through their obesity, children with low HRQOL tend to be those with the highest body weight. Children with low HRQOL most often exhibit internalized symptoms such as depression. Conversely and further validating the argument that obesity is a 2-stage disease, obese adolescents who had the highest level of depressive symptoms were shown to persist in their obesity over time.[213] It is tempting to presume that an obese child would seek to escape the negative internalizing that accompanies obesity by modifying their environment, escaping the damaging influences, and losing weight. However, it is never that simple.

The relationship between obesity and psychiatric conditions, the current treatments and related studies point to higher rates of somatoform disorders – those disorders which convert emotional distress into the physical symptoms of an illness. It is now widely held that psychosomatic conditions such as undiagnosed pain and mood and anxiety disorders are attributable to obesity. In addition, most anxiety symptoms are believed to be related to the corrosive negative impact obesity has on a child's self-esteem; another demonstration of the correlation between poor body image and psychiatric comorbidity.[214]

The cyclical characteristic of obesity in which psychosocial and psychosomatic conditions are actually bolstered and sustained by the obese child's self-image and perception leads to speculation as to whether or not obesity may actually result from other currently classified psychiatric disorders. However, many of the psychiatric disorders associated with obesity appear as adaptive responses. That is to say, negative coping strategies such as substance

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abuse, avoiding exercise out of shame or embarrassment and eating in private are mental health consequences closely tied to being overweight.[215] In other words, depressed children and adolescents may eat in response to stress, and those eating patterns and depression-induced inactivity may lead to overconsumption. This overconsumption typically continues long after the depressive disorder has remitted.[216]

Moreover, children with psychiatric conditions are more vulnerable to other social factors that contribute to obesity such as abuse, neglect and non-family centered home life. Research has shown that neglected children are nine times more likely to be obese that children who are properly cared for.[217] For children who have suffered some form of trauma or neglect, eating serves as a means of self-affectation and also as compensatory mechanism to cope with neglect and feelings of low self-worth and self-esteem resulting from automatic thoughts about themselves.

Schemas are mental codifications about the way the world works based upon repeated personal experiences beginning with childhood, and they form experiential rule books of life. Schemas result in automatic thoughts that are extensions of the rule book that become so engrained that those who form them don't even realize they have them. Negative schemas are called upon whenever critical events take place. For example, a child who is continually frightened by a neighbor's ferocious barking dog will likely associate fear with all dogs of that particular breed, without considering evidence to the contrary. As such, the schemas of overweight children about how the world works may be formed at time when they are being ridiculed and ostracized.[218] An obese child's negative automatic thoughts can trigger self-deprecating beliefs that they are ugly, unworthy and un-loveable. These beliefs can trigger harmful coping strategies such as turning to food or harmful substances, thereby renewing the

cycle again and again.[219] And, because they are automatic thoughts and beliefs, they do not end after the person loses weight. Negative schemas live on – often it the form of pervasive psychological disorders.

Not all self-esteem issues that befall obese children have such destructive effects. But, there are equally pervasive aspects of a child's personality that are negatively affected by being overweight, or having been overweight. Shyness, oversensitivity, and becoming easily discouraged when faced with adversity are common personality impacts. Phlegmatic tendencies and adoption of other defensive personality traits such as developing a protective comedic personality – becoming the "jolly fat person" as a protective shield against weight bias – are also common adaptations to the stigma of being obese.[220]

As yet, there is insufficient empirical evidence to understand exactly how growing up obese implicates future personality disorders because obese children have not been longitudinally tracked, and should be for 15 or 20 years to produce a meaningful measure. The psychological distresses of childhood obesity continue as the child matures, and overweight adults are more likely to end up somewhere in the mental health system than non-overweight adults. In addition, it is not surprising that mental health professions actually expect that their overweight adult patients will have more psychological problems than their typical weight patients. Accordingly, more negative outcomes are attributed to overweight patients.[221]

Differential treatment and discrimination continue to accompany many obese people. At this writing, there are no anti-discrimination laws protecting obese children or adults from mistreatment and stigma.[222] For some obese victims of stigma and discrimination, recourse may be sought in the United States by pursuing claims under the Americans with Disabilities Act of 1990 (ADA); even though obesity itself is not a disability, many of the diseases' secondary

conditions are. Aggressively defending obese victims, the Equal Employment Opportunity Commission (EEOC) has successful filed and settled claims against employers.[223] However, the biases that plague obese persons' internal and external personas will most likely continue unabated and proliferate as the numbers of obese children continue to climb. Legal recourse alone will only serve to placate the offense and won't effectuate the root cause – the obesity itself. It is clear that effects of obesity-related victimization and bullying, and the negative attitudes and beliefs are so compelling as to demand ethical intervention strategies to protect the vulnerable.

4. F.   *Parens Patriae*: Parenting the Community

"The determination of who bears specific responsibility for the care of vulnerable others thus needs to be informed by a careful understanding of the ways relationships of vulnerability, dependence, and obligation are socially constituted nationally and transnationally."[224]As a relational notion, vulnerability, according to Mullin means that people are "vulnerable *to* others, both to their actions and their inaction when we need their help.[225] She further asserts that children "are particularly vulnerable to acts and omissions of caregivers charged with significant responsibility for keeping them safe and healthy and for aiding in their physical, emotional, intellectual, and moral development."[226] Somebody must take care of those who cannot yet fully take care of themselves in the face of such vulnerability.

It is from the notion of relational care that the authority to act as a parent emerges. With respect to children, a *social parent* is, according to Mullin, "anyone who is charged with such responsibility, whether a child's biological parent or not, whether paid or not…it is understood in the context of their relationship."[227] The social parent is the embodiment of the relationship between the vulnerable child and the one upon whom they depend. Throughout the remainder of

this chapter, Mullins' social parent theory is in interstitial concept in establishing ethical accountability to those most affected by pediatric obesity and alleviating their harms.

Merely establishing causation is not dispositive to reversing the harms from current obesity trends. As demonstrated throughout this chapter, the psychosocial harms to be avoided include the damaging stigma, permanent emotional harm, and the social rejection resulting from being obese. These are socially constructed harms. As such, these profound social costs along with discrimination of all sorts are significant public health risks that warrant community intervention in executing remediation strategies. As an interdependent unit, it is incumbent upon the community – as a social parent - to consider its impact on obese children in the face of obesogenic influences, and its duty to protect them. The strategies employed must take into account the cultural influences and community values that affect obesity trends.[228]

4. F. 1.   Private Lives Publically Held

Individualism and individual choice and the freedoms associated with them undergird the prevailing ideology in the United States. In conformance with societal norms and generally accepted values, it is widely recognized that a person should be allowed to choose what is best for them. Consequently the ideology of individual responsibility is further reflected in the pervasive view of obesity generally – that the individual and their choices are to blame for their obesity. A person is believed to be what they eat. Despite this belief, because of the social and economic forces which have contributed to and enabled the obesity problem to thrive, an effective solution will not come from the obese individuals' efforts alone. Intervention of a higher sort, directly involving the pediatrician on many levels, must occur.[229]

Childhood obesity is not an example of a personal choice that is worthy of respect or criticism, but rather a public health and societal problem. However, balancing the autonomy of the parent and their right to raise their children their own way, according to their views and values is paramount. Parents have a right to raise their children according to their perceived best interests, and interference against their will is highly controlled and limited to only the most serious cases.[230] However, where the best interests of the child is threatened, and where the choices of the parent endanger a child's life or, in the case of public health, the lives of obese children generally, third-party intervention can be ethically justified.

The polarity between the individual and the collective, or the private and the public view of health is the quintessential tension in public health ethics. Particularly as applied to childhood obesity, it requires a balance between the individual rights and freedoms of the child and their caregivers and the collective needs of the government to promote and sustain a healthy community.[231] This balancing must consider the risks of harm to members of society with and without the intervention, as well as the threat to fundamental rights of people to choose to live unhealthy lifestyles, and the potential for unwarranted intrusion into private lives. Public health ethics must also look beyond the individuals, governments and communities and consider the unique ethical issues that arise from interventions into obesogenic environments - specifically the family unit, and schools.

Understanding and balancing these rights and ethical issues of the child is further nuanced by the considerations of agency and responsibility. Not only must public health advocates and practitioners who are concerned with childhood obesity consider the child, they must determine who has ultimate responsibility for execution of the intervention. Public health

ethics considers the moral duties the government owes to the child and their caregivers, and the community.[232]

A number of theories dominate discourse in public health ethics. But because public health and childhood obesity are value-laden and subject to various social contexts, public health ethical justification cannot rely upon one single dominant theory. It requires a framework from which the principles of the duty to do good and avoid harm, intersect with the individual rights to be left alone, and the state and HCO's responsibilities to advance the stakeholder community's best interests. This dissertation suggests that a theory of *principled communitarianism* applies the best of all three objectives.

Communitarianism emphasizes the social and interdependent nature of life and undergirds the notion that what is best for the community ought to determine society's moral thinking and it attributes responsibility of execution to the community.[233] The harm principle – which compels forbearance of conduct or behavior that would harm someone other than the actor - is distinctive in that it does not permit mandatory interventions unless the intervention will prevent harm to vulnerable third parties.[234] As applied to public health, the notion of principled communitarianism extracts the best of the values of the harm principle and communitarianism in order to adopt the idea that public health interventions are a shared enterprise. A principled communitarian theory should look at, among other factors, quality of life of obese children and determine whether or not the psychosocial, physiological and psychological implications are so severe as to impact the child's ability to enjoy a healthy life thereby justifying the intervention.[235]

Moral justification alone does not guarantee successful interventions, however. Obese-centered public health intervention, like most public health initiatives, will further require that people modify their behavior and lifestyles to comport with the intervention, and in many cases

abandon previously held beliefs about obesity's causes and effects. The need to educate and sensitize, and reconsider preconceptions about the dignity of the person is essential in order to reshape the culture and societal contexts of obesity;[236] and help the population of obese children reshape views of themselves. The failure to implement and comply with these interventions will allow the harm from obesogenic influences to survive and thrive. When the community, which includes the children's family and caregivers, fail the child, the state and other social parents must act within their proper authority.

4. F. 2.   Moral Authority: Social Parents and Care Ethics

With an emphasis on communal goods and services[237] communitarianism provides entrée into to the world of socio-cultural influences which are the building blocks of an obesogenic environment. The focus is on the communities within which the different environments co-exist. Folding in the harm principle's concern for intervention for the sake of avoiding harm, the interdependent community and its constituents are responsible for and accountable to its children who are vulnerable to obesity.

But where the community, including the parents and legal guardians, fail to provide necessary and adequate protection for the child, and are negligent by their actions or inactions, the state as a sovereign may become a de facto parent.[238] The fact is that no parental authority, regardless of its intrinsic character, exists independent of the sovereign. In the United States, the federal government has a supreme duty to all of its subjects, and the sovereign states have inalienable duties to protect its children.[239] By analogy, this dissertation argues that Mullins' social parent, empowered by its contextual relationships to its vulnerable children, has a moral and legal duty to its obese pediatric populations. The moral authority of the social parent in healthcare defines the ethical accountability to this stakeholder community.

Mullins' care theory, from which the social parent stems, attends to the social arrangements that either generate or mitigate vulnerability, and considers "how attention to the different domains of children's relationship with their caregivers" can identify solutions.[240] Although her work is largely directed to the emotional maltreatment of children and its consequences, the multi-factor nature of obesity and its concomitant physical and emotional harms justifies its applicability as an appropriate care theory. By understanding the relational contexts, Mullins' care theory "directs attention to the needs that are the source of children's vulnerability and the role of the caring relationships in meeting those needs."[241] Of the different relational domains responsible for the satisfaction of certain needs, the domain concerned for the child's protection and security most prominently undergird the social parent's moral duty. This moral duty further presumes that the child's best interest is paramount when considering the autonomy and exclusivity of parental responsibility vis-a-vis the best interests of their child.

The best interests of the child is the current legal standard in most jurisdictions, however, care theory looks at the relational interests of social parents as well as the child. This potentially puts disproportionate emphasis on the presumed parental love for the child. To that end, Mullins aptly argues that "any version of care theory that attends to vulnerability cannot simply trust parents or assume they will seek help" and must recognize the need for increased state intervention[242] when necessary and appropriate.

Under the common law, states' attorneys general may bring actions against parties who directly or indirectly harm the health or well-being of the citizens of their state. The source of this legal authority is the doctrine of *parens patriae*. Translated literally, it means "parent of the country" and was originally promulgated by the British Crown to protect minors and incompetents; later evolving into a broad sweeping common law theory.[243] To assert *parens*

patriae, the state must first have an interest that is separate and apart from the individual interests of those impacted by the harm or threat. It must also have a quasi-sovereign interest in the health, well-being and economic life of its residents. An example of the exercise of *parens patriae* authority in the United States is the recent litigation brought by attorneys general against the tobacco industry for the inherent harms to the citizens of its states caused by its products.

Applying the same precedent against the food industry for its role in the obesity epidemic may not be as straightforward as tobacco litigation; although consumer groups concerned with obesity are projecting increasingly active voices against this industry.[244] There is not an easily traceable chain of causation between the conduct of the food industry, the food itself, and obesity, as there is in tobacco-induced health risks.[245] Nevertheless, that disconnect did not deter William Sorrell, during his tenure as Vermont's attorney general, from convening more than 100 food industry stakeholders over a two-year period to successfully focus on obesity prevention legislation and policy changes.[246]

Regulating the food industry, nonetheless, is most appropriately the province of state and federal legislators. However, it is a well-settled law that the state *is* permitted to intervene in order to protect child's mental and physical health as in cases of *medical neglect*. As obesity is a medical and psychologically-affected condition with far reaching implications, it logically flows that the state would have similar *parens patriae* legal authority to act in cases of obesity-related neglect of minors.[247]

It is incontrovertible that the community has a legal duty to protect its vulnerable and is particularly responsible to protect its children from harm. Situations of child abuse and medical neglect are most often the purview of state laws addressing domestic relations and child protective services. Pennsylvania law, for example, provides that all persons and agencies that

are responsible for a child's welfare have a duty to protect against abuses, report known or suspected abuse, and consider the child's best interests at all times.[248] This includes mandatory reporting obligations of pediatricians and other clinicians. This duty to protect against abuse is clearly articulated within the statutory definition of medical neglect, and is expressly conferred upon parents and those who provide care and supervision, and/or control of a child in lieu of parental care.

Medical neglect and abuse is the failure to provide medical or psychological care necessary to prevent, or to treat serious physical or emotional injury or illness by someone who is required to provide such care. Such neglect occurs when a parent or other responsible party fails to act[249] or to provide care in an emergency, or to address an acute illness that results in harm or injury to the child. But it also occurs when a parent fails to respond to medical recommendations for conditions that are treatable or when such treatment would prevent a life-threatening condition. Determining whether or not the presence of persistent obesogenic environments and the failure to remove obesogenic influences constitutes medical neglect on the part of the family or other responsible party requires an intense balancing of interests, harms, benefits and duties.

Because the family is considered the center of family life for most Americans, its decisions are rarely subject to state challenges except for the most special circumstances which threaten the physical and emotional health of its children.[250] In the instant matter, invoking the doctrine of *parens patriae* can be morally and legally justified when obesity-related conditions are exacerbated by medical neglect. In exercising *parens patriae* through application of medical neglect statues, the state is essentially challenging the parents' failure to prevent or remediate the

physiological and psychosocial harms from obesity. The circumstances warranting state intervention and the gravity of those interventions each fall into three general categories.

U.S. courts have typically held that interventions addressing medical neglect under the doctrine of *parens patriae* look at the degree to which the neglected medical treatment is life-saving, life-prolonging, or quality-of-life enhancing. State intervention is most strongly advocated when the treatment is life-saving. Because childhood obesity is often a two-stage disease, interventions that either reverse or prevent obesity before a child reaches adulthood can also be life-prolonging. Courts have also upheld interventions which neither save nor prolong life, but instead improve the quality of the child's life. Proponents of state intervention in such cases argue that it is necessary to protect the child's psychological health and the right to a live a *normal* life.[251]

It has long been held that treatments and interventions intended to improve or enhance quality-of-life or degree of flourishing, are difficult to weigh and measure. Because these objectives are subjective, the state's ability to intervene based upon inconsistent values and competing interests is a challenging task. For example, morbidly obese parents of a moderately obese child may consider her quality-of-life superior to that which they experienced at her age. On the other hand, their present condition may be all that is needed to invigorate the desire to reverse her condition and free her from obesity-related constraints. In either event principled communitarianism looks at the balance between the harms and benefits of the intervention in harmony with the values unique to the community.

Principled communitarianism would consider obesity-related medical neglect as an abrogation of the parents' duty to provide a child with a quality-of-life based upon the minimum quality-of-life threshold that the community's values will tolerate. In other words, most

communities would agree that intervention is necessary and appropriate when a child's life is in imminent danger. However, the majority of obese children face consequences that are less imminent. The principled communitarian would take into account the risk that such a low standard might create if intrusion into family life were to occur where a child suffers from minor to moderate obesity. In these cases that the community must counter-balance the long-range consequences created by stigma, discrimination and other factors described throughout this chapter against the continuity of family relations. In addition to its values, the community's appetite for intervention must be respected vis-à-vis its state negligence statutes. Some statutes clearly articulate the degree of harm necessary, but many do not. As such, the state and its communities have a duty to rescue its children from the clutches of known *and* unknown dangers.[252] As members of the community of stakeholders, the HCO and its pediatricians share in this moral and legal duty. This dissertation submits that, because of the relational dynamics, and consistent with care ethics, the HCO and its clinicians and pediatricians are social parents to their pediatric patients struggling with obesity. Therefore pediatricians and HCOs, in addition to the state, have the moral authority to intervene on behalf of the child, when conditions warrant, through the doctrine of *parens patriae.*

4. F. 3.   Intervention as a Shared Moral Duty

Although litigation, as well as the mere threat of it can be a powerful motivator for legislative and public policy changes, some opponents to state intervention aptly argue that coercion alone does not create a strong enough foundation for permanent change.[253] In fact, the fear of a nanny state - a government that is perceived as having excessive interest in controlling the welfare of its citizens particularly in the enforcement of public health and safety[254] – can be a formidable adversary to state intervention. However, commentary from the Johns Hopkins

Berman Institute of Bioethics underscores that government interference into obesity control and prevention does not amount to a nanny state interference. It contends that the health implications for being overweight and the obesity-related disparities create a government duty in the name of social justice.[255] With that, social justice in accordance with principled communitarianism, supports *parens patriae* interventions incorporating notions of fairness, respect for the values of the community and the individuals, and adoption of community-based approaches to policy.[256] True community-based initiatives presuppose collaboration across the various stakeholder and social parent relational groups.

Interventions represent different degrees of intrusion and must be weighed against the community's interests, responsibilities, and convictions. Interventions must respect the parents' interests, as well as the concerns of pediatricians and other healthcare providers, the state, and the children. Interventions range from benign mandates such as public education in order to increase interest in healthier lifestyles, to interference with family eating habits.[257] Whether they impact legislation, public policy or social norms, all obesity-related interventions will involve some degree of modifying and even restricting, individuals and community behavior.

Although they are not the only target for change, parental behavior and habits play a significant role in childhood obesity. Parents will receive a citation if their child is not snapped into a seatbelt while they drive, but there is, to date, no penalty for feeding kids to death. Children have a right to be protected against unhealthy influences, and even the most caring families may be letting their children down in that regard.[258] Nevertheless, in accordance with principled communitarianism, the chosen method of intervention must be in proportion to the gravity of the obesity in harmony with community values. For example, a child with a BMI of 28 should not be removed from the parents' home in the absence of another more threatening

situation. In addition, when introducing interventions that modify parental behavior, the community must guard against the slippery slope suggesting that if one intrusive measure is good, more must be better. Increasingly intrusive measures may infringe upon larger principles of autonomy eventually resulting total government control.[259]

Consider how, in 2000, the New Mexico Children, Youth and Families Department (CYFD) exercised *parens patriae* authority, and removed three-year-old Anamarie Martinez-Regino from her home and the custody of her parents. She was taken from her parents on the grounds that they repeatedly failed to comply with medical orders to correct the present and long-term health effects of her morbid obesity.[260] At the age of three, Anamarie stood less than four-feet tall and weighed 131 pounds. She was hospitalized several times for extended periods and for various obesity-related conditions – losing weight during each hospital stay – but experiencing significant weight gain soon after returning home. The family physician was alarmed and took his concerns to the CYFD. The state held that they had probable cause to remove the child – a clear victim of medical neglect.

This case gained notoriety and created a ground-swell of divisive camps within the community; many believed the government had overstepped its authority. The medical community supported intervention on the basis of threats to Anamarie's long and short-term health. Many feared removing Anamarie from the home was the first slippery step towards allowing the state to take draconian measures against parents anytime parental conduct was called into question. In the final analysis, Anamarie's parents reached a sealed court-approved agreement with the state allowing the child to return home.[261]

The Martinez-Regino case illustrates how the doctrine of *parens patriae,* in its most extreme form, illuminates the injustices suffered by obese children, the need for balanced

intervention, and how core community values that can be polarizing. A shared cultural model of core values does not presuppose that everyone agrees with every decision made according to the model, but rather, the community agrees with the values that support the decision.[262] The instant case further evinces how, a community of interdependent people, share in the responsibility of ensuring that a child's personal dignity is preserved by the community itself and the social network it creates. The community may disagree as to the outcome, as the case of Martinez-Regino suggests, but it did not disagree with the direness of the concern, and the physician's affirmative duty to report.

Not all *parens patriae* interventions are as severe an Anamarie's experience. However, even in non-threatening interventions, the government's police power to intervene cannot be arbitrary. It must be rationally related to the public health protections targeted and reasonably designed to correct a situation impacting public health.[263] As such, interventions should be developed within an integrated chronic disease prevention model resident within the community and home settings.[264] For example, the U.S. Institute of Medicine suggests that interventions for obesity prevention target nutrition and physical activity, behavioral treatment, decreasing the prevalence of sedentary activities, and social and psychological support involving families.[265] Hassink goes so far as to suggest that intervention into childhood obesity begin before birth as fetal life and intrauterine environment factors are influenced by maternal obesity to the extent that it may render a child more likely to develop childhood obesity.[266]These interventions require environmental and individual behavior modifications which are necessarily supported by the interplay of families and the medical community.

The pediatrician's duty as a social parent is not unprecedented as they are concerned about the health and growth of the children they treat practically from the moment the children

are born. The correlation between good nutrition and optimal baby growth, weight and

development are foundational principles of pediatric medicine. Identifying failure to thrive, and

weight or height accelerations and decelerations have long been considered early warning signs

of significant illness.[267] Since the late 19th and early 20th centuries, pediatric medicine's concern

for good food and nutrition consumption underscored efforts to promote breastfeeding, safe milk

supplies, remediate vitamin deficiencies, and even advocating healthy school lunches. Moreover,

the development of premature infants as well as those children who are vulnerable to the effects

of certain chronic conditions, remain integral concerns of pediatric practice.[268]

Despite this, some primary care pediatric practitioners contend that universal obesity

prevention and management is an inappropriate use of their time and is best left to the parents

and family. They further argue that the sanctity of physician-patient relationship would be

compromised by discussing this sensitive and stigmatizing topic. They want to minimize

judgment repugnance.[269] Fortunately however, there are those who do consider secondary or

selective prevention – that which seeks to mitigate or reverse *existing* obesity – as an opportunity

to responsibly collaborate with parents and unify the effort- even if they do see parental

involvement as a significant barrier.[270] However, many parents are not comfortable discussing

the child's weight with the child for fear that the efforts are fruitless or attention will undergird

the stigma and further erode self-esteem.[271] They expect the pediatrician to address the child's

weight if it's a problem.

Consider that almost all childhood obesity prevention and management programs

recommended by practitioners require calculating and charting BMI once-a-year during well-

child visits; including emphasizing healthy nutritional guidelines and encouraging physical

activity. But, despite the efforts of the practitioners, there is very little evidence of monitoring or

accountability of the parents or family once the recommendation is made. An example of a public policy adhering to the theory of principled communitarianism would be one that supports mandatory reporting of all children whose obesity remains unchecked and unaffected for a period of more than 12 months. This reporting would be transmitted via a data base registry would be validated during each well-child visit. The physician's duty to report parental noncompliance would be mandated as a duty to report under appropriate state statutes and professional codes of conduct.[272]

Regardless of which view prevails, a proper relationship with food and the interplay of physical activity must be taught to children, because it will be very difficult for the child to change the way they view food once they reach adulthood.[273] Family-based treatment interventions that promote and teach self-management of healthy eating can positively alter parent and child behaviors, and thought patterns in order to also combat negative psychosocial consequences.[274] By exercising *parens patriae* authority, the government can promote such self-management interventions linking physicians and families to culturally tailored and competent programs[275] in order to support healthy nutrition and lifestyles.[276] Providing tax subsidies for weight loss, finding a community champion,[277] increasing provider reimbursements for improved outcomes from obesity management, and limiting foods that can be purchased with government sponsored food stamps, are rationally-related and ethically justified government interventions.[278] And, as activist child health experts, pediatricians should exercise their authority as social parents by leading community coalitions and legislative endeavors to take healthy eating lifestyles beyond the clinic walls.[279]

4. G. Conclusion

Ethically accountable healthcare organizations have a moral duty to create opportunities for the communities of stakeholders they serve. Their obligation to the common good includes empowering the most vulnerable within those stakeholder communities, specifically pediatric populations. Throughout history, children represent a highly vulnerable stakeholder group. They have been exploited and harmed, intentionally or not, and oftentimes during efforts to support policies to protect them; such as excluding them from clinical research. The need to empower children, and the importance of research to understand the pathology of diseases and disorders involving them is compelling. This is particularly evident when understanding children infected with HIV, those who are victims of abuse, and those with cognitive disabilities.

Children with illnesses and disorders are contingently and contextually vulnerable vis-a-vis the cultural and environmental influences within which they live. Additionally, their vulnerability is magnified by those who wield power and authority over them. It is that power and authority that establishes the moral duty of the HCO, and its moral agents to understand and respect the humanness of these children. To that end, physicians and researchers, who are often the same person are obligated to adhere to ethical principles of autonomy, beneficence, and fairness throughout the ethical research process. Adherence to these principles entails an understanding beyond the intrinsic characteristics of the child and their special needs. It requires examination of their experiential and conjectural perspectives.

Because healthcare and clinical research are relational, the importance of the child's interpersonal and social relationships with authority figures such as researchers, physicians and caregivers, underscores the relevance of relational ethics. Specifically, the goodness-of-fit model of relational ethics assesses all aspects of clinical treatment and research, against the child's

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capacity to understand, their relationship with those upon whom they are dependent, and the cultural and personal values that shape their world.

The collaboration between asymmetrical stakeholders such as the physician, researcher, child, and even the broader community undergirds the moral accountability to vulnerable pediatric populations. Their moral obligation and responsibility to better understand population health in order to mitigate and prevent the psychosocial and physiological effects of pediatric obesity includes executing their social parent duties. A social parent embodies the relationship between the vulnerable child, the need which gives rise to their vulnerability, and the ones upon whom they depend. The authority of interdependent social parents, and their attendant duties to protect obese children in the face of obesogenic influences, is akin to the legal doctrine of *parens patriae.*

By exercising this authority, self-management of healthy eating habits and culturally tailored programs linking parents and physicians will improve outcomes for obese children specifically, and public health obesity management generally. The challenges facing children with HIV, those who are maltreated, those with intellectual disability, and children living with obesity rarely improve with age or maturity. As such, the practical and ethical considerations for this vulnerable population create ongoing opportunities for HCOs to enable ethical accountability, social responsibility, and collaboration with communities of stakeholders across the child's life continuum.

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Chapter 5 - Community Stakeholders in Healthcare: The Elderly and Persons with Disabilities

5.   Introduction

Vulnerability impacts certain stakeholder populations when consequences and conditions render them susceptible to physical, emotional, economic and social harm or disadvantage. People are also vulnerable from social biases that have less to do with their actual conditions and more to do with social perceptions and preconceptions about them. Biases disadvantage, discriminate, and disempower. They are innately evolutionary, however. Humankind's earliest ancestors needed to quickly decide, based upon their perceptions, whether a person, situation or animal was likely to threaten their survival.[1] They characterized such encounters and made judgements accordingly. Today, elderly persons and persons with disabilities are often similarly judged and victimized by biases.

For example, at some point in the life continuum, the elderly face a culture that treats them differently from youth; buoyed with the presumptive undercurrent that the future is less relevant for them as they have lived a good life already.[2] Youth represents beauty and promise, whereas the elderly demonstrate the transient nature of life and the death that is certain for everyone.[3] Similarly, persons with disabilities often face biases that render them the "other" in dehumanizing ways; these biases often suggest that they represent a "counterpoint to normality."[4] Such biases exacerbate their vulnerability and threaten the dignity of their lives.

Propagation of such biases without substantiation also unfairly and unjustly denies opportunities to those who very often need them the most. Creating opportunities for the most vulnerable and inaudible stakeholders across the life continuum is a moral duty of the ethically

accountable healthcare organization (HCO). Applying stakeholder theory, an HCO is accountable to people and the environment, and ought to serve the common good for the sake of many.[5] To that end, this chapter is dedicated to examination of the duties of ethically accountable HCOs to the third of three vulnerable stakeholder categories set forth in this dissertation: the elderly and persons with disabilities.

Aging is an ambivalent reality. Presumably, the vast majority of people hope to live a long life, however few relish the thought of growing older. Hardly anyone can admit a willingness to embrace and welcome the physical, emotional and oftentimes economic challenges that can accompany physical maturity. Yet, the reality that "aging, or just living life does entail inevitable change"[6] is uncontroverted, and begins the moment one is born. Although the process of aging as a stage of human development can be positive, living a long life can present challenges to the vulnerable elderly, and to the communities within which they live. Nowhere are these challenges more visible than in the resource allocation and mechanisms that provide access to long-term healthcare services to the very old.

This chapter begins with a view of the demographic profile of today's elderly stakeholder and aged populations, and their contextual vulnerability vis-à-vis ageism biases and their unique health needs. It then explores the current public policy trends for addressing their needs; including a brief summary of age-based rationing and the different propositions advanced by Daniel Callahan, Norman Daniels, Paul Menzel and John Kilner. This thesis then presents a justification for revised public policy to address the unmet long-term informal care from an ethic of care model that relies upon the interconnectedness of people.[7] It then illustrates how caregiver and provider advocacy supports person-focused, compassionate long-term care through the musings of Tellis-Nayak, Nancy Fox, and Muriel Gillick.

Progression across the life continuum to old age practically guarantees people will become dependent and at risk of severe illness and disability.[8] For some however, disability is not a progressive old age event, but rather some permanent consequence of war, injury, illness, or genetic precondition. According to the World Health Organization, "disability is part of the human condition."[9] Because concern for the human condition is at the heart of healthcare, promoting the dignity of persons with disabilities is a moral duty of the ethically accountable healthcare organization. The remainder of this chapter focuses on the healthcare profession's obligation to enhance the lives of those with disabilities by creating enabling environments within which they can flourish.

It begins with an illustration of the definition and demographic of human disability. It then explores the relationship between disability and human dignity, what it mean to be human, to flourish, and to have a good life. Relevant evolutionary and theological interpretations of the human condition of disability, including those by Celia Deanne-Drummond, William May, and Hans Reinders are introduced. Specifically they investigate humankind's desire to improve the human condition of disability through genetic intervention. The argument for ethical accountability to this stakeholder community, further unfolds to assert justification for creating enabling opportunities that eliminate barriers to flourishing, reverse ableism biases their effects, and impart a culture of disability ethics. It explores these matters through thought-leaders such as Michael Oliver, Alicia Ouellette, Jackie Leach Scully and Eva Feder Kittay. Underscored by care ethics, this chapter concludes that all of humanity moves "in and out of relationships of dependence through different life stages and conditions of health and functionings,"[10] and that care as a virtue is essential to understanding another's needs.[11]

5. A.   The Elderly Population – The Cared For and the Caregiver

The term "elderly" typically conjures images of a frail and fragile person. Mindful of the distortions of this imagery, the social sciences more positively refer to the population of aged individuals 65 and older as "older adults."[12] This dissertation uses these and other similar conventions interchangeably without adopting a clear preference. Irrespective of the imagery evoked, any conversation addressing their needs must emerge from an understanding of what it means to belong to this stakeholder community, by examining a few of the notable definitions. Traditionally, "'elderly' has been defined as a chronological age of 65 years old or older, while those from 65 through 74 years old are referred to as 'early elderly' and those over 75 years old as 'late elderly.'"[13] Its origins are attributed to the German Empire more than a century ago when 65 was the age by which persons were eligible to receive national pension plan benefits.[14]

Patterning itself after the European nations' establishment of chronological eligibility for old age insurance programs, in 1935 the United States determined age 65 as the benchmark retirement age through the adoption of the Social Security Act.[15] Today, 65 is hardly considered old age as people are living well past that milestone into their 90s, and beyond. In 2016, the number of people over age 65 in the United States was 49.2 million, representing 15.2 % of the population.[16] Persons over 85 account for about 6.4 million people, 52 times more than there were in 1900. In 2016, there were 81,896 people over the age of 100 in the United States;[17] more than double the 32,194 reported in 1980. It is vitally important, however, that today's elderly represent more than mere census statistics. They are a heterogeneous population of persons who once were parents, teachers, veterans, laborers, physicians, and most often caregivers themselves. They represent the human condition in transition.

5. A. 1.   Living with Unmet Needs

Aging is an individualized process. Individuals age differently and have highly diverse needs, often influenced by their chronological age. Some demographers contend that these differences and the sheer size and proportion of the population considered "old age" points to a need to establish age groups in order to differentiate the "young old" from the "oldest old." Some argue for applying a four-age-group model breaking society into young people, working people, younger retired people, and the oldest people. While others suggest adoption of an "oldest old" based on two groups the 50-74 year old group, and the 85+ group.[18] Despite the need for differentiation, there are some generalities within each of these age groupings that medicine and science explore to objectively meet the unmet long-term health care needs of the elderly.

From the Greek *geras* meaning 'old age' and *iatrikos* meaning 'physician', geriatric medicine is one of several groups of specialties defined by the patient's stage of human development, such as pediatrics and neonatology; rather than by organ system, such as cardiology and neurology.[19] Geriatrics is concerned with disease and health problems specific older adults.[20] Accordingly, the benchmarks of geriatric medicine rely upon the age of the patient. Because it is unlike most other specialties which look primarily to the physical and biological aspects of illness, geriatrics by design pigeonholes its patients according to where they are on the life continuum. As such geriatrics is innately predisposed to the unconscious or conscious biases of the healthcare professional, according to their preconceptions of 'elderly'. There are inherent risks to such biases. Using stereotypes in the course of care can result in, among other things, premature, and/or missed diagnosis "when clinicians fail to see their patients as more than their perceived demographic characteristics."[21]

Coined in 1968 by geriatric medicine pioneer Robert Butler, *ageism* is "a systematic stereotyping of and discrimination against people because they are old."[22] It can be conscious (explicit), or unconscious (implicit), and is not the exclusive province of healthcare. It is an attitude that is influenced by cultural ideologies and practices.[23] Throughout history in less industrialize societies, older adults have been valued for their wisdom of counsel, and serve as inspiring role models to the younger members of society.[24] In the United States, however, society tends to presume that old age renders people unable to make good decisions because intellect, wisdom, and decision-making capabilities are compromised by age.[25]

Ageism can be subtle; for example, when healthcare professionals bypass direct communication with the elder patient and address younger family members first.[26] Ageism can also be overt as reflected in a survey of Johns Hopkins medical students revealing that 80 percent would aggressively treat pneumonia in a 10-year-old girl, while only 56 percent would do the same for an 85-year-old woman.[27] In either case, power relationships are linked to ageist assumptions and ideologies, including those that suggest that all elderly are mentally infirm; leading to treating old persons in authoritative and dismissive ways.[28]

Stereotypes, prejudice, and discrimination can clearly present obstacles to health equality; not only in terms of quantity, but quality of care. A recent U.S. study evidenced "age-related treatment of heart attacks relative to national treatment guidelines, with older patients less likely to receive standard diagnostic procedures and recommended treatment."[29] And unlike other forms of discrimination that rely upon immutable biological characteristics such as sexism and racism, ageism will affect anyone who lives long enough.[30] Although ageist tendencies can penetrate the entire healthcare system, this dissertation concentrates primarily on its impact on vulnerability in the clinical setting, and with respect to long-term care policy.

When the elderly can no longer care for their basic needs, and/or they are denied dignified methods of dealing with their functional decline, their dependency on other caregivers renders them particularly vulnerable. They are subject to threats or events that have the power to advance them towards adverse and harmful outcomes.[31] Understanding the nature of elder vulnerability entails examining contingencies, threats and risks, and the extent to which they are defenseless against them. According to Schroder-Butterfill and Marianti, vulnerability in this context of the elderly is a probabilistic concept that has incremental outcomes based upon their proximity to harm. She argues that "a person's risk of suffering harm – her vulnerability – is the incremental outcome of a set of distinct but related risks."[32] Probabilities are aligned to the exposure to a threat, the materialization of the threat, and the ability to cope or defend against the threat. This is a particularly useful framework for understanding the elderly who must consider proximity to and accumulation of risk exposure across the lifetime. There is an incremental reality to the dynamic process of aging. The probabilities of risk are best addressed when those with moral authority recognize and act upon their interrelationships with the elderly and their collective obligations to them;[33] enabling them to live their best lives.

Medical advances and technology have made it possible to prolong healthy human life. These advances naturally include prolonging the lives of those with complex, chronic, disabling conditions, and functional disabilities. The elderly represent some of the most acutely sick persons requiring some of the costliest and protracted care. The top four leading causes of death – heart disease, cancer, cerebrovascular disease and Alzheimer's – are nearly all accompanied by prolonged periods of functional decline, disability, and high rates of health services preceding death.[34] According to the 2017 International Health Policy survey, more than one in three people (36%) of adults over the age of 65 in the U.S. had multiple chronic conditions.[35]

Women are more likely than men to suffer from multiple chronic conditions such as diabetes, hypertension, migraines, digestive problems and other orthopedic maladies that are not necessarily imminently life-threatening; although they generally result in limitations to mobility, physical and social activities.[36] Stroke, heart attack and cancer are more common in men[37] who utilize more in-patient hospital services – reimbursable by Medicare – whereas women use more prescription and custodial care services. The net result is that Medicare covers a smaller portion of women's healthcare needs.

Paradoxically, women outlive men despite being disproportionately impacted by chronic healthcare and access issues.[38] In 2016, there were 27.5 million women over age 65 compared with 21.8 million men; or a ratio of 126 women for every 100 men. Beyond age 85, the ratio increased to 187 women for every 100 men.[39] Because women tend to marry men who are older than themselves, they are less likely to share their later life with a spouse. This fact helps to explain why 75 percent of nursing home residents are single women.

Marital status is also directly linked to a number of economic, physical and emotional measurements of well-being as a person ages. Older married persons typically have higher household incomes, better health and lower incidences of depression than their unmarried counterparts. Further, they experience reduced risks of institutionalization as spouses tend be the primary caregivers for their frail and disabled partners.[40] Statistically, in 2017, 70 percent of men over the age of 65 were married, compared to only 46 percent of women; of the unmarried elderly women, 33 percent were widows.[41]

Historically there has been a pervasive and strong societal dependency on family as primary and even sole caregiver to the elderly. The presence of family caregivers is in general a significant factor in keeping older people out of nursing homes. Fifty-percent of older people

with long-term care needs who do not have family caregivers are in nursing homes, while only 7 percent who have a family member to care for them are placed in long-term care institutions.[42]

Stalled population growth and the imbalance between the population of young and elderly persons means that fewer offspring and other family members will be available to care for the elderly. The fact that couples and unmarried offspring have more elderly parents to care for than they have children to assist in that care, negatively draws on the human capital available to provide informal care to the elderly.[43] Because of upward trends in the age composition of the elderly, and the fertility histories of women who will be retiring, the shortage and the need for long-term care solutions will be much greater.[44]

5. A. 2. Long-Term Care

For purposes of this paper, long-term care refers to the services and support relied upon by those who need daily help in order to function day-to-day. Such help includes a wide array of services including personal care, assistive technologies, care coordination, home modification, transportation and rehabilitation. Assistance may be needed regularly or intermittently, for periods of months, years, or for the remainder of a person's life.[45] The need for such care is measured according to the person's ability to perform daily activities and tasks.

The notion of long-term care incorporates formal (paid) and informal (typically unpaid) services. Persons over the age of 65 account for approximately 75 percent of formal long-term care spending in the United States.[46] Specific examples of formal long-term care services are adult day care, in-home care services, care provided in residential facilities, and intermediate and skilled nursing facilities.

In comparison to the delivery of high-technology healthcare for the acutely ill, for which there is a strong preference in the United States, long-term care services are considered "low-

technology" low-cost care. Nancy Jecker states that most of the health care dollars spent in the United States are spent on acute care, high-technology medicine centered on intensive, short-term, crisis-driven health care.[47] Yet, those who need long-term care are those whose care is chronic rather than acute. Long-term care is a continual need, not episodic as is typically the case with acute care.[48]

Chronic health conditions most often restrict the elderly's ability to perform activities of daily living (ADLs) such as dressing, bathing, and eating as well as instrumental activities (IADLs) such as meal preparation and housekeeping. Because these chronic conditions and the accompanying limitations require continual rather than episodic care, the need for long-term care is ongoing, most often permanent. A great percentage of the oldest old living in community settings face ADL challenges – over 25 percent require assistance bathing and showering, 40 percent have difficulty walking without assistance and 10 percent need assistance with toileting. A sizeable proportion of the oldest old also report difficulties with IADLs - 17 percent need help to use the telephone, 24 percent cannot do light housework without assistance, and 23 percent cannot prepare meals alone.[49] Formal long-term care services most commonly include skilled nursing and other personal care home settings. Informal long-term care options are most desirable and appropriate for many elderly with ADL and IADL limitations who desire to remain in their home setting.

Home care is an informal outpost of the healthcare system by which services are brought to patients in a setting that reinforces autonomy and self-respect, social integrity, familiarity, safety, and low cost.[50] Providing supplemental services to the elderly in their homes most often provides a cost-effective alternative to nursing home and other forms of long-term formal care. In addition, it provides the elderly with a sense of continuity and safety in their comfortable

setting, allowing them to 'age in place' near family and community networks.[51] The elderly frequently associate living in their own home with independence as it provides evidence of their ability to make decisions for themselves.**[52]** It remains the one place where they can be themselves – and be free from their "sick" identity and be more at home with their changing bodies.[53]

Despite the need and the benefits such services confer, current policy trends, ageism, and age-based rationing and allocation attitudes can obstruct access to these vital services. Such attitudes bolster providing them to only those who are perceived to have the most dire, means-tested needs; while denying them to those on the fringes. Moreover, even though they are significant consumers of healthcare services, the Institute of Medicine recently issued a report alleging that negative attitudes toward the elderly exist even within healthcare communities and disciplines across care settings.[54] Equally significant is the public ignorance, dogma and stigma that influence the social figments associated with formal long-term care; particularly the negative connotation of nursing homes.[55] Such attitudes widen the chasm of unmet needs, and further punctuate the imperative for policy change.

5. B. Public Policy and Age-Based Allocation and Rationing

The purpose of public policies are to articulate how governments distribute resources, influence behaviors, and help to ensure the security of its constituents. They also reflect common consensus about values, and tell a story about people, history and what is important to the populace. Policies try to solve problems or support core beliefs.[56] Throughout the past several decades, certain core beliefs concerning the rationing of healthcare needs of the elderly have dominated policymaking thinking in this space. Public policy concerning care for the elderly is shaped and influenced by perceptions of what it means to be aged, and how the human lifespan is viewed in the United States.

Older people are viewed as a homogenous and undifferentiated constituency, and the human lifespan is typically considered to be a lifespan of production; spanning a pre-work, work, and post-work life continuum. Those who have surpassed the age of 65 are seen as all belonging to the same spot on the lifespan and therefore sharing the same undifferentiated needs. This myopic thinking sparked many of the federal programs designed to provide for elderly – chiefly Medicare. While these programs reflect compassion towards the elderly, many of them encourage a view that the elderly are all weak, inferior and fragile.[57] Smith recalls that, coupled with ageist ideology, the need to control rising healthcare costs and expenditures relating to the elderly, while improving access to care, established the basis for allocation and rationing.[58]

Allocation of healthcare resources considers what resources ought to be committed to a particular program, and is typically assessed at a macro level considering only statistical lives. When resource assessments consider the impact on the micro level of identifiable lives, it is known commonly considered *rationing*.[59] This paper accepts the definition of *rationing* adopted by the Catholic Health Association as "the withholding of potentially beneficial services because policies and practices establish limits on the resources available for health care."[60] Because governments and HCOs encounter the elderly at the macro and micro levels, they regularly make decisions that involve both allocation and rationing. This paper highlights the predominant views of age-based rationing and allocation in order to demonstrate that applying an ethic of care is the moral alternative to purely age-based considerations, and therefore supports the provision of dignified, long-term care services.

The belief that the elderly population is a "bottomless pit of needs" and that meeting those needs will disproportionately stress already stressed financial resources - undergirds much of current public policy and forms the basis for age-based rationing.[61] Scarce medical resources

is a reality, and as such there is no longer a debate about whether healthcare should be rationed, but rather how to do it equitably.[62] Influential scholars and bioethicists have shaped the course of public policy with respect to rationing, and their range of thinking spans a continuum from rationing of services based on a perceived natural lifespan, to a care-oriented approach with "care" as the core principle.

5. B. 1.   Perspectives on Age-Based Rationing

Daniel Callahan's original communitarian model is the most extreme call for age-based rationing of health care for the elderly. He argues that patients over 80-years-old ought to be considered to have lived a natural life span, and for the sake of the good of the community, they should not receive certain life-saving procedures and services, but merely accept a tolerable death.[63] His expectation is that the elderly will consider the value of their remaining lives in relation to the larger intergenerational community, and because of their advanced age, they should prepare themselves to pass the torch of life to subsequent generations.[64]

According to Callahan, the elderly experience a meaningful life when they serve the young, and that they serve as models of morality when they surrender medical services in favor of the young. One way to ensure that the elderly comply with this moral expectation is to compel them through age-rationing measures.[65] Callahan's model is myopic at best. His approach misses the richness of experiential reasoning and thought that the elderly bring to the intergenerational community of younger people. It caters to a "youth oriented culture" demeaning the status of older people.[66] Moreover, he fails to consider that the life plans of the elderly do not end at a prescribed age, but rather remain an inseparable part of their optimal functioning, relative to their condition and capabilities.

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Norman Daniels proposes his Prudential Lifespan Account of rationing. According to this Account, the just distribution of limited health care resources between the young and the old entails varying the health services provided through the different stages of life. A distribution supported by stable policies at each stage. He argues that providing different levels of services – essentially, treating people differently based upon their life stage – does not breed inequality if *everyone* in the same life stage is treated the same way all of the time. This means that society would treat the young one way as a matter of policy, and the aged another, and this is done over their whole lives and the net result is that all persons are treated equally.[67]

In contrast to Callahan, Daniels contends that it is necessary to provide healthcare to the elderly in order to help them maintain their own degree of functioning and a fair opportunity to enjoy their life plans. Unlike Callahan, Daniels does not assume that one stage of life is more valuable than life at another stage, but rather the Prudential Life model turns on the judgments that people would make concerning their care at each of the different stages of life; according to an agreed upon principle.[68] As such, Daniels argues that providing public long-term care services ought to be incorporated into the life of the prudent planner.

Incorporating vestiges of Daniels' Account, Paul Menzel's Prudent Consent model of rationing works from peoples' rational and prudent self-interest based upon the needs and goals of their lives. It is not an age-based model, but one that is more "age-influenced" - based upon the quality of life that the individual anticipates. This model allows persons to choose the beneficial care that they want now and also what they anticipate wanting in later years; thereby placing the rationing determination squarely in their hands. It respects autonomy and the integrity of self-determination.[69]

Part of the challenge for United States as it considers the long-term care of its elderly population, is that very little attention and planning takes place until the need for elder care arises. The Prudent Consent model foresees a proactive rather than reactive system of rationing influenced only by the characteristic of age rather than the age itself. The Prudent Consent approach encourages persons to self-manage their lives and their resources and to take accountability for long-range needs based on how they want to live their lives. In addition, this approach presupposes that nobody will receive benefits unless they have contributed some share of the costs, thereby avoiding the risk of free-riding.[70] Menzel contends, however, that despite the hollow words, preserving the integrity of self-management and avoiding free-riding are not core values in the United States. As such, getting people to give up their attachment to their own self-interest will require what Menzel calls, "moral missionary" work.[71]

Expressing his alarm at the utilitarian culture that seeks to maximize the good of the greatest number of younger citizens at the expense of adequate care for the vulnerable elderly, John Kilner questions the wisdom of age-based rationing entirely.[72] Kilner examines the standard age-based argument that as healthcare for elderly persons is costing more, and the population of elderly is rising faster than any other population, it is necessary to cut back on all health resources available to the elderly, including long-term, low-technology care. His position argues instead for a standard of policy making that considers the person first before other economic and social considerations.

Kilner presents a person-first approach. That is, the person needing long-term care is a *person who is elderly*, not an "elderly person." And, their needs are examined through economic, cultural, social and political lenses. Accordingly, he concludes that one of the primary reasons that society considers cutting back health services for the elderly is the cultural preoccupation

with youth. And, he describes the increasingly utilitarian view in the United States that actions should produce the greatest benefits for the greatest number of people. Coupled with the general bias towards favoring those who are most productive within the market-driven U.S. economy, the net result encourages the view that the elderly are nonproductive and subject to rationed services.[73]

Kilner advances several strong arguments contending that such age-based rationale guiding current policy trends are not ethically justified. He attacks the economic argument on several fronts. Rising health care costs are due to a number of other factors that have no direct relationship to the elderly, and that other countries with similar trends include the economic impacts of other dependent groups – such as children – into the cost allocation equation. He further questions the wisdom of a society seeking to ration available healthcare resources rather than controlling other aspects of spending rampant in an excessive consumption-driven economy.[74] But most germane to the issue of long-term care is his contention that the most needed form of elder care demands the least economic impact.

Most health care rationing focuses on lifesaving care, yet a very small proportion of services for the elderly are of a lifesaving nature.[75] Most elderly need informal "life-sustaining" care. Moreover, even in the event that lifesaving care is necessary, Kilner agrees that those incidences and the likelihood of repeat episodes can be lessened by providing basic low-technology, preventive care – such as in-home medication management and assistance with ADLs and IADLs. Reformulating the national policy on equitable resource distribution necessarily begins with an understanding of current policy trends and implications.

5. B. 2.   *Current Policy and Trends*

Society's frail and elderly have unmet needs. Policymakers as well as ethically accountable healthcare organizations must understand better how current cultural and economic contexts coupled with the healthcare system's reimbursement payment structure, fail to sufficiently provide for these needs. As an example, Medicaid and Medicare programs were constructed as entitlement programs designed to assist low-income beneficiaries, and serve as primary insurance for the elderly over 65, respectively. However, even though they were intended to help the disadvantaged and needy, they represent indirect forms of rationing as Medicaid's restrictive eligibility requirements more often than not limit individual enrollment, and Medicare's reimbursement rates and coverage limitations often fail to provide needed services after the acute episode has passed.[76]

Since its inception in 1965, the central focus of Medicare has been on paying for medical services for acute and life-threatening conditions, not chronic, disabling conditions. Although it is widely accepted as insurance for the elderly, historically it was more accurate to characterize it as a funding mechanism for hospitals and professional providers. However, recent cost-containment initiatives and payment methodologies have lowered hospital reimbursements such that the elderly are being discharged sooner thereby going home "quicker and sicker."[77] Ironically, post-discharge events, which frequently lead to readmissions, often exacerbate the unmet needs of the chronically ill elderly.

From discharge - the point at which acute care is no longer provided, the elderly and their family are most often left to go it alone without access to necessary life-sustaining services. Current policy trends fail to consider the total-care delivery package which takes into account a comprehensive view of the elderly patient before, during and after acute care treatment.

Healthcare cannot be considered independent of the social services required to support the elderly when their capabilities begin to decline.[78] Yet, despite its packaging as social insurance aimed at keeping the elderly alive, current Medicare trends demonstrate little appetite for any sustained care beyond acute that would actually allow them to *live*.

Although Medicare is the primary funding source for home healthcare, nearly three-quarters of the nation's elderly pay for these services out-of-pocket. At least one reason is that despite the fact that Medicare reimburses for home care, it does so on the condition that the services are skilled versus informal, and that they be hands-on, short-term illness resolution services such as occupational and physical therapy modalities. Moreover, they are reimbursed on a payment-per-visit basis and terminate as soon as the fiscal intermediary administrator determines that the skilled services are no longer medically necessary and reimbursable. As such, Medicare home-care services do not fully meet the post-discharge home-care needs of most elderly, but appear to be a substitute for extended hospitalization leaving much of the residual of necessary services up to the elderly to purchase.[79]

Part of the reason why Congress, when it passed Medicare in 1965, opted not to cover informal long-term care services had to do with the prevailing assumption in the United States that the needs of the elderly are solely the purview of the family. As such, exclusion of these services was supported by the fear that if a public benefit was available for family caregivers, the inducement for fraud would have alleged family caregivers coming from everywhere. This is a woefully short-sighted and cynical view of family caregivers, as today most caregivers want respite, not remuneration or replacement.[80]

In the United States there is a compelling interest in keeping the elderly out of skilled nursing facilities for as long as possible, yet there are few if any informal care communities

prepared to care for them as they transfer out of acute care facilities.[81] Societal needs have

significantly changed since social welfare programs were initially designed in 1935. At that

time, such programs responded to family arrangements that are no longer operative today, and to

a vastly different population composition. The social programs available today have not kept

pace with this changed demographic.[82]

The economic cost of informal caregiving services is staggering and has steadily

increased since the beginning of this century. "At $470 billion in 2013, the value of unpaid

caregiving exceeded the value of paid home care and total Medicaid spending in the same year,

and nearly matched the value of the sales of the world's largest company, Wal-Mart ($477

billion)."[83] In 2014, approximately $217 billion of the value of unpaid care was attributed to care

for persons with Alzheimer's or other dementias. Contrast this to the $613 billion in total 2014

Medicare expenditures[84] and it becomes apparent that the mere presence of informal caregivers

is a vital part of Medicare cost-containment and deserves the attention of policymakers.

Caregiver needs are important and policy trends must be attentive to the crucial role they play.

Throughout the U.S. healthcare system, more generous attention is paid to high-

technology, high reimbursement procedures and services rather than those that are low-cost, low-

technology. One reason for the proliferation of costly technology is that cost-effectiveness is not

a Medicare criterion for determining whether to reimburse manufactures for new technologies.

There is very little incentive for manufacturers to invest in low-cost alternatives.[85]

Hence, the United States system pays more for short-lived, costly procedures and

relatively little for low-cost, high-yield cognitive and other informal care services.[86] The low-

technology needs of the frail elderly are as much a part of their illness/pathology as those of the

acutely ill. Nevertheless, decisions of who is entitled or not entitled to receive them are based on

seemingly arbitrary assessments examined against standardized guidelines. Public policy

supports not paying for low-technology informal care whenever an assessment model is

conducted without regard for the delivery of care, or the facts and circumstances unique to each

person's illness-related need.[87]

Enacted in 1965 as a health benefit program to assist certain disadvantaged segments of

society – primarily low-income beneficiaries – Medicaid is a means-based, state run entitlement

program. Medicaid does authorize states to include home-based services and waiver programs

intending to keep people at home and in the community and out of nursing homes.[88] The

majority of states have set the coverage and eligibility limits such that the requirements fall

drastically below the federal poverty guidelines, which means that less than one-third of the

chronically ill and disabled elderly can qualify – leaving the remaining two-thirds forced to get

by without necessary services.[89]

Because eligibility for Medicaid services is means-tested, many elderly are forced to

draw down and significantly dilute their assets in order to become sufficiently impoverished to

qualify for needed care. In the Commonwealth of Pennsylvania, for example, a chronically ill

elderly person who has anything in excess of $8000 in assets[90] would have to spend the excess

on qualified expenses in order to become eligible for assistance. The mere process of forcing a

disabled elderly person to relinquish assets that likely represent the net sum of a lifetime of

productive achievement and accomplishments can be, in many ways, more painful than the

chronic condition. To beggar in order to receive care runs afoul of the very market-driven

economy that motivates the policy trends purporting to support self-determination and

autonomy.[91]

The U.S. system of long-term care resides within a residualist model whereby the government provides resources only after informal attempts have failed – either through resource depletion or other failures. This model ensures that every claim for care becomes a needs-based claim that is structured more on the perceived failings or inabilities of family, or other caregivers, to take care of their own. These needs-based claims are catalysts for demobilizing possibilities of shame, guilt and embarrassment for everyone – including the elderly person.[92] Society must move from providing health only to the residue of a person's health and dignity, to providing long-term care services that views caregiving as a collective societal concern, not merely a private matter. One viable approach to this is through social insurance.

Such products could be designed to provide formal and informal long-term care services to all chronically ill elderly who are in need. Universal compulsory social insurance programs such as Medicare work as a distribution channel for payment for health services because they create large risk pools while avoiding the stigmatization and stereotyping that often occurs with means-tested programs such as Medicaid.[93] Social insurance for long-term care would eliminate the need for a chronically ill elderly person to expend their assets and risk emotional and financial impoverishment. The compulsory draining of lifetime savings for long-term care actually discourages people from planning and saving for care in the first instance.[94]

Paying into social insurance in the same way that people pay into Medicare through payroll taxes would help to ensure lifelong, intergenerational risk sharing and would further ensure that caregivers and the elderly would obtain at least a minimum of basic long-term services – driven largely by coverage limits and insurance product design. According to Rosemary Tong, publicly funded eldercare would force society to engage in dialogue about caregiver and cared-for vulnerability as well as how the care is distributed between the state and

the private caregiver.[95] And, while the creation of social insurance for long-term care would only partially address the question of how much to pay for these services, it would at the very least address *who* should pay for them.

Coverage would require the establishment of care standards and quality measurements for formal and informal care, however, those considerations are beyond the scope of this essay. Nevertheless, for social insurance to be developed effectively and to receive broad support and acceptance of prospective beneficiaries, the insurance must be functionally based, not population centered. That is to say, it must include coverage for other long-term care stakeholder groups, including those intellectual and physical disabilities, who may or may not be elderly. To that end, it is important to note that despite ageist thinking, and the fact that chronic illnesses and disabilities positively correlate to age, aging does not necessarily equal disability.[96] In sum, new social mechanisms to provide long-term care must be created in response to social changes, particularly in the nearly 50 years since Medicare and Medicaid were enacted.

5. C.   Reshaping Public Policy through Ethic of Care and Compassion

Families and other informal caregivers must be empowered and enabled to discharge their duties to care for their elderly. Similarly, society must be able to sufficiently meet the healthcare needs of their most vulnerable citizens. The ethically accountable healthcare organization has a moral duty to respond to the needs of these stakeholder populations and provide later-life experiences that preserve human dignity and self-respect. The HCO is uniquely empowered with authority to effectuate the change necessary to fulfill these needs. To that end, it is necessary for them to engage and work to reshape public policy to better target benefits to those with the greatest needs. As Weber suggests"[h]ealthcare organizations are major stakeholders in public health policy…through either their own government affairs offices

or the efforts of advocacy organizations such as the American Hospital Association, the American Medical Association, and the American College of Emergency Physicians."[97] As such they are powerful influencers, and the value of their voice to serve this community of stakeholders cannot be overstated.

With the patient at the center of an imaginary hub and spoke model, the delivery of appropriate, affordable and quality care depends upon the relationships between the encircling and interconnected communities of stakeholders. These multi-stakeholder communities include, family, professional and facility providers, social workers and therapists. Many stakeholder groups are often strategic partners not typically aligned with healthcare systems.[98] These communities are further influenced by, facility administrators, state, local and federal governments, and professional associations who establish standards of care, transportation agencies, as well as third party payers. In addition, certain extenders such as religious communities, social and civic organizations and volunteer agencies can be collateral caregivers and are integral to this model.

Acknowledging this interrelatedness, Holstein, Parks and Waymack advocate for an ethic of interconnectedness in policymaking.[99] They argue that policies that consider individuals as solely independent and autonomous persons do not have the gravity and effectiveness of policies that purport to serve the majority of the population. The interconnectedness of the individuals to their groups are bound together by the values and ethics of the group.

Since prehistoric times, humankind's survival relied upon collective team cohesion and support against life-threatening elements. That reliance continues and is amplified today, as societies are more interconnected, specialized and complex; rendering connection a prerequisite for survival physically and emotionally.[100] HCOs and policymakers can more readily effectuate

policy changes to expand access to long-term care, once they acknowledge the need for such access and understand the interconnected community values and experiences attributed to it. Interconnectedness requires that policies represent a commitment to what Holstein, Parks and Waymack refer to as "intergenerational solidarity" and a rejection of the view that individuals and families can address the economic and social difficulties of caring for their elderly family alone.[101] They depend upon resources and support from the wider community.

However, ethical healthcare policy making, and specifically long-term care, is not just about allocation of limited resources. Ethics, according to Smith, "[i]s an unparalleled regulator of value selection and must therefore be factored into the formulation of a national elderly healthcare policy."[102] It is about compassion, and understanding the voices of those in need, the ethical principles guiding decision-making, and the care that undergirds those decisions.

5. C. 1.   The Ethic of Care.

"Everyone who reaches adulthood does so because someone else cared for her or him."[103] The simple truth of Groenhout's account illuminates the reality that care is an emotion involved in providing for the needs of another, and is indispensable for human life.[104] Caring is not theoretical. It is an empirical reality that begins before birth in the form of a primitive caring relation, and the survival of the infant is wholly dependent upon continuation of that relation.[105] Such caring, for Carol Gilligan, entails "paying attention to seeing, listening, and responding with respect… it is a relational ethic grounded in a premise of interdependence."[106] Hence, as a normative theory of ethics, ethic of care arrives at moral decisions and actions from the understanding that is acquired from interpersonal relationships.

For Virginia Held, "care has many forms, and as the ethics of care evolves, so should our understanding of what care is."[107] Nell Noddings espouses that caring "[i]nvolves attention,

empathetic response and a commitment to responding to legitimate needs. It is sometimes referred to as an attitude, but it is more that; it is a set of dispositions to respond positively to in interpersonal relations.[108] She further argues that it "[i]s not merely a fuzzy feeling, nor is it a prescription for how all care-fors must be treated. It is a moral response to expressed needs."[109] Because it is relational at its core, the moral response is not only individualistically expressed; it is collective.

The fact that lives are interconnected, and that isolation and misguided autonomy increase the probability of risk and vulnerability, underscores the need for an ethic of care and collective responsibility.[110] Recognizing the relationship to those most vulnerable, care is further defined as "practices of responsibility in which the different persons involved take responsibility in a process of reacting to vulnerability."[111] According to Vanlaere and Gastman's personalist approach, "the dynamics and content of care are determined by the proper nature and origin of the relationship between these persons, the vulnerability of the persons, and the context within which the care takes place."[112] The most consequential common denominator to all of these perspectives for health *care* is the human relationship that binds stakeholders, and the ethic of care model that guides actions and decisions.

Healthcare is about human relationships. The traditional medical model approach to care recognizes the interdependent interactions between clinician, patient, and third-party payers for the purpose of diagnosis and treatment of disease or conditions, and payment for services. However, many more stakeholder relationships are involved when in-home and other community-based long-term care services for the elderly are considered.[113] In addition, there are social determinants that can also cast significant impact on the care, quality of life, and health of the elderly such as proximity to children, access to food and nutrition requirements, adequacy of

clothing and shelter, social isolation and access to healthcare services generally.[114] For a number

of reasons, these factors are not always apparent or made available to the provider of services

under the medical model, and are often not considered in the care plan. Adherence to the ethic of

care model brings these additional factors to the conversation because it supports a collective and

communal, rather than individualistic approach to care.

This communal care ethic does not vitiate the liberal notion of living freely and

autonomously, but rather reinforces the connectedness and sameness that makes people who they

are and fortifies them; it is, in many ways the ethics of empathy. The ethic of care balances

individual rights, freedom and human connections. It affords people the ability and opportunity

to develop and maintain nurturing relationships. To that end, moral leaders must not forget that

humankind will cease to exist when people stop caring with, for, and about one another; and

"without carefully developed and nourished relationships of care, human life cannot be lived to

the fullest."[115]

Thereupon, it is worth considering how the Judeo-Christian tradition perceives the human

lifespan as encompassing a lifetime of dynamic mutual giving and receiving. Parents sacrifice for

their children who then sacrifice for them.[116] Catholic traditions also teach the exercise of

responsible stewardship at every stage of life.[117] When policymakers and healthcare leaders

imbed these virtues into policy and practice, the moral justification for public support of long-

term care communities becomes self-evident. Stewardship promotes the authentic good of human

beings and human society, and preserves human dignity and self-respect; with particularity, it

benefits the aged and their caregivers.[118] Importantly, human dignity transcends a person's age,

condition, gender health, religion or stage of development. The inherent dignity and sacredness

of all human life is paramount.[119]

In applying the ethic of care, a transparent dialogue must also include the voices of the professional providers and practitioners who have direct or indirect treating relationships with the chronically ill elderly. The policies they follow must also consider the challenges they encounter as formal caregivers, as well as their ethical obligations that are prescribed by their profession. At the core of this dissertation is the recognition that few relationships are more sacred than the relationship between a physician and her patient. Therefore in support of ethical long-term care policymaking, professional and facility providers have a moral duty to work collaboratively[120] and in relation with other stakeholders, to advocate for the chronically ill elderly.

While respecting fidelity to her patient, E. Haavi Morreim aptly argues that in the face of limited resources and widespread rationing, there is an urgent need for providers to advocate for their patients.[121] Within the context of care for the elderly, such physician advocacy is necessary in order to explore alternative post-acute services to support the long-term needs of the elderly patient. Effective advocacy for elder services demands a commitment to the relational aspect of care.

The traditional view of the physician's duty to her patient has been that the patient's vulnerability, illness, impairment and even ignorance created strong duties of fidelity and personal commitment to the patient. To assuage the assertions that the imbalance of power between the physician and patient unfairly compromised the patient's decision-making capabilities, the principle of autonomy permitted the patient to decide themselves, free from controlling influences.[122] However, as older patients encounter increased challenges to their self-determination, the principled approach to ethical advocacy may be insufficient.

The values of independence and autonomy fit best within the acute care setting, and have been overemphasized within the context of old age policy.[123] In long-term care, the decision-making does not typically center on single matters such as consenting to a particular treatment or course of care. It is dynamic and nearly always implicates others and their resources.[124] As suggested by Ludwick and Silva, "facilitating autonomous decision-making for patients would be very straightforward if healthcare professionals could simply designate patients as competent or incompetent to make decisions. However, in reality, decision-making is more nuanced."[125]

By adopting an ethic of care, the ethically accountable physician and HCO will see their roles vis-à-vis the elderly patient differently. Instead of merely seeing an elderly patient who is discharged from an acute setting because they are healthy enough to leave, but too frail to live without informal care, the ethic of care asks that the providers accept that they are "self-in relation" with the elderly patient.[126] It demands a degree of attentiveness that implies having sufficient knowledge of what to look for and taking responsibility for care.[127] In adopting an ethic of care, the provider will "strive to find solutions that reinforce relationship and uphold values of caring, empathy and integrity."[128] Thus, she should be compelled to give a voice to the elderly patient and advise them of alternative care settings, and even facilitate the provision of services by administering outreach to ancillary services.

A healthcare professional who becomes so imbedded in an elderly person's care enabling them to take better charge of their lives in their home care setting, contributes to the elderly person's dignity and self-respect. However, this advocacy, which arises from a normative ethic of care applied to providers runs counter to the traditional medical model of care. As illustrated earlier, the preferential medical model of high-technology diagnostic and treatment modalities

and respective payment systems which favor compensation for complex care rather than informal in-home care dis-incentivizes physicians to promote such essential modalities.

Yet, the ethically accountable provider who embraces an ethic of care, will begin to see her role in relation to the interconnectedness of the larger community and support the values and norms that will reshape public policy for the elderly. She will have clearer insight into the impact of decisions on other relationships and points of view that are important to the patient.[129] When compassion effectuates positive change for her patient through an ethic of care, this change will help reshape the norms and values for all physicians, health *care* practitioners and policymakers. Her expression of compassion is "the most noble of human relations which lets us into the personal world of the other and shares the other's pain and trouble" [130] according to Tellis-Nayak and Tellis-Nayak. Such person-centeredness can transform the culture of long-term elder care for the patient, the caregiver, and the community.

5. C. 2.   Caregiver and Community-Based Person-Centered Care

While the principle goal of long-term community-based care is respect for the human dignity of the aged and chronically ill elderly, policies must also respond to the needs of the children, in-laws, spouses and other informal family caregivers. Because, as Virginia Held suggests, "persons need to care together for the well-being of their members" and "we should not lose sight of the deeper reality of human interdependency"[131] which supports collective responsibility for caregiving. This collective recognition includes the interests of the caregivers and their resource needs; both human, economic, and spiritual.

Sound policymaking must also to take into account the needs of the changing family structure, find ways to support mutual caring activities, and challenge dangerous caregiver assumptions; particularly those that ignore the needs of women caregivers. Caregiving by

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women is the unspoken foundation of contemporary long-term care policy. That is not a surprise, as Gilligan holds, that "[w]omen not only define themselves in a context of human relationship, but also judge themselves in terms of their ability to care."[132] According to the U.S. Census Bureau findings, in 2017 56.4% of the 51 million providers of informal eldercare were women; 43.8% of them were between the ages of 45-64.[133] Roughly 36 percent of unpaid caregiving to all older Americans is provided by daughters and daughters-in-law, and sons and sons-in-law account for another 16 percent. Such caregiving typically lasts 4 years.[134]

Most often, women caregivers are multigenerational[135] and hold other primary caregiver roles – that of mother, wife and daughter - which add to the complexity of the informal long-term care model. Children of female primary caregivers are often collaterally impacted by the efforts of their mother to care for and sustain their elderly grandparents and/or parents. While family neglect, either real or perceived, is generally unintentional, it is a quite often a natural consequence of family caregiving. Additionally, feelings of stress, sadness and fatigue are commonly reported by elder caregivers and other members of the affected family.[136]

An ethic of care-based system of long-term care policies and programs will help to situate older people in the context of home, family and community without exploiting others who care for them. It will ensure that equal attention is paid to the voices of the recipients and the caregivers to ensure that reciprocal care is morally responsive care. Understanding individual voices and relationships are essential to HCO's in executing their responsibility to disrupt and be a change agent for the good of the vulnerable elderly. Gilligan contends that voices are instruments of resistance that bolster transformative change.[137] The power of voice to effectuate change is particularly evident when person-centered and compassionate care ethic is the objective.

The factors that affect health outcomes of a community of stakeholders are rooted in complex systems. As submitted by Nancy Fox, the long-term care problem is an emergent system. With complex causes, there are generally not just one or two solutions. Fixing the problem requires understanding it holistically, not just according to its parts.[138] According to Muriel Gillick, one way to consider long-term elder care holistically is to reorient the single-minded thinking about the patient as only an individual, and consider them in relation to their caregivers, their home environment, and their wider community. She contends that physicians ought to be the architect of plans that consider their homes and community design.[139] The effects of these environments can determine the extent to which a person's health thrives or fails.[140] Providing the elderly with technically competent and compassionate person-centered care that considers their health state, what they value most, and is achievable within their unique environments[141] is not merely aspirational. Noteworthy examples of person-centered compassionate care models inspired by physicians to change the culture of aging, are providing long-term care that is life-affirming, humane and meaningful for all affected stakeholders.

As a resource created by long-term care professionals advocating for culture change in all models of elder care services, the Pioneer Network was formed in 1997.[142] Its mission is to change the culture of aging in American by encouraging communication, networking and learning opportunities to create residential environments for the elderly that are person-directed.[143] As the antidote to institutionalization, the Pioneer Network advocates for caring communities for elders to live in.[144] The Network espouses movement away from provider and staff directed long-term care towards care that is person-centered; where elder preferences and past patterns form the basis for staff decisions making. Ultimately, the goal of the Pioneer Network community is to go beyond person-centered to person-directed care wherein the elderly

make their own decisions about their routines and the staff align patterns to meet their preferences.[145]

Community-based long-term care for the elderly interconnects the caregiver and the elderly patient to an environment that focuses on flourishing rather than illness. Thereupon, the Eden Alternative, an international non-profit organization was founded in 1991 by Dr. Bill Thomas, to "create a life worth living for elders in their care."[146] Its founding mission is to transform the way elder care is provided throughout the world. As of 2019, the Eden Alternative Philosophy has positively impacted more than 111,000 elder care organizations globally, through education, training and provider partnerships.[147]

According to Thomas, the bulk of elder suffering is due to the three plagues of loneliness, helplessness, and boredom.[148] The Eden Alternative antidote to these plagues is a reciprocal caregiving environment that includes plants, animals and children. As an elder-centered community, the Eden Alternative Philosophy creates opportunities for elderly to give *and* receive care. It de-emphasizes top-down bureaucratic care decisions and places the maximum decision-making authority in the hands of the elderly themselves or into those closest to them.[149] Medical treatment, according to this model, is subordinate to genuine human caring.

Also founded by Dr. Thomas, The Green House Project opened its first elder home in Tupelo, Mississippi in 2003. Thomas, a self-described nursing home abolitionist, began tearing down nursing homes and building in their stead small home-like settings designed for ten to twelve residents.[150] These small homes provide private rooms and bathrooms, bright, open kitchens and intimate dining settings similar to single-family dwellings. Without long hospital-like corridors and communal meal rooms, they are designed to closely resemble the familiar way that many of the residents lived their independent lives. In addition, because of the small, family-

like atmosphere, elder residents interact with staff and other residents on more personal levels; forming deeper relationships.

Their organizational structure is different from traditional nursing homes. Green Houses practice consistent assignment. This means that the same aides routinely care for the same few residents. This helps to promote relationship. In addition, the staff are cross-trained to work in a variety of different roles from laundry to helping prepare meals. This more consistent contact also helps the staff become aware of subtle changes in residents' conditions which helps them spot potential health concerns early.[151] To that end, research from the Robert Wood Johnson Foundation concluded that the Green House model is a preferable model of care.[152] The study demonstrated that hospitalizations and readmissions were lower than traditional nursing homes, 38 percent of residents were less likely to have pressure ulcers, and 45 percent less likely to have catheters. All of which suggests that emphasizing quality of life did not necessitate sacrificing quality of care.[153] These models, rooted in philosophies promoting person-directed, relationship-based care, are changing the culture of care for the vulnerable elderly. The ability and capacity to care for, and to be cared for by, another is united to the concept of human dignity.[154]

5. D.   The Dignity of Disability

In 2019, the Centers for Disease Control and Prevention reported that 1 in 4 adults in the United States had some form of disability. According to that report, they were most commonly seen in adults over the age of 65.[155] Despite the statistical reporting and demographics, it is difficult to measure the number of persons with disabilities, as it is not a single state, but rather a multidimensional human condition.[156] As such, understanding disability as a human condition is a complicated and dynamic endeavor.

Akin to the nature of elderly populations, disability is a condition that resides on the human life continuum. The positive and negative effects of disability can wax and wane in a variety of forms over time, affecting the ability of the person with disability to flourish. Some conditions exhibit periods of long stability, some disabilities are characterized by steadily increasing impairment, and some, particularly those that originate from injury, may even demonstrate improvement.[157]

According to the International Classification of Functioning, Disability and Health (ICF), disability is an umbrella term defining the negative aspects of impairments, activity limitations and participation restrictions affecting an individual with a particular condition, and that individual's contextual factors.[158] Defined in this matter, disability refers to the challenges associated with specific areas of functioning, and not the underlying condition itself. Specifically it looks at impairments to physical or mental functioning, activity limitations such as walking, or eating, and participation restrictions such as employment, transportation, or access to social settings.[159]

The ICF characterization of disability is concerned with the interaction between the person and their environment, which is most often where impediments to flourishing are found. The moral duty of the ethically accountable healthcare organization is to improve the human condition and dignity of persons with disabilities and palliate vulnerability by creating environments which enable them to flourish. To that end it also demands that persons with disabilities, to whom leaders are accountable because of their role as stakeholders, are afforded the dignity to live with their disability identity in right relationship with their environment.[160] Like the elderly, persons with disabilities are a heterogeneous group representing the human condition.

5. D. 1.   Understanding the Human Condition

Protagoras observed that "of all things the measure is Man; of the things that are, that they are, of the things that are not, that they are not."[161] Accordingly, in representing the human race, man was the reference point from which all things of the world were known – including what it meant to be human. Granting this subjective latitude to determine the terms of human existence to man alone was bold and daunting. So much so that more than two-thousand years after Protagoras espoused this ethical relativism, the human race has proven unable to even agree on *how* to measure its world, much less on how to universally define and measure what it means to be human. Understanding the nature of humanity, what it means to be human, and to possess those characteristics and traits that are uniquely and typically human, has been the object of attention for philosophers, anthropologists, politicians and theologians practically since the beginning of time. Humanity's ongoing search to define itself is further complicated and distracted by its unending desire to improve itself - a self not even fully understood – through technology,[162] biomedicine and genetics. In its quest to improve the human condition, humanity wrestles with reconciling the attraction of eliminating all unacceptable characteristics and traits not deemed typically human, against those held to be ideal.

To profess that someone is disabled presupposes that there exists criteria for what it means to be *non-disabled*; to be ideally human. To say that a being possesses ideal human characteristics is largely a social construct. From an evolutionary perspective, humans and their embodied nature are distinguished from other animals. They are studied according to how they live in relation to tensions within their environment, as well as in terms of human biology and characteristics.[163] They continually strive to change and break from the forces of nature. These continual changes are driven by the human reflective capacities of knowledge and intelligence.

Of course, the mere fact that humans are dynamic thinkers living in response an environment that is, at times unfriendly, does not sufficiently explain what it means to be ideally human. Irrespective of its malleability, according to Allen Buchanan's observations, a human nature possesses good and bad, common and natural, characteristics and dispositions that are impervious to change and external influences[164] – such as the ability to make moral decisions and engage one another socially. According to this view, without these and other impervious and constant characteristics, a being would not be human.[165]

The Judeo-Christian tradition has greatly influenced western thought on the question of humanness. It holds that what makes the human animals *human* is the fact that they are made in the image and likeness of God. Sharing the fact that they bear God's image – that is, His presence which remains within all created humans - human beings are in special relationship with God and serve as co-creators and stewards for humanity. As stewards, humans have divinely bestowed dominion and are responsible for overseeing things produced for the good of humanity as well for the persons producing them.[166] This dominion presupposes the duty to change and improve life for the rest of humanity. Despite the grace imbued with this stewardship, their frailties as exposed through the fall of man, illustrate that what separates humans and distinguishes them from being mirror images of God; it is their sinful nature. Before the fall, a human being was the embodiment of body and soul in perfect union with God. There was order. After the fall, the human body and its soul experienced disorder and became disengaged from God. The incarnation of Jesus Christ gave humanity a model to emulate and an opportunity to restore unity and emerge from sinfulness.[167] Human transformation is central to Christian thought. "God becomes like us so that we may be might be made like God."[168]

Both the evolutionary and theological perspectives of what it means to be human prescribe the need for humans to change and to improve. Evolutionary humans measure humanity's physical and intellectual fitness against the chances of survival and elimination of death in a hostile environment, and Christian tradition measures human sinfulness against the pursuit of Christ's redemption from an evil world through life in Jesus Christ. Human transformation is central to Christian thought. Both scientific and religious traditions agree that a fundamental human characteristic is the aspiration to become transformed into healthier, more grace-filled, productive and enlightened beings. Even with these characteristics, humanity does not provide normative rules dictating when and which parts of human beings can be changed or even destroyed in its pursuit of self-improvement. What is clear is that human life is challenged by a host of complex variables, including theological concepts, physical parameters, limitations, and even its genetic framework; which can all affect human life. This is what Walter Doefler refers to as *conditio human* or *the human condition*.[169]

The human condition – the endeavor to move humanity through these challenges and variables – is collectively seen as broken and flawed. Accordingly, the human condition, whether it is viewed theologically or scientifically is something that strives to eliminate human limitations, alleviate the suffering and improve the quality of human life and human fulfillment. Understanding the depth to which humanity may dive as it pursues elimination of limitations – particularly those perceived limitations associated with human disability – requires examination of the concepts of human flourishing and the good life. What constitutes a good life, and the quest to select the qualities of human nature which ought to be preserved, is as old as humanity itself. This thesis does not explore the many dimensions of this question, but will accept for the sake of brevity that those qualities attributed to a good life depend upon what a good life is

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considered to be.[170] This dissertation adopts the perspective that the measurement of a good life is one which promotes and allows for human flourishing.[171]

5. D. 2.   Human Flourishing: Abilities and Attitudes

As Jonathan Glover examines human flourishing, he rightly states that what constitutes a flourishing life, is not the same for all humans. Much of human flourishing relies upon the innate differences attributed to each human and their unique circumstances and environments. In addition, the good and flourishing life is only observable on the basis of life as we know it; it does not consider things untried.[172] Further, there is no universal notion of normalcy with respect to the good and flourishing life. It is "how life seems to the person who lives it."[173]

To that end, and with respect to human disability, Glover contends that while all human disabilities involve some functional limitations, the mere presence of a functional limitation does not create a disability; and a disability does not necessarily impede flourishing. A person with a disability can have a good life in the same way a person without one can be miserable. The real measurement of a disabling quality is found in the impairments or obstacles to human flourishing. To that end, much of the ability to flourish depends upon the person's reactions and responses to the circumstances and settings that confront them.[174] This dissertation will demonstrate that the reactions and responses that impact flourishing extend beyond the person with the disability, and include those attributed to the wider communities and environments within which they live. In sum, a flourishing life is not devoid of flaws or limitations, but is rather one which respects those limits and learns to live alongside rather than beneath them.

Persons with disabilities can flourish on their own, because what constitutes flourishing is dependent largely on their preferences. A disability which renders someone unable to engage in

a particular activity may not be a disability at all if the person would not value that activity or want to engage in it even if they could.[175] That is one reason why most persons with disabilities, their families and loved ones express a sincere appreciation for the lives they live according to their preferences. The joy that someone with a disability experiences in the ordinary course of their lives – the joy *they* appreciate – can be markedly different from that which the able-bodied experience; hence, the experiences are often misunderstood or ignored altogether. It is often the inability or unwillingness to identify those preferences, by those upon whom persons with disabilities depend, that impedes their flourishing.

Deficient societal settings and distorted perceptions of reality concerning persons with disabilities inhibits flourishing. For example, the absence of wheelchair ramps, poorly designed transportation systems, and the dearth of education on how to interact with persons with functional limitations impairs human flourishing, oftentimes more than the limitation itself. The ability to flourish is further hampered by cultural assumptions of what is *normal,* and society's frequent intolerance, discriminatory practices and preconceived opinions about persons with disabilities and their limitations.[176] It is the way that normalcy is constructed that creates problems for those with disabilities.[177] Such constructs and preconceptions further presuppose an understanding of the experiences of those with disabilities. Because most people rarely talk about the positive, relational life experiences of persons with disabilities, such experiences are not generally associated with their flourishing. Furthermore, the dearth of shared experiences results in more distorted preconceptions. It is for this reason that the presence of biases towards persons with disabilities thwarts and creates real barriers to their flourishing on many societal levels, including the delivery of healthcare.

The same way that ageist tendencies discriminate and disadvantage the elderly, implicit and conscious biases towards the idea of disability as well as those *with* disabilities reinforce stereotypes, obfuscate flourishing and adversely affect the good life. Implicit, or unconscious biases associate attitudes and stereotypes towards categories of people without conscious awareness. They happen automatically and are hard to control or suppress.[178] They are generally formed by personal experiences, attitudes, and culture; and develop and take shape over the course of a lifetime. Specifically, implicit biases about persons with disabilities are pervasive.[179]

While they are not consciously offensive, implicit biases reflect and reinforce stereotypes when they are directed at members of marginalized groups such as persons with disabilities. Implicit biases are typically subtle and not overtly offensive, however, they can offend. For example, when someone addresses questions meant for a visually impaired person to their companion, the message sent is that the person who is blind cannot think and respond independently. These micro-aggressions reinforce negative stereotypes.[180] To extricate the roots of biases against persons with disabilities, society must develop, through relational encounters, greater understanding of the experiences and attitudes of persons within disability communities. As a vital characteristic of human flourishing, the good life must recognize the gravity of human relationships and the experiences emanating from them.

The relationships between persons with disabilities and their families, the persons they choose as friends, and the communities within which they live can enhance and enrich the ability to flourish beyond any biological characteristic or quality.[181] Martina Holder-Franz warns that society must guard against creating a myth of normality that values people merely for their biological characteristics and qualities. With great insight she contends that life is vulnerable and relational, and persons with disabilities ought not to be judged by their *ability* but rather by their

availability for relationships.[182] Studies show that persons with disabilities generally show warmth towards their own communities and peers. And the more visible the disability – such as using walker or other assistive device, the stronger the positive attitude toward the disability community.[183] When persons with disabilities are introduced to others according to what they enjoy doing, and the friends they have rather than what they cannot do, others will naturally discover commonality with them. And with that, the desire to create relationships with them that makes life rewarding for everyone involved.[184] Relationships are necessary to flourish. "The flourishing of every person, whether disabled or not, is dependent upon others, on the support of our families, friends, communities, and social structures, as well as the cultures given to us by religious and national traditions."[185] Personhood is sustained by relationship, and what sustains relationship is love.[186]

Christian theology teaches that humans are to live in communion with each other, to share with one another and to serve one another. The Greatest Commandment is about humans and their loving relationship to their neighbor.[187] Human flourishing demands loving relationships that promote dignity, friendship and caring. Rather than adhering to attitudinal barriers which create roadblocks to flourishing, humans must be motivated by a belief in the goodness of creation and the image of a God that is present in everyone in order to reveal God's face and to allow His grace to emerge. Grace allows humanity to witness the reality that each person is limited and broken in some manner and is need of others. This enables all persons, and in particular those with disabilities, to live what Matt Edmonds calls a *graceful life.*[188] This togetherness promotes interdependence which welcomes the presence of God, and helps to eliminate the fear that often pervades the willingness to get to know a person with a disability. Christian interdependence honors the value of all individuals – despite their limitations – not by

what they can or can't do, but by simply being who they are.[189] Interdependence means persons

are dependent upon God and each other, but it also acknowledges God's *dependence* upon

everyone to be agents for God's healing throughout the world.[190]   Healing and cure are seminal

objectives often sought when justifying improvements to the human condition; particularly when

such improvements seek to eliminate disease and suffering associated with perceived disabilities.

5. E.   Improving the Human Condition of Disability

The flawed human condition seeking to continually improve human life for all persons

must reconcile with the fact that disability exists within a social world that privileges some

bodies and minds over others. Thus, it creates a world allowing some capacities to flourish while

others do not.[191] Implicit biases against persons with disabilities are further propagated by the

fact that the social world is largely designed for and supportive of able-bodied people. This

reality further stigmatizes those who are not;[192] promoting preferential communities and

lessening the opportunities for experiential relationships. It is as if societies and their cultures

were designed and formed around the presupposition that everything is to work and be

productive according to a preconceived design plan.

To that end, ableism emerged as the social prejudice in favor or persons who are able-

bodied. In its most fundamental state, ableism contends that the able body is better than the dis-

abled, and anything other than a fully able body is considered broken. Ableist thinking conflates

disability with disease, illness and pain, and can adversely influence improvements to the human

condition. According to Reynolds, ableism has been a central and unquestioned part of medicine

across its history.[193]

5. E. 1.　　The Medical Model: In Search of a Cure

Throughout most of history, the idea of disability has been a medical one. Whether the objective criteria of illness or injury resulted in rehabilitation or institutionalization for persons who were blind, deaf or mentally ill, the biological explanation of the condition defined the person. Today, classifications of diseases become the labels attached to persons with particular conditions or disorders. For example, a person possessing the clinical characteristics of autism is considered autistic, just as one experiencing seizures related to epilepsy is branded an epileptic. Such characterizations are dehumanizing, as they place the disorder ahead of the person. Inquiry into the person becomes not a question of who, but rather *what* they are. In addition, in an attempt to be precise and pragmatic, the description of the disorder presupposes the person's needs, their abilities, and disabilities.[194]

Because the *medical model* of disability views disability as a problem of the person that is directly caused by disease, trauma or other health condition, addressing such biologic matters instinctively requires medical care. The medical model relies on two assumptions, according to Iezzoni and O'Day. The first assumes that individuals will strive to *overcome* their disabilities, and the second presupposes that clinicians know what is best for their patients.[195] This model of disability relies upon objective diagnostic criteria and observations that, per se, are not demeaning to the person. However, a person's needs are linearly connected to a clinically identified abnormality, which in the spirit of medicine, must be normalized.[196] When definition and diagnoses become synonymous with disabilities, we confront what Edmonds refers to as the tyranny of normality.[197] To that end, the medical model of disability is flawed in that the association of disease or disorder suggests that there is something wrong with the person that needs to be fixed, or cured.

Still and all, medicine has enabled significant breakthroughs in the treatment of conditions affecting individuals with disabilities; many of which are attributed to extending their lifespan. Advances in medical technology, including devices, pharmaceuticals, surgery, and the creation of new clinical care pathways have added years to lives.   For example, due to multiple medical advances, the life expectancy of a person with Down syndrome has increased from 20 years in the 1980s to more than 60 years today.[198] Because of developments in cardiology, people with Becker muscular dystrophy are living decades longer in the 21st century.[199] Such life-extending advances improve upon clinical understanding of disease as well as diagnostic and therapeutic successes.[200] Nevertheless, the World Health Organization cautions that adding 'years to life' is devoid of benefit without adding 'life to years.'[201] Lengthening life-expectancy without mitigating vulnerability and enabling flourishing merely transitions the person with a disability from one vulnerable stakeholder community to another.

Embodiment is the crux of the medical model. It defines the disability as a physical property of individual that requires medical intervention, according to Tobin Siebers.[202] In essence, this model proposes a superficial distinction between disability and ability. Chiefly that disability is a medical matter, while ability concerns ones natural gifts, physical prowess, imagination and the capacity and desire to strive – the essence of the human spirit.[203] Because the medicalization of disability holds that something is wrong with persons with disabilities, to the extent that they are underserved because they compete with other groups for resources, this model generally regards that *they* are the source of their own problem.[204] They lack ability.

Paradoxically, this perception of inability materializes and is very often compounded into reality within the care environment. As a delivery mechanism for medicine, the healthcare setting according to disability advocate Alicia Oullette, is "a dangerous and difficult place" from

the perspective of disability.[205] Those with mobility limitations may have difficulty entering

exam rooms, using physical examination tables, or mammography and other imaging

equipment.[206] Communication issues are also associated with general access issues, but also

relate to the ability or inability of the care provider to recognize the person's capacity to hear or

understand what is being said.[207]

Oullette further contends that bioethicists perpetuate the problem by applying decision-

making frameworks that legitimate biases when determining when it is appropriate to use

medical technology to promote health and maintain life. In particular she argues that they rely

on assessments of health, medical appropriateness, quality of life and familial best interests to

justify decision-making for persons with disabilities. Factors which ignore the unique cultural,

social, and personal aspects of the disability.[208] In addition, they are often assessed from the

paternalistic perspective of the non-disabled bioethicist, clinician or physician, supported by the

medical model undercurrent that the defect must be cured if the person is to achieve full capacity

as a human being.[209]

The distinction between cure and healing is frequently blurred. When the word *cure*

appears in the English language, it typically refers to the elimination of a disease and its

symptoms.[210] A cure is sought in order that a person may be restored to the same health and

physical condition as before the disease appeared, or as if it hadn't appeared at all. If a cure

seeks to eliminate disease and suffering, it must be distinguished from *healing* which, as Nancy

Lane asserts, is a *process* of integration and wholeness and not simply being free from illness,

and is not necessarily a physical manifestation. According to Lane, healing is letting go from

false and unrealistic expectations. Healing allows one to live with a disability rather than suffer

from it.[211] Healing brings about grace, peace and well-being and often involves finding a sense

of meaning and purpose – a spiritual wholeness, but not necessarily a cure.[212] Accordingly, a healing may or may not include a cure, and a cure clearly does not ensure a healing.

Because society traditionally perceives healing very narrowly and typically recognizes it only in the physical improvements and manifestations of those persons with an easily detectable disorder or disability, its inclination is to follow only the physical effects of the healing or cure. This tendency severely limits how society ought to see the collateral, life-affirming, impact to the able-bodied as well as disabled persons who are spiritually healed, even in the absence of a cure. To find a cure, society turns to the medical arts. By exercising prudence, religious traditions espouse the view that humans can intervene as stewards of the faith and co-creators of life to cure *and* heal; seeing medical professionals as God's agents on earth.[213]

It is in society's best interest to place a high value on health and well-being, to value good health over ill-health and to reduce morbidity and improve overall health. However, as Wilkinson correctly argues, placing a high value on good health, ought not to conclude that those who are ill or disabled are valued less. The value of health cannot mean that less value is accorded to those who are blind, paraplegic or cognitively impaired. Important to this is the objective reality that one who is disabled is not necessarily unhealthy. A particular impairment may be unassociated with any disease pathology. While presumably most people would prefer being able-bodied to being disabled, and healthy rather than unhealthy, the reality is that much of what is considered *normal* and *able*, and the attitudes about certain illnesses are subject to normative belief.[214]

The medical model provides very little, if any, understanding of the descriptive realities of disability, and there is little incentive to investigate beyond what it takes to fix the impairment. Moreover, the medical model misses the universality of disability. Failing to see the ubiquity of

disability is incongruous with the reality that even the most robust members of society are only temporarily able; in time, all are broken to some degree.[215] As such, the ambition to fix impairments appears unreasonably and unnecessarily aspirational. So, a principle issue for contemporary society seeking to improve the human condition is whether it is right to judge what it means to be healthy, normal, and able; and in particular to determine the state of any future person by eliminating disability through genetic intervention.

5. E. 2.   Genetic Interventions: A Search for Perfection, or Path to Flourishing?

There are inherent cultural and societal challenges in determining which human characteristics render a person able-bodied or disabled, or *normal* versus *abnormal*. However, applying a medical model that relies on the human genetic code can prescribe a predictable baseline of acceptable and healthy genetic characteristics. Influenced by the principles of beneficence and autonomy genetic technology and medicine undergird the duty to improve the human condition by preventing mortality, morbidity, and disability.[216] This is so because genetic technology has the capacity to fundamentally change human nature by preventing the birth of certain persons who may have a disease or disorder for which there is no cure.[217] Understanding the societal impacts and the human practices that result from genetic technology[218] is an imperative that must begin by examining its deep roots in the evolution of eugenics.

The term *eugenic* was coined in the late 19th century by Sir Francis Galton to refer to those who were *well born* and was applied to the study of heredity.[219] For Galton, Charles Darwin's cousin, heredity centered on discovering ways to improve the genetic makeup of the human race by removing undesirable individuals from the societal gene pool. These studies and subsequently well-funded eugenic movements in the United States clearly did not reflect the American principle that all men are created equal. Yet, the U.S. Supreme Court decision in 1927

upholding the eradication all *imbeciles* through forced sterilization bolstered and fortified this movement.[220] Henceforth, it became an obligation and reproductive duty of all good citizens who were the *right type,* to leave behind their blood in the world through procreation, and to prevent the *wrong type* of person from reproducing. A form of birth control, forced sterilization laws mandated that prisoners, residents of mental facilities and paupers – those deemed manifestly unfit – be irreversibly prohibited from reproducing. [221]

It wasn't until Hitler's perverse world of eugenics, genocide and mass murder resulted in the systematic execution of those persons classified as *defective* that the American eugenics movement began to die. Eventually, any association with Nazi eugenics was shunned. However today, eugenic-like conduct has been reintroduced into American culture. In contemporary times, eugenics is typically characterized as a study of the conditions under which the human condition or the biological character of the human race and its offspring can be improved. For Wilkinson, it is not whether eugenics expressed in this manner is intrinsically wrong, but rather, whether or not a particular form of eugenics is morally acceptable or not.[222]

Often influenced by political and social controls, *positive eugenics* occurs when the goal of a eugenic activity is to produce humans of high quality by increasing the *good* gene pool – to enhance the human condition. And *negative eugenics* seeks to reduce undesirable genes that cause disease and disability – to prevent harm to the human race by minimizing the number of sick babies born.[223] The positive and negative dichotomy of eugenics and the motivating factors for each type, determines whether disability is seen as a defect requiring enhancement or elimination, a condition that seeks healing, or as an illness seeking a cure.

Mahowald contends that negative eugenics under the guise of genetic advances appear largely through prenatal testing, the killing of embryos, and abortion of fetuses with genetic

disorders. This is evidenced in the way that the presence of the single trait of Down syndrome or other chromosomal anomaly has come to define the whole person in utero without ever getting to know the rest of the person.[224] To that end, Jeffrey Bishop contends that the objectifying tools of medicine – ultrasounds, prenatal testing and screenings – reduce the disabled fetus to a faceless object in the womb.[225] It is in this sense that modern medicine, in its endeavor to prevent the coming of a person, leans towards negative eugenics. It is also in this way that the person born with a genetic anomaly and functional disability is vulnerable to becoming a dehumanized dysfunctional object.[226]

For some opponents like Joseph, prenatal testing is a form of backdoor eugenics, and for others like David Wasserman, genetic technology could be used irresponsibly to deliberately create children with disabilities.[227] Such selective impairment is controversial and uncommon, but not fictional or imaginary; as shown by the McCullough and Duchesneau case involving an American deaf lesbian couple who deliberately selected a congenitally deaf sperm donor to successfully give birth to a deaf daughter.[228] Wasserman also maintains that preconception and prenatal selection are incompatible with the unconditional welcome that parents should exhibit towards their unborn child.[229] Ethicists who argue against eliminating disability aptly contend that genetically screening out and deselecting disability, or even attempting to correct characteristics of disability in the absence of a diagnosis, advances the view that the objectified person is unfit. Such beliefs may be projected onto the persons themselves. And even ethicists who support negative eugenics admit that continued efforts to reduce the number of sick babies will increase the list of unfit characteristics, qualities and conditions to be eliminated; further propagating discriminatory ableism.

Contemporary eugenics, particularly selective reproductive techniques such as preimplantation genetic diagnosis (PGD) emboldens preconceived notions about what kind of life is desirable versus those that are less meaningful, have less purpose, and deemed unworthy to live.[230] For Wilkinson, the notion that deselecting embryos that are believed to carry a disabling condition in order to avoid creating a low-quality life is unacceptable. He asserts that the happiest person with a disability will likely experience a better quality of life than the most miserable able-bodied person.[231] Wilkinson further contends that selective reproduction such as PGD and prenatal testing accompanied by selective termination presents the risk that present and future children are commodified, discarded and replaced with a more desirable variety.[232] Similarly, Paul Ramsey considers all forms of genetic control unethical arguing that positive eugenics suffers from cultural influences determining normalcy and defect. Instead, he favors very limited negative eugenics through voluntary childlessness and avoiding pregnancy altogether if a known genetic predisposition existed. Taken further, some ethicists see eugenics as genetics in the absence of Christian thought.[233] On balance, however, not all efforts to improve the human condition through genetic interventions carry the indicia of negative eugenics.

Although it is possible to improve the human condition and create opportunities for people to flourish in the absence of biological interventions, disease avoidance typically involves some physical interventions. Population screenings administered to preemptively identify conditions, and testing to determine the probability of having a child with a hereditary condition are methods of disease avoidance commonly employed today. Appropriately administered and consistent with approved criteria, many screening techniques improve the lives of children with certain conditions.[234]

Newborn screenings were considered revolutionary when introduced in the 1960s, and now detect and provide early intervention health benefits and treatments for more than 30 genetic diseases and abnormalities. Pre-symptomatic identification and diagnosis can help to establish early intervention treatments such as introducing dietary modifications to avert a life-threatening consequence; and moderate the effects of a disease while improving prognosis. In addition, advocates further suggest that screening can assist parents in their future reproductive planning and avoid a *diagnostic odyssey* once actual symptoms present.[235] To that end, newborn screening provides a mechanism for human flourishing which serves to avoid needless suffering for newborn children and their families in order to improve the human condition without controversy. Although, as mechanisms for improving the human condition, newborn screening and carrier/prenatal testing are opposite sides of the same coin. While the presumed intent of newborn screening and prenatal testing is to create a healthier world, the primary difference between the two turns on the choices future parents make.

As partners in care, and because they wield enormous power over the care and treatment of persons with disabilities[236] ethically accountable healthcare organizations and their clinician leadership also play a crucial role in these decisions. The scope of their influence on the human condition extends beyond the constraints imposed by the medical model of disability. Their influence and actions depend upon adoption of ethic of care and disability ethics frameworks to enable flourishing lives.

5. F   Creating Enabling Environments through Ethic of Care and Disability Ethics

Joel Reynolds attributes negative health outcomes, ill-conceived state and federal policies, oppression, discrimination, and stigmatization of persons with disabilities to clinician misunderstanding of disability and the resultant miscommunication between them. He argues

that anyone who wants to improve their understanding as well as improve health outcomes must first reflect upon "the meaning of disability and the moral obligation and responsibilities owed to communities of disabilities."[237] The medical model of disability, with its reliance on medical description and labeling, is largely responsible for much this knowledge gap. Pathology alone does not prepare the healthcare professional to contribute to a flourishing life for patients with disabilities. The impetus to transform healthcare organizational leadership in this milieu is derived by examining its moral obligation through the lens of ethic of care and disability ethics.

For Jackie Leach Scully, there are two ways to consider disability in terms of ethics. She distinguishes the ethics of disability from disability ethics. For Scully, the ethics of disability reflects upon the morally correct way to behave towards persons with disabilities in everyday interactions such as employment policy, law, and healthcare.[238] The ethics of disability implicates normative moral behavior based on what has been determined necessary and appropriate for persons with a disability. It derives its normative standards from the medicalized view that disability is a nominative pathology – a deficit that is determined by reference to a norm of physical or mental function.[239]

Offering a differentiating view, Scully refers to disability ethics as "the particular moral understandings that are generated through the experience of disability."[240] That is to say, it is a form of ethical analysis that is "consciously and conscientiously attentive to the experience of being/having a 'different' embodiment…disability ethics looks at the embodied effects of impairment." [241] Understanding disability through the experience of one with a disability provides needed insight into the judgments of the moral issues in disability communities. Scully advocates undertaking a phenomenological approach to understanding the embodied experiences of persons with disabilities.[242] Unless and until ethical analysis moves beyond merely

understanding the features of disability, and towards the perceptions and understanding of the world of disability, Reynolds' gap of understanding and attendant biases will persist. Assimilating the experiences of persons with disabilities into a culture of disability ethics entails starting from a collective perspective on the giftedness and of every person, explicitly those persons with disabilities.

5. F. 1.   The Gift of a Flourishing Life

To live and thrive within an optimal range of functioning does not demand physical or cognitive perfection. It first entails embracing all life as a gift through acceptance, tolerance, and stewardship that capacitates a good and flourishing human life.   A good life that enables human flourishing is measured and enriched by the experiences, opportunities and even the choices available to that person. Although, with respect to choice, Hans Reinders asserts that what accounts for having a good life is not whether a person would choose to live their life again, if given the choice. But rather, such account is found in the recognition that their life is good merely because *being* is in itself good.[243]

The goodness of human life must also recognize that humanity's exercise of free will and choice can run counter to the argument that all human beings are good. According to Aquinas, humans can exercise their free will to perfectly or imperfectly actualize their natural capacities.[244] When such faculties do not function properly and result in imperfect reason and choice, the human being is imperfect; as evidenced by the choices giving rise to humankind's fall. However, reliance on perfection of the human capacities to establish human goodness is antithetical to persons with profound disabilities, as many of their capacities may exist only marginally; if at all. According to this account, disabled persons lacking capacity are

imperfect.[245] For all that, reason and proper faculty functioning alone cannot account for the goodness in persons with disabilities. There needs to be something more.

Fortunately, that something more is found in the Judeo-Christian tradition espousing that life is good because it is given with divine intentionality, and cannot, therefore, be anything but good. The goodness of life is a gift of divine goodness – a *donum*; a gift and giftedness that has a divine purpose.[246] Life as a gift is received from God who intended it to be good and is grounded extrinsically in God's act of giving.[247] The goodness of life, therefore, is preordained because of its giftedness.

The goodness of human life turns to humanity's willingness to learn how to acknowledge giftedness, respond to Him, and find peace with Him. God's gift of life cannot be returned if it isn't exactly what was desired, or doesn't quite align with normative beliefs. Gracious recipients of gifts know that the highest compliment a person can pay the giver is to show gratitude, and to love, protect, and care for the gift. This good and great gift of human life was created by God. He gave it to humanity to guard and protect, and to be its stewards.[248] And so it is that the highest expression of gratitude a human can give God is to thoroughly respect and care for their good life,[249] and empower it to thrive.

Recognition of giftedness is empowering to persons with disabilities. Scarlet fever left Helen Keller deaf and blind at 19 months-of-age. Yet her life story is "a paragon of several key virtues…that commonly constitute a good life: courage, strength, resiliency, self-knowledge, compassion and wisdom"[250] Despite immeasurable odds, her life's triumphs included achieving academic excellence at the most prestigious universities. Empowered by her experiences as a disabled woman, she established the American Civil Liberties Union, and exemplified a life of advocacy and inspiration. Her life was not something to be judged against the idealized norm of

a life typically stifled by such debilitating limitations. That is to say, Keller didn't flourish as a disabled women. She flourished as a person first. It was the context of her disability – its giftedness - that made her flourishing what it was.[251]

Autism is not a barrier to flourishing for William Stillman. An award-winning author and internationally recognized autism support advocate, Stillman is the founder of the Pennsylvania Autism Self-Advocacy Coalition. He has educated state and federal government leaders and program sponsors, as well as families and caregivers, on the giftedness of persons with autism. As a writer with Asperger's Syndrome, his works have illuminated the giftedness of persons with autism by telling their stories of extraordinary spirituality and sensory capacities that very often exceed those of persons not on the autism spectrum.[252] He describes how an inability to produce verbal speech is not a barrier to communication for persons with autism who may understand dormant telepathic intuitions by merely observing the verbally communicative world.[253] Keller and Stillman's lives exemplify the giftedness that is made manifest through disability. Their victories, in harmony with their giftedness, afford communities the opportunity to celebrate and embrace them as such.

As all of humanity are called to be co-creators with God, the duty to respect and care for the giftedness of the good lives of others is obligatory. The Catholic Church and other Christian faiths recognize the duty to be stewards for Creation and improve the human condition through activities that demonstrate a continual respect for human life. It is a communal imperative that calls everyone to accept the giftedness of the disability "without resentment, receiving and giving love as companions together in God's time."[254] Improving the human condition of disability by receiving the gift of life in this way involves the collective willingness of persons and groups. It calls upon the receptivity of the person with the disability, the community in which they live, and

their family or caregivers. Illustrated this way, acknowledging the giftedness of life is triune as it is interdependent on the presence of God within each of those three bodies of persons.

William May further illustrates this unity of persons as one centered on proclaiming the Gospel of Life by caring for others for whom God has made humanity responsible.[255] To proclaim the Gospel of Life in this way, requires communities to enter into relationship with, and help to empower and support people who suffer or are otherwise vulnerable; particularly in this context, persons with disabilities. In confronting the moral duty of the HCO, May contends that "a unique responsibility belongs to health-care personnel: doctors, pharmacists, nurses, chaplains…administrators and volunteers" and those in relation, to build a new culture of life that considers the inviolable worth of every human life.[256]

For Eva Feder Kittay, persons with disabilities should not be seen outside of those connections and relationships that have infused their life with value. In the same way, others in relationship with persons with disabilities should not see themselves as separate from them. The carer and cared-for coexist within an inextricable bond that defines and nurtures the dignity of the persons.[257] Moreover, care, whether given or received, is an indispensable and central good; and for Kittay, it is impossible to have a life of dignity without care – it is an expression of a person's dignity.[258]

Though inextricably bound, the contextual vulnerability that is constitutive of disability draws forth the reality of mutual dependency – or *interdependency* - between the carer and the cared-for. Just as the ethically accountable healthcare organization is an interdependent construct, its normative stakeholders are also interdependent and rely upon the relational quality of their human interactions with providers of care. To that end, care and interdependency undergird the ethic of care in disability. As Kittay beautifully portrays, "giving care to another

infuses the other with the worth of the one who does the caring – to do damage to the cared-for is also to violate the caring individual."[259]

By its very nature then, the ethical accountability of HCO leadership, specifically concerning its clinicians, researchers and providers of care, must see themselves as 'selves-in-relation' to their patients and other stakeholders with disabilities. These providers of care must come to understand that their sense of well-being is also tied to the care and well-being of another.[260] Over and above the imperative of interdependency, the moral duty to protect and care for the vulnerable rests with those who are most empowered, and especially those to whom a person is most vulnerable.[261] For Kittay, authority and power to care for the vulnerable is paramount because "providers of care…have to co-exist with the individuals they care for…they exert direct control over the minutiae of the life of their charge."[262] Hence, their moral duty to enable flourishing and effectuate change in the lives of persons with disabilities is unequivocal.

5. F. 2.   Ethics and Removing Disabling Barriers

Disabilities, as part of the human condition, are contextually vulnerable. They are so in part because they are the "product of a social response to embodied difference, not just as an individual pathology."[263] This social response is the central point of the social model of disability. In contrast to the medical model, the social model "shifts attention from a medical description of a person to a consideration of how the environment creates obstacles for people who have disabilities." It purports that society's social, political and physical arrangements need fixed, not the person with the disability. [264] For Scully, the social model suggests that disability is a product of the interaction, at both personal and structural levels, between the physical or mental impairment and the social world in which the affected person lives.[265] To illustrate simply, it is not the mobility impairment that prevents the person in a wheelchair from entering a doctor's

office for care; it is the absence of wheelchair ramps, and even more significantly, it is the gap in understanding the experiences and preferences of that person. And to that end, the model anticipates a commitment from society and its accountable members to promote mutual understanding and effectuate change.

According to Tobin Siebers' perspective of the social model, disability is not reduced to a physical or mental defect, but is rather a cultural and minority identity. For Siebers, to refer to disability as an identity means that it is "an elastic social category both subject to social control and capable of effectuating change."[266] That is to say, that the cultural and minority identity of disability is powered by a force and a voice that can be effective and audible, or stifled and disempowered. As with other minority identities, disability suffers from negative connotations, such as ableism. Healthcare leaders have an obligation to comprehend the effects of the social model of disability on the community of persons with disabilities they serve, and to reverse these negative connotations through their actions, and by innovating for change.

Michael Oliver posits a most determined social model argument, asserting that illness may be caused by disease, and impairment by some injury or condition, but disability is caused by social organization.[267] According to this analysis of the social model, social organizations actually create disability and disadvantageous conditions when they discriminate against persons with impairments, through ignorance, exclusion and isolation. The inability to participate in mainstream social activities is deemed the fault of society, culture, and the environment; not that of the underlying condition or impairment.[268] Oliver's assessment of the social model does not ignore the significance of impairment on the fulfillment of human flourishing, and does not diminish the importance of medicine or therapeutics. On the contrary, this model acknowledges that the disabling condition is in many ways due to the lack of medical and related services[269]

that ought to be provided through social constructs and persons with authority. All intended for the sake of furthering a culture of life.

Building a culture of life must consider other impediments to flourishing that can be influenced and even *deconstructed* by those with authority. For example, social determinants of health refer to the socioeconomic, psychosocial and community systems that contribute to disparities in access to healthcare. These overlapping and intersecting categories can also impact access to employment, education, and other aspects of life. Wilkinson submits that social determinants of health such as poverty, poor schooling and environmental causes can particularly impede flourishing for those with disabilities.[270]

Statistics show that individuals with disabilities are more likely to experience difficulty securing employment, receive preventive health care services, and gain access to and use health information technology, compared to those without disabilities.[271] These determinants coupled with environmental conditions and barriers, amplify the disparities and compound the negative impact to flourishing. The World Health Organization established recommended principles to address key issues in order to achieve health equity among persons with disabilities and to mitigate impediments to flourishing. These issues include the need for better health data to inform program development concerning critical issues of health disparity; the need for evidence-based health and wellness programs that can be transferred from clinical settings to community-based programs to promote greater access; and the need to improve facility/environmental designs and public and private infrastructures[272] Instituting these principles to serve as a catalyst for change involves the explicit and affirmative obligation of ethically accountable healthcare professionals.

Given the interdependency that is inherent in the relationship between the provider of healthcare and the person with disabilities, the effectiveness of that relationship first calls for reconciliation between the experiences of the disability community, and awareness of its healthcare providers. For Oullette, establishing an informed *disability-conscious* requires that the healthcare community engage in civil discourse with disability scholars, advocates and experts to understand the cultural and social dimension of disability.[273] Although Oullette's work centers specifically on disability-consciousness in bioethics, the framework she suggests for developing disability-consciousness is adaptable to the care provider and social communities. She contends that carers ought to incorporate principles such as respect for inherent dignity in all decision and action points; including, for example, avoiding language and terminology that offends such as "abnormal" and "normal."[274]

Clinicians also have responsibilities to develop what Reynolds refers to as a *disability humility*. Such humility is directed to learning about the experiences, cultures and history of disabilities. It also entails a willingness to admit that understanding the dynamic condition of disability will never be complete.[275] Studies show that physicians may be poorly prepared to meet the medical and psychosocial needs of this community that are required to create environments that support good care and positive experiences"[276] because they lack formal training. The absence of life span perspective on care is particularly evident when patients with disabilities transition from pediatric care to adult care physicians. Moreover, "clinicians and members of society at large have a responsibility to educate themselves about disability and actively work against the effects of ableism that have long undermined the justice and effectiveness of health care delivery."[277] This responsibility mirrors the cultural humility required to understand the pediatric and elderly communities.

When disability humility prevails, clinicians will also recognize and act upon their responsibility to communicate more effectively with their patients with disabilities. Their deference to the disability perspective will enhance their ability to listen. And, they will come to appreciate and respect the authority of those with disabilities as experts about their own lives and community experiences.[278] Disability humility will help to lift the voices of those with disabilities far above the barriers that very often silence them.

Removing the barriers to flourishing is a matter of collaboration. It calls for initiating enabling environments that respect the identity of disability, reverse negative thinking and ableism, understand the culture of disability, and promote access to care that is dignified and welcomed. In the traditional model of care, the relationship between clinicians and patients promote clinicians as experts in what is best for their patients, and patients as passive to their direction. This paternalistic posture intensifies the vulnerability of patients with disabilities. The collaborative care model, however, departs from this traditional view.[279]

According to this model, clinicians and patients share their expertise. Clinicians are experts in diseases and conditions, and patients are experts concerning their own lives and preferences.[280] Together they identify problems, issues and health management matters and collaboratively set goals that are jointly managed. The share responsibility and work interdependently, however clinicians teach patients how do self-manage their worlds to help them flourish independently, as much as possible.[281] Collaboration in this way not only unleashes the voices of persons with disabilities, it admits to their rights and responsibilities, their individual and collective identities, and their capacity to flourish in right relationship with their environment.

5. G.   Conclusion

While vulnerability is an ontological condition that impacts all beings across the across the human life continuum, consequences and conditions render certain stakeholder populations more susceptible to physical, social, emotional, and economic harms. Vulnerability is amplified by aggravating influences such as biases, negative public policy trends, societal and cultural pressures, and barriers to flourishing within particular environments. The healthcare delivery setting is one such environment that, very often, intensifies human vulnerability. Because individuals and organizations with authority and power to impact the lives of at risk populations have a moral duty to attend to their interests, improving the human condition for vulnerable stakeholders is a moral imperative of the ethically accountable health care organization.

The elderly and persons with disabilities are particularly vulnerable stakeholders who are often victimized by disempowering and discriminatory biases that threaten their dignity, deny them needed healthcare and services, and prevent them from flourishing. Cultural, political, and medical models can undergird and promote ageist and ableist tendencies that adversely influence opportunities to meet the unmet long-term care needs of the elderly, and create barriers for persons with disabilities. While medical advances and technologies have made it possible for both of these stakeholder groups to add years to their lives, the challenge for accountable healthcare professionals is to ensure that those years are filled with lives that flourish.

To enable and empower these vulnerable individuals to experience a life that preserves human dignity, autonomy, and respect for the giftedness of all human life, policymakers and healthcare communities must focus on the interdependency and interconnectedness of care. To that end, ethically justified care for the elderly must shift its focus to community-based

interdependent relationships. Relationships that support low-technology, informal care standards based on the ethic of care.

Improving the human condition for persons with disabilities entails recognition that the goodness of human life is not determined by physical or mental perfection, but rather by its giftedness. The giftedness of human life requires acceptance of the responsibilities that all have to one another as stewards in relationships of care. It also requires recognition of the mutual dependency between the one providing care and the one to whom it is provided. The interdependency that is inherent in the relationship between the provider and the person with disabilities calls for the provider community to establish a disability consciousness that is strengthened by disability humility.

Healthcare is about relationships. Relationships which, as they span the life continuum, are comprised of bi-directional interactions and care experiences that represent the dependency of all human life upon one another. The objective truth is that no one exists who has not been cared for. For the human condition to continue to evolve and improve, the ethically accountable healthcare organization must remain in relation with its most vulnerable stakeholders to satisfy their needs, and to ensure that their moral response to those needs is cloaked in care.

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Chapter 6 - Conclusion

Like the human body, a singular healthcare organization (HCO) is an amalgamation of affiliated and interdependent pieces and parts that provide, support, and help to sustain health for a wide array of stakeholders. Composed of facility and professional providers, insurance companies, and patients, the HCO must maintain function and order while cohabitating with environmental forces that threaten its ability to maintain organizational homeostasis. One way that organizational homeostasis is achieved and measured is through ethical decision-making in light of competing interests and values. Hence, homeostasis in this sense is observable through the ethical accountability of healthcare organizational leadership to its diverse communities of stakeholders.

Organizational moral agency is the cornerstone of ethical accountability and decision-making to support a common morality of norms, moral principles, and rules that are shared by moral persons across different cultures. *Ethics,* as it is used throughout this dissertation, represents the moral beliefs, behaviors and rules adopted by people to prevent conflict and preserve the norms of moral society. Moral soul is the distinguishing characteristic of accountable leadership; and it innervates the ethical decisions of an HCO's individual and institutional moral agents, who are the embodiment of an organization's moral soul. Just as soul is a unique attribute of humanness, the good that is attributed to an organization is manifest through the actions motivated by its soul. Moral agents act, and are unified to the HCO through its moral soul.

An HCO acts through the collective decision-making of its moral agents whose beliefs, norms, and values ought to be aligned with the organization's moral identity, as expressed through its culture of ethics. Robust ethical cultures endeavor to transfer ethical identity onto the

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organization's moral agents and decision-makers; most particularly onto and through its leadership. In as much as soul is aligned to moral agents, conflicts of interests and disengagement from an organization's values and norms can upset an HCO's homeostasis. Imprudent and undiscerning decision-making, Faustian bargaining, and conflicts of interest and conscience can weaken accountability and threaten the organization's moral soul. The Allegheny Health, Education and Research Foundation (AHERF) case study is a vivid example of an HCO's dispossession from its moral soul.

Specifically, AHERF's actions and decisions did not respect the interdependent character of an HCO. The death of its soul and its inevitable demise, gave rise to criminal and civil investigations revealing a host of individual and institutional moral deficiencies. Deficiencies which, had they been identified, communicated and remedied could have not only saved the HCO, but enabled its moral soul to remain intact for its own sake as well as that of its stakeholders. Because the moral soul of an organization is manifest through rational and systematic decision-making, it is exhibited most vibrantly when its actions yield to the interests and preferences of its communities of stakeholders.

Rational decision-makers care about the consequences of their actions, and their impact on others to whom they are accountable. The stakes and consequences are even higher in healthcare as decisions made directly affect the length and quality of human life rather than solely on products, services and profitability. Accordingly, stakeholder theory, an approach to organizational ethics that heeds to the rights and interests of those who affect, or are affected by an organization's decisions,[1] is well suited to healthcare. It shifts the managerial mindset from a focus on shareholder interests alone to communities of normative and derivative stakeholders.

Thus, it allows organizations to exercise social responsibility by applying moral theory and right behavior to management decisions.

Because of the complexity of the intertwined and interdependent interests within an HCO, applying normative stakeholder concepts such as the ethic of care, and principle of stakeholder fairness is critical to ensuring homeostasis. Both theories look respectively to the relational quality of human interaction, and to the principles of fairness that serve as an undercurrent to decision-making; as well to the moral commitment to the HCO's communities of stakeholders. Obligations between stakeholders and the idea of accountability are bi-directional and multi-dimensional. Because stakeholder relationships exist between persons or groups of persons, there is a fundamental moral duty to treat people with respect, and to recognize their human dignity. HCO's have additional moral obligations because of the role-based nature of their relationships. Depending their particular role (e.g. that of employer, enforcer, strategists, etc.), accountable leaders must act in deference to those multi-stakeholder obligations.

The duty of stewardship in healthcare underscores the tenet that all resources of the HCO are held in trust by the organization and its leadership for the good of others.[2] It is a fiduciary duty and an ethic that transcends healthcare and is integral to other disciplines. Accordingly, the diversity and vulnerability of stakeholder communities, and the balancing of competing and conflicting stakeholder claims means that ethically accountable leadership in healthcare must be cognizant of stakeholder expectations; especially those that are less obvious.

To that end, not all HCO stakeholder interests are purely corporeal. Having and keeping secrets is innately human and affords individuals the opportunity to control aspects of their life and establish boundaries between themselves and others. The ethics of secrecy underscores the importance of secrecy in healthcare as a stakeholder interest. Because few industries cut as close

to the core of what it means to be human as healthcare, the secrets that a patient conveys to her physician in the course of their relationship creates a sacrosanct duty of confidentiality that is the cornerstone of trust in that relationship.

Trust in others enables intimacy and is needed most when a person surrenders some aspect of control to another. Surrendering control of ones secrets to a powerful HCO contributes to stakeholder vulnerability. As such, an HCO's moral duty to preserve trust, promote human flourishing and respect human dignity includes recognition of the individual's right and interest in the confidentiality and privacy of their most intimate thoughts, facts, and secrets.

Although the terms are often used interchangeably, confidentiality and privacy are not the same thing. The physician's duty of confidentiality is rooted in antiquity through principles of ethics such as autonomy, and codified professional codes, oaths, laws and rules of conduct that bind the physician as a keeper of secrets. Privacy is a legal right. It is an expectation and privilege of confidentiality held by a patient enforceable by and rooted in law. Compliance with privacy mandates is a preeminent concern in contemporary healthcare as it is a core legal obligation of the HCO.

The interdependent character of the HCO which includes the divergent interests of stakeholders who frequently want patient information, practically ensures that the sharing of patient secrets is no longer binary. This reality, coupled with duty of confidentiality, and the patient stakeholder's rights and expectations of privacy present ethical dilemmas for the HCO. Oftentimes, the rights and interests that internal and external stakeholders have in patients' secrets and their other health information are in conflict with the physician's fundamental moral precepts and professional responsibilities to respect confidentiality and patient privacy. For example, information used for advanced analytics, complex care management, patient data-

dependent technologies, clinical collaboration, genomic medicine, as well as compliance with the rules of civil and criminal procedure can test the mantle of confidentiality.

In addition, technology and medical advances, and the competition for more data, better data, and immediate access to it conflict with and threaten confidentiality and privacy. Every aspect of the transformation of American healthcare is dependent on improved third party access to patient information, so much so that healthcare is predominantly now an information business. These competing values and interests underscore and challenge the physician's dual allegiance; that which she has to her patient in preventing breaches of trust, and that which undergirds her role in supporting transformative medicine.

But, not all breaches of patient confidentiality and privacy are unlawful or inappropriate. Compelled disclosures of patient information to normative and derivative stakeholders can often override the physician-patient fiduciary relationship. Disclosures necessary for public health, infectious disease control, workers compensation, litigation defense, and to prevent imminent harm to others are examples of legitimate and necessary exceptions to absolute confidentiality and privacy rights. In these cases, the law recognizes these legitimate interests and ensures that appropriate notices of certain disclosures are made to patients and their representatives to promote transparency and trust.

However, as dataism dominates and mathematical algorithms replace human discernment and thought, humans will move away from making their own decisions and move toward artificially driven and machine learning digital tools that decide matters for them, using their data. In healthcare, a large part of data-centered decision making control has already been ceded to algorithmic analysis, but not necessarily at the will of the patient. Beyond threats to individual control and privacy, algorithmic inferences can result in discriminatory biases fueling decisions

that are harmful to the patient and other stakeholders. The future of privacy in healthcare is more than the maturation of a legal right. Privacy as a stakeholder interest is an indivisible constituent of human dignity that involves respect for human flourishing in a digitally connected world.

A data-driven world that makes decisions devoid of human judgement must regain human accountability. Because confidentiality and privacy expectations are created from social values that are defined by culture, it is incumbent upon the ethically accountable healthcare organization to create a culture of ethics that recognizes its duty as an accountable keeper of secrets. This begins by creating an overall data strategy that relies upon principles of data ethics incorporated into ethical decisions, actions and practices constituent of its data governance model. It also entails recognizing that an HCO's moral agents must exercise their moral judgements in place of the void left by algorithmic and machine learning decisions. They must do what machines cannot in recognition of the vulnerability and fragility of human dignity that is part of the human condition. A condition so closely tied to the context of the healthcare experience.

As a condition of human life, vulnerability is the universal and inevitable capacity and ability to be harmed. All of humankind is susceptible to harm by virtue of its dependent nature. However, susceptibility to harm is relational in that power inequalities and dependency render some stakeholders more prone to injury than others. Vulnerability is also contextual in that certain social, economic and cultural factors create and exacerbate risk of harm; thereby expanding the scope of at-risk stakeholder groups.

Those in positions of power and authority have special responsibilities to the vulnerable. As such, ethical accountability in healthcare includes an HCO's moral commitment to the most vulnerable and disempowered normative stakeholder communities it serves across the life

continuum. This commitment to empower and enable human flourishing while respecting

human dignity includes an obligation to mitigate threats, and provide for unmet needs. Because

of the long and notorious history of exploitation towards children, pediatric populations represent

a stakeholder community that depends upon this obligation of the HCO and its moral agents.

Particularly compelling is the moral duty to empower children by understanding the pathology of

diseases and disorders that affect them through clinical research; most notably the pathology of

HIV, child abuse and mistreatment, and cognitive disabilities.

Ensuring adherence to ethical principles of autonomy, beneficence and fairness

throughout the clinical research process is essential. Because healthcare and clinical research are

relational, for physicians to fully adhere to these principles they must understand the importance

of children's experiences, their interpersonal and social relationships, and unique perspectives.

For instance, children infected with HIV are contextually vulnerable to clinical research practices

as they are introduced to their disease state reality and struggle to reconcile living with a highly

stigmatized communicable disease. Children who are victims of maltreatment or neglect are

similarly vulnerable to the effects of injury research that explores non-accidental trauma. And,

children with cognitive disabilities are contingently and contextually vulnerable to research as

they are heavily dependent upon the authority and control of others, and often experience

communication and sensory barriers.

Relational ethics recognizes the importance of these contexts in addressing contingent

vulnerability of pediatric populations. According to the goodness-of-fit model of relational

ethics, the vulnerability of the child is considered beyond her age and capacity. The researcher

and/or physician applying this model of relational ethics will assess all aspects of clinical

treatment and research against the child's capacity to understand, their relationship with those

with authority upon whom they are dependent, and the cultural and personal values that shape their world.

In addition to clinical research considerations, moral accountability to vulnerable pediatric populations includes the responsibility to understand and manage population health; that is, understanding the epidemiology of a particular population. Principles of stewardship, normative stakeholder theories, community-oriented health programs and the duty to provide for the common good underscore the commitment from the HCO to influence public health vulnerabilities. In particular, the HCO has a moral obligation to mitigate and prevent the psychosocial and physiological effects of pediatric obesity, which is upheld as a critical public health threat.

Pediatric obesity is a multi-factoral, two-stage disease. Respectively, it is a disease that has wide ranging genetic, societal and behavioral causal factors. Left unabated, pediatric obesity continues into adulthood as a two-stage disease, increasing the likelihood of higher death rates in middle age from heart attack, diabetes, depression, and respiratory disease. In addition, obese children are contextually and conditionally vulnerable from the physiological and psychosocial effects of pediatric obesity. Obesity-related medical conditions such as Type II diabetes, hypertension, asthma and sleep apnea will threaten the life of a child if they become sufficiently severe. As significant are the psychosocial effects from stigma, shame, bullying and isolation pervasive in Western culture's obsession with thinness.

The contextual and conditional aspects of vulnerability underscore the fact that individuals are vulnerable to the actions and inactions of others. Children are particularly vulnerable to the acts and omissions of those responsible for keeping them safe, as well as for their physical, emotional, intellectual and moral development. It is from the notion of relational

care that the authority to act as a social parent emerges. The social parent theory contributes to ethical accountability and undergirds the relationship between pediatricians, families of children living with obesity, and the communities of obesogenic influences within which they coexist.

Tensions in public health ethics appear during attempts to reconcile the individual and collective, or the private versus public view of what must occur in the name of community health. Where those with authority fail to provide for adequate protections, the state as a sovereign may become a de facto parent invoking the legal doctrine of *parens patriae.* The legal standard for this doctrine is the notion of what is in the best interest of the child. Because of relational dynamics consistent with care ethics, the HCO and its clinicians and pediatricians are akin to social parents, and share in the moral duty to act and intervene, when conditions warrant, on behalf of the vulnerable child.

Vulnerability, a human condition universally present across the life continuum, is further amplified by aggravating influences such as biases, negative trends in public policy, societal and cultural pressures, and barriers to human flourishing within particular environments. The elderly and persons with disabilities represent vulnerable and largely inaudible stakeholder communities whose human dignity and flourishing are threatened by such influences. The healthcare setting can be particularly intimidating to vulnerable stakeholders. As such, the power, authority, and influence of the HCO underscores its moral duty and ethical accountability to positively impact the lives of these groups, and to improve their human condition and dignity.

The elderly are a demographically diverse, heterogeneous group whose members age differently and have highly individualized needs that are often influenced, rightly or wrongly, by their chronological age. Even the science of geriatric medicine benchmarks medical decisions according to the stage of development of the patient rather than the functioning of the organ

system, or the biological aspects of illness. Ageism, which can be subtle or overt, discriminates based upon biased assumptions of elder needs. It affects power relationships and presents obstacles to health equality, access and particularly to decision-making concerning long-term care.

Chronic health conditions, which affect a majority of elderly in the U.S., most often restrict their ability to perform activities of daily living. These limitations increase their dependency upon others to not only provide for, but understand their unmet needs. Such dependency in the absence of understanding their needs and those of their informal caregivers, does little to mitigate their vulnerability. To reshape the public perception and policy concerning rationing and allocation of limited long-term care resources, those with influence must recognize the cultural and economic contexts, the changed demographic and family arrangements, and the social services necessary to empower the vulnerable elderly.

HCO's are significant stakeholders in public health policy. Their interdependence with the communities of stakeholders they serve demands that they understand the values and experiences of the members within these communities. To that end, a relational ethic of care emphasizes the relationship between the physician, the elderly patient, and the context within which the care addressed by public policy will take place. Adherence to the ethic of care model also brings additional factors such as social determinants into the care decisions, thereby embracing a communal rather than individualistic approach to care. The ethic of care model encourages the HCO and its professional moral agents to engage in effective advocacy for long-term elder care services that are community-based. It enables them to see themselves as in-relation with the elderly patient, exercising empathy and compassion for their dignity.

Acceptance of the reality that care is relationship-based and person-directed will also assist in redefining the culture of care for the vulnerable who live with disabilities. Akin to elderly stakeholder populations, disability is a human condition that exists on the life continuum, and persons with disabilities are a heterogeneous group. As normative stakeholders, persons with disabilities must be afforded opportunities to live in right-relationship with their environment. Correspondingly, the ethically accountable HCO has a moral duty to improve the human condition and dignity of persons with disabilities to palliate vulnerability by creating environments enabling them to flourish.

There is no universal standard for determining what it means to flourish. A flourishing life depends upon the unique differences, circumstances and environments attributed to each individual. Moreover, what it means to flourish in life is determined by the person who lives it, and is dependent upon individual preferences and experiences. Barriers to human flourishing, are often the result of misperceptions and cultural assumptions of disability, normalcy and preferences that foster intolerance or discriminatory practices.

Much like ageism, ableism represents the implicit and conscious biases that reinforce stereotypes against persons with disabilities. This species of bias is cultivated by a society that is designed for and supportive of those who are able-bodied. At its core, ableism forms judgements about persons with disabilities according to perceived abilities, notions of brokenness and associations with illness, and has been a central influence on medicine throughout history. As such, the medical model of disability provides little towards understanding the descriptive realities of impairment beyond those characteristics of illness or disease, which are not synonymous with disability.

Negative health outcomes, discrimination, and stigmatization can be reversed when accountable healthcare organizations and its care professionals examine their moral obligations through the lens of ethic of care and disability ethics. To that end, it must begin with an understanding of disability through the embodied experience of those with disabilities and the communities within which they live. It relies upon the collective and interdependent willingness of persons and groups to build and support a disability culture. Specifically, a culture that shifts the attention away from the medical description of a person, and moves toward understanding society's role in creating enabling environments. To extricate the roots of biases against persons with disabilities, society must develop, through relational encounters, greater understanding of the experiences and attitudes of persons within disability communities.

Ethically accountable HCOs and their clinicians are responsible for developing a disability humility that entails learning about the experiences, culture and history of disability to ensure they can work against the effects of ableism. Moreover, removing barriers to flourishing is a matter of collaboration between the physician, the community of stakeholders, and patients. It enables each to direct their expertise and voices to the issues that matter most in the quest to improve the human condition – those complex variables that challenge human life across the life continuum.

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