An Ethical Framework for Organizational Resource Allocation for Patient Services in Health Care

Natalie Dick

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AN ETHICAL FRAMEWORK FOR ORGANIZATIONAL RESOURCE ALLOCATION FOR PATIENT SERVICES IN HEALTH CARE

A Dissertation
Submitted to the McAnulty College and Graduate School of Liberal Arts

Duquesne University

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

By
Natalie Dick

May 2018
AN ETHICAL FRAMEWORK FOR ORGANIZATIONAL RESOURCE ALLOCATION FOR
PATIENT SERVICES IN HEALTH CARE

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ABSTRACT

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May 2018

Dissertation supervised by Dr. Gerald Magill

Unanswered questions on how to allocate scarce resources in health care settings are often left to either bedside decision-making or, at best, the organizational policy level. Yet, there is little attention and no consensus on how organizational policy should address resource allocation in health care. An ethically sound framework is needed to guide policy development for resource allocation within health care organizations. In addition, a more comprehensive study of concepts tied to moral obligations of health care organizations is needed in terms of human rights, health disparities, and patient care quality. Until now, human rights literature has largely focused on obligations of governments and rarely addresses which obligations organizations may have to protect or promote the human right to health. This dissertation seeks to address the gaps in literature about the moral obligations of health care organizations to protect human rights and develop equitable resource allocation policies. The purpose of the dissertation is to establish an ethical framework for organizational resource allocation in health care.
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Chapter 1: Introduction

A framework for resource allocation in the face of resource limitations is needed for ethical health care organizational policy development, implementation and evaluation. The need for this framework is supported by human rights principles, maximization of patient care quality, and equitable treatment for all communities and individuals. The thesis of this dissertation is to present an ethical framework for organizational resource allocation in health care to enable organizations to develop sound policy when facing finite or constrained resources.

A population’s need for health services often exceeds the availability of critical resources. When this occurs, health care organizations are compelled to allocate resources in terms of which services they will provide and who they will to serve. The need for health care resource allocation is increasingly prevalent in these settings, yet there has been a gap in commonly accepted guidelines for making these decisions. Ethical debate on issues such as rationing and medical futility have attempted to address this gap but until now have posed inadequate solutions. At the core of this problem lies the moral obligations of health care organizations.

Unanswered questions on how to allocate scarce resources in health care settings are often left to either bedside decision-making or, at best, the organizational policy level. Yet, there is little attention and no consensus on how organizational policy should address resource allocation in health care. An ethically sound framework is needed to guide policy development for resource allocation within health care organizations.

In addition, a more comprehensive study of concepts tied to moral obligations of health care organizations is needed in terms of human rights, health disparities, and patient care quality.
Until now, human rights literature has largely focused on obligations of governments and rarely addresses which obligations organizations may have to protect or promote the human right to health. This dissertation seeks to address the gaps in literature about the moral obligations of health care organizations to protect human rights and develop equitable resource allocation policies. The purpose of the dissertation is to establish an ethical framework for organizational resource allocation in health care.

The dissertation title is, “An Ethical Framework for Organizational Resource Allocation for Patient Services in Health Care.” The purpose is to present an ethical framework to facilitate ethical decisions by organizations about policy regarding health care resource allocation for patient services. The ethical framework reflects the design of the chapters in the dissertation, as follows. The ethical framework focuses upon pivotal components that organizations must integrate when making ethical decisions about policy regarding resource allocation for patient services. There are three pivotal components in the ethics framework: respect for human rights in health care (chapter 2); the meaning of quality care for patients (chapter 3); and the social determinants of health (chapter 4). These components constitute the ethical framework of the dissertation in the sense that human rights in health care provides a foundation for integrating individual and social perspectives as presented in the quality of patient care and in the social determinants of health. In other words, the integration of these pivotal components (human rights, patient care quality, social determinants of health) presents an ethics framework for organizational decision-making about policy regarding resource allocation. To illustrate the relevance of the ethics framework, it is applied to the complex topic of medical futility and rationing (chapter 5) and then it is explained in a policy perspective to guide organizational decision making (Chapter 6).
Access to quality health care is a human right, based on principles of equity, respect for human vulnerability and social responsibility. Unfortunately, inequalities in health care due to race, ethnicity, culture, socioeconomic status, and access to health care can prevent individuals from realizing this right. Health care organizations have a duty to address these inequalities via their express moral agency, and begin to do so by facilitating cultural competency and promoting shared decision-making.

Cultural competency and shared decision-making are important tools to promote health equity and human rights but, especially within the context of finite healthcare resources, health care organizations need additional and even more robust guidelines for addressing inequalities. Presently, health care organizations lack a commonly accepted framework for assessing benefits and allocating resources to protect equitable health care access. There is a need for a framework focused on resource allocation within the confines of limited health care resources.

The framework for resource allocation should involve all stakeholders, including physicians, patients and ethics committees where needed. Within this structure, the patient first presents their values and goals, and the physician then provides an intervention’s intended outcome, benefit and likelihood. The ethics committee or consultant works as a moderator when there are communication barriers or value conflicts between the physician and patient.

Most importantly, in this resource allocation framework, the patient values and goals are at the front and center of the decision-making process. This framework will help to achieve the goals of equitable access healthcare, thus protecting the human right to equitable quality health care.

CHAPTER TWO explains the foundations of health care as a human right based on principles of equity, respect for human vulnerability and social responsibility. First, the right to
healthcare is established and explained in terms of equity. Respect for human vulnerability and social responsibility are then explained as the moral foundations for healthcare as a human right.

Human rights are based on the intrinsic dignity of human beings and should be afforded to every person on the planet with no exceptions. Human rights encompass protections for all human beings so that all persons can achieve self-determination. Health is a human right because it is a prerequisite for any human to act freely and access to quality health care is a prerequisite for health. Access to quality health care is therefore a prerequisite for humans to achieve the right to self-determine and live freely.

Health and health care are requirements for participation in a democratic society since they are requirements for functional ability. Realizing this right to health is influenced by many factors. These factors include: insurance coverage, public versus private funding, the link between social inequalities and health, access, health disparities, and resource allocation. To operationalize a right to health, these issues need to be addressed through adequate and equitable access to health care.

Health has emerged as a human right over the past century. Notable declarations on human rights and health include the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and the Universal Declaration on Bioethics and Human Rights. In 1948, the Universal Declaration of Human Rights outlined equal and unalienable rights of all human beings founded in freedom, justice, peace, and inherent human dignity, including a provision outlined in Article 25: “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the
event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."²

Additional clarification on the right to health was established in the 1966 UN General Assembly International Covenant on Economic, Social and Cultural Rights. This covenant recognized that all humans have equal and unalienable rights, including rights to self-determination, to be free from discrimination of any kind – including discrimination based on gender and race, to work, to have safe work conditions, to have fair wages, to enjoy an adequate standard of living – which includes freedom from hunger, to education, to take part in cultural life, and to achieve the highest attainable standard of physical and mental health.³

Further, the 2005 UNESCO Universal Declaration on Bioethics and Human Rights defined human rights as related to health and included principles of human dignity and human rights, benefit and harm, autonomy and individual responsibility, consent, persons without the capacity to consent, respect for human vulnerability and personal integrity, privacy and confidentiality, equality, justice and equity, non-discrimination and non-stigmatization, respect for cultural diversity and pluralism, solidarity and cooperation, social responsibility, sharing of benefits, protecting future generations, and protection of the environment, the biosphere and biodiversity.⁴ Although the foundation of the right to health has been laid, there is still a need for these rights be clarified in terms of positive and negative obligations to availability, accessibility, acceptability and quality of health care.

The meaningful realization to the right to health includes obligations to both the positive right to health and a negative right to health. The positive right to health means that there is a positive obligation to protect health access and informed decision-making, while the negative right to health means that there is an obligation to avoid interference with health access and
informed decision-making.⁵ These obligations should be explained with a consideration for real costs and benefits, as well as a structure for resource allocation that is universal (rather than culturally and economically relative.)⁶

The availability, accessibility, acceptability and quality of health care relies in large part on health care financing. It must be noted that universal affordable health coverage has not been achieved by private, for-profit providers or insurance in any North American country, so states (and tax dollars) have become responsible for filling in the gaps to cover poor and seriously ill through public programs.⁷ Health care organizations are thus constrained by the availability of both the insurance market and government resources to provide equitable care for all individuals.

Health equity means empowering people, particularly socially disadvantaged groups, to eliminate systematic health inequities and unfair differences that are socially produced, and is essential to the right to health since health and agency have a mutually reinforcing relationship.⁸ This means that a person without agency is likely to have poor health outcomes, while poor health diminishes a person’s agency. Health equity can be considered in terms of horizontal equity and vertical equity. Horizontal equity explains that those with equal need should be treated equally, while vertical equity explains that those with different needs should be treated differently.⁹

Horizontal equity demands that individuals who are equal should be treated equally. An appeal to horizontal equity must first define which individuals are determined to be equal and thus should be treated equally.¹⁰ Individuals can have equal needs for different reasons. Multiple dimensions of health care access, including geographic distribution of resources and financial barriers to care, have been shown to influence health system horizontal equity in terms of health service use.¹¹
The availability of health services is an important determinant of health, so health care resource allocation should be based on equitable and fair distribution. Specifically, health equity could be promoted through improved access, support for primary care, enhanced health information technology, payment model reform, national quality strategy, and monitoring of disparities. To achieve horizontal equity, individuals with equal needs should have the ability to meaningfully access an equal amount and type of health services and goods. To achieve vertical equity, those with different needs should be able to access a different amount and type of health services and goods.

Health equity is socially patterned and dependent on hierarchies of economic resources, social resources, power and prestige. Different persons have different needs based on these hierarchies and social patterns. Individuals and communities with greater needs should receive greater health resources according to the concept of vertical equity. This can be further conceptualized as empowering individuals and communities to make decisions and use health services. This empowerment should be a policy objective at the national, state and organizational level as measured by policy outcomes.

Equitable access means that there should be no unjustified difference in the amount and quality of health care one individual has over another. Social inequalities should particularly be addressed to eliminate inequitable health outcomes, since social inequalities are closely related to health inequality. Social inequalities contribute significantly to the manifestation of human vulnerability and demand social responsibility from non-vulnerable members of the population in accordance with human rights protections.

The principles of respect for human vulnerability and social responsibility are most relevant to health and human rights and explain the organizational obligations to protect or
promote the human right to health. Vulnerability is a common human experience, although the degree of vulnerability that humans face varies greatly. Social responsibility describes the obligations that humans have toward one another, especially toward other more vulnerable humans. These two principles combined create the foundation for health as a human right. A respect for human vulnerability is a foundational element of the right to health. All humans are vulnerable in some capacity based on the mortal human condition, although some humans face the extra burden of special vulnerability.

Human vulnerability is inextricable from health care since it is the very state in which individuals need health care services. Respect for human vulnerability recognizes that all humans will at some point(s) in their lives be vulnerable. Some human vulnerabilities are given greater prominence in health care than others. This prominence given to specific vulnerabilities reflects social views on which behaviors are personally controllable, which separates social perception of sinners versus victims. Framing vulnerabilities within social contexts and structural inequalities will help to clarify which behaviors are truly controllable and which are impossible or very difficult to avoid based on a person’s social, political, or economic context.

There is a connection between all humans based on their common vulnerability, however some humans face greater vulnerabilities than others and deserve special protection. Individuals and groups with special vulnerability are at risk for poor health status and unmet healthcare needs due to multifactorial and interacting risk factors, especially those related to inability to pay for healthcare services – including low income, inadequate insurance coverage, and lack of regular source of care. Vulnerabilities become compounded when a person is born into a structural system of marginalization. The material and psychological stresses of social inequalities and marginalization during periods of development can cause physiological changes
that form the basis of a child’s ability to cope with future sources of vulnerability. The disparities in access to health services between those with special vulnerability versus those who do not are largely based on socioeconomic factors.

Based on the intrinsic dignity of human beings, there is an explicit social responsibility to protect marginalized groups and individuals, meaning that health resources should be allocated for the vulnerable. Furthermore, protection of vulnerable groups and individuals is good for social systems and communities as a whole, not only for the vulnerable person under protection. Lack of opportunity experienced by the vulnerable leads to degradation of the entire social environment, meaning that attention to vulnerable groups contributes to general safety and quality of life for the entire community. An indicator for overall social harmony and community well-being is then the degree to which the vulnerable are cared for and protected.

Vulnerable persons or groups should have special protection since they have a greater likelihood of being wronged due to inherited characteristics such inability to avoid exploitation, susceptibility to harm, or lack of access. Vulnerable individuals are disadvantaged in their ability to advocate for themselves, so society has an obligation to protect and advocate for them. This means that individuals, groups and organizations within a society have a social responsibility to those who are vulnerable.

Social responsibility in health care describes the moral responsibility to take care of those who are vulnerable in a society based on the nature of humans as social beings. Health care organizations have moral obligations rooted in social relationships that they participate in, especially related to access to quality health care, access to adequate nutrition and water, living conditions and the environment, marginalization and exclusion of any person or persons, and poverty. Because a health care organization benefits from the vulnerabilities of individuals and
groups within the social system that it is integrated with, it also has obligations to those who are vulnerable.

In addition, health professionals engage in social contracts with patients, where they are expected to put the interests the patient first, an expectation that is founded in justice when freely agreed upon by all participating parties. The social relationship between the health care professional and patient necessitate mutual responsibilities between both parties.

The social dimension of health care leads to social responsibility of hospitals and health care delivery organizations, and is carried out by adequate corporate governance plus corporate strategy where organizational values meet obligations to maximize available resources. Corporate social responsibility is especially important as a strong predictor of clinical governance effectiveness, including high standards of care, transparent responsibility, and accountability.

CHAPTER THREE will discuss patient care quality as a function of human rights, and describe the responsibility of health care organizations to protect health care quality and patient safety. Patient care quality is a function of human rights. For humans to be able to meaningfully exercise their human rights, they must be healthy and vice versa. This section will first define quality in health care and then discuss how it is inextricably connected with human rights.

Quality in health care encompasses patient safety, clinical outcomes, clinical processes, patient satisfaction and cost. Patient safety involves avoiding harm to patients as part of their medical care. This includes avoiding medical error. Medical errors can cost billions of dollars in annual cost to the US health system.

Quality in health care encompasses the health outcomes and associated processes that patients experience in the health care setting and is often measured in terms of outcomes and
process measures. Process and outcomes measures each have strengths and weaknesses. Process measures are direct, easy to interpret, and sensitive to differences in care quality, though they do not reflect all aspects of care like outcomes measures, while outcomes measures include potential inconsistencies with data collection and difficulty of proper risk adjustment are major disadvantages. Efficiency is also a component of outcome and process methods. A method that incorporates multiple, dynamic variables including resources, time periods, patient groups and uncertainty of treatment paths could help to identify bottlenecks and improve hospital efficiency.

Both process and outcomes are important components of health care quality. Process and outcome measures are often guided by governmental regulatory programs and payor financial incentives. While regulatory policies and financial incentives can support health care quality, they can also present barriers to quality if they are poorly designed. For example, poorly aligned or fragmented financial incentives can impinge on the patient’s awareness of value or fail to adequately address provider accountability. Likewise, governmental regulatory bodies can fail to support health care quality if they are not well-designed. Thus, the health care organization plays a crucial role in facilitating and ensuring quality patient care processes and outcomes.

Patient satisfaction and patient-reported outcomes are also an important component of health care quality. Patient-reported factors such as current behaviors, baseline health-related quality of life, disease progression or regression, and treatment effects can help clinicians target interventions to improve care quality. Patients can also report their satisfaction with health care services to indicate the quality of care provided.
Although there are many factors that can influence patient satisfaction, a comprehensive approach that includes various service elements - such as multiple data sources to drive improvement, accountability for service quality, service consultation and improvement tools, service values and behavior, education and training, ongoing monitoring and control, and recognition and reward - could be the most effective in improving patient perception of excellence.\textsuperscript{33} This approach can also include attention physician communication, staff demeanor and empathy, facility quality, nursing care, housekeeping, food, technical services, and access to care.\textsuperscript{34} In addition, factors such as reputation of the physician, reputation of the healthcare organization, health plan affiliation, and appointment availability are important to patients when selecting a provider.\textsuperscript{35} Patient satisfaction, such as satisfaction with nursing and staff care, can also influence a patient's willingness to recommend and willingness to return to a provider.\textsuperscript{36}

Cost is also an important aspect of health care quality due to the finite nature of health care resources. When costs are too high, access and availability of resources diminish. In addition, allocating resources toward health care produces opportunity cost for other socially beneficial services.\textsuperscript{37} In the United States, government (taxpayer) funding accounts for almost two thirds of health expenditures, which includes spending on public employee health benefits, tax subsidies to private health spending, and direct government payments to Medicare, Medicaid and the Veterans Health Administration.\textsuperscript{38} This means that high health care costs can reduce or eliminate resources for other public services that may benefit the well-being of the population. In the era of cost-containment, health care organizational leadership have an imperative to take medical management approaches with a goal of achieving the best outcomes for the lowest cost, and eliminating inappropriate or unnecessary variation in care.\textsuperscript{39}
Health care costs can be influenced by many factors, but it should be noted no singular reason can be blamed for high health care costs in the United States. Overutilization, for example, has been named as an important reason for rising healthcare costs in the US, but should not be overemphasized. High utilization of certain services, such as primary care, may actually have a much higher benefit to cost ratio, even though high utilization of other specialty services may yield low return on investment.\textsuperscript{40} Cost drivers are impacted by risk factors of patients like age and case mix and while cost and quality are interconnected, the relationship between cost and quality is not always the same.\textsuperscript{41}

The cost of complying with the right to quality health care should also be mentioned since it is related to the likelihood of an organization or government compliance with positive rights to health. For example, the likelihood of a state complying with the Convention on the Rights of a Child immunization protocol is dependent on capacity to meet associated bureaucratic costs such as building a primary care delivery system, setting up and maintaining appropriate incentives, and monitoring performance.\textsuperscript{42}

Quality health care is a human right. In general, human rights discourse has involved a growing awareness of rights related to health, including considerations for its associated complex ethical and legal dimensions such as cultural relevance, regional indicators, individual versus communitarian values, equality of access, and resource allocation.\textsuperscript{43} Though this discourse is an important first step to integrating health and human rights, explaining health as a human right lacks an important degree of precision. This discourse should instead be framed in terms of quality health care as a human right, which both encompasses and more adequately defines obligations to protect the right to health.
Human rights can improve the effectiveness of quality care at the physician-patient level when the physician incorporates the patient's will and interests into the interaction, thus respecting the patient's individual dignity and rights. A human rights-based approach can also help health care project leaders to pre-emptively address socioeconomic issues and potential violations of rights, uncover design and implementation issues that impact access to interventions, expand the breadth of outcome variables to measure success, and provide opportunities for greater inclusion and project reach. Health and human rights-based claims of justice can be used to support the protection and promotion of the functional capabilities required for the exercise of positive freedom.

The basic rights to health and health care traditionally have fallen into three domains: the basic moral domain, the legally enforceable political domain, and the international domain (or domain of relations between different political societies.) These three domains – individual/moral, political/legal, and global – generally provide the existing framework for human rights and health discourse. This framework lacks crucial domain in health and human rights discourse, however: the organizational domain. The organizational domain exists as a layer between the basic moral domain and the political domain, and is an essential missing piece to this framework. The health care organization is the functional domain is where the right to health is effectuated.

Health care organizations should facilitate quality through an ethics lens. Using ethical standards as a foundation for developing quality improvement activities can help to prevent inadvertently causing harm, wasting resources, or contributing to inequalities. Specifically, quality in health care should be approached from a human rights perspective to ensure that health care delivery is equitable, respect for human vulnerability is maintained and organizational social
responsibility is realized. This can be accomplished by involving stakeholder dialogue and empowerment of the poor, of communities, and of consumers when developing the relationship between corporate operations and human rights.49

The essential responsibilities of health care organizational leadership include setting clear direction, building the right leadership team, and creating the right culture.50 Organizational leadership should also work with clinical teams in both the inpatient and outpatient settings to ensure that there are resources and a structural foundation to support ethical decision-making.51 Leaders of health care organizations should also focus on organizational culture since culture can influence how effective a health care organization is at achieving its goals.52

Organizations can incur cost related to ethical conflicts including both direct and indirect costs associated with operations, legal issues, and marketing and public relations.53 This can further exacerbate problems created by poor quality since fewer resources may infringe upon the ability to make quality improvements. The organizational domain is where the right to quality health care, and therefore the right to health are realized. Organizations can be held accountable to moral obligations related to these rights based on principles of organizational moral agency. Specifically, health care organizations have moral obligations to protect patient safety and ensure quality of care.

An organization’s moral authority and identity, including its mission, vision, and values, combine and result in an organization’s moral agency. Health care organizations have moral agency based on their unique identity and moral authority. Organizational identity, including organizational structure, represents the context in which a healthcare leader can accomplish the mission of the organization.54 Corporate conscience is expressed as moral agency that manifests in its mission-focused organizational traditions, policies, rules and leadership action.55 The
operational effectiveness of achieving this mission can then be measured through indicators of availability, quality and efficiency.\textsuperscript{56}

Moral agency explains that a health care organization has a metaphysical personality and existence distinct from its specific members, with rules of governance and hierarchical structure, resulting in unique, distinct shared, intentions and coordinated behaviors, carried out by parties who make decisions and carry out actions on behalf of the organization.\textsuperscript{57} The health care organization is not a random amalgamation of the assets and individual persons who facilitate and use its services, but a unique entity that is larger than the sum of these parts. This is reflected in the unique expressed missions and values of health care organizations.

An organization’s mission statement is an expression of the unique moral identity of the organization. An organization’s mission statement can improve its focus, such as increasing attention on innovation or improving the balance between financial goals and the non-profit mission.\textsuperscript{58} Likewise, expressed organizational values demonstrate the unique moral identity of the organization. Organizational values in health care are important assets to innovation, growth, ethical decision-making and quality, and can have a positive impact organizational success.\textsuperscript{59} Organizational values are the moral underpinnings of its decision-making – describing what agents acting on behalf of the organization ought to do, and can motivate an organization’s agents to arrive at intentional action based on the needs of collective.\textsuperscript{60} The organization has agents which enact its mission and values. These agents are expected to act on behalf of the organization, based on the organization’s unique identity.

Based on moral agency through expressed moral authority and organizational identity, health care organizations have specific obligations to promote health care quality and protect patient safety. Organizations have obligations to promote and protect quality health care and
patient safety, based on their role in carrying out the human right to health. The organization itself facilitates processes and outcomes of quality health care, based on organizational attributes that influence quality such as executive management, culture, organizational design, incentive structures, and information technology management. The organization itself is the driver of quality health care, based on these traits. Health care organizational obligations include protecting patients and staff members right to privacy, facilitating informed consent, facilitating quality improvement activities, and reviewing potential safety risks to patients (such as randomized designs, novel treatments, involvement of researchers, delayed feedback of monitoring and external funding.)

Organizations should also monitor quality outcomes to promote continuous quality assurance and improvement. These quality measures should have a strong evidence base, accurately reflect whether the intended process has been provided, be closely tied to the intended improved outcome, and have little or no chance of creating unintended adverse consequences.

Organizations should take a proactive approach to addressing potential ethical conflicts related to patient safety, ideally collaborating with ethics committee members, clinical staff, and providers to develop ethically grounded protocols, and establish systematic processes to ethical practice and ultimately promote the goal of quality. This can be carried out by the health care organization’s agents, including executive leadership. For example, executive leadership can improve quality and safety by creating a culture of transparency, cooperativeness, inclusiveness, and shared responsibility by focusing on communication, systems, teams, and accountability. The health care organization should use an integrated approach to addressing issues related to quality in health care. The institute of medicine has advocated for systems approach, focusing on interconnection of problems with the root cause analysis focusing on system flaws. Health care
quality encompasses the interconnected components of the health care organization. These components cannot be separated and need to be addressed as at the whole organization level to adequately address health care quality. Quality health care is a human right carried out by health care organizations.

CHAPTER FOUR describes the importance of social determinants of health related to health care organizational policy. Social determinants of health – including race, ethnicity, culture, socioeconomic status and barriers to access – have a serious impact on health outcomes. Although addressing social determinants of health can be particularly challenging when facing diversity in cultures, beliefs, and backgrounds, health care organizations can mitigate the inequalities related to social determinants of health by focusing policy on cultural competency and shared decision-making. Health equity can be achieved at least partially by reducing disparities in health and securing access to highest possible quality of health care for all individuals and groups.  

Social determinants of health include key components of race, ethnicity, culture, socioeconomic status, and access to health care. Organizational policy founded in cultural competency can help to alleviate some of the inequalities presented by these factors.

Social determinants of health present ethical challenges to organizational policy. The two most salient challenges are diversity and barriers to access. A diverse population with varied races, ethnic backgrounds and belief systems can lead to major challenges in health care. When individuals in a society have varying backgrounds and belong to diverse social, religious and cultural groups, it can be difficult to create a health care system that applies to all individuals fairly. This is further complicated by (real or perceived) weaknesses of traditional bioethics itself, which often faces criticism that it is based on western principles, methods, and philosophy.
and that it is lacking in its attempt to address the role of social and cultural values – specifically those that define health, illness, pain, and death.\textsuperscript{69} If those analyzing ethical challenges to health care hold a specific world view, they may not be able to seriously consider other legitimate perspectives from other cultural groups. Barriers to accessing health care in a multicultural setting include: Demographics – such as age, ethnicity, religion, and education level; Culture – including worldview/perceptions in life, time orientation, and primary language; and Health care system barriers – including access to care, financial resources, and poor doctor-patient communication.\textsuperscript{70}

Barriers to access can exacerbate health disparities and negatively impact quality of care. Health care access barriers, including financial, structural and cognitive barriers, can result in inadequate screening, late presentation to care, and lack of treatment resulting in poor health outcomes and health disparities.\textsuperscript{71} Individuals and communities often face multiple barriers to access simultaneously. For example, those with low health literacy are also more likely to be uninsured.\textsuperscript{72}

There are many interventions that organizations can engage in to improve health access for the populations they serve. For example, health care access could be improved for low income people by creating leadership coalitions, building shared information systems, seeking catalyst funding, filling in gaps of service such as prescription drugs, creating care models that achieve improved health outcomes, enlisting private physicians to volunteer for uninsured and underinsured people, and achieving sustainable funding for care through state/local government, business and community partnerships.\textsuperscript{73} In general, inequalities should be addressed through interventions that make it an easy choice to engage in healthy behaviors.\textsuperscript{74}
access is an important first step to making healthy choices easy and moving toward equity in health care.

In a multicultural society such as in the United States, there are varying approaches to establishing ethical standards and boundaries for bioethics. These approaches can include secular and religious bioethics. The approach which can be used as a normative ethic is based on human rights. Secular and religious bioethics are offer competing theories of how to define “right” or “good” in health care. Many secular philosophers believe that reason can deem certain behaviors ethical or unethical through thought process, social negotiation, experience, sense or perception. Religious theories are also common when approaching ethical theory in health care. Religious theories tend to rely on revealed truth or natural theology. Revealed religious truth or “faith knowledge” means that members of a particular religion have knowledge of true morality that has been revealed to them through their religious doctrine. Natural theology is a theory of religious ethics that states that there are natural ways of knowing moral norms, and that these norms are revealed by reason. These varying and often conflicting theories offer a range of approaches to health care ethics in multicultural societies.

Choosing one of these normative moral theories – secular or religious – may not be possible because, in a multicultural society, individuals will have conflicting values, backgrounds and cultural beliefs preventing them from agreeing on what is right and what is wrong. Morally diverse individuals and groups can attempt to engage with each other through bridging foundational differences, but should keep in mind that agreement about moral a philosophy does not necessarily mean that it is justified, i.e. consensus can arise out of pressure from power structures or mindless conformity rather than true moral justification. Using methodologies of bridging theories and justifying actions can be helpful when navigating
through differing moral beliefs within a multicultural society, however human rights should always serve as the foundation for this discourse.

Human rights principles are principles that apply to everyone simply for the reason that they are part of humankind. Human rights can and should be applied to health care ethics because of its universal application and ability to create a guideline or framework for ethical decision-making. The United Nations’ Universal Declaration on Human Rights provides common standards for fundamental human rights to be universally protected, and includes articles outlining these established rights. These rights include respect for human vulnerability and justice, which should be applied in the multicultural health care setting.

Organizational policy focused on cultural competency can address social determinants of health and thus improve quality and health equity. Human rights serve as a foundation for ethical policy within health care organizations. In order to begin addressing the ethical challenges presented by a multicultural society – including race, ethnicity, culture, socioeconomic status, and barriers to access – health care organizations should develop a policy of cultural competency. When founded in human rights, this organizational policy can impact social determinants of health and ultimately improve quality of care. Cultural competence falls into three buckets – organizational cultural competence, systematic cultural competence, and clinical cultural competence, each with their own unique challenges such as problems with lack of diversity in health care leadership and workforce, poorly designed systems for diverse patient populations, and poor cross-cultural communication between providers and patients. Organizational policy can address each of these buckets. This policy can focus on interventions such as evidence-based cost control, improving financial incentive structure, providing
meaningful interpretation services, using community health workers, incorporating multi-disciplinary teams, and improving patient education and patient empowerment.81

All levels of the health care system, including payers and regulatory bodies, should emphasize cultural competence at a system level, striving to provide culturally and linguistically appropriate health care services, which will ultimately impact access, utilization, and health status of minorities.82 Health care organizations such as hospitals and health care systems should work together with payers and regulatory bodies to create policy that provides the most benefit for the patient population. Health care organizations can look to the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards) for guidance on developing cultural competency policies. The CLAS standards include provisions for governance, leadership, workforce, communication and language assistance, engagement, continuous improvement and accountability – with the goals of decreasing health disparities, enhancing health equity, and improving quality.83 These can be used as a foundation for policy development and implementation within health care organizations to foster culturally competent care.

Social determinants of health can have a significant impact on access to quality care and quality outcomes. For example, Asian immigrants in the United States are less likely to have health insurance or use health care services, and face barriers to quality health care including linguistic discordance, health-related beliefs and cultural incompetency of health systems, issues with accessing health services, and discrimination in the health care system.84 Multiple social determinants of health can also intersect to affect quality outcomes. For example, age and race can intersect to create disparities among those in the elderly population, with racial minorities demonstrating worse health outcomes than whites of the same age group.85 Solutions to address
this problem are multifactorial and include developing a diverse healthcare workforce that reflects the diversity of the patient population.\textsuperscript{86}

Health care organizations can also address health disparities caused by social determinants of health by merging foundations of clinical and organizational ethics to develop policy focused on shared decision-making. Clinical ethics can be applied through organizational policy to mitigate social determinants of health through on shared decision-making between the physician and the patient. Policy to support shared decision-making should focus on two key features: ethics consultation and the informed consent process.

Shared decision-making can be used by health care providers and patients to determine the best treatment option based on the patient’s values, beliefs and goals. The essential elements of this process are: recognizing that decision needs to be made, understanding the evidence, and incorporating patient values.\textsuperscript{87} Shared decision-making can improve care quality, improve patient experience, and reduce costs – including the cost of surgeries and hospital admissions – through low-cost interventions such as telephone health coaching.\textsuperscript{88} When patients have a chance to consider the options along with their risks and benefits as they relate to their personal values, beliefs and goals, they have the information that they need to make a truly informed decision. Organizations can provide physicians with the education and tools to help patients participate in shared decision-making. The organization should focus on policy related to informed consent and ethics consultation to support shared decision-making and reduce barriers that physicians and patients face when making decisions. This can be operationalized through policy focused on informed consent and ethics consultation.

Informed consent is a crucial component of shared decision-making. Informed consent encompasses legal rules, ethical doctrine, and an interpersonal processes based upon rights and
duties, as well as consequences of actions, and is intended to protect bodily integrity and autonomy.\textsuperscript{89} It is the mechanism in which patient autonomy and right to make decisions about one’s own body and health are fulfilled. Legal or institutionally effective rules and requirements of informed consent are intended to create conditions that enable autonomous authorization and promote shared decision-making.\textsuperscript{90} The health care organization, the physician, the patient have important roles in this process. Informed consent is based on decision-making capacity and it should be assumed that a patient has decision-making capacity unless there is proof otherwise.\textsuperscript{91} When a patient does not have decision-making capacity, surrogate decision-makers should be able to understand the patient's values and apply them to treatment decisions.\textsuperscript{92} Health care organizations should develop policies and procedures to protect vulnerable patients without surrogates that include the development of practical guides for clinical providers, increasing the number of patients who complete a medical power of attorney document, and supporting rigorous efforts to search for a surrogate decision-maker.\textsuperscript{93}

Shared decision-making as supported by organizational policy can reduce health disparities related to social determinates of health. Informed consent and ethics consultation can support this process. Patients are influenced by risks and resources in their physical and social environments often related to multiple dimensions of race, ethnicity and socioeconomic status, which combine and accumulate to influence health outcomes.\textsuperscript{94} Socioeconomic status is one dimension that significantly affects a patient’s ability to effectively interact with the health care system. Patients with a disadvantaged socioeconomic status tend to have worse outcomes compared to those in more advantaged situations. For example, long term breast cancer survival outcomes could be improved by targeting patients with low socioeconomic status.\textsuperscript{95} Through shared decision-making as carried out through the informed consent process and ethics
consultation, the burdens of health disparities related to disadvantaged socioeconomic status can be mitigated.

Race, ethnicity, culture and language can also have a significant impact on health outcomes and shared decision-making. Although often intertwined with socioeconomic status, race, ethnicity, culture and language present unique barriers to shared decision-making within the health care setting. For example, a high socioeconomic position may not necessarily alleviate the toxic effects of discrimination related to the psychosocial conditions and stresses tied to minority status. These factors should be considered as presenting unique challenges to clinical ethics and the shared decision-making process.

The location in which a patient lives can significantly affect their ability to access health care and engage in shared decision-making. This can be especially true for individuals and groups who live in rural areas. Barriers to receiving health services in rural areas can include lack of knowledge of available resources, cost of services, difficulty navigating the system, difficulty finding qualified providers, and proximity to services. These factors can all influence a patient’s ability to engage in shared decision-making. A patient’s geographical location can affect their access to health-related services as well. For example, a neighborhood food environment can have a significant impact on health and accessibility to healthy food can be affected by physical distance from food sources, personal mobility, and environmental barriers such as safety concerns, and facilitators such availability of public transit service. These factors influence health outcomes for groups and individuals in disadvantaged geographic areas, including many rural areas. In addition, health care needs such as housing and transportation can be affected by geographic location and availability of health resources. For example, adults with multiple sclerosis, can face barriers to obtaining specialized housing, transportation, and
resources needed to manage their progressive and episodic illness. Socioeconomic factors could also act in concert with geographical barriers to health care from both individual and neighborhood level factors. Informed consent and ethics consultation solutions could help to alleviate some of these barriers to accessing health care and achieving quality health outcomes through shared decision-making.

CHAPTER FIVE explores concepts of medical futility and rationing as foundations for resource allocation. Health care resources are finite, yet demand for needed health resources are virtually unlimited. This leads to the unfortunate reality that some people will be afforded access to the health care resources they need, while others will not. Compounding this problem, political discussions surrounding rationing, including claims of so-called “death panels,” have hindered the ability of policy-makers to have meaningful discourse about fair dissemination of limited health care resources. As a result, many of these resources have been distributed sporadically with little or no ethical grounding.

Based on human rights that demand equitable, quality health care to all, health care organizations have an obligation to develop more ethically sound ways of employing their limited resources. These decisions should be founded in justice, and should not be influenced by non-medically relevant patient characteristics such as race, ethnicity, culture, socioeconomic status and geographical proximity to health care providers.

The basis for discourse surrounding resource allocation has heretofore focused on two key concepts: medical futility and rationing. These two key concepts will be examined as background concepts for resource allocation. Resource allocation will then be explained as a concept which transcends the existing understandings of futility and rationing.
Futile medical care can be thought of as a treatment or medical intervention where there is no benefit, or where the amount of benefit achieved is judged as not worth its costs. When unpacking this broad definition, however, flaws with applications for the medical futility concept emerge. There is much ambiguity when exploring expected or possible outcome(s), and also how likely those outcome(s) are to occur. This leads to the real possibility of drastic differences in opinion among stakeholders regarding the futility of a particular patient in a particular situation. Importantly, there has been no consensus on an acceptable threshold for probability that a treatment will achieve a patient’s goals. This can lead to violations of equity when disagreements in medical futility among stakeholders are influenced by bias, especially when these biases are related to social determinants of health. Opinions of futility could be susceptible to opinions on whether specific patients are worth of a perceived high-cost, low-benefit treatment. When these judgements are made based on any non-medically relevant criteria, they unjustified and in violation of the right to quality health care.

To make a determination of futility in a clinical setting, a patient’s goals should be weighed against the probability of achieving those desired outcomes. If treatment intensity has no relationship to survival, does not improve quality of life, does not improve suffering, does not increase chances of a faster discharge, or help the clinical team and patient meet some other specified goal, then the treatment in question should not be offered. The treatment in question would be considered to be medically futile. Although seemingly straightforward, this definition gains complexity and has contested relevance in application. Generally speaking, there is a lack of consensus on the criteria for futility, with related available data inconclusive and susceptible to subjective interpretation. This creates an environment where medical futility is understood
as a vague concept, and specific guidelines for judging a case to be futile are difficult to establish with unanimous agreement.

When it appears that a treatment may be deemed "medically futile," the provider and patient (or surrogate) should discuss the options to determine the patient’s value system and whether the treatment is appropriate or not for the patient. The role of the patient or surrogate is to provide the values and goals of treatment option.

Futility reflects physician’s professional, not personal integrity, and goals of a futility policy must have the ability to attract nearly universal agreement among health care providers, as well as acknowledge political realities. No such universal agreement has yet been achieved. The lack of consensus in definition among physicians themselves clouds understanding and application of medical futility, and a clearer professional standard may be a key to provide clarity for futility standards. As of yet, physicians nor politicians have been able to agree on overarching, specific standards for judging medically futile interactions.

Physicians can personally avoid “futile” with patients, give patients and families time to comprehend and express their understanding, clarify goals of care, assess whether all reasonable options have been attempted, avoid offering options that are not medically appropriate, establish guidelines and limits for interventions in place, and address emotional needs of patients – and when they need support with these issues, physicians can have a patient care conference, review steps with a colleague and/or request an ethics consult.

Due to the problems that would come with mandating specific criteria to invoke medical futility at the bedside, it may be more useful to apply medical futility as a foundation and launching point for decision-making, helping to elucidate the limitations medical care. The concept of medical futility could possibly help physicians develop acceptance that they are
powerless in some clinical situations. The concept itself then may be useful, but only as a starting point or foundation for a benefits assessment framework to emerge.

Social determinates of health can further complicate the ethical application of medical futility concepts, especially if bias is introduced into medical futility discussions. Serious injustice can occur when social determinants of health, such as race, ethnicity, education, socioeconomic status, or geographic location negatively affect a patient’s care in medical futility cases. The potential for grave, life-or-death consequences in medical futility cases means that bias or unequitable treatment related to medical futility decisions opens the possibility for gross injustice. When considering medical futility judgements, two patients with a similar condition should be treated similarly and morally immaterial facts such as race or ethnicity should be ignored. Biases due to social characteristics should be avoided in order to ensure equity under the right to quality health care.

Ethics committees serve as a resource to health care institutions and address ethical dimensions of clinical guideline development, policy advisement, and case review, and are required as a part of the Joint Commission for accreditation. They are an essential part of ethical decision-making within organizations. Ethics committees operationalize their ethical support for decision-making through ethics consultation, which offer a structured method to promote ethical decision making for professionals, patients, and families. Ethics committees can mediate ethical questions when they arise during the shared decision-making process.

In all questioned medical futility cases, ethics consultants and ethics committees should look to identify biases related to social determinants of health when facilitating medical futility discussions. In their role on the ethics committee, ethics consultants should listen for and address unspoken biases, while focusing discussion on clinically relevant information such as risks,
whether the resource is scarce, complicated comorbidities such as addiction, concrete history of non-compliance, long-term risks, psychosocial conditions, and whether the intervention will prolong a painful dying process.\textsuperscript{110} Only medically relevant information should be included the resolution of a medical futility conflict.

Although only medically relevant information should be considered when making a final decision about futility, the process of determining the medical facts of the case should consider social determinants as potential barriers to a just outcome. Ethics consultants can facilitate an understanding of barriers that patients face to achieving a just outcome through cultural competency and shared decision-making. Ethics committee consultations should also address potential barriers patient shave to understanding important information related to costs and benefits of care as compared to the patient’s goals. At times, patients make serious choices without a full understanding of the proposed intervention. For example, Do Not Resuscitate (DNR) patients may tend to have more concrete understanding of resuscitation, while full code (FC) patients may tend to understand resuscitation in a more abstract sense.\textsuperscript{111} Patients should be elevated to a place where they fully understand the benefits and costs of an intervention.

Finally, it must also be considered that biases may be entrenched within ethics committees themselves, which organizations should attempt to avoid. Although ethics committees are used to provide due process and a fair method for reaching resolution to a conflict, problems with this role may occur when ethics committees do not represent the diversity of the population, have financial ties to the hospital they serve under, or if they are reduced to a systematic process for overriding family requests that seem unreasonable to the clinical team.\textsuperscript{112} Ethics committees should then have mechanisms to avoid these biases, especially when dealing with cases of medical futility. Health care ethics consultants should be able to help health are teams unpack
biases, especially in the protection of vulnerable, marginalized, and disempowered patients and families, helping to equalize the power dynamic in defense of justice. Ethics committees should be facilitators of just decision-making, protecting patients with special vulnerability.

Medical futility arguments are often invoked in the context of the limited resources available in health care, thus pulled into arguments related to rationing of health care. The idea is that, if expensive but futile interventions could be avoided, costs to the system could be saved, and resources spent in futility could provide benefit other patients. As long as the approach is through a lens respect for human vulnerability and social responsibility, and the application is filtered through ethically sound policies and processes, allocation of health care resources can be a an ethically justified way to promote equitable access to quality health care.

While rationing relies on potentially unjust, inadaptatle criteria for resource allocation, resource allocation provides a framework that can adapt to specific patient situations and characteristics (including social determinants of health), importantly including considerations for quality of care, patient safety, cultural competence, and shared decision-making. With quality care equitably maximized, human rights will be protected and health care delivery will become more ethically grounded.

Due to the reality of limited health care resources, justification for systematic rationing of health care has been attempted, albeit in ways that have been strongly contested. There is no consensus on who should be entrusted to make rationing decisions, nor is there any consensus on how rationing decisions should balance equity, efficiency and efficacy when facing a scarce health care resource.

Rationing is typically based on specific patient characteristics, or group characteristics of patients that are in similar situations. Where demand for a therapy is beyond the resource
capabilities of an organization (such as with transplantation), guidelines can be developed to select and categorize patients for optimal use of those scarce resources with use of hierarchical guidelines for patient selection.\textsuperscript{115} This type of rationing can only be justified when applied to very specific situations in very specific contexts, while overarching judgements applied across types of care are impossible to uniformly justify.

Rationing discussions in the United States have focused primarily on insurance eligibility and coverage but there is a need for more public debate on resource allocation related to financial stability, trade-offs of cost containment versus achieving health goals, and how limited public financing for healthcare should be.\textsuperscript{116} There is room for bias in rationing based on ability to pay because public attitude can influence how much payers are willing to spend.\textsuperscript{117}

Arguments for rationing have been made for various patient characteristics with resistance. For example, age-based rationing has been argued as morally defensible in certain situations, but has also been seen has ageist, discriminatory, and morally objectionable.\textsuperscript{118} Others have argued that patient characteristics like productivity and lifestyle could be used for resource allocation.\textsuperscript{119} Others have looked for common characteristics based on healthcare needs. Previous use of resources for example, has been argued as a valid rationing criteria, with justification based on protecting a basic level of benefits for all persons.\textsuperscript{120} All of these criteria have serious flaws in that there may be clearly justified exceptions to these rules, and when exceptions to the rule are denigrations to the dignity of human lives, they should not be ignored or discounted. In light of the controversy around rationing arguments, there has been some shift from rationing language to language of waste avoidance, which are complimentary but not synonymous terms.\textsuperscript{121} Waste avoidance gets more to the point of resource allocation, where attempts are made to avoid using resources that do not add value.
When rationing decisions are made, it is suggested that they committees should be used, with public input and consideration of political realities.\(^{122}\) While this process may work for very specific interventions such as transplant, developing rationing policies for a larger scope of interventions can cause major problems and also, importantly, may face insurmountable political barriers. In addition, contentious rationing decisions can be left to the court system, but this is far from ideal. Allowing resource allocation decisions to be made through a court appeals process could undermine fairness by granting greater access to wealthy people, reducing transparency, compromising predictability and tainting the public’s perception of process fairness.\(^{123}\)

Ethical resource allocation is based on a foundation of goals and tolerable costs and is organized through a framework for organizational policy. Ethical resource allocation will be explained in terms of goals and tolerable costs. Goals and tolerable costs, provide the foundation for making decisions in health care’s resource-limited settings, including but not limited to cases of medical futility.

When facing limited resources, resource allocation should be employed through a fair and legitimate process, with resources pulled from ineffective or low benefit treatments to be reinvested in more effective, higher-value care.\(^{124}\) A framework is needed for assessing low benefit care versus care with high benefit, considering tolerable costs and risks to patients based on their personal values. Patients often need a focused and accessible explanation of risk assessment including framing of the evidence, determining their own predisposition toward risk, the likelihood of risk occurring, possible side-effects, what is involved in each potential course of action, and which short term and long-term risks are important to them based on their values and goals.\(^{125}\) An understanding of these risks and benefits in terms of the patient’s values will create the foundation for resource allocation policy for health care organizations.
The dimensions of equality that are normatively relevant need to be clearly defined since implicitly unfair allocation will occur without the employment of explicit allocation criteria.\textsuperscript{126} A transparent discussion is needed to determine how comparative effectiveness research can be balanced between physician discretion, patient autonomy and system-level restrictions, with a goal of using clinical data to inform decision-making within a flexible system responsive to the complexity of health care.\textsuperscript{127} This resource allocation criteria can be mapped out into buckets of feasibility, health level, health distribution, responsiveness, social and financial risk protection, and improved efficiency.\textsuperscript{128} It will also include cost considerations since there is a need for clear, explicit, transparent, inclusive process to determine how costs should be controlled, based on a shared social understanding.\textsuperscript{129}

A resource allocation framework will incorporate other related concepts, such as accountability for reasonableness and evidence-based medicine, although existing concepts are not comprehensive and must be supplemented with additional framework elements. For example, evidence-based medicine seeks to generalize treatments, which may not be appropriate for all individuals in an ethnoculturally diverse context such as in the United States.\textsuperscript{130} Evidence-based medicine will work for resource allocation only within the ethical framework as described henceforth.

CHAPTER SIX will focus on the specifics of the framework for resource allocation, and how this framework will improve health care quality and promote human rights. This includes addressing fairness in value assessments, the issue of medical futility, and the framework process, methods, and evaluation mechanisms.

Resource allocation should focus on patient-directed goals, using cultural competence and shared decision-making as tools to alleviate inequalities caused by social determinants of
health. Focusing on assessment of patient goals and tolerable first and foremost will ensure that
treatments are aimed at the patient’s values and goals of care. The resource allocation framework
should be founded in fairness and value. This will be demonstrated through application to
medical futility end-of-life care debate.

Fairness, based on concepts of equity and justice, as well as value will be the basis for
resource allocation assessments. The resource allocation framework will be based in fairness and
equity both on both macro (organizational policy) and micro (bedside) levels. Fair bedside
rationing is needed in some cases, such as in triage (limited provider time, limited beds, limited
staff), in situations where resources are strained or subject to fixed limits (limited blood supply,
limited flu vaccines) and when the physician has an opinion that specific intervention will not be
worth the additional human or economic cost (assessment of individual benefit, assessment of
individual cost.)\(^{131}\) The resource allocation framework will incorporate the need for bedside
decision-making related to resource allocation.

Fairness is related to human rights as it is crucial for respecting the dignity of all persons.
If a person circumvents evidence-based, transparent, and unbiased resource allocation through
undue influence, they unjustly deny the dignity of the patient or patients who are consequentially
deprived of that same resource.\(^ {132}\)

The resource allocation framework will also be incorporate value, but only as long as it is
tightly connected with equity and justice. Value can be determined through various approaches,
but the recommended approach as part of this framework will be robust comparative
effectiveness analysis. An in-hospital comparative effectiveness center can be used to frame
existing literature within the local context, use local evidence where there are gaps in the
literature, complement and strengthen national activities, adapt and implement measures locally, and address the hospital’s own questions about quality, efficiency and effectiveness.\textsuperscript{133}

The value of life is at the core of the medical futility debate. Medical futility cases are often brought up at the end of life when interventions are prolonging life but not achieving many or any other goals of care. Addressing medical futility is part of the resource allocation framework because these are often the cases that provide the least benefit and some of the highest (human and financial) costs. Often, there is conflict in medical futility cases due to underlying, unrevealed beliefs and values that are not being addressed in the case. End-of-life interventions can have broad, underlying social or ritualistic benefits to patients such as addressing feelings of guilt and responsibility, reflecting upon the ambiguity between life and death, providing a social script for letting go, and giving space to being the grieving process.\textsuperscript{134} The resource allocation model, facilitated by health care providers, staff, and ethics consultants, can help to unearth some of these underlying issues to address the true reasons for conflict.

Medical futility should be addressed partially because of its implications for moral distress on physicians and nurses. Repeated experiences of moral distress can have a negative impact on quality patient care, burnout, job satisfaction, morale and can lead to exhaustion.\textsuperscript{135} Although, alternatively, moral distress could possibly reflect nursing discomfort with moral subjectivity in some cases.\textsuperscript{136}

The value of life is transcendental (which is the basis of its intrinsic dignity), finite (there is an end to life for all living beings), priceless (one cannot put a monetary value on life), and it is given (a person cannot create their own life).\textsuperscript{137} Since the value of life is priceless but finite, the value of life does not depend on its length. Prolonging life is merely a benefit of treatment, not a transcendent outcome above all others. Medical futility assessment during end-of-life care
should examine all benefits of treatment, not just incremental length of life added. All human life is priceless, regardless of social value, but life is not infinite. There is no moral obligation to spend an infinite amount of money to save all life years and provide for a virtually unlimited demand for health care, especially at high cost with marginal benefit. Only patients can define the level of benefit and cost they experience from an intervention, so their values and goals need to be at the center of this process. Truth telling is at the core of this process. Providing false hope goes against the professional ethic of truth telling. In addition, family members can suffer psychological effects and regrets following end-of-life decision making, and the clinical team should help to prevent this distress to the extent possible, as long as it is not at odds with the patient’s wishes and it does not cause suffering for the patient.

The resource allocation framework includes process, methods, assessment and evaluation. In this section, the process for resource allocation will be developed, including roles of the physician, patient or surrogate, and ethics committee. The resource allocation process will have two parallel tracks. First, will be the macro track for developing policy and procedures at the organizational level and second will be the micro track where policies and procedures will be carried out at the bedside. Each will be consistent with and in support of the goals of human rights and equity. A human rights framework will ensure that resource allocation includes a meaningful democratic deliberation with a prominent focus on equality and fairness.

The macro track will be facilitated by the organization’s ethics committee, or a similar committee with at least one trained bioethicist. This track will be responsible for the policy decision-making process as consistent with the accountability for reasonableness framework. Accountability for reasonableness has been applied with some success as an ethics-based, procedural guidance for fair resource allocation through its four conditions of relevance,
publicity, appeals and enforcement. Accountability for reasonableness is complementary to human rights and clarifies some obligations based on human rights, with an emphasis on a transparent process for resource allocation. It will help to guide a fair, transparent process although it does lack normative fairness criteria for decision-making, which is important because resource allocation should not only be legitimate in process but also fair in design. A major flaw with accountability for reasonableness is its assumption that reasonable equals fair. This approach puts process over principles and avoids practical decision-making guidance for distinguishing relevant versus irrelevant reasoning, lacking any theoretical underpinnings to the concept of fairness. Although accountability for reasonableness will be incorporated into the framework, it will not be the sole approach.

The macro track will also be responsible for consultation, developing and testing decision-making, family support tools, and data analysis. Decision aid development for vulnerable populations will focus on the eventual end users by assessing end user needs, pilot testing with end user cohorts, and partnering with community-based organizations. This committee will also facilitate and coordinate essential physician and staff training on cultural competency, shared decision-making and nursing assessment for patient goals, values and risk tolerance.

The micro track will be facilitated through shared decision-making and cultural competency at the bedside. This process will involve either an electronic or nurse-facilitated pre-appointment assessment of goals, values and risk tolerance. The physician will then discuss the patient’s assessment and determine the best treatment option for the patient. Criteria will be developed to trigger a consultation when risk is calculated to be greater than benefit for the selected treatment. The patient will then participate in a consultation to ensure that the selected
treatment is aligned with the patient’s goals and values. A decision-making framework should include the following components: identification of the need for a decision, a process for making the decision, and an action to be taken based on the decision. This will be incorporated into the bedside decision-making process.

Decision support tools as developed by the ethics committee will be used as needed at the bedside. Decision support tools should integrate clinical practice guidelines to both patient decision aids and deliberation support tools. For example, an option grid may be developed and used. The option grid includes frequently asked questions and answers to possible treatment options, and is used through a process of describing the goal of the grid, checking if the patient wishes to read the grid themselves or if they want them to be read to them, handing over the grid to the patient with a pen so that they can mark down notes and questions, creating space if they wish to read the grid themselves, asking encouraging questions and discussions, and telling the patient that they should take the grid with them for the opportunity to discuss options with others more information, encouraging referral to other specific sources. It is useful to implement an iterative design process that engages the end-users when developing health care decision support tools. Web-based decision-making aids could help facilitate discussions between patients and clinicians, and help patients to make informed, individualized decisions

The provider, patient and ethics committee will all have crucial roles in the resource allocation framework. The physician-patient interaction should be based on shared decision-making and mutual respect. Studies suggest that there is more discordance about decision-making preferences than concordance between health care providers and patients, although the degree to which this discordance occurs and the reasons for disagreement require further study. Although more research is needed, there is some evidence to suggest that patient-
centered care with interventions such as patient assessment, healthcare professional-patient collaboration, acknowledgement of patient expertise in their own illness, education and patient engagement, can help to reduce symptom burden, readmissions, and improve quality of life.\textsuperscript{154}

Shared decision-making involves a respect for the patient perspective and strengthening the patient-care team relationship.\textsuperscript{155} It is aligned with the goal of patient-centered care.

Patient-centered care maintains that patients should be involved in their own care and can lead to both better outcomes and decreased cost, but it can be difficult to implement when there are workload and workforce constraints, fragmentation of care and a destructive power dynamic between the healthcare professional and patient.\textsuperscript{156} Patient-centeredness complements quality measures and show the essential quality perspective of patient experience.\textsuperscript{157} Patient satisfaction may be influenced by unrealistic expectations and poor perception of benefits and risk so improved shared decision-making through decision aids with relevant personalized evidence-based information can be a useful, ethically sound approach to treatment decision-making.\textsuperscript{158} Collaborative decision-making and patient-centered care may address the issue of health care professional moral distress. Moral distress reflects health professionals’ frustration and failure to meet moral obligations, and could be addressed by encouraging ethical action and allowing questions to be raised and discussed.\textsuperscript{159} Often, this occurs when the health care professional must weigh their professional obligation to the individual patient in front of them versus what is best for the society as a whole.\textsuperscript{160} The resource allocation framework will alleviate this distress by creating a clear structure for decision-making in these contexts. Staff will also be engaged to empower them in the process. When the health care team is takes ownership of a process, positive and necessary changes in culture can occur.\textsuperscript{161}
From the patient’s perspective, patient-centered care will help to address any social disadvantages that may be negatively impacting their health, even if they seemingly should share personal responsibility for their health outcomes. Appeals to personal responsibility can be problematic if incentives create inequalities based on access or reciprocity-based responsibilities don’t allow for flexibility in the amount an individual can reasonably be expected to contribute.\textsuperscript{162}

Ethics committees will also play an important role in the framework. Ethics committees should be embedded into the broad framework and continuous process of organizational resource allocation, approaching ethics consultation in four stages: training, identifying scarcity-related problems, supporting decision-making and evaluation.\textsuperscript{163}

The resource allocation framework will include a robust assessment and evaluation component. The framework will include its background and philosophical foundations, the process for engaging in resource allocation, and mechanisms for assessment and evaluation. Physicians should first ask about the patient’s desired goals upon admission and present possible treatments that have a reasonable chance of achieving those goals or, alternatively, set expectations when goals are unachievable and present alternative options for the patient to consider.\textsuperscript{164}

The framework will encompass an organizational resource allocation policy with an end-of-life decision-making subset. Resources will be tied to specific benefits. The process will include defining the patient’s goals, determining the patient’s tolerable costs (such as quality of life measures or complications,) and ensuring stakeholder understanding of patient goals and values. When specific policy needs to be developed based on scarcity of resources, a general assessment will be performed of the benefits of the intervention and which types of patients
would benefit from the intervention. The process will be transparent with an appeals process. For example, the problems associated with current approaches to Do Not Resuscitate (DNR) orders could be addressed through better management of hospital culture, inclusion in policy discussions, provider communication skill training, and better aligned financial incentives.165

In addition to the process for addressing general and specific resource allocation, the framework will include a continuing education requirement for nurses and physicians. Health care organizations should invest in quality communication programs to help physicians navigate discussions around patient goals, navigating hope versus truth, making sense of illness, refocusing on reality, encouraging patients to discuss their fears, navigating family relationships and patient hesitations for “giving up,” as well as helping physicians to confront their own struggle with impotence in times of futility.166 In addition, a common ethics course for nurses and physicians could help them to develop an ethical skill set and instill in them a confidence to exercise moral convictions, thus helping to avoid moral distress such as feelings of powerlessness, guilt, sadness and anger.167

Finally, the ethics committee or consultant(s) will have an important role in the framework. The ethics consultation can help to address conflicts experienced between families and health care providers, including consideration of other’s perspectives, acknowledgement of diversity, empathizing, and working together with involved parties to relinquish domination and find a common ground.168

The framework will be evaluated for effectiveness. Successful resource allocation can be evaluated based on process elements of stakeholder engagement, clarity of process, clear and transparent information management, level of consideration for values and context, and revision or appeals mechanism, as well as outcomes elements including stakeholder engagement, shifted
resources, decision-making quality, stakeholder acceptance and satisfaction and positive externalities. Multi-dimensional outcomes will be considered knowing that a health care service or intervention often has interdependent resources, such as in the case of cardiothoracic surgery where both an operating room and bed for postoperative recovery are needed to admit a new patient. The management of resources will be assessed. Management of healthcare resources should incorporate the complex behavior of natural and social systems of health care including multiple inputs and outputs, multiple perspectives and an environment of uncertainty.

CHAPTER SEVEN will conclude the analysis. An organization’s moral agency assigns its ethical obligation to protect the human right to health care, based in the foundations of equity, respect for human vulnerability and social responsibility. This obligation is particularly important to reduce social inequalities within health care, based on social determinants of health including race, ethnicity, culture, socioeconomic status, and access to health care. Health care organizations can start to address these issues by using cultural competency and shared decision-making, but these tools must be incorporated into a larger framework to promote health care equity within the confines of finite resources.

A framework of resource allocation puts the patient’s goals and values first, with recommended interventions presented in response. Resource allocation can also be used be in a broader sense when distributing specific finite resources. Based on obligations of moral agency, health care organizations are ethically obligated provide this framework, guiding the actions of its agents and protecting the human rights of the patients it serves.

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83 https://www.thinkculturalhealth.hhs.gov/content/clas.asp


87 Légaré, France, and Holly O. Wittman. "Shared Decision Making: Examining Key Elements and Barriers to Adoption into Routine Clinical Practice." *Health Affairs* 32, no. 2 (Feb 2013): 276-84.

Chapter 2: Human Rights in Health Care

2a A Right to Health Care

Human rights are based on the intrinsic dignity of human beings and require protections for all persons to achieve self-determination. Health is a human right because it is a prerequisite for any human to act freely and to make autonomous choices. Until now, the duties related to this right have not yet been clearly defined, but this chapter will explain that the right to health requires a right to quality health care. The right to quality health care is fundamentally supported by principles of equity, respect for human vulnerability and social responsibility.

2ai Health Care as a Human Right

Health and health care are requirements for participation in a democratic society since they are requirements for functional ability. Health was not always assumed to be a right, however, and this right has evolved over the past several centuries.

The Emergence of Health as a Human Right

Human rights discourse emerged in the mid-1700s and showed its influence in the American Declaration of Independence of 1776 and the French Declaration of the Rights of Man and Citizen in 1789. It continued to develop after mass human rights violations during the two world wars, and it grew into a global discourse through the establishment of the United Nations. Bioethics has emerged alongside of human rights and is used to guide systematic health-related human rights decisions and analysis.

Human rights discourse originated in both America and in France. In America, human rights discourse first focused on both particularistic and universalistic version of rights language,
while the French embraced the universalistic version.\(^1\) The American focus on universalism and particularism was related to its core cultural value of independence. As Americans made arguments for independence, human rights dialogue moved toward a universalistic approach, although human rights became a secondary priority compared to concerns over the new national framework.\(^2\) While Americans saw human rights as secondary to its new national framework, the French saw rights as a primary concern for its framework to rebuild its government. For these reasons, *The Declaration of Rights of Man and Citizen* in France was established before *The Declaration of Independence* in America. *The Declaration of Rights of Man and Citizen* laid out general principles of justice including equality in the law, no arbitrary imprisonment or punishments, and the accused as innocent until proven guilty.\(^3\) These became the foundations for spreading acceptance of human rights principles.

The declarations of rights in America and France were both were formal, public statements that claimed that rights already existed but needed to be defended.\(^4\) Although they were a good start in defining human rights, these declarations proved to be thin and became secondary considerations to other political and social issues of their time. It took two World Wars and the creation of the United Nations to prioritize human rights and bring it to a global forum. The emergence of the concept of “Right to Health” was an important part of this dialogue.

Although the Universal Declaration of Human Rights recognizes that a person has a right to adequate health and wellbeing, including medical care, its social impact on the right to health has been minimal until recently. In the year 2000, the UN Committee on Economic, Social and Cultural Rights issued General Comment 14, which clarified the scope, duties, and entitlements related to the right to health.\(^5\) These rights include the right to the highest attainable standard of
health, which was originally defined by the World Health Organization Constitution in 1948. In addition, further clarification has been offered by a Right to Health Statement issued by the UN High Commissioner for Human Rights and the United Nations Special Rapporteur on the Right to the Highest Attainable of Health in 2005. This statement explains that the right to health means clean water, sanitation, accountability in health care decisions, the abolition of user fees for primary health care, and training of health care workers, and clarifies that the right to health does not mean the right to be healthy or that a government is expected to fund expensive health care technologies. Rights discourse continued on in clarification and specification.

The 2005 Right to Health Statement was an attempt to unite idealistic goals with a respect to potentially limited resources. This clarification could be helpful for any nation, but is most applicable for health-related rights in developing countries. It demonstrates a pragmatic approach for global health issues, looking for solutions that can be applied to all nations, not only those which have a lot of resources or a high level of wealth. This is important because global health is not something that can be improved without actionable policy. It must address real issues such as health inequalities and how resources are distributed. When moving from high-level declarations to specific policy and advocacy issues, questions arise such as: “Who is responsible for health inequalities?” and “How should resources be distributed?” The answers to these questions are not easy since they are based in value judgments. To answer the increasingly complex global health questions of the modern world, a methodology that facilitates a systematic ethical analysis should be used. Global bioethics is the link that can facilitate this analysis and help global health advocates make decisions on specific health-related human rights issues.
The right to health forms the foundation of the right to quality health care, which ultimately informs the responsibilities of organizations to address health inequity. The basis of the right to health has been set forth by the United Nations. In December of 1948, the United Nations established a standard of human rights for all persons through the *Universal Declaration of Human Rights*. Notably, Article 25 of the *Universal Declaration of Human Rights* states that “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services(…)”9 This article establishes a basis for discourse on health care as a human right.

In 2005, UNESCO (United Nations Educational, Scientific and Cultural Organization) clarified the right to health by creating the *Universal Declaration on Bioethics and Human Rights*, which describes key principles for recognizing and resolving ethical dilemmas in bioethics.10 In 2015, the United Nations further clarified its approach to health and human rights through the *Sustainable Development Goals and Agenda 2030*, which contains the goal of good health and well-being.11 The goal of good health and well-being includes “universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.”12

The World Health Organization (WHO) adds additional clarity to the right to health. According to the WHO, the right to health involves freedom to control one’s own body, freedoms from interference in pursuing health and wellness, and equitable, systematic protection for all to achieve the highest attainable level of health.13 This definition highlights the importance of health equity, which has yet to be achieved in the United States. Health inequity persists due to widespread disparities in access and outcomes based on social determinants of health.
The United Nations Sustainable Development Goals were adopted on September 25, 2015 and include the goal to “ensure healthy lives and promote well-being for all at all ages.”\textsuperscript{14} The sustainable development goals highlight the continuing global focus on the right to health. Although human right discourse has not been met unchallenged, it continues to provide a moral standing to demand change that protects the inherent human dignity of all humans.\textsuperscript{15} Human rights, including the right to health, recognizes that humans are not simply a means but an ends, and is based on the respect of humanity and dignity that is equal and inherent in all humans and should be protected by laws and social arrangements.\textsuperscript{16} Health in particular should be protected by civil society structure and its representatives is essential for the fulfillment of other human rights and fundamental freedoms\textsuperscript{17}

\textit{Availability, Accessibility, Acceptability and Quality}

In August 2000, the United Nations Committee on Economic, Social and Cultural Rights (CESCR) clarified preconditions for the right to the highest attainable standard of health as availability, accessibility, acceptability and quality.\textsuperscript{18} These preconditions are also the foundations for the right to quality health care.

The precondition of availability states requires that “Functioning public health and health-care facilities, goods and services, as well as programs, have to be available in sufficient quantity…”\textsuperscript{19} This means that there must be an adequate number of health delivery systems, as well as an adequate number and amount of essential services provided by those systems. All persons must have the right kind of and amount of health care services available to them in a meaningful way.

Problems with health care availability persist across the United States due to inadequacies of health resources to meet health care needs. This can cause a high level of strain on the US
healthcare delivery system. For example, primary care availability affects the disproportionate use of emergency and urgent care services in the United States. When primary health care is unavailable due to long wait times, individuals are left with no other choice but to use urgent or emergency care. This causes an inefficient use of and undue burden on already scarce resources. In this case, primary health care is not effectively available for individuals to utilize. When there are not enough health care resources to meet the needs of individuals in a community, the criteria of health care availability is compromised.

Concerns of availability are not limited to direct medical care. Availability of community pharmacies vary substantially across areas and are often misaligned with local population needs. Availability concerns cross the continuum of health care into ancillary and secondary health services which directly affect the realization of the right to health. In order to meet the requirement of availability, all types of required services must be available to individuals who need them. This includes general and primary care, inpatient hospital care, medical devices, pharmaceutical drugs, and chronic condition management.

There are several specific contexts in which the precondition of availability is especially challenging within the United States. The precondition of health service availability can be particularly difficult in rural communities. There is an availability gap between rural and urban medical care related to rural health shortage of physicians, hospitals, and associate health professionals. Although this problem persists, health care delivery services can and should work to address these availability gaps for rural populations. Namely, availability of health services in rural communities can be improved through an integrated approach focused on continuity of care, distribution of health workforce, capacity development through existing networks, and collective action. A focused effort on improving these availability issues in rural
areas can help to promote the right to health. Availability of health care services does not only extend to physical resources, but also human resources. When there are not enough providers or health care staff to meet the community needs, availability requirements are not met. Health care delivery organizations have a clear role with related obligations within this integrated approach.

Health care delivery organizations can use a variety of approaches to address the availability of health care services, thus meeting this precondition to health and human rights. Technology is one example of how health delivery organizations can improve availability. Technology can improve availability of care for specific and changing patient needs, such coordination of primary and specialty care for those with multiple chronic conditions.\textsuperscript{24} One example of this approach is the use of telemedicine. Telemedicine and other technologies could be used to bridge the availability gap by allowing remote access to timely medical advice and expertise.\textsuperscript{25} For example, rural hospital tele-ICU, is a tool that can be used for extra support and assistance addressing availability problems of critical care workforce shortages, difficulty recruiting and retaining, long distance between patients in hospital and home community.\textsuperscript{26} In addition, telemonitoring can be used to manage chronic conditions for vulnerable patients. Telemonitoring can also be used to support chronic disease management, which will only become more important as both the population life expectancy and chronic disease incidence increase.\textsuperscript{27} These are just a few examples of how technology can address gaps in availability of health services.

In addition to availability of services, individuals and groups must also have \textit{access} to available services to meet the conditions of health and human rights. Access includes the meaningful ability to use available health care goods and services.
The precondition of accessibility states that “health facilities, goods and services have to be accessible to everyone without discrimination(...)”\(^{28}\) This means that all individuals must have equitable access to health care delivery systems. In other words, all individuals who need a health care service must have equal opportunity to use available health care goods and services. Barriers to equitable access can include issues like lack of reliable transportation and inadequate insurance coverage.

While a large amount of political discourse and public policy is focused on access in terms of health care financing, reimbursement systems are not the only factor that infringe upon equal access to health care.\(^{29}\) There are many reasons why individuals and groups may lack access to the health services that they need. Timely access to health care may be affected by factors like appropriate staffing, logistics of scheduling appointments, patient arrival times, and providers keeping to schedules.\(^{30}\) Health care services may be available, but if they are not available at a time when a patient can utilize the services, they will lack access.

Transportation and physical access can also be a barrier to realizing the right to health. Older adults in rural areas face transportation barriers to access medical care as compared to their urban counterparts.\(^{31}\) Those who do not live in areas with reliable public transportation may lack transportation to health care facilities, other than emergency ambulance service. Also, those who need ongoing non-emergency medical transportation, such as those with end stage renal disease, can face barriers to access where frequency and timing of visits is an imperative for compliance with treatments.\(^{32}\) Even if a service such as dialysis is available, if a person is unable to access that necessary service, they will not be able to utilize it and ultimately lack the opportunity to pursue their right to health. A person may also lack access to transportation for health-related
goods and services such as healthy food and medication. Access to transportation can inhibit one’s ability to achieve their highest possible level of health for many reasons.

In addition to resource barriers to access, socioeconomic barriers can limit or eliminate meaningful access for some marginalized groups. For example, there is a variation of neighborhood risk and access to care – especially in the southeast US where the legacy of racial segregation prevails and there is a negative correlation between concentration of black residents in individual’s neighborhood and satisfaction with health access.\(^{33}\) Another example of socioeconomic access barriers is illustrated by the homeless population in the United States. Barriers to access faced by the homeless go beyond health insurance to general mistrust of healthcare providers, lack of access to primary care provider, and fear of legal ramifications.\(^{34}\) Barriers related to socioeconomic status that affect access to health care can be multifaceted and complex. They can be physical or psychological, and very depending on a person or group’s specific situation.

In addition to physical health care access, access to health services also includes access to information. Access to information involves clear, direct communication that meets the needs of those with low literacy level and low English proficiency, plus any other potential structural barriers facing the patient population.\(^{35}\) An individual needs access to information for rational decision-making about health care needs. If a person is not able to understand health-related information due to language barriers, they will not be able to make informed decisions. Likewise, if health information is not appropriate for the literacy level of the patient, they will not be able to understand the critical information to inform their decision making. Health literacy is also an important consideration. Health-related information should be provided in terms that a person without a medical background or training can understand. Even if a person can read
health information accurately, the format of the information is also important for health care information access. If information is shared on a web-based platform, some patients may not be able to access the information due to technology issues. A person may either not have access to the required technology or not understand how to use the technology. The medium for sharing information must be appropriate for a person to access essential health information.

Although technology presents some challenges, it can help with some access issues when used appropriately. For example, an improved model of hybrid telepsychiatry could help elderly, homebound adults connect with psychiatry services. Although there are technology solutions for some barriers to access, other delivery and policy interventions must be initiated to address the overarching issue of access. Interventions to improve health care access should include focused community and neighborhood interventions. Interventions based on community and group-based needs may begin to address some of the socioeconomic barriers to meaningful healthcare access. Addressing these needs may also begin to facilitate acceptability and quality preconditions of the right to health.

The preconditions of acceptability and quality state that all health facilities, goods and services must be respectful of medical ethics and culturally appropriate (…) and “health facilities, goods and services must also be scientifically and medically appropriate and of good quality.” Like availability and accessibility, responsibilities for these conditions also lie within health delivery organizations. Health delivery organizations are those who carry out medical interventions and are responsible for monitoring and ensuring acceptable and quality care delivery.

In order to be acceptable and high-quality, health services must be responsive to population and community-specific needs. Rational deliberation toward health incentives may be
inhibited for those in the most disadvantaged environments, so smart design should be prioritized over incentives and mandates. An acceptable and quality health system will use systems design to provide health care delivery that meets the needs of the population it serves. Continuous quality improvement will be an integral part of quality management, and current evidence-based practices will be incorporated into quality design.

This systems design should use an integrated health care model. Health delivery models should move away from specialized episodic models to integrated longitudinal model that connects acute and community health systems with non-healthcare service systems. An acceptable, quality health care delivery system will be integrated and meet patient needs across the continuum of care. This integration will include important collaborations with communities and other related health services across the continuum. Intersectional interventions are needed to improve acceptability and quality of care that include attention to social, commercial, cultural, economic, environmental, political determinants of health. A wholistic approach to health that encompasses integrated care across the health care continuum will meet the criteria of acceptability and quality.

Health care delivery systems have special responsibility to transform their organization to meet these preconditions to the right to health. Health delivery leaders can transform acceptability of health delivery by: building teams around shared vision; developing and executing pillars of strategy at every level of the organization; commitment to teamwork; fostering a high-reliability learning organization; alignment of people with a shared language; Continuous and effective 360-degree communication and accountability; translation of big picture goals in meaningful ways; transparency; tailored organizational structure; and translation
of best practices. In these ways, health care delivery organizations can move toward the establishment of preconditions for the right to health.

**2aii Equity in Health Care**

The availability, accessibility, acceptability and quality of health care should be established on a foundation of health equity. Equity means fairness, not necessarily equal treatment – i.e. equality of opportunity versus equality of outcomes. The right to health involves the right to fair and equitable health care that is available, accessible, acceptable, and provides high-quality. The UNESCO Declaration on bioethics and human rights includes the principle of equality, justice and equity that states: “The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.” The principles of human rights indicate that distribution of health care should be fair. A systematic approach to health equity should be used to protect health and human rights. Without a systematic approach founded in bioethics, non-equitable approaches may be used.

Specifically, human rights discourse should address disparities in health care outcomes and help to define duties of health care organizations to provide quality care. These disparities are related to both horizontal and vertical equity. Horizontal equity requires that those with equal need be treated equally, while vertical equity requires that those with different needs be treated differently, but fairly.

*Horizontal Equity*

Horizontal equity states that those with equal need should be treated equally. Unfortunately, unfair health inequities exist in the United States, hindering the ability of marginalized groups to realize the right to health. This is problematic in terms of disparities in
health care availability, accessibility, acceptability, and quality. Health care is instrumental to quality of opportunity since unfair disease and disability restricts normal opportunity and limits a person’s fair, normal range of skills preventing them from accomplishing a life of flourishing.\(^4\) Individuals will not be able to meet fair opportunity to accomplish life goals without equitable access to health care.

Inequalities in health outcomes can occur for various, often intersecting reasons. In general, inequalities in flow from three major sources: the workings of social structure, voluntary personal choices or behaviors, and natural differences in human endowment or fortuitous events outside of social structure.\(^4\) In terms of health outcomes, inequalities can exist based on social context, personal lifestyle choices related to health, and/or genetic fortune or misfortune. Social context involves social vulnerabilities that may affect a person’s health. For example, vulnerable groups experience a disproportionate burden of cancer incidence and mortality, at least partially attributed to early experience that create downstream risk for cancer such as adverse childhood experiences, maternal alcohol consumption in pregnancy, childhood obesity, high or low birth weight, benzene exposure, exposure to tobacco in utero and early stages, and early exposure to infection.\(^4\) Voluntary or personal choices may also affect incidence of cancer – for example engaging in risky behaviors such as tobacco use. A person’s genetic predisposition to cancer may also play a role. These risks and inequalities in health outcomes may grow from one or a combination of these social, personal behavior, and natural differences in human biology. The principle of vertical equity states that those who have equal need for health services – regardless of the inequalities in risks that a person may face – should receive equal availability and access to acceptable, quality care. The principle of vertical equity states that those who have equal needs, should be treated equally.
While those who have equal need for quality health care should receive equal availability and access to quality health care, barriers often exist to prevent the realization of this right. Addressing health inequities involves addressing the underlying reasons for unjust access, availability, acceptability, and/or quality of health care. Health inequities occur across the social gradient and are related to social and economic conditions where people grow, live, work and age. A person’s environment and socioeconomic status can cause them to experience negative, inequitable health outcomes. Health inequities are affected by economic inequities, disparities in geographical dispersion of health services, and both direct and indirect costs of health care access. The social inequalities that individuals face can create significant barriers to realizing the right to quality health care. Based on horizontal equity, these social and economic reasons do not justify denying a person’s right to quality care.

Some vulnerable groups face higher risk and worse health outcomes than others. The inequity of health outcomes for those with the same health needs reflects horizontal inequities of the health care delivery system. There are many examples of horizontal inequities in health care. Over the last 30 years, breast cancer mortality rates have improved overall, yet many geographic areas have actually seen a widening mortality gap in breast cancer outcomes between black and white breast cancer patients. When advances in health care therapies and technologies are not available for all persons equally, horizontal equity is unmet and the human right to health is violated for those experiencing disparate care. Addressing disparities in health care outcomes is a step toward improving horizontal equity in health care.

Horizontal equity is needed for the pursuit of health, or the realization of the right to health. The principle of health equity creates an essential moral support for the justification of quality health care as a human right. Human rights, including the right to health, protect the
fundamental conditions or opportunity for pursuing a good life as well as the essential resources
needed to meet these conditions. The right to health is not meaningful if it does not require
resources or support for persons to realize that right. The right to health involves the right to
achieve the highest attainable level of health, and the support resources and services for all
persons to protect a person’s ability to pursue health. All persons should have equal opportunity
to pursue the highest achievable level of health, per the human right to health. Since many
individuals face inequitable conditions that prevent them from pursuing the highest quality of
health care available, this human right is not currently being realized either globally or within the
United States. State governments have a significant role in protecting equitable availability,
accessibility and acceptability of quality health care, but the responsibility for carrying out
conditions to protect this right lies within health care delivery organizations. Health care delivery
organizations have a responsibility to protect health equity at the level of health care delivery.

Health delivery organizations can use data to inform decision-making about horizontal
health equity. Data is an essential for effective implementation and monitoring of health equity
metrics. Disaggregated data should be used to illustrate patterns and indicators of health
distribution within the population and inform policies, programs, and practices related to health
promotion. This data can inform health delivery organizations on how to provide equitable
services. Health care leaders can drill down on aggregated data to analyze any gaps in equitable
health outcomes and how these gaps may be improved or addressed.

Data related to health equity can frame horizontal equity and areas of improvement in a
productive way. Data analysts can find areas of opportunity where cooperation and capitalizing
on existing resources can reduce inefficiencies and unfair distributions to create more equitable
service delivery. In general, a paradigm of cooperation should be used since competitive, market-
driven approaches create winners-versus-losers mentality which engenders health inequity.\textsuperscript{54}

This approach, combined with data to inform decisions, will help health delivery organizations to provide equal care to those with equal needs. Health care delivery organizations should cooperate not only among themselves, but also with community stakeholders that have an interest and can make an impact on key health issues. With data and information to inform decisions, health care organizations can develop interventions to create more equitable interventions and policies.

Importantly, the concept of cooperation rather than competition is aligned with, rather than against American ideals of individual freedoms. In addition to ethical dimensions, cooperation and fairness can create an improved economic environment. The free market can benefit from distributional fairness in health because it can lead to higher consumption demand, more productive members of society, and reduced crime through reduced poverty.\textsuperscript{55} Health equity creates conditions where citizens can pursue the “American Dream,” – or the opportunity to achieve regardless of social circumstance at birth. When distributional fairness exists and individuals have fair economic opportunity, the concentration of wealth moves to the population that will increase demand through consumption. In addition, those who are healthier and more educated with more employment opportunities will be more productive members of society. Poverty and crime rate also creates a positive social environment for the free market to thrive, while simultaneously creating an improved quality of life for all citizens.

Health Delivery organizations can support horizontal equity in many established and innovative ways. New approaches to health equity may help – including innovations in technology. For example, social media can be used to facilitate knowledge translation and build relationships to impact social determinants of health and equity.\textsuperscript{56} Health care delivery
organizations have a responsibility to develop and apply approaches to protect horizontal equity, and treat all individuals with equal need, equally. This includes health equity in all areas of the triple aim of health care. The Triple Aim of health care reform – or improved outcomes, patient experience and cost control - should be guided by a framework of health equity that promotes institutional accountability.\(^5\) Health equity should include equitable opportunity for positive health outcomes. It should also include equitable opportunity for positive patient experiences. In addition, cost control and financial incentives should be implemented equitably among the patient population. The triple aim will be most effective when health care delivery organizations are accountable for monitoring and protecting horizontal health equity. Monitoring and data analysis should include segmenting data to ensure that no marginalized groups have unfair, poor outcomes compared to the general patient population.

Health delivery organizations have an obligation as well as the ability to protect horizontal equity. Individuals with equal needs should be treated equally according to horizontal equity. Also in accordance with equity, individuals with differing needs should be treated differently but fairly. This is described as vertical equity. Health care delivery organizations also have obligations to ensure vertical equity for the individuals and populations that they serve.

*Vertical Equity*

Vertical equity means that patients with differing needs should be treated differently, but fairly. Patients may have differing needs for various reasons that may arise from existing inequalities. For example, inequities in access and insurance status can result in patients presenting in late stages of disease.\(^5\) When a person faces barriers to pursuing the highest attainable degree of health, they have an elevated need for protection of the right to health. Vertical equity explains that those who need more, should get more in terms of health services.
and protection of their right to health care. Those persons with special or extra needs related to
the pursuit of health can justifiably receive more resources or support to optimize their health,
based on vertical equity.

For example, those facing inequalities of access should be given preferential treatment
due to need, based on vertical equity. For example, if a specific neighborhood patient population
lacks transportation to the local hospital, a shuttle system may be instituted between the affected
neighborhood and the hospital. Since the specific neighborhood has a need, they will have
preferential treatment over other neighborhoods that do not lack transportation. Equity
considerations are important because, even though health is somewhat the product of voluntary
actions, it is more significantly affected by genetic, environmental and social factors that could
be avoided by medical and public health interventions. If medical and public health
interventions would be able to address the factors that inhibit one’s ability to pursue health, then
those medical and public health interventions should be implemented. Those who are unable to
access health care because they lack adequate social and economic resources such as education,
transportation, or health insurance, should be given a greater amount of assistance than those
who have adequate social and economic resources.

Many health outcomes are influenced by meaningful access to adequate, equitable health
care resources – including quality of life outcomes. For example, the quality of a person’s end of
life years are only weakly correlated with chronological age, while other aspects such as
behavior, genetic inheritance, social factors have a stronger correlation with end of life quality. These behavior, genetic, and social factors can be addressed through targeted interventions to
improve quality of life in those who suffer worse quality of life outcomes. Health delivery
organizations protect fairness and equity by providing proportionate care to those who need it more based on these factors.

Differing medical needs are not only based on social factors, but also on disease state. For example, barriers to access of care for rare diseases include delayed diagnosis and limited or nonexistent treatment options.\textsuperscript{61} Efforts to protect equitable treatment and access for those with rare diseases would protect vertical equity. Patients who receive less attention or are not effectively assessed because of their type of disease may face vertical inequity based on their disease state. Likewise, if a person has an advanced stage of a particular disease, they can legitimately receive more health resources and treatment options based on their medical need. This is justifiable based on vertical equity.

In addition, the needs of changing population demographics will affect health care delivery response to vertical equity. The population in the United States is getting older and more diverse. Growing population diversity and increasing burden of chronic, interacting needs are contributing to increasing complexity of patient needs.\textsuperscript{62} Those with greater needs based on these demographic changes should be protected based on vertical equity. This will become increasingly important as the population ages and becomes more diverse. Patients will have highly variable health problems and present to health care delivery systems with differing levels of health care needs. Health care delivery systems should provide different, but fair treatment to those who present with varying degrees of health care needs.

Health care delivery systems can use various tools to address vertical inequity. Disparities in health vary between communities and effective interventions have been employed to improve health equity in some geographic areas. These successes can be used to create solutions based successful interventions in terms of how to measure disparities and local
variation, developing interventions from common elements of success, testing interventions, and building coalitions and feedback loops. Community-based interventions that target individuals and groups with greater risk and health needs can help to reduce vertical inequity of health. Providing targeted, additional interventions and resources to those who need it the most is aligned with vertical equity, which states that those with differing needs should be treated differently, but fairly.

Communities lacking equitable health care availability, accessibility, acceptability and/or quality should be included in the development of health delivery interventions to promote vertical equity through multi-sector partnerships. Developing multi-sector partnerships that include community stakeholders can help with identifying and addressing the inequitable social structures and economic systems that contribute to health inequity. Health care delivery systems can learn about the social, economic and environmental risks and community-specific needs through these partnerships. When there are specific socioeconomic or community needs, the key stakeholders can offer not only root causes but also propose solutions that could be meaningful to their community.

For example, some communities have a high incidence of obesity, and have a greater health needs due to obesity-related health problems. Health care delivery organizations can tap into existing resources and create new, community-specific interventions to address health problems in vulnerable groups, like those with high incidence of obesity. The CDC has a toolkit to address disparities in obesity incidence, addressing the role of environmental factors and the persistence of health disparities related to age, income, education, gender, race, ethnicity, and geographic region. This is just one example of a tool that health delivery organizations can use to target, monitor and address community or group-specific health needs and promote vertical
equity. Health care delivery organizations can work with communities to use both existing tools and to develop innovative ways to affect their barriers to health.

Promoting health equity is essential for protecting health and human rights. Human rights protect the fundamental conditions of pursuing a good life, or conditions necessary for engaging in basic activities like deep personal relationships, active and passive pleasures, and attaining knowledge. When a person does not have a fair chance to pursue a good life, they are not being afforded human rights. Health equity is a critical component of the right to health. In addition, the health equity and the right to health are prerequisites to all other human rights, since a person must be healthy before they can pursue any other opportunity.

The obligations of health care delivery organizations to protect horizontal equity are related to the nature of human vulnerability. Obligations related to vertical equity are related to special vulnerability. Social responsibility in health care explains why these obligations exist to protect these vulnerabilities, thus promoting health equity.

2b Human Vulnerability & Social Responsibility in Health Care

Respect for human vulnerability and social responsibility are the most relevant principles for health and human rights and explain the organizational obligations to protect or promote the human right to health. Vulnerability is a common human experience, although the degree of vulnerability that humans face varies greatly. Social responsibility describes the obligations that humans have toward one another, especially toward other more vulnerable humans. These two principles combined create the foundation for health as a human right.
2bi Respect for Human Vulnerability in Health Care

The UNESCO Universal Declaration on Bioethics and Human Rights includes the principle of respect for human vulnerability and personal integrity, declaring: “In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.”67 This means that the concept of vulnerability must be integrated into assessments of health and human rights. The respect for human vulnerability is linked to respect for personal integrity.

Rights and interests of the vulnerable should be protected, although criteria on how to protect the vulnerable needs more robust and integrated guidelines.68 Criteria and guidelines for protecting vulnerability will be described in this dissertation.

There are two major views of human vulnerability that will be discussed in this chapter: the universal view of vulnerability as the fragile, ontological condition of humanity and relational vulnerability, which affects those who have diminished capacity to protect their own interests.69 The nature of human vulnerability will be discussed first. The nature of human vulnerability describes how all humans are fragile and share a mortal condition. Special vulnerability describes how some humans experience an elevated level of vulnerability based on specific and special conditions or circumstances.

The Nature of Human Vulnerability

The nature of human vulnerability describes the common human condition of vulnerability. All humans have a common vulnerability based on the shared potential to be wounded physically psychologically, morally, and spiritually and the shared ability to suffer.70
All humans have this common capacity to be harmed, and thus vulnerability is part of human nature and common to all humans.

All humans share a degree of vulnerability based on the mortal human condition and capacity for suffering. All humans are vulnerable at some point in their life continuum. Vulnerability, which can occur at any time in individual's life, is dependent upon internal and external factors within the lifecycle continuum, is linked to risk and susceptibility, and involves an interplay between environment and individual. Humans have the capacity to become vulnerable due to both internal and external factors. Internal factors include human biology and susceptibility to physical and mental suffering and disease. External factors can also cause vulnerability, such as a person’s economic resources, and how well they are able to respond to environmental stressors. Both internal and external factors will interact to create vulnerabilities during a person’s life.

For example, if a person is having financial troubles and at the same time is diagnosed with cancer, these two vulnerabilities work together to create the person’s overall vulnerable situation. The nature of human vulnerability describes how all humans are susceptible to this type of suffering. All humans may, at any time in their life, financially struggle while at the same time receive a diagnosis of cancer. Some individuals may be more or less susceptible, but all individuals have some level of susceptibility to this suffering. The financial/cancer diagnosis example is just one example of a way in which any human has the potential to suffer but there are infinite examples of this common potentiality for suffering. Therefore, the human condition includes a common potential for suffering, or vulnerability. Both individual and environmental factors will affect the manifestation of a person’s vulnerability. How the nature of human
vulnerability manifests in each person may differ related to the individual and environmental factors that a person faces, but the potential for this suffering is equal in all humans.

The nature of human vulnerability is the foundation for the justification for health equity and health and human rights. All humans are vulnerable, so all humans have a level of equal need for protection of their human integrity. The complex and subtle realities of a patient’s disease experience can inhibit their ability to self-manage, so vulnerability and dependency should be included as guiding principles for both health policy discourse and clinical practice. There is a potential in all persons to lose the ability to self-manage and become dependent based on the realization of their common human vulnerability. Health policy and clinical practice should recognize that all humans have this potentiality and principles of horizontal equity should be incorporated into policy and practice to protect this common vulnerability.

Protecting the right to health and equitable availability, accessibility, acceptability and quality of care will ensure health equity – specifically horizontal health equity – and elevate the capacity for and recognition of humanity in all persons. Human vulnerability bonds and binds people, tending to the intense social needs of humans by allowing for the possibility for compassion to suffering and connection with the common humanity of mortality and fragility. The nature of human vulnerability, and the protection of health equity through the right to quality health care facilitates the recognition of common humanity and dignity, and creates a higher level of understanding and respect for what it means to be human.

The nature and importance of human vulnerability creates an obligation to protect those in whom this vulnerability has manifested. The nature of human vulnerability explains that all humans have the potential to be harmed, or to suffer, and reciprocity would entail an obligation to protect others with the understanding that oneself would be protected when in need. Since all
humans are vulnerable or susceptible to physical and emotional injury, attack, wound or damage, all humans need a level of protection or prevention of harm or violation of personal integrity. Providing this protection helps others within human societies, but also is protection for oneself knowing that the nature of human vulnerability means that oneself could experience injury, attack, wound or damage at any time.

All are vulnerable but some are more vulnerable because of membership in group such as those who are poor, marginalized groups, disadvantage, people of color, low socioeconomic status. Those who face vulnerability in addition to the nature of human vulnerability, have special vulnerability that must be protected under the principle of vertical equity. The universal vulnerability of the human condition allows for circumstances that lead to special vulnerability, such as those related to disease, disability, personal conditions, environmental conditions, and limited resources. The nature of human vulnerability is the precondition for special vulnerability. The nature of human vulnerability should be protected in respect to horizontal equity, while special vulnerability should be protected with respect to vertical equity.

Special Vulnerability

The Council for International Organizations of Medical Sciences (CIOMS) Guidelines as revised in 2002, have defined vulnerability as: "a substantial incapacity to protect one's own interests owing to such impediments as lack of capability to give informed consent, lack of alternative means of obtaining medical care or other expensive necessities, or being a junior or subordinate member of a hierarchical group;” and outlined special protections afforded to vulnerable groups: “accordingly, special provision must be made for the protection of the rights and welfare of vulnerable persons.” A person who is unable to protect their own interests and needs special protection has special vulnerability. A person may not be able to protect their own
interests based on inability to give informed consent or because of power dynamics that keep them from making free and autonomous decisions. Individuals who experience special vulnerability and are unable to advocate for themselves and their own interests deserve special protection in terms of the human right to health.

Health care delivery organizations have the power and the obligation to protect and address the sources of these special vulnerabilities. Special vulnerability is a harmed condition that leads to limited opportunities leading to deprivation of worthwhile experiences, missed possibilities and missed opportunities. In these terms, vulnerability has a clear negative impact on the realization of the human right to health. Special vulnerability impacts the degree and manner that individuals are able to pursue opportunities for health and well-being. Special vulnerability is the realized potential of the nature of human vulnerability. It can be caused by risks associated with group membership, or group vulnerability.

The European Court of Human Rights has characterized group vulnerability, which has allowed it to substantively address aspects of inequality. Although this characterization risks stigmatizing, essentializing, stereotyping, it can be useful (when aligned with the work of international and human rights organizations) for prioritization of scarce resources, guiding state preference to those who need the most. Based on special vulnerability, some individuals have a claim to more resources than others, and many individuals with these claims are part of marginalized groups that make them especially vulnerable. Identifying groups with special vulnerability can be an efficient ay to allocate resources to groups with a history of marginalization. This cannot be the only approach, however, since the risk of overgeneralizing may miss vulnerable individuals and groups that do not fit into the explicit group categorization of need.
Special vulnerabilities hinder the ability of individuals to pursue opportunities and reach potential for well-being. In other words, obstacles that restrict capacity for flourishing create special vulnerability. The goal of vertical equity is to remove these obstacles for flourishing. The human right to health offers protection for vertical equity in health and the ability for all humans to have equal opportunity to flourish. The opportunity to flourish entails the opportunity for self-actualization and reaching one’s potential.

Geographic, demographic and socioeconomic characteristics can impact the special vulnerability of individuals and groups. When studying special vulnerability, it is helpful to examine these characteristics to determine the root cause special vulnerability. Neighborhood risk factors can give insight to chronic diseases, which can disproportionately burden minorities and low-income populations. There are many factors that can lead to special vulnerability caused by the environment and social context of individuals and groups.

Special vulnerability can be caused by a multitude of reasons and special vulnerabilities can have a compounding effect. Individuals and groups may face double disparity when they are both medically overburdened and medically underserved, facing a disproportionate number of environmental hazards plus limited health care access. These environmental factors can include individual and group risk factors. The environmental and medical risks faced by an individual can create a high level of special vulnerability that may impact the realization of the right to health if vertical equity concerns are not addressed. Analyzing and addressing these vertical equity concerns should incorporate community feedback and involvement in policy decision-making. Vulnerable populations, such as African Americans, should be given fair, proportional representation in policy decision-making decisions that affect them. Involving vulnerable
populations in decisions that affect individuals in their communities can help to provide the appropriate services and care and promote vertical equity.

In addition to environmental and socioeconomic vulnerabilities, life course can cause special vulnerabilities. Age-related vulnerability is heightened at both the early and late years of life, and the lowest age-related vulnerability somewhere in between. Special vulnerability is explained as conditions of one’s life – either internal or external - that lead to diminished ability to realize opportunities and rights. Those who have diminished abilities based on age-related restrictions face special vulnerability. This includes the elderly and young children. Age-related vulnerability tends be highest at the beginning and end of life, with the lowest level of age-related vulnerability in the middle of a person’s life cycle.

Life course also influences a person’s vulnerability through early development that affects coping mechanisms later in life. The life-course perspective explains that health later in life is shaped by earlier experiences or previous stages of life course, so systematic economic and social factors can create vulnerability or resilience at end of life. This can accumulate over one’s lifetime and over generations. Those who have faced harmful conditions early in life, may face greater vulnerability later in life due to their early exposure. Likewise, those who have faced health-reinforcing experiences early in life may face a higher level of resilience later in life. The differences in vulnerability caused by the life-course perspective can create vertical inequities, or greater needs in those who have had harmful health-related experiences earlier in their life.

Special vulnerability should also be considered in terms of health care research. Special vulnerability is related to health care research in terms of barriers to sampling, recruitment, participation and retention of socioeconomically disadvantaged as research participants. National and international laws and guidelines have been established to protect these
vulnerabilities. The Belmont Report, signed into law in 1974, explains vulnerability in terms of human research subjects and includes special protections for vulnerable groups such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized. In addition, international guidelines have been established to protect special vulnerability in research. In 1964, the World Medical Association Declaration of Helsinki created guidelines to protect vulnerable individuals participating in research involving human subjects. The Declaration of Helsinki was last updated in 2013, and the current version includes clarification on special groups with vulnerabilities: “Some groups and individuals are particularly vulnerable and may have an increased likelihood of being wronged or of incurring additional harm.” Although there are risks to conducting research with vulnerable groups and individuals, it should still be completed in respect to protecting health equity. Research should look at how healthcare resources can be distributed to alleviate injustice for vulnerable populations.

Health care delivery organizations have an obligation to address special vulnerabilities and protect vertical health equity. Special vulnerability is related to structures, institutions, and processes that cause and exacerbate health inequalities that hinder vulnerable groups’ equal claim to goods and services needed to live dignified flourishing life. Organizations can accomplish this by developing a paradigm shift should occur when facing vulnerable individuals and populations from protection of, to protection against. This shift re-focuses responsibilities from specific vulnerable individuals and groups toward conditions that create vulnerabilities.

Addressing special vulnerabilities in health care delivery organizations involves accurate and reliable assessment of vulnerable patients. Although assessment of psychosomatic characteristics of vulnerability are generally straightforward, assessment of functional and social domains of vulnerability demonstrate a high level of variability among physicians and may
benefit from a consistent vulnerability assessment instrument to promote a uniform and accurate assessment of vulnerability.\textsuperscript{93} Physicians do not reliably assess functional and social domains of vulnerability, so these areas should be consciously integrated into vulnerability assessments at the health care delivery level. Special vulnerability can be complex and multidimensional, including psychosomatic, functional and social elements.

In addition, health care delivery systems should implement programs to monitor and address special vulnerability and vertical equity at the system level. Health care delivery systems should use data to monitor and analyze potential inequities in health within their system. Health information systems can support special protection of vulnerable groups by tracking health inequalities, creating systems of accountability, and strengthening the empirical base for human rights analysis and decision-making.\textsuperscript{94} Health care delivery organizations can use this data to focus interventions that address these vulnerabilities. Data analytics can provide information on if and where inequalities may exist. It can also create accountability for those who are tasked with improving inequalities or protecting vulnerable groups. It also can help with the broader picture of human rights discourse, providing empirical data to support interventions that promote and protect human rights.

Health professionals providing care within health delivery systems also have a critical role in addressing special vulnerabilities in their patients. This starts with developing a level of trust with vulnerable patients. Health professionals can begin developing trustworthiness by recognizing vulnerabilities and willingness to trust based on context-specific assessment of personality, culture, race, age, prior experiences, socioeconomic and political circumstances.\textsuperscript{95} A patient’s approach to interactions with the health care system and health care providers may be
affected by their particular vulnerabilities. Physicians must address this issue in their everyday interaction with patients to effectively provide equitable health care.

Those with special vulnerability deserve special protection with respect for vertical equity. There is a correlation between vulnerability factors and health care disparities in access, treatment options, and prevention.\textsuperscript{96} Those facing special vulnerability face barriers and obstacles to receiving the care that they need, that others without special vulnerability do not face. This creates inequities in health care delivered and received. In addition, those with special vulnerability have a greater likelihood of being wronged or denied legitimate claims to physical integrity, autonomy, freedom, social provision, impartial quality of government, social basis of self-respect or communal belonging.\textsuperscript{97} The denial of these legitimate claims have clear implications for the realization of human rights – not just the right to health, but as a prerequisite for the meaningful realization of all other human rights as well.

General and special vulnerability are interdependent since the special protection for those who particularly vulnerable is based on fairly protecting what is due to everyone.\textsuperscript{98} All humans are vulnerable, but some individual and environmental factors will cause the expression of special vulnerabilities.

Social responsibility in health care explains why health care delivery organizations have obligations to protect general and special vulnerabilities. This is supported by foundations of social responsibility and confirmed by the social nature of health care.

\textbf{2bii Social Responsibility in Health Care}

The UNESCO Universal Declaration on Bioethics and Human Rights outlines the principle of social responsibility for the right to health:
“Taking into account that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition, progress in science and technology should advance: (a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good; (b) access to adequate nutrition and water; (c) improvement of living conditions and the environment; (d) elimination of the marginalization and the exclusion of persons on the basis of any grounds; (e) reduction of poverty and illiteracy.” 99

Social responsibility in health care has many dimensions and includes access, environmental issues, and reduction of health disparities. Social responsibility describes the obligations that humans have toward one another based on social structures, norms and obligations. Social responsibility also includes the obligations that organizations and government bodies have toward the society in which they function, and individuals within that society.

Foundations of Social Responsibility

Social responsibility is based on the social nature of humanity. The self is fundamentally embedded in social world where values and emotions are directly related to social connection.100 Humans would not have a sense of self if not for social context. The emotions and understanding that create the human experience are inextricably social. A person is defined and identifies him or herself by the way in which he or she is perceived by others, and perception of the self interacting with others. If a person asks oneself, “who am I?” the answer will be related to the social world in which they live and breathe. For example, a person may answer this question by describing their occupation, their familial obligations, or their personality. All of these answers only have meaning within a social environment.
The complexity of human social nature is what makes humans unique from other animals. Humans are intensely social with a unique ability for high-level manipulation of social information, consciousness, understanding of self and understanding of others. Humans have the capacity to understand and synthesize social information to create definitions of themselves and others. Social interactions are an essential element of human self-actualization. One knows themselves and realizes their potential through interactions with others. A person would be unable to discover who they were and what they were capable of without human relationships.

The social environment of an individual explains the social norms that they carry with them, and how these norms affect their decision-making process. Social norms and socialization can help to explain behaviors such as reciprocity, the norm of equity, and the norm of social responsibility. Belief in reciprocity, or mutual exchange, is facilitated by social norms and the socialization that one has experienced within their lifetime. A person’s belief is fairness, or equity is likewise influenced by socialization and accepted social norms. The role of social responsibility, the place of social responsibility, and beliefs related to how social responsibility should be carried out is also influenced by this socialization process. A person’s worldview, including the way in which humans should rightfully interact, is influenced by social norms that a person has developed through socialization experiences.

The identity of an individual is dependent upon the social nature of human dignity. How a person interprets their own identity and connection with other humans has significant implications for health and wellbeing. The wellbeing of individuals is inextricably linked to the wellbeing of others, and can be influenced by a host of social experiences such as plagues, pandemics, wars, acts of terrorism, and advances in medical science. The influence of these
social experiences can be positive or negative: negative, for example, in the case of plagues, pandemics, and wars; and generally positive in the case of advances in medical science.

Overall, the social nature of humanity has positive effects on well-being and health.

Social arrangements can enable mutual advantage for participants that is a greater sum than its parts – including greater economic opportunities and freedom to self-actualize. Of course, this ability to gain greater economic opportunities and self-actualization only occur when there are fair terms. Equal participation in democracy can be hindered if social arrangements are not established in foundations of equity.

The advantages of the social nature of humans can be explained in terms of social capital. Social capital, or productive social cohesion, allows individuals to share collective energy and benefit from social support. What a social group can accomplish together is more than the sum of its parts. People working in social groups can synergize and accomplish more as a social group than they could have individually. Social capital is the economic benefit of socialization, where social support systems are turned into energy or productivity. Social capital explains why social group membership is beneficial for humans from an economic perspective.

This productivity is especially profound when it is inclusive of the whole population. Inclusive growth through education and health creates a more productive labor force by increasing productive employment opportunities for all, removing social constraints and contributing to the overall economic growth and welfare of society. This means that societies are more productive when there is more equity in health and education. A healthy population has a larger and more productive workforce than an unhealthy population. Investing in health and education has positive implications for economic growth and social stability.
Prioritizing social concerns, especially in policy discussions, has been met with some resistance in the United States. This is because social norms in the United States tend to favor individualism, or favoring self and one’s own circle over greater societal concerns. Unfortunately, staunch individualism can ultimately diminish, rather than enhance, freedom unless it is balanced with forms of cultural practice and a greater vision of social solidarity. When individualism is not balanced with social solidarity, corporate control can become the dominant economic power and political influence, rather than democratic control of citizens.

The social nature of the human condition brings about responsibilities based on social conditions. Responsibility occurs when an actor has freedom of will or action and blameworthiness. In other words, responsibility occurs when an entity has freely acted to bring about a consequence. When a person freely acts, he or she has the capacity to be deliberate, and the deliberate action brings about a consequence – that person is responsible for the action. The social nature of being human creates responsibilities related to social consequences. If a social consequence is caused by a freely acting, deliberate entity, then that entity is responsible for the social consequence of that action.

Social responsibility is related to protection of the most vulnerable individuals and groups in the society, and promoting equity among all persons. Social responsibility can be carried out by individuals, institutions, and governments. Governments often fulfil moral obligations to help the poor based on responsibility to society, although policy fixes directly related to welfare may only go so far to address the complex social issues including racial wounds, education, and employment opportunity. The institutions and individuals within a society are in an effective position to have meaningful influence on some of these significant social issues affecting poverty and health outcomes.
Balancing individualism with social solidarity can be facilitated through social responsibility, making social responsibility a useful concept for social institutions in the United States. Social responsibility – which includes responsibility for impact of behaviors on others, activities that benefit others, cooperation in social groups and basic concern for others – helps to enhance one’s own meaning of life and gain perspective on one’s own problems. Actions founded in social responsibility create positive outcomes for the recipient of services, but also the provider of services. Acting in a socially conscious way provides a better sense of self because it provides evidence of one’s place in the world.

Humans are both biological and social beings who engage with environments and societies to create patterns of health, disease and well-being. Health care is inherently social because of the connection between environments and the patterns of health, disease and well-being. Social environment has a causal relationship with health and disease, and addressing social dimensions of health is needed to support health and well-being.

The Social Dimension of Health Care

Disease is experienced, defined, and addressed through the complex domain of human experience that provides its explanation, expectation and meaning. Thus, social and environmental responses to disease management are crucial components of treatments and therapies. Humans experience and understand disease through their social understanding of health and illness. A person’s expectation about the disease process and treatment, as well as how they interpret its meaning is based on social understanding of health and disease.

The social dimension of health care explains its responsibility to protect the right to health care. Rights, including the right to health, are both positive and negative. Negative rights
involve the elimination of infringements upon individual liberties (such as right to free speech,) while positive rights involve obligations to work toward goals that facilitate access and conditions that make individual liberties possible (such as right to a fair trial.) There are both positive and negative rights related to the right to health. Negative right to health involves eliminating infringements upon ability to obtain the highest attainable level of health. This involves removing barriers or obstacles to achieving health. Removing barriers to health related to social determinants of health would be an example of responsibilities related to the negative right to health. The positive right to health includes obligations to facilitate access to conditions that make health possible. This includes providing available, accessible, acceptable, quality health care for all persons.

The obligations to protect and promote the right to health lie within health care delivery organizations, including administrative leadership, providers and staff. Health care delivery organizations have a social obligation to improve quality of life within the communities they serve. This is due to the nature of health care delivery. The purpose of a health care delivery organization is to improve the health of the population it serves. The actions it facilitates and policies it employs have a direct impact on individuals and communities it serves. The health care delivery organization has responsibility because of the deliberate action it takes that has direct impact on health of individuals and communities.

Health care delivery institutions have social responsibility in that they carry out deliberate actions that create significant social consequences. The actions facilitated by health care delivery organizations result in allocation of health care resources, and thereby allocation of health opportunity. Health is a prerequisite for a productive, well-functioning society, so the decisions
that health care delivery organizations make – especially in terms of resource allocation – have explicit social consequences.

Human decision-making is performed within a social environment. Decisions are not made in a vacuum. Individuals weigh the implications of decisions in relation to their social context. Decisions about health and well-being are made in a social context which affect individual rational decision-making, so people's choices are seldom genuinely, fully autonomous and a purely individualistic approach to health improvement is inadequate. Approaching health care as though individuals make siloed, fully autonomous decisions will leave crucial components of the patient’s needs and decision-making processing out. Humans can only be fully cared for with consideration of their social environment. The implications for health equity and respect for human vulnerability can also only be fully considered within the social context.

Health care delivery systems have social responsibility and are social organizations. Health care is a social good, and should not be commodified based on the ethical dimensions of health care goods and services. These ethical dimensions are based on equity, respect for human vulnerability and social responsibility. The commodification of healthcare can create barriers to access for the most vulnerable and distort the dynamic of healthcare delivery. Instead, a rights-based approach should be used to develop equitable structures including financial and infrastructure resources. The purpose of a health care delivery system is to provide a social good, and so has social responsibilities along with this purpose. A rights-based approach will facilitate equitable, socially responsible healthcare delivery.

The right to health is realized through health delivery organizations. The realization of the fundamental right to health must be reasonable, progressive and subject to continuous improvement, availability of resources, accountability, evidence-based standards, and must be
translated into health policies and interventions, practical applications, health practice, and health interventions.\textsuperscript{118} Health care delivery organizations must take reasonable actions that progressively address the human right to health through continuous improvement. Availability of resources and accountability for actions is a key component of successfully promoting this right. Evidence-based standards can be used to develop policies and interventions that can be used in health practice and practical interventions.

The social responsibility of health care delivery organizations is evident, but honoring this social responsibility is more difficult than simply recognizing it. Social institutions have been built to provide security and protection of human ontological vulnerability, although these institutions face inevitable social conflict due to scarce resources, human degradation of the environment, and competition for limited space.\textsuperscript{119} Allocation of resources remains a challenge to health care delivery and the practical implementation of the right to health. When there are limited resources, allocating health care goods and services equitably, respecting both general human vulnerability and special vulnerability, and honoring social responsibility is a major challenge for health care delivery organizations. A human rights approach will help to clarify ethical resource allocation within health care delivery organizations.

Health care delivery organizations are as important for health and human rights discourse as state actors in health and human rights. There is a significant impact on health created by non-state actors, which transcends conventional human rights discourse.\textsuperscript{120} Although conventional human rights discourse has focused on state actors, the human right to health is carried out through health care delivery organizations. These organizations must have standards to protect health equity, based on their social responsibility to protect and respect human vulnerability.
Health and human rights has, until now, been general and focused on broad, non-specific state-level protections. Now, health and human rights should move from general to specific practice guidelines on health issues, defining core obligations that can be universally applied, as well as the duty-bearers of this right. This should be translated to the responsibilities held by health care delivery organizations. Health care delivery organizations have explicit social responsibility to protect these rights, and have the capability to impact the protection of health and human rights in a meaningful way.
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Chapter 3: Patient Care Quality & Patient Safety

3a Patient Care Quality & Patient Safety as a Function of Human Rights

Patient care quality is a function of human rights. For humans to meaningfully exercise their human rights, they must be healthy and vice versa. This section will first define quality in health care and then discuss quality in terms of human rights.

Quality in health care can be partially defined through the “triple aim” of health care quality: care quality, patient experience and cost. Quality care also encompasses patient safety. First, this section will provide definitions for these key components of quality in health care. Second, this section will describe how these aims of quality in health care should be incorporated with discourse on the human right to health. This includes the imperative to reduce disparities in health care and defining standards of care that should be protected. Although a conceptual definition of health and human rights has already been developed, ways in which this right should be carried out or carried out in the everyday practice of health delivery organizations has not yet been defined. This section will explain how the right to health specifically requires that all individuals have access to quality health care.

3ai Defining Quality in Health Care

Quality in health care encompasses patient safety, health outcomes, associated processes, patient experiences and costs that result from health care delivery. Patient safety requires that a patient protected from harm, avoidable adverse events and medical error. The “triple aim” of quality is also useful in this description, which describes improving health, improving patient experience, and reducing costs.\textsuperscript{1} Assessment of overall quality in health care should include considerations of these four domains.
Patient Safety

Patient safety includes prevention of medical errors, prevention of avoidable adverse events, protection of patients from harm or injury, and healthcare provider collaboration within the integrated health system.²

In 2000, patient safety rose to prominence through the Institute of Medicine (IOM) released a landmark report: To Err Is Human: Building a Safer Health System. To Err Is Human reported that 44,000-98,000 people die in hospitals because of medical error each year.³ In 2001, the IOM followed up on To Err is Human with Crossing the Quality Chasm: A New Healthcare System for the 21st Century. Crossing the Quality Chasm Six aims for improvement, stating that health care should be safe, effective, patient-centered, timely, efficient, and equitable.⁴ Following these reports, the Joint Commission established the National Patient Safety Goals in 2002.⁵ These have evolved since their initial development and, as of 2018, include goals in the areas of ambulatory health care, behavioral health care, critical access hospitals, home care, hospitals, laboratory services, nursing care centers and office-based surgery.⁶ The National Quality Forum (NQF) also developed a list of serious reportable events. These include serious, largely preventable harmful clinical events in the domains of surgical or invasive procedures, products or devices, patient protections, care management, environmental events, radiologic events, and potential criminal events.⁷ Other programs to reduce patient safety events include the Centers for Medicare and Medicaid services (CMS,) the Institute for Healthcare Improvement (IHI) and the Agency for Healthcare Research and Quality (AHRQ.)

The Centers for Medicare and Medicaid Services (CMS) has implemented initiatives to improve patient safety through reimbursement programs. These include reimbursement-related incentives tied to patient safety indicators (PSIs) such as death among surgical inpatients with
serious treatable complications. The Institute for Healthcare Improvement (IHI) has also focused on patient safety and safety culture. The IHI works with health care providers to develop integrated safety across the continuum of care, leadership methods to address safety, and approaches to address patient safety issues. In addition, the AHRQ has developed tools and resources for health care delivery systems and providers to improve patient safety.

Organizations that focus on improving patient safety address the need for a patient safety culture. Patient safety takes more than capital investment in buildings and infrastructure; It requires organizational management approaches and targeted strategies to promote safety culture. There are various tools that can help health care leaders to develop a culture of safety within their organizations. A culture of safety must be implemented wisely, however, where adverse events versus preventable adverse events versus negligent error are assessed. An effective assessment of events and errors involves the integration of a just culture within the culture of safety. A just culture requires that administrators recognize errors from faulty systems but also hold staff responsible for choices, holding them accountable when necessary. A just culture will help health care administrators, providers and staff to face accountability without unnecessary blame. Safety incidents are usually due to faulty systems.

Faulty systems are often seen in communication and patient transition events. Common safety incidents related to patient transitions, such as referrals and discharges, can be addressed by developing a structured, integrated approach to transitional safety. There are clear roles for health administration, providers, and staff in transitional safety. During shift-handoffs, nursing staff have a high risk of communication related safety events. Intra-shift handoff effectiveness has a significant impact on patient safety. Leaders should promote intra-shift handoff communication by valuing nursing knowledge, supporting improvements in safety culture with
positive working relationships, facilitating open dialogue, providing adequate staffing resources, allowing for sufficient time with patients, decreasing distractions and noise, providing dedicated handoff time, minimizing concomitant meetings, providing opportunities for continued learning, and providing structured but flexible written tools for handoff.\textsuperscript{15} Clear communication between shift handoffs, as well as interdisciplinary communication among providers and staff can reduce avoidable adverse events. Transparency is also a useful tool for improving communication and clarity of patient hand-offs and interdisciplinary communication.

Transparency can be used to improve leadership accountability, clinician engagement, patient trust, and a culture where identification and investigation of errors generally promotes discussion rather than blame.\textsuperscript{16} An example of transparency in practice is morbidity and mortality conferences. Morbidity and mortality conferences can be useful communication tools to address safety issues, but they need to use a structured method for analyzing cases and need to connect improvement-related decisions with actions and a timeline.\textsuperscript{17} Transparency and communication must lead to actionable responses to reducing future errors.

Solutions for improving communication can include innovation and technology. Health technology can help with preventing adverse events by improve communication, providing point of care references, assisting with calculations, performing monitoring functions, facilitating hand-offs, and providing clinical decision support.\textsuperscript{18} Although technology can be useful in improving patient safety and reducing errors, technology use often meets barriers at to integration. Barriers to integration of electronic patient safety reporting systems include underreporting and low quality of reports, acceptance and effective use of systems, inadequate instructions and training, lack of reporter-friendly classification, and lack of time and lack of
Leaders of health care delivery systems should address these barriers to ensure smooth transitions and implementation of technology solutions to impact patient safety.

The patient also has a role in patient safety, and should be considered to be part of the patient safety team, in addition to administration, health care providers and staff. A patient’s participation in engagement with safety is influenced by factors such as knowledge, health condition, beliefs, and experiences, and can be encouraged through professional development of providers, focusing on patient-centered care, and clearly defining roles of the patient, staff, and physicians. When providers work together with patients and involve patients in the patient safety process, the patient is able to act as a barrier to medical error, empowered to be their own advocate.

There are many ways that health care leadership, providers, staff and patients can promote patient safety to reduce avoidable adverse events. Reliability-seeking organizations can reduce safety incidents, improve staff perceptions of the organization, and reduce costs by standardizing processes, promoting checks while avoiding redundancy, equalizing authority, developing communication skills and promoting teamwork processes. Initiatives in these areas can improve patient safety when developed and implemented systematically across the health delivery system.

Although patient safety is a critical first step, it does not paint the whole picture of health care quality. Clinical outcomes, process, patient satisfaction, and cost complete the health care quality continuum.
Clinical Outcomes & Process

Clinical quality includes outcomes and process measures. Outcomes measures for quality are useful because they show whether a desired result in patient care was achieved or not. Resources for quality improvement are often limited, so a health system needs to prioritize indicators that will have the greatest expected impact in terms of net health benefits, the number of people effected in population, current compliance with measure, probability for quality improvement and effectiveness of quality improvement. Outcomes measures achieve these goals since they show results that directly affect the patient’s health.

Since improving patient health is the goal of a health care system, outcomes measures may seem to be the most obvious way to measure health care quality. However, using outcomes measures has challenges and there are many barriers to defining meaningful quality outcome indicators.

First, determining which outcome measure is appropriate and how it should be defined warrants serious consideration. A needs assessment should be performed before developing quality indicators for monitoring, and should include assessment on illness burden, opportunity for improvement, the connection between improving care and improving health, and gap assessment for existing indicators. If criteria in these categories are not met, then a selected outcome measure may not be the best indicator of quality patient care.

In addition, outcomes reporting for quality must incorporate an ethical framework to avoid the selection of unjust or inappropriate measure. This is especially important when quality data is reported to consumers. An ethical framework should be used to guide development and implementation of quality reporting for consumers, in order to ensure data legitimacy, integrity and quality, transparency, informed understanding, equity, privacy and confidentiality,
collaboration, accountability and evaluation. Consumers must be given an appropriate explanation of context and methodology for quality measures reported to them, or there is a risk of misrepresenting the care quality of a specified health care entity or entities.

Certain measures may be misrepresented and unfair comparisons between organizations may occur if quality indicator definitions are not comprehensive. For example, the interpretation of readmission data depends on whether planned and unplanned readmissions are both included or not. Planned readmission may, in fact, be an indicator of good care quality, while unplanned readmissions could be an indicator of surgical or nonsurgical complications. If both types of readmissions are included and this information is distributed to the health care consumer, it may be impossible to tell which organizations have better quality since data that could indicate both good quality and bad quality are compounded into one measure.

The error of choosing a measure simply because it is easily measured and collected should be avoided as well. Instead of simply prioritizing time and cost-effective quality measures (which can be counterproductive,) health care organizations should look for valid quality measures are clinically meaningful, transparent, supported by scientific evidence, link process to health outcomes, consider anticipated benefits and harms, are reported to all appropriate stakeholders, and balance the time and resources required for data with anticipated benefits of the metric. If a measure is chosen that does not have real meaning for quality, any time and effort on collecting and reporting that measure will be wasted and add inefficiency to the health care system. It could also contribute to loss of credibility in the eyes of health care providers when assessing future quality reporting, even if future reporting is improved in its methodology.

Outcome measures can be a useful tool to measure health care quality, but should be developed with sound methodology. Hospital governing boards can help to ensure that sound
quality indicators are chosen. Hospital governing boards are associated with better quality
outcomes when they have a board quality committee, establish strategic quality improvement
goals, are involved in quality agenda-setting, include quality on board meetings, look
benchmarked data, and link senior executive evaluation to quality measures. The board can set
the environment in which quality outcome assessment is given the appropriate amount of
thought, attention and time. Other hospital leadership and organizational structure is also
important for the valid development and application of quality outcome monitoring. In general,
the success of a quality improvement program depends on context and organizational cultural
factors including leadership from top management, organizational culture, and data
infrastructure. Outcome measures can be very useful to assess health care quality. Process
measures can also be used to assess quality, and can complement and balance quality outcome
reporting.

Process measures are often chosen to assess health care quality since they can be more
straightforward in definition than outcome measures. A process measure simply states how often
a defined process (or piece of a defined process) was completed or not. Choosing a process
measure that indicates quality, collecting accurate data reflective of the process, and determining
how to define the population for which the process measure should be applied are the major
barriers to defining meaningful process measures for quality assessment. Process measures
should always be directly tied to a desired health outcome. In order to ensure accurate
associations between specific processes and outcomes, quality indicator measure selection
should include assessments on the proximity of the outcome to the process, power to detect
differences, the ability to explain or control for confounding factors, and stability of measure
specifications over time. The process measure should be closely tied to the desired outcome,
there must be power in the process to create a positive difference in the desired health outcome, the process measure must be directly causal of the desired outcome (confounding factors must not explain the change) and measurement must be possible over time. If these criteria are met, then the process measure should have a sound definition.

Defining process measures is the first step to developing valid process measures; However, even if the process measures have been well-defined, data analysis for the defined process measure still can create barriers and challenges to effectively use process measures for quality assessment. Information systems can help to monitor and improve performance of health care providers, but steps should be taken to ensure that data definitions are accurate, that measurements correlated with quality improvement, and that both process and outcomes measures are considered.\textsuperscript{30} Data entry, abstraction, and interpretation must all be systematically and accurately carried out.

Process measures are important because they are often the cause (or source of prevention) of quality outcomes. Incidence of adverse medical events, which are typically tracked by a hospital’s risk management or quality assurance departments, often result from system failures such as inadequate communication, inappropriate staffing levels, lack of training, and poor patient handoff processes.\textsuperscript{31} If the processes associated with these failures are fixed, quality outcomes may also be fixed if it is directly correlated with the process.

Process measures include not only data analysis and reporting, but also quality improvement methodology and quality improvement tools. Quality improvement tools should be developed through staff engagement, local input, and experience-based design to adequately interpret and frame the social context of the health care organization, including political systems, relationship dynamics, language, assumptions, perceptions, and culture.\textsuperscript{32} These tools are used to
effect change in a process, and therefore its associated outcome measure. Quality process improvement tools should be developed within the context of an individual health care organization, considering the social confines of the organizational structure and leadership.

There are many types of process improvement tools. Surgical process improvement tools, such as structured communication tools, clinical mapping tools, and error reduction instruments can help to standardize and coordinate care, can reduce variations in delivery patterns and outcomes.³³ Other tools can be used to reduce variation as well. Six Sigma can be used can be integrated into an organizations current quality improvement program to reduce error, eliminate defects and achieve efficiency.³⁴ Reducing variation in a process is essential since variation from the best pathway of care often indicates error.

Other methods of effecting positive change in quality and process improvement involve leadership development. Leadership development can improve quality and efficiency when it results in workforce improvements, enhanced education and training activities, reduce turnover, and identify specific strategic priorities.³⁵ Educating the staff and providers within a health care organization is an important part of process improvement within a health care organization.

The process for quality assessment and improvement itself can be a positive change for quality in a health care organization. For example, a fractal system could be implemented to organize workers around common goals, link hospital levels, support peer learning, provide accountability, and encourage local solutions while using existing available resources.³⁶ This would create new processes and pathways to develop quality improvement tools while not requiring a huge burden on already finite resources. This is only one of an infinite number of processes that could be changed with the goal of affecting health care quality. The needs and context of the health care organization will dictate what type of intervention is needed, so
process improvement methodology, implementation and monitoring should usually be completed at the individual hospital or health care organization level.

Process measures are direct, easy to interpret, and sensitive to differences in care quality, though they do not reflect all aspects of care like outcomes measures, while outcomes measures include potential inconsistencies with data collection and difficulty of proper risk adjustment are major disadvantages. Interventions to take care of patients with multiple health problems should address the interrelatedness of comorbidities in lieu of looking for simple solutions which may be ineffective.

Each of these quality indicator types have strengths and weaknesses. They are complimentary in nature and should be used together to assess the overall quality of health delivery. Process and outcomes are important ways to measure care quality in health care. Patient satisfaction or patient experience is also a crucial component to the assessment of health care quality.

Patient Satisfaction

Patient satisfaction is a key indicator of health care quality. It is directly related to the patient’s experience with the health care system and affects both real and perceived care quality to the patient. Patient satisfaction has a reciprocal relationship with quality processes and outcomes. If patient satisfaction is improved, outcomes and processes of care can be improved. If outcomes and processes of care are improved, then patient satisfaction may be influenced. For example, patient satisfaction with service quality and timeliness of care are an independent predictors of breast cancer survival. Likewise, some patient satisfaction measures can be improved through improvement in quality processes and outcomes. Patient satisfaction is inextricable from other care quality indicators, and is also an important quality indicator itself.
Patient experience can be influenced by several factors. For example, patient satisfaction has been predicted by factors such as meeting preoperative expectations, satisfaction with pain relief, and satisfaction with the overall hospital experience.\textsuperscript{41} Interactions with nursing can also influence patient satisfaction. In fact, nurse job satisfaction can improve the perception of quality of care by patients.\textsuperscript{42} All interactions that a patient experiences in the health context may affect their reported satisfaction. Patient satisfaction can even be influenced after discharged through processes of follow-up care. For example, proactive telephone follow-up by staff has been an effective method to enhance quality and patient perception of care, resulting in higher patient satisfaction and early identification of side effects.\textsuperscript{43}

Assessment on variables that influence patient satisfaction, such as patient expectations, can be completed through patient satisfaction surveying.\textsuperscript{44} Surveying can ask patients directly about their self-reported experiences with the health system. The data can then be aggregated and analyzed for trends, ultimately pointing to opportunities for quality improvement.

Patient satisfaction is an important indicator of health care quality and can be measured through surveys that allow patients to self-report their experiences. Patient satisfaction can be influenced and enhanced by many approaches to patient care, and can be especially influenced by an approach of shared decision-making.

Shared decision-making is a process that can directly affect the quality of patient care through enhancing patient engagement. This occurs via an established collaborative relationship between the physician and the patient. There are three essential elements of shared decision-making: recognizing the need for a decision, understanding the best evidence, and incorporating the patient’s values and preferences.\textsuperscript{45} The physician and patient must both accept and recognize that a decision needs to be made, discuss and create a mutual understanding about the patient’s
values, discuss evidence that could possibly affect the decision, and then incorporating the patient’s values into the possibilities to land on a choice that is the best for the patient given their particular values and circumstances.

Shared decision-making can be facilitated through validated tools that help both the patient and physician communicate about treatment options and values. Standardized decision aids, such as written materials, videos and interactive electronic presentations, can help patients clarify their values, determine how those values relate to decision, analyze information about treatment options, and weigh risks as well versus the likelihood of achieving their treatment goal. These types of decision tools should be used when they can help to facilitate communication between the physician and the patient.

Shared decision-making can have a positive impact on care quality and patient satisfaction. However, sharing responsibilities of decision-making should follow a logic of care rather than a logic of choice, since a logic of choice may impose a burden on some patients. Shared decision-making is for both parties (physician and patient) to come together to agree on a process for decision-making that works for them within their individual context. This will help to ensure that shared decision-making is consistent with the values of patient-centered care.

Patient-centered care puts the values and needs of the patient at the center of focus for health care decision-making. It includes elements of governance priority, culture of continuous improvement, IT best practices, evidence protocols, optimized resource use, integrated care, shared decision-making, targeted services, embedded safeguards, and internal transparency. Often, patient-centered care is carried out through a medical home model. A patient centered medical home model can help with the development of long-term relationships between physician and patient and care coordination.
patient-centered care can help to ensure that patients are heard and that their satisfaction is prioritized.

In to shared decision-making at the patient level, community shared-decision making can help to improve quality at the community level. It can help to engage local consumers on health care decision-making early and consistently for perspective on governance decision-making, program design and implementation, and information dissemination.\textsuperscript{50} If members of the community are involved in health care governance, a foundation of shared decision-making can be established for all patients, where the needs of patients and the community are incorporated both at the policy level and the individual patient level.

The last major component of health care quality assessment is cost.

\textit{Cost}

The cost of health care is important to health care quality because it is part of the equation for health care value. Health care resources are, by nature, finite and prioritization based on ethical analysis and value calculations are essential to ensure that resource allocation is not unjust.

The approach to cost savings in health care at the organizational level requires opportunity analysis and process improvement. Methods that work for an individual health care organization will be context-specific. Some methods that can be used to achieve quality-based savings are effective data system and management structures, regular feedback based on data, change oversight, risk adjustment, incentive alignment and using local clinical teams.\textsuperscript{51} For cost analysis, in addition to care quality analysis, patient risk must be considered before interventions can be developed based on raw data. A stratified approach based on patient risk can be helpful to avoid undesirable outcomes, patient experience and cost measures.\textsuperscript{52} Distribution of data related
to cost and other quality measures should also be stratified or adjusted for risk to avoid misleading data presentation.

Consumers of health care want to see data on cost and quality. Consumers want to see quality data on physician level and cost data for personal out-of-pocket expense, so there is a need to pull together data sources for integrated, timely, and relevant consumer health care reporting. Determining a methodology for putting together these key measures would create a relatively comprehensive consumer reporting system for health care. Cost and quality reported together represent value of health care.

Most importantly, health care organizations should facilitate quality through an ethics lens. Using ethical standards as a foundation for developing quality improvement activities can help to prevent inadvertently causing harm, wasting resources, or contributing to inequalities. Specifically, quality in health care should be approached from a human rights perspective to ensure that health care delivery is equitable, respect for human vulnerability is maintained and organizational social responsibility is realized.

3a1i Provision of Quality Health Care as a Human Right

The basic right to health and health care that fall into three domains: the basic moral domain, the legally enforceable political domain, and the international domain (or domain of relations between different political societies.) These three domains – individual/moral, political/legal, and global – generally provide the existing framework for human rights and health discourse. This framework lacks crucial domain in health and human rights discourse, however: the organizational domain. The organizational domain exists as a layer between the basic moral domain and the political domain, and is an essential missing piece to this framework. The health care organization is the functional domain is where the right to health is carried out.
Human rights are carried out in the organizational domain through the function of health care quality.

*Human Right to Quality Care*

The right to health should be understood as the right to health care due to its role in protecting basic human interests. Quality health care is essential for humans to thrive and to realize other rights. This right to quality health care is supported by the United Nations 2030 Agenda for Sustainable Development, which outlines a plan to eradicate poverty, eliminate hunger and ensure that all human beings can fulfil their potential in dignity and equality, including equitable and universal access to quality health care where no one must be left behind. Health care disparities must be eliminated and all persons must have access to quality care, regardless of their social position.

The human rights lens on health provides context and understanding for where there are disparities and injustices, but they need to be taken a step further than understanding to be operationalized. This is where health care organizations have a duty to carry out the human right to health through the provision of quality health care for all individuals. The right to health provides the foundation for why all individuals have the right to quality health care, but it does not currently specify how this right is to be carried out or applied in context. Although there are other key factors to enjoying health, quality health care is essential for almost all humans to realize their highest attainable level of health.

Other important factors are environmental determinants, such as access to clean drinking water and healthy food. If an individual is not receiving these basic environmental determinants of health, the health care organization can care for the patient and provide a structure to identify and assess whether unhealthy environments are experienced by an individual.
can then provide a structure to help coordinate improvements in the patient’s environment, whether they be community or individual interventions.

Once the right to health is defined, there is a need for detailed policy prescriptions and accountability.\textsuperscript{59} This means that the government has a role in oversight and policy that will support health care organizations in providing equitable, quality health care. Health care organizations should work with their federal, state and/or local government to ensure that the right to quality health care is being protected and that accountability for this provision is adequately expressed. The government will also need to provide support and resources for the health care organization to provide quality health care, especially in systems where there is one or more government payment system for health care services. The rights will be enacted through the organizational structures and processes to improve quality and monitored through organizational metrics of process measures, outcomes measures, patient satisfaction measures, and cost.

In terms of reporting, standardization and accountability are also important at both the government and organizational level. Accountability measurements for human rights should be standardized to ensure accurate reporting and that definitions do not change over time.\textsuperscript{60} Health care organizations should work with governmental regulatory and oversight bodies to develop and enact reporting to monitor the success of interventions that protect human rights, related to the provision of quality health care. Standardized reporting is essential for tracking outcomes of interventions and policies over time. If the reporting metrics are not stable and definitions change, it will be impossible to see whether interventions had an impact on the desired outcomes and whether those outcomes are trending in the right direction.
Health care organizations also have an obligation to human rights based on their corporate or business characteristics. Like corporations, health care organizations have social responsibilities. Corporations have a responsibility to protect, respect and remedy human rights when they are in the position to do so.\textsuperscript{61} If non-health care organizations and corporations have these duties, then health care organizations experience these duties to an even greater extent. Health care organizations are in a great position to directly remedy human rights, namely the right to the highest attainable level of health.

Likewise, multinational enterprises have a duty to protect human rights.\textsuperscript{62} Although health care organizations are not usually multinational, they have a duty to protect rights within their own country, just like a multinational enterprise has the duty to protect rights across all of the countries they have business encounters in. Health care is a service industry but is also a business, and has parallel obligations of business. However, health care organizations also have duties that expand upon those of a business since they are commonly mission-driven with established organizational values. In addition, the social nature of the health care organization, and its place in the social structure of the community in which it operates gives it special duties on top of what other for-profit organizations or corporations may have.

If corporations and multinational enterprises have an obligation to protect human rights, then so do health care organizations. In fact, health care organizations have more of an obligation than a non-service oriented corporation since their explicit mission is to improve the health of the individuals and population they serve. A health care organization’s duties are inextricably tied to their mission and reason for being, which is to promote and protect health. Naturally, this points the health care organization into the position where protecting the right to health is within the organizational purview, and should be tied to the organizational mission.
Human rights related to health give a method of analysis and framework for action to shape specific intervention, including applying health and human rights framework to practice.\textsuperscript{63} Health care organizations should use human rights as a basis for developing interventions to protect and promote health care quality, thereby reducing disparities in health care and supporting human dignity.

A human-rights based approach can be applied to all quality improvement phases including conceptualization, design, implementation, monitoring and evaluation, and can ultimately help to focus outcomes on disparities and gaps in services provided and opportunities for greater inclusion.\textsuperscript{64} Human rights should be used as the foundation to improve quality in health care, and quality in health care should support human rights related to health. The right to health requires that health care organizations provide quality health care for all individuals.

*Ethical Responsibilities of Health Care Organizations*

The United Nations Guiding Principles on Business and Human Rights outlines specifics of the *protect, respect and remedy* framework that can be used to define duties and responsibilities of governments and health care organizations. The *protect, respect, and remedy* framework is a principles-based conceptual and policy framework aimed at protecting human rights through state duty to protect against human right abuses, corporate responsibility to respect human rights, and effective access to remedy human rights violations.\textsuperscript{65} According to these principles, states must take appropriate steps to prevent, investigate, punish and redress abuse through effective policies, legislation, regulations and adjudication; businesses must address adverse human rights impacts where they are involved, seek to prevent or mitigate adverse human rights impacts directly linked to their operations, products or services; and there should be access to remedy where states make appropriate steps to ensure access to effective judicial or
non-judicial remedy of human rights violations. The protect, respect, and remedy framework offers a starting point for outlining the responsibilities of governments and health care organizations to protect human rights related to quality health care but these definitions must be expanded for practical application.

Health care organizations or delivery systems are responsible for creating and sustaining quality in health care, but the measurement of quality is often dictated or guided by governmental regulatory programs and payor financial incentives. These can include measures of outcomes, process, satisfaction or cost. Regulatory policies and financial incentives can support health care quality, but they can also present barriers to quality if they are poorly designed. For example, poorly aligned or fragmented financial incentives can impinge on the patient’s awareness of value or fail to adequately address provider accountability. Likewise, governmental regulatory bodies can fail to support health care quality if they are not well-designed. The health care organization, therefore, plays a crucial role in facilitating and ensuring quality patient care processes, outcomes, patient satisfaction and cost. Health care leaders must follow government and regulatory systems for quality assessment, but must also consider ways to assess quality on the organizational level.

The World Health Organization’s offers general, broad global standards for government responsibility and health policies and creates some legal accountability, but is vague in standards for giving specific mandates to operationalizing rights. Health care organizations are the locus of where these rights will be enacted, and where the power lies to affect change in health care quality improvement. This gives them the duty to uphold these rights by providing quality health care for all individuals. International organizations and governments provide some oversight, the
foundation and groundwork for human rights to be enacted, but are necessarily implemented at
the organization level.

Part of the governmental duty to protect human rights related to quality health care is
providing universal access, which the United States has yet to achieve. On a national level, the
United States Congress and the Supreme Court have contributed to the evolution inconsistent
framework with an incomplete set of rights, with some but not all rights defined regardless of
ability to pay, including the Emergency Medical Treatment and Active Labor Act (EMTALA),
Medicare, Medicaid, the Children’s Health Insurance Program (CHIP) and the Patient Protection
and Affordable Care Act (ACA.)69 When a government body has a piecemeal approach to the
provision of health care without universal access, it is not supporting optimal provision of quality
health care and thus not supporting the human right to quality health care. To clarify universal
access, a specific, basic minimum of care should be defined to prioritize efficiency, comparative
effectiveness, cost-effectiveness, contextual factors (including the value of hope and the increase
in value we see in life when reference points change,) and underlying common values.70
Government bodies should consciously work toward defining and achieving a basic minimum
threshold for health care services provided, as well as care quality criteria in the categories of
process, outcomes, patient satisfaction and cost.

States can help to support this mission where health care organizations fail. Federally
supported health centers can help to address health care disparities and barriers to meaningful
health care access in underserved communities by providing comprehensive preventative
primary care, focusing on vulnerable populations, encouraging consumer participation, providing
enabling services, cultural and linguistic sensitivity, community partnership, and continuous
quality improvement.71 States have obligations to human rights and health, but the provision of
quality in health care is ultimately in the control of health care organizations, giving them the ultimate responsibility for protecting these rights.

The right to health means the right to the highest attainable standard of health, inclusive of freedoms and entitlements, requiring that all services, goods and facilities must be free from discrimination, available, accessible, acceptable and of good quality.\(^7\) The right to quality health care without discrimination is an essential part of these inclusions. Based on the provision of quality health care is a human right, both governments and health care organizations have obligations to protect this right and mitigate disparities in health among the populations they serve.

The intention of the UN “protect, respect remedy” framework is to give guidance for corporate behavior related to human rights and can be used to close gaps between perceptions of justice within social institutions, given that culture and morals not universal and there may be competing perceptions of justice within an institution.\(^7\) Human rights provides a language for health care organizations to find a common definition of ethical management and practice. Human rights discourse is used to create a common moral value, vocabulary and framework for accountability.\(^7\) In this way, health care organizations can use human rights as the foundation to ensure that quality health care is accessible to all. This will include outcome, process, patient satisfaction and cost of health care. Based on human dignity, individuals have the rights to achieve the highest obtainable level of health. As described, this can be measured through process and outcomes measures and also reflected in satisfaction with health and health care. In addition, cost can be incorporated into quality assessment since it directly reflects upon value experienced in health care and in a broader sense relates to health care priority setting.
The corporate responsibility to protect human rights is especially relevant for health care organizations based on their inextricable relationship with protecting and promoting human rights, specifically the right to health. Corporations are social institutions, and health care organizations have unique social responsibilities since they provide essential services for social well-being. The mission of health care organizations as providers of a social good give them the responsibility to respect and promote that social good. They must do this by setting and achieving standards of the human right to quality health care.

Standards of human rights are based on the common value of dignity and equality of human beings. Specific health-related human rights should be operationalized by health care organizations and should focus carrying out the provision of quality health care for all individuals. Specific standards for how to provide quality health care should be defined. These standards should be measured through quality reporting and measurement, including process, outcome, and patient satisfaction metrics. Cost should also be considered due to its potential impact on population health.

Human dignity is the basis for developing standards that protect the human right to quality health care and human rights support and protect the absolute human inner value of dignity, which is present by virtue of being human and is what calls for certain universal rights. Health care organizations have an obligation to protect this dignity, as dictated by the foundations laid by health and human rights discourse. Standards should specifically be included in all of the buckets of quality, including process, outcomes, satisfaction, and cost, and should be refined on the individual organizational level to ensure the ability to implement these standards at the local level. This means that the outcomes for human rights may be uniform for all hospitals, but the processes and structures to achieve those outcomes may differ. The scope of
human rights obligations for corporations should be defined, rather than relying on due diligence, which gives leeway in moral commitment. In addition, respect for human rights at the organizational level should be monitored by the state government. Although there is a need for a common set of standards to measure the respect for human rights by corporations, this standard has yet to be created. Nonetheless, organizations should be proactive in respecting and promoting human rights within their organizations. Approaches to achieve suitable standards for the protection of human rights can include physician engagement, communication strategies, and integration with hospital governance.

Physician leaders should be engaged to ensure health care quality. Four critical components should be considered when engaging with physicians: choosing the right physician leader, providing access to relevant quality and cost data that physicians trust, utilizing evidence-based care guidelines, and creating culture of individual accountability. These four components can help to achieve goals of the human right to quality health care.

Communication strategies can also be used to promote the right to quality health care within a health care organization. Organizations can improve communication strategies including interventions that are message-based, training-based, technology-driven, community-driven, and policy-driven, activist interventions. These approaches can be used to effectively communicate with patients and internally within the health care organization in order to support the provision of quality health care.

Hospital governance also plays an important role in the protection and promotion of human rights within the health care organization. The role of hospital governance is to enact social responsibility through a shared vision of common, promotion of shared values and common ethical standards to create organization value. Founded in human rights, this can be an
effective way to promote care quality and reduce disparities for populations served by the organization.

Health care governance has a unique role to play in the protection of human rights within its organization. Differentiations between governance, management and clinical can be defined as follows: clinical governance encompasses the structures, systems and standards that create culture and control clinical activities, and create clinical accountability; clinical management encompasses processes and procedures to promote efficient, effective and systematic high-quality, safe care; and clinical practice is the direct delivery of quality health care by physicians. The role of governance is to oversee the management and clinical practice at its institution and to set the environment and expectations for the protection of human rights. They can create actionable assessments of quality within their organization to ensure the provision of quality care in terms of outcomes, process, patient satisfaction and cost. When creating these assessments, health care governance and executive leadership should consider factors of physician variability, including organizational factors and physician practice patterns. When systematically performed, these assessments can help to facilitate the provision of high-quality care.

Underlying determinants of health and associated obligations should be defined and prioritized based on both technical and underlying values of that patients that could influence their choices about health care, with consideration for both private morality and public policy needs based on equity for those who need services the most, based on the seriousness of their condition. The health care organization will need to balance the needs and rights of the individuals they serve and the populations they serve as a whole. A combination of these two approaches will be the best way to address disparities based on social determinates of health.
while protecting and supporting the human right to quality health care. In order to mitigate the interactive, multiple risks that affect health care quality within vulnerable populations, a multifaceted approach should be applied through both policy and health care organizational approaches. Through both policy and organizational approaches, the right to quality health care can be protected and promoted.

Quality health care is a human right. In general, human rights discourse has a growing awareness of its relevance to health, including considerations for its associated complex ethical and legal dimensions such as cultural relevance, regional priorities, individual versus communitarian values, equality of access, resource allocation, and priority setting. Though this discourse is an important first step to integrating health and human rights, explaining health as a human right lacks an important degree of precision. This discourse should instead be framed in terms of quality health care as a human right, which both encompasses and more adequately defines obligations to protect the right to health.

Human rights are based on the dignity of the human being. Since all humans have intrinsic dignity, all humans deserve the same rights regardless of any social category in which they identify with, including but not limited to race, ethnicity, socioeconomic status, age, and gender. Human rights based on the nature of human dignity requires the elimination of health disparities related to these categories.

Health care quality can be defined through clinical quality, including process and outcome measures, patient satisfaction, and cost. The emergence of health as a human right requires that health care organizations eliminate disparities related to these measures through provision of health care quality to all individuals.
3b Organizational Responsibility for Health Care Quality

An organization’s responsibility to protecting the right to quality care is based on its moral agency. The moral agency of health care delivery organizations bestows responsibilities upon them to protect the human right to health. This is clarified by the mission and values of health care organizations. Organizational obligations to health and human rights include the promotion of quality care and the protection of patient safety.

3bi Organizational Moral Agency

Organizations have ethical obligations through their moral agency. The organization’s moral agency is defined by their mission and values, and is carried out by agents acting upon their behalf. These agents navigate the ethical environment of the organization using professional and clinical ethics principles.

The organization’s moral agency is based on its moral identity. Health care organizations are unique from other types of organizations based on the special goods and services that they provide. The healthcare organization’s mission and vision should bear this in mind and address the special stakeholders that healthcare enlists. This can be laid out in the organization’s mission and values, which serves as the foundation for an organization’s moral identity.

Organizational Identity and Moral Authority

The healthcare organization’s agents embody and act out its moral identity. The moral identity encompasses the organization’s mission and values, but mission statements are only words until they are acted upon. Agents of a health care organization can use professional ethics and clinical ethics in conjunction with the organization’s moral identity to enact the moral identity of the organization.
The moral identity of an organization is needed for practical purposes, although it is only an analogy or metaphor at its core. The organization’s moral identity must be operationalized to enact meaningful moral agency, and how an organization’s mission statement is operationalized is key to its impact. An organization enacts its mission and vision through agents who act on their behalf. In health care this can range from executive leadership to frontline staff. When an agent is confronted with specific ethical dilemmas that are not explicitly covered by the organization’s mission statement and values, they can rely on professional and clinical ethics to guide their decision-making, ensuring that they are still facilitating the organization’s moral identity and agency.

Organizational ethics relies on the actions of agents working on the organization’s behalf, including individuals, and institutional boards and committees. The organization’s moral agency is enacted by the aggregate of its agent’s actions. The agents have their own moral identity, but when acting on behalf of the organizational moral agency, they must follow the organization’s mission and values. The organization can be seen as a community, with the moral identity of the organization and the moral identity of its agents as entwined. The community values guide the overall actions of the agents, and the aggregate moral identity of the individuals within the organizational community influence the moral identity of the organization as a whole.

The agent can experience ethical conflict when their own moral identity and that of the organization clash. Ethical conflict can be caused by the varying pressures of health care leadership, including those of environmental factors, financial incentives, board of directors, and stakeholders. When an agent of a healthcare organization faces this type of conflict, they can rely on professional and clinical ethics to mediate.
A professional is a group of individuals with important and exclusive expertise, internal and external recognition, and autonomy in matters of expert practice, and specific ethical obligations or codes. A physician is an example of a professional. Individuals can have multiple roles within an organization and their role-defined obligations have the potential to conflict, such as when a physician’s role as professional clashes with their role expectations as employee. Professionals are expected to abide by code of ethics and this code should override other considerations if a conflict arises, even if commitments to the organization conflict with the professional role. A physician acting upon the moral agency and identity of an organization may face a conflict of personal versus organizational values, and in this case, they can rely on professional codes of ethics to override personal and organizational ethical codes.

Professional ethics is especially important because the tensions that can arise between self-interest and service to patients can undermine a physician’s credibility. Because the physician-patient relationship is of utmost importance, professional ethics helps to protect the trust between the physician and the patient. The physician has responsibilities to several individuals and groups, but the patient is their first and foremost priority and they are bound by professional ethics put the interest of their patient first at all times.

According to the American Medical Association, the physician has ethical responsibilities to society, other health professionals, and to self but her first and foremost responsibility is to her patients. This means that if a physician’s role as a professional requires that she acts a certain way, while her employer mandates that she does the opposite, the physician is morally obligated to follow her professional code of ethics rather than the organization’s ethical code. The organization should preemptively attempt to avoid such conflicts and put the patient at the center of their mission and values.
Physicians are not the only professionals that practice in health care. Nurses and other providers are part of professional groups as well. Like physicians, nurses have a professional ethics codes, although the nurse not traditionally had the level of autonomy or control as physician, and have typically been employees of physicians or hospitals with a supportive role. Nurses face similar issues to physicians when facing conflicting roles within the organization. Like physicians, they are expected to take their commitment to patient advocacy as their primary duty, with obligations to the organization as secondary.

It benefits health care organizations to support professional codes because of the crucial role they play in the physician-patient relationship. As a professional, the physician takes the role of an advocate, which is important because patients want a physician they can trust to advocate for their individual interests. Maintaining this physician-patient relationship is an important part of quality care, which should be the highest priority for health care organizations. Health care organizations should find a way to placate these conflicts within their organizational policy. Clinical ethics can also help to mediate the role between the organization and its employees.

Clinical ethics addresses issues that arise from the care of patients and considers the rights of patients as its primary concern, prioritizing patient’s personal autonomy. Clinical ethics is like professional ethics insofar that it puts the patient as the highest priority, but it is different in that professional ethics looks to the professional code as the highest authority, while clinical ethics considers patient autonomy to be the highest authority. Clinical ethics typically focuses attention on particular and individual cases, considering issues such as who should be involved in decision-making and who is most affected by a decision. According to clinical ethics, the patient choice is considered to be most important in this decision-making process.
When there is a conflict between what is best for the overall patient population that the organization serves versus professional obligations in specific cases, clinical ethics can mediate a solution, such as in the case of clinical futility.\textsuperscript{102} For example, if a patient is on a ventilator and is receiving no benefit, the ventilator use could be considered futile care and there may be a question of whether its support should be withdrawn. The physician may have her own opinions about what is best for the patient and organizational leadership may have a conflicting stance on the best course of action. In this case, clinical ethics principles can be applied to help the patient (or their surrogate) come to a decision about how to proceed. Clinical ethics can be the mediator when professional and organizational ethics collide, favoring individual choice and clinical context.

The United States is a pluralistic society of people different values, where no one specific group has a special claim to morality.\textsuperscript{103} Clinical ethics recognizes this fact and places the final decision on the individual patient’s wishes. Ideally, organizational policy is also formed to respect the differing values and beliefs of patients that a health care organization serves.

Organizational policy should be formed to prevent ethical problems from occurring, rather than relying on reactive responses as ethical problems arise.\textsuperscript{104} Although clinical ethics is a useful tool to mediate unforeseen issues, an organization should attempt to preemptively prevent these problems from occurring through policy based on their mission and values. Organizations should also consider clinical ethics in their policy formation because of the potential of conflicts with clinical issues. Organizational policies can cause questions of clinical ethics when they have been made or changed without consideration for clinical impact on individuals.\textsuperscript{105} Organizations must consider the influence of their high-level decisions on day-to-day operations.
In sum, organizational moral identity, professional ethics, and clinical ethics are all important for quality of patient care and should work together to achieve the highest standards for the patients. On all of these levels, there is moral obligation to address inherent inequalities that can affect the way patients seek and receive care. Because not all patients enter health care services with the same needs, organizations are not obligated to provide the same level of services. The structural inequalities that influence and create social determinants of health should be considered when determining patient care needs.

Organizational Mission, Vision and Values

There are no absolute requirements for a health care organization’s mission statement, but in general, it should relay its major commitment to patient care and overall health status of communities, maintaining public confidence, and providing fair and equitable treatment to employees. When developing its mission statement, the organization can follow criteria such as alignment with external directives, academic commitments to education and research, clinical impact, community needs, external partnerships, internal interdependency, and resource implications. Whatever content that the healthcare organization decides to include in its mission statement, the benefit of its primary stakeholders, namely its patients, should be at its core.

The organization can follow several steps to ensure that the mission statement effectiveness is maximized: the organization should involve employees from every level of hierarchy in the organization during its development; the mission statement should be clearly communicated; measurable operational targets should be established based on the mission statement; and the mission statement should be periodically revised to ensure that it remains
current. These steps will help the organization to ensure employee engagement with the mission statement.

A health care organization’s mission statement can aid in performance improvement by clearly defining what the organization is trying to achieve. Importantly, it should not be diluted with corporate buzzwords and politically correct terminology, and instead should show how concepts can be practically applied, and should reflect the organization's true identity. The organization’s mission will be the guide for how its moral identity will be enacted by the organization’s leadership and other agents. The organizational values are also an important piece of the organization’s moral identity.

The healthcare organization’s values represent what is most important to the organization and is part of its moral identity. It is important that the organization maintains values that facilitate trust between the organization and patients. A trust relationship between the patient and the healthcare organization is essential for the health and financial well-being of patients, the management of limited resources, and the physician-patient relationship. Clearly expressing organizational values will help to facilitate this trust. Values help the organization to maintain integrity by establishing commitments, integrating these commitments into daily operations, and planning for scenarios where organizational values may face conflict. Organizational values, therefore, create the foundation for the relationship between the patient and the healthcare organization.

It is important for organizations to communicate values that are meaningful. An organization's established mission and values should not be diluted with corporate buzzwords and politically correct terminology, and instead should show concepts that can be practically applied, and should reflect the organization's identity. This will help the organization to
operationalize its mission and values. How an organization’s mission and values are operationalized is essential to their effectiveness. Healthcare managers can incorporate an organization's values into daily operations by recognizing the value system at work, determining what is within their own sphere of influence, incorporating values of internal stakeholders, and committing to the established organizational values system. This approach will systematically incorporate the organization’s values into everyday actions and tasks.

In addition, the organization’s values can help to define what it considers to be essential versus non-essential care. It can also be difficult to parse out genuine patient needs versus preferences, and when a preference becomes strong enough to become a need. This question involves values and its answer depends on who is making the judgment. If the organization clearly defines its values, these judgements can be preemptively addressed, at least to some degree.

The moral identity of an organization explains what an organization is, not merely what it does, and provides framework for the behavior of individual agents working on behalf of the organization. The agents of an organization carry out the organization’s moral identity. The actions of the organization’s agents then reflect upon the moral identity of the organization, meaning that the organization’s moral identity and the actions of its agents are reciprocal. The organization’s moral identity, as defined by its mission and values, will need to be translated into actions made on behalf of the organization. The actions of the organization’s agents and the ethical framework in which they work is imperative to upholding the organization’s moral identity.
3bii Organizational Obligations to Health Care Quality and Patient Safety

Quality, patient safety, and medical error are closely related. Medical error is a subset of patient safety, which is a subset of quality care. Organizational systems can and should address structures of inequality can influence quality/patient safety. Although there are regulatory bodies which attempt to address health care quality and patient safety, an organization’s internal policy will create more of an impact for patients than these broad programs. These compliance programs, which focus primarily on regulations, laws, and social norms, are important, but ethics programs can cover a broader range of issues and have a wider impact on issues directly related to patient care. Organizations face a moral imperative to address quality and patient safety issues because of the ethical obligations they hold, based on their moral agency.

Quality improvement begins with an organizational focus on its mission, values, goals, and expectations as demonstrated by organizational leadership and carried out by staff. The organization’s moral identity and agency are key to improving quality and patient safety outcomes.

Promoting Quality Care

The Institute of Medicine has defined quality outcomes as safe, effective, efficient, personalized, timely, and equitable. Quality is the broad umbrella under which other more specific measures of care live, such as patient safety and medical error rates. Poor quality can be caused by the overuse of procedures that do not improve health, underuse of procedures that could improve health, and misuse of procedures and can be related to issues such as safety, effectiveness, patient-centeredness, timeliness, efficiency and equity. Quality is part of the health care value equation which is quality over cost. Because health care faces finite resources, quality must always be measured against cost. Cost in this case can be thought of as purely
financial compensation for services and goods, although purely financial costs are not the only consideration.

Due to the nature of health care, resources are not unlimited. Among many examples of this include: a limited number of doctors or nurses, a limited number organs for transplant, a limited amount of blood products, a limited amount of dialysis machines, and a limited number of hospital beds. These are far from the only examples of limited health care resources and health care leaders often need to make decisions on how to allocate them in the most effective, efficient, and fair way. Organizational ethics can guide health care leaders to make these types of decisions.

The cost of these resources is one of the prevailing issues that health care leaders must address. Because of this, cost-containment is a prevailing challenge for health care organizations. There are reoccurring ethical tensions when determining how to balance and prioritize cost and quality, taking resource constraints and in market competition into consideration. Looking for a new approach to cost-containment, health care regulators, payers, and organizations themselves have started to look at ways to improve quality of care to reduce unnecessary costs to the system. In today’s health care environment, organizations must continuously maintain or improve quality of services while holding down rate of cost growth, focusing on improving processes and/or outcomes. Although the primary goal of a health care organization is first to take care of patients, this goal cannot be met if it does not remain financially viable. In other words, if a health care organization does not make a profit, it cannot pursue the mission for the organization. Weighing the priorities of profit and patient care is at the crux of many ethical dilemmas in health care.
Clearly defining goals will help to ensure that decisions are aligned with the organization’s values. The organization’s goals are not goals of any one individual working for the organization, but those of the organization as a whole, reflecting the organization’s moral agency. There will always be ethical questions that arise from unforeseen circumstances, but organizational policy should attempt to address the organization’s approach to as many of these possible quandaries as possible to ensure that decisions are made that are consistent with the organization’s values. Specifically, quality and patient safety goals should be articulated to address structural issues, reduce inefficiencies in process and improve patient outcomes.123

Quality can be approached through process improvement or monitoring outcomes measures. Process improvement and outcomes are closely related, and it is often advisable to address both process and outcomes. Using process measures is advantageous because they tend to be specific and actionable, addressing the “how” of health care quality improvement. Outcomes measures show whether the process measures are working to achieve actual improved patient care, addressing the “why” of health care quality improvement. For example, an outcome goal could be to reduce infection rates by 10%. The corresponding process goal would be to increase hand washing by installing hand sanitizer dispensers in each inpatient room. A successful QI program always incorporates an emphasis on systems and processes, a focus on patients, a team approach, and meaningful use of data.124

In addition to improved clinical processes and outcomes, patient satisfaction should also be considered as part of quality improvement. Patient satisfaction is important because patients who are more satisfied have better compliance with treatment, communicate relevant information to their provider, are more likely to return for follow up, and experience better outcomes.125 Some examples of process measures for patient satisfaction would be to ask physicians to make
eye contact and sit down when talking to patients in the outpatient clinic. An outcome measure could be patient satisfaction scores as measured by CAHPS (Consumer Assessment of Healthcare Providers and Services) surveys. As with clinical quality outcomes, process and outcome metrics are important for the measurement of patient satisfaction.

Once quality process improvement interventions have been implemented, process and outcomes measures must be continuously monitored and valued. Health care organizations and their agents can use PDSA (plan, do, study, act) cycle, to run small, frequent tests of change for quality improvement efforts, continuously learning and modifying programs from both successful and failed tests. Monitoring is an important component of quality improvement since it shows whether an intervention is working and allows for an approach to be revised as needed.

Problems with quality can arise from variation in services, underuse of services, overuse of services, misuse of services, and disparities among populations. Addressing all of these facets of quality is important, but at the core of these issues is the structural inequalities that individuals and populations face. Addressing these structural inequalities is key to quality improvement. Organizations have an ethical obligation to address these inequalities based on their ethical responsibilities as demanded by their moral agency. Ethics programs can synergize with quality programs to help organizations balance their commitments to both consumers and payers, informing potential areas of conflict between the goals and expectations of consumers, payers, and organizational values. Having clearly articulated organizational values and mission can help health care organizations deliver the highest standard quality of care.
Included in health care quality improvement is patient safety. Patient safety is a subset of quality and its process and outcomes goals should also be aligned with the organizational mission and values.

**Protecting Patient Safety**

Patient safety is an important component of health care quality. Patient safety describes health care delivery that does not cause harm to the patient. Medical error is one way that a patient can be harmed through medical care. Preventable adverse outcomes can arise from medical error such as medication errors, communication problems, discharge process, retained sponges, and missed diagnoses, although these errors do not always result in serious consequences, and adverse outcomes are not always the result of error.\(^{130}\) A patient safety event is described when the patient is harmed in a way that was not a part of their normal course of disease or ailment.

This will include the development of a culture of safety. Developing and maintaining a culture of safety involves facilitating an environment where professionals feel comfortable addressing safety issues openly, making safety a management priority, creating a learning organization, valuing employees, thinking in terms of systems, and considering safety as everyone’s responsibility.\(^{131}\) Additionally, an organization can adopt a patient-centered model. A patient-centered model considers patients as decision-makers, participants in their own care, and evaluators of their care.\(^{132}\) Creating systems that encourage patients to be an active part of their care and recovery greatly improve outcomes.

In sum, improving and maintaining the highest level of quality care and patient safety are primary goals of health care organizations. Although organizations can create some policies that address quality and patient safety issues on the surface, they should also look deeper into the
structural roots that cause some patients to be higher risk for adverse events and outcomes. Because structural issues related to social determinants of health are so influential on health outcomes, they should be a primary concern of any health care quality improvement program. Further reinforcing this concept is the ethical obligation of health care organizations to address these issues, based on their moral agency and duty to protect human rights. Human rights forms the ethical foundation for addressing structural inequalities with the goal of improving and maintaining patient safety and quality of care.

By definition, human rights must be natural, equal, and universal and must apply to every human simply because of their status as a human. Because organizations have moral agency, they have an ethical obligation to provide safe, high quality care based on respect for the human rights of the patients they serve. The right to safe, high quality healthcare is explained by the key human rights principles of respect for human vulnerability and personal integrity, social responsibility, and health equity.

Organizational values should emphasize the human rights principle of respect for human vulnerability and personal integrity. Ethical excellence includes commitment to care for vulnerable populations, such as those without insurance, those with serious illness, the disabled, the poor, those who do not speak English, those with mental illness, and the very young. In most cases, these special groups face structural barriers to health care that affect their quality and patient safety outcomes. This can be due to numerous special problems of the vulnerable, such as psychological barriers, lack access to appropriate care at the appropriate time, and barriers to getting treatment such as nature and severity of illness.

Social conditions can alleviate, exacerbate, or even cause these vulnerabilities. Vulnerability represents the finitude and fragility of life, and describes contexts in which a
A person is incapable of protecting his or her own interests due to insufficient power, intelligence, education, resources, and/or strength. Vulnerability is inherent to life and can be used to describe all humans, making it a key tenant of human rights. All humans may, at some point in their life, face circumstances which render them vulnerable as individuals, families, groups, communities or populations, including disease, disability, personal conditions, environmental conditions, and/or limited resources. These circumstances can be experienced in different ways, for different durations, and at different times in people’s lives. Not all vulnerabilities are experienced to the same degree or have the same amount of influence on different people’s lives.

While all of humankind is vulnerable as part of the human condition, certain individuals, groups and situations have “special vulnerability” determined by natural or social determinants, leading to increased risks to freedom, autonomy, integrity and general welfare caused by social exclusion. Structural inequalities facilitate these risks, including risk for exploitation, neglect and abuse. Special vulnerability can be prevented by addressing its contexts and causes, and thereby fostering equal rights, human dignity, and personal integrity. The contexts and cause of many of these vulnerabilities are social determinants of health caused by structural inequalities inherent to the social systems people live in.

The protection of personal integrity stems from the prevention of vulnerability. As with vulnerability, protection for personal integrity is also more urgent for some groups and individuals than others. Some persons and populations are also need special protection for personal integrity. Health care organizations have a special obligation to care for those in need of this protection. Health care organizations have an obligation to respect these negative rights and facilitate these positive rights in support of this human rights
principle. This is especially true because vulnerability is caused or exacerbated in certain contexts and situations in healthcare, such as access to healthcare, provision of appropriate healthcare, inequality of power in healthcare, “double standard” research, equivocal donations, inappropriate research, social vulnerability, vulnerability as a result of lack of research, stigmatization, unfair pressure, premature applications of technology, genetic information and patient privacy, unexpected risks, and unconsented collection of genetic data.141

Because health care is a special type of service that tends to skew in favor of the socially privileged, health care organizations should take special precaution to ensure that these vulnerable populations are protected. Vulnerable individuals and populations are worthy of special protections because of their relative or absolute incapability to protect their own interests based on insufficient power, intelligence, education, resources, strength, or other necessary attributes to protect oneself from abuse or exploitation.142 An individual or population can be especially vulnerable for many reasons, and it is important to recognize the structures which cause these vulnerabilities, as well as the ways in which the vulnerabilities manifest themselves in order to reduce their negative impacts. Vulnerability is universal, and all people are vulnerable at some point in their life. Although all people face vulnerability, some experience transient vulnerability due to temporary circumstances, while others experience vulnerability that is inherent to the political systems, socioeconomic circumstances, or other factors that individually or collectively constrain their capacity for freedom.143

In sum, recognizing systems that create these vulnerabilities, whether transient or permanent, is an important step toward making meaningful policy to protect these
individuals and populations. Health care encompasses unique goods and services which are inextricably linked to vulnerability and human integrity. In healthcare, vulnerability is especially important in the physician-patient routine relationship, research setting, and biotechnological advances. These unique aspects of health care introduce power relationships which have the potential for abuse and exploitation. As a human rights imperative, these vulnerabilities should be recognized and addressed – especially for those with inherent and special vulnerabilities. Health care organizations have an ethical obligation to address these special vulnerabilities in order to improve quality of care and patient safety. Because the health care organization has moral agency, they are expected to act based on ethical merits of decisions. A respect for human rights should be at the core of this decision-making, including an endorsement of social responsibility.

The respect for human vulnerability helps to explain why organizations have an obligation to address structural inequalities. Because of this principle, organizations have a moral duty to protect and prioritize vulnerable populations, namely those that experience structural barriers to accessing healthcare.

Social responsibility explains that humans should consider and avoid ways in which their actions may negatively affect social conditions. In relation to health, social responsibility emphasizes a shared commitment of all stakeholders to promote and protect social conditions that influence health such as birthplace, nationality, and age. The health care organization has the responsibility to their stakeholders based on their moral agency and ability to enact ethical decisions.

Social responsibility demands positive action to improve social conditions of those who suffer from socially-constructed vulnerability. Freedom can be theoretically available,
but it is not effective unless it allows people freedom to act. Health care organizations need to facilitate effective, not just theoretical freedom. This can include engagement in social development.

Social development is multi-faceted and takes careful planning and consideration of limited resources. It involves the development of material conditions, formal and cultural structures, and education, and should be part of deliberate governmental policy. The responsibility of governments to promote social development is of crucial importance to the health of populations. Although health care organizations cannot directly change many of these conditions, recognizing the importance of social conditions and social development can be the basis for preferential treatment for some groups. Health care services are an important part of a person’s social environment, and improving health can help individuals achieve in other areas of social development. Improving health is both an outcome and prerequisite for development. The health of individuals and populations affects abilities to gain effective freedom for economic growth such as the ability to hold a job and educational opportunities. In turn, improved economic and social conditions improve health.

Although social responsibility is a solid foundation for supporting development, it can be difficult to carry out in real-world contexts. Social responsibility requires resources to pursue goals that are often limited. This means that goals within healthcare and society as a whole need to be weighed and prioritized with an emphasis on fairness and based in common humanity. A person who faces a social situation making them more vulnerable would possibly warrant more resources from a health care organization due to greater need. Based on social responsibility, physicians have an ethical obligation to spend time
addressing the social inequalities that adversely affect health.\textsuperscript{148} Since these social conditions can greatly affect, or even cause certain health outcomes, they warrant serious attention from medical providers. Physicians, acting as agents for the health care organization, can help the organization to carry out social responsibility in this way.

The interdependence of social structures and health should always be considered when making difficult choices of resource allocation. Structural inequalities should be eliminated or at least minimized when determining allocation of limited or scarce resources. Ethical analysis can help to prioritize resources when there are competing needs such as health care, building infrastructure, and education.\textsuperscript{149} Health care organizations can do their part by improving the health care system and supporting human rights. Respect for human vulnerability and social responsibility combine with the principle of health equity to form the basis of a human rights approach to quality improvement and patient safety.

Equity involves fair, equitable and appropriate treatment of people, so that equals are treated equally and unequals are treated unequally.\textsuperscript{150} In health care, this can mean giving the most resources to individuals who need the most. In this care, equals mean equal need, so those who have equal need should be given equal treatment, while those who are better off should receive less treatment and those who are worse off should receive more treatment.

Health is a universal, basic human need that typically depends on economic and social structures of social hierarchy that distribute resources.\textsuperscript{151} In a just system, this resource distribution is created through patient need, not through ability to pay or social status. The right to health care is based on equity because it represents fairly distributed access to social protection and mitigates unfair opportunity imbalance caused by factors outside of a person’s own control.\textsuperscript{152} All humans should have an equal right to health care
based on equity and fairness. Health disparities are a result of systematic inequalities between groups based on social disadvantage, and should be viewed through the lens of social justice.\(^{153}\) A health care organization has an obligation to address social inequalities that are a result of unjust social systems. Because of its emphasis on the mitigation of inequality, justice includes making a preferential option for the poor. This is because the poor suffer the worst health outcomes, produced by structural mechanisms of exploitation and poverty.\(^{154}\) Because of the health outcomes that result from structural inequalities that create this injustice, health care organizations have a moral obligation to address these issues.

Alternatively, development may seem like a useful approach, but it is limited by the oppressive systems that it attempts to work within. Unjust systems will only beget injustice, even if that injustice is temporarily mitigated. The only way to address these inequalities for long-term improvements is through a social justice approach. Health care organizations have a duty to provide a just system of care for the patient population it serves. This duty is based on an equal concern approach to health care, which is founded in a social obligation to justice and human rights rather than one of charity.\(^{155}\) When health is viewed as a human right and a social justice approach is taken, double standards for the rich and poor are erased. A justice-based approach addresses the root of the problems rather than simply functioning as a strategy for managing inequality. The preferred approach for addressing structural inequalities in developing countries is the social justice model. This model looks at inequalities as human-made and addresses the structures that create and maintain poverty and make people sick.\(^{156}\) The role of the health care organization is to improve the health of the patients they serve, and addressing these
Structural inequalities will be the most effective way to achieve this because they explain the root cause of poor outcomes.

Poverty is a human rights issue that affects health outcomes. Eradicating poverty is often seen as an idealistic and unrealistic goal. However, based on principles of human rights, the goal of complete eradication of poverty is the only one that is acceptable. It is also important to avoid self-fulfilling prophecies that are detrimental to poverty and health. Human rights and health advocates should avoid self-fulfilling prophecies related to poverty, or predictions that influence outcomes. Predicting that one will not be able to influence a social environment can actually influence the ability to achieve that goal.

The goal of eradication of poverty and achievement of the highest level of achievable health for all is the only goal supported by human rights. Similarly, health care organizations should strive toward an eradication of preventable adverse patient safety outcomes. The prediction that an organization can eliminate these poor outcomes will be the first step toward achieving this goal. To carry out commitments to human rights, the structures of how health care and the social world around it must be addressed, including the design and maintenance of institutions that minimize human rights violations. Human rights principles support the duty of healthcare organizations to address structural inequalities that cause poor health outcomes. Moral agency explains why health care organizations have an ethical duty to address these issues. Because healthcare organizations have ethical duties, they are able to have moral obligations to address these issues that result from human vulnerability and are founded in social responsibility and health equity.
Organizational ethics exists within an external and internal moral climate and reflects how an organization’s performance aligns with expectations set by social norms as well as its own goals and values. An organization’s moral agency describes how the organization enacts these goals and values. In the case of health care, these goals and values are focused on providing safe and quality care. Providing safe, quality care requires that organizations address structural inequalities faced by the patients they serve. The obligations of organizations to address these structural issues are based on human rights principles, namely respect for human vulnerability, social responsibility, and equity.

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Chapter 4: Social Determinants of Health

4a Social Determinants of Health & Cultural Competency

Social determinants of health – including race, ethnicity, culture, socioeconomic status and barriers to access – have a serious impact on health outcomes in the United States. Determining how to address these issues is a challenge exacerbated by the multicultural nature of the US population. It can be difficult to navigate through the different cultures, beliefs, and backgrounds that a diverse population offers.

Due to the pluralism created by a multicultural society, bioethicists need to seek a common ground between methodological differences through moral discourse based on foundational theories, principles, and casuistry.\(^1\) One way to explain this moral discourse is in terms of religious ethics and secular ethics. Religious medical ethics is based on claims that a religion has a way of knowing divine truth or divine will and typically presents in two forms – with truths revealed or naturally knowable by reason.\(^2\) Secular ethics, on the other hand, relies on approaches of reason or approaches of experience or moral sense.\(^3\) Given the diversity of religious and secular perspectives in a multicultural society (such as the United States), major challenges are presented by both religious and secular medical ethics foundations. Instead of choosing an ethical theory that favors a certain group or theory, a normative ethic can be formulated to address challenges associated with social determinates of health through foundations and applications of human rights.

Human rights should be the basis of a normative ethical approach to health care ethics in a multicultural society because it is founded in respect for human vulnerability and justice. This means that it is an approach that considers the different needs of individuals while uniformly granting the same rights to all. Human rights can help to address social determinants of health,
considering the nature of human vulnerability and applying the principle of justice to reduce health disparities. Through applying human rights principles, organizations can implement cultural competency programs and policy in order to reduce disparities caused by social determinants of health and ultimately improve quality of care. In other words, the human rights principles of respect for human vulnerability and justice can be applied through organizational policy focused on cultural competency, and ultimately address social determinants of health to improve quality of care.

4aii Ethical Challenges to Organizational Policy Stemming from Social Determinants of Health

A diverse population with varied races, ethnic backgrounds and belief systems can lead to major challenges in bioethics and present the need to address ethical pluralism in the context of diverse philosophical, spiritual, and religious beliefs. These challenges are especially pertinent in relation to social determinants of health. When individuals in a society have varying backgrounds and belong to diverse social, religious and cultural groups, it can be difficult to create a health care system that applies to all individuals fairly.

This is further complicated by (real or perceived) weaknesses of traditional bioethics itself, which often faces criticism that it is based on western principles, methods, and philosophy and that it is lacking in its attempt to address the role of social and cultural values – specifically those that define health, illness, pain, and death. If those analyzing ethical challenges to health care hold a specific world view, they may not be able to seriously consider other legitimate perspectives from other cultural groups. This is one barrier to ethical analysis of multicultural health promotion, but these barriers include many factors related to: Demographics – such as age, ethnicity, religion, and education level; Culture – including worldview/perceptions in life, time orientation, and primary language; and Health care system barriers – including access to
care, financial resources, and poor doctor-patient communication. The various barriers that face a multicultural society when addressing health disparities related to social determinants of health must be addressed in order to improve health outcomes based on an ethical foundation of human rights.

Social determinants of health include key components of race, ethnicity, culture, socioeconomic status, and access to health care.

Diversity

Race, ethnicity and culture are important factors that have great influence on socioeconomic status of groups and individuals. These factors can seriously impact the quality and amount of health care that an individual receives.

Culture, ethnicity and race play important roles in patients’ ability to understand and interpret health care information and instruction. Culture describes (learned) patterns of social conduct – including everyday social interaction, local shared local knowledge, language patterns, family structures, values, symbols, interpretive categories, and ethnic traditions – and can strongly influence an individual’s understanding of illness, death, dying, decision-making, truth-telling, decision-making, “reasonableness,” autonomy, meaning symptoms and illness, understanding of appropriate social roles of family, and attitudes toward advance care planning. This patient background has the capacity to influence their ability to make many life-altering positions and can thereby contribute to health disparities among groups who have a greater ability to access and apply health care information versus those who do not.

Even when a person understands the health information they are receiving and can access the health care they need, cultural barriers can persist based on community expectations and also expectations of oneself. Cultural experiences and religious beliefs can be so intricately tied to a
person’s personal identity that a person may not feel free to act autonomously when there are foreseeable adverse consequences of choosing to act any other way than community desires, or acting in a way that will result in loss or radically altered sense of self. 8 If a person feels that they will lose their identity by acting against the norms of their culture, they may be unlikely to act against them. This can be further exacerbated by providers who do not understand the reasons why a patient acts a certain way because they are unfamiliar with their culture.

Although culture, ethnicity and race should be taken into consideration when making health decisions, there are some potential pitfalls and weaknesses in focusing on culture and ethnicity. It can promote cultural stereotypes, “essentialize” values, overlook variations, obscure importance of other issues such as socioeconomic status, and limit insight into what should be accommodated or tolerated.9 Health care leaders and providers should be wary of overgeneralizing based on these factors to avoid discrimination and further exacerbate the health disparities caused by these factors.

Stereotypes that apply biases or even epidemiological data to the individual without considering their individual characteristics can be extremely harmful – especially for those in marginalized groups. Avoiding stereotypes and overgeneralizations based on race, culture and ethnicity is especially important because of the serious disparities in health care and health outcomes faced by minorities in the United States. Importantly, there has been an unequivocal amount of evidence that minority groups often do not get the same level of health care treatment in the United States. For example, African Americans have been shown to have lower survival rates for lung cancer than Caucasian Americans, which is largely explained by their lower rate of surgical treatment – the optimal treatment for early –stage, non-small cell lung cancer.10 In this
case, the health outcomes of African Americans is directly related to the type and amount of treatment they tend to be offered.

Other research shows that Asian Americans and Hispanic Americans have been shown to experience lower patient satisfaction, receive less preventative care services, engage in less physician counselling, and are less likely to receive care to manage chronic conditions than African Americans or whites.\textsuperscript{11} In addition, non-white patients have been shown to be less likely than white patients to receive adequate pain treatment.\textsuperscript{12} This shows that different minority groups have varying experiences with the health care system – making analysis of effect of race, culture and ethnicity complex, multivariate and multi-layered. Because of the complexity of analysis, it is also a challenge to determine why these outcomes vary between minority and majority groups.

The varying health outcomes of different minority groups in the United States could be attributed to differing views of these groups and their physicians. When the cultural background of a patient and a physician differs, their opinions on issues such as life-sustaining technology can differ since they often have faced different life experiences related to ethnicity, socioeconomic status, gender and access to care.\textsuperscript{13} When the majority group holds the majority of health care provider roles, minorities may have fewer opportunities to relate to their caregiver.

There are many ways that health care providers can address these disparities in race, culture and ethnicity. According to the American College of Physicians, racial and ethnic disparities can be reduced through changes to the health care system including: providing all legal residents with health insurance, believing that all patients deserve high quality health care, acknowledging cultural and linguistic needs of patients, recognizing pre-conceived perceptions, delivering accessible patient-centered care, promoting a diverse workforce, addressing social
determinants of health, reducing the effect of environmental stressors, and supporting more research and data collection related to racial and ethnic disparities. These are just some of the strategies that health care organizational leaders and health care providers can use to reduce or begin to eliminate the disparities in health based on culture, race and ethnicity.

Culture, race and ethnicity are significant challenges to ethical organizational policy formation within a multicultural society. These, along with other factors contribute to disparities in health outcomes. Closely related to culture, race and ethnicity lie health care disparities created or perpetuated by socioeconomic status.

Socioeconomic status is an important indicator of health status and outcomes. The way that socioeconomic status affects health can be explained on many levels, and has significant supporting evidence to support the ways in which its influence functions.

Socioeconomic status influences many health risks that have serious implications for adverse health outcomes in poor individuals and groups. Low level of wealth or socioeconomic position moderately contributes to health behavioral risks of obesity, smoking and physical inactivity for adults 50 and over, meaning that promoting healthier lifestyles among these populations could help to close the gap in health inequalities. This is an important part of the picture and can be addressed in part by increasing access to health care and health information, and by supporting programs to improve lifestyle influences of poor health outcomes. This is one part of the picture of health and socioeconomic status, which affects health on many levels.

Socioeconomic status not only affects physical health, but importantly also has a serious effect on mental health. Socioeconomic status and demographic variables have been directly and independently shown impact changes in mental health, which can be attributed (at least partially)
to increased exposure to stressors experienced by socioeconomically disadvantaged groups. A disadvantaged socioeconomic position has the potential to impose a large amount of undue stress on an individual and thus impact mental health status. Impaired mental health status then has the potential to negatively affect socioeconomic status by causing disability, creating a vicious, self-perpetuating cycle. It is therefore important to address socioeconomic status and its relation to mental health, with an emphasis on early intervention.

Socioeconomic inequalities can also lead to increased risk of anxiety and depression, which is a gap that widens over the life course and could be addressed by prevention strategies in early life. An approach to improving mental health for the socioeconomically disadvantaged, especially at an early age, can improve functional capability and reduce the risk of further intensifying the negative effects of poverty.

Focusing on groups in low socioeconomic states can shed light on inequalities inherent to the health care system. For example, socially advantaged better positioned to benefit from biomedical advances that can lead to social inequalities and it is important to note the health provider’s influence on decisions, strength and uniformity of recommendations, uniform protocols, dissemination of health information and design new treatment protocols that prevent or alleviate health disparities. Biomedical science often focuses on social advantaged groups so redirecting research and health improvement initiatives can begin to address some of the disparities between availability of interventions to improve health. In addition, conditions and diseases that particularly affect those in socioeconomically disadvantaged groups can be further emphasized in research and provision of care to reduce the disparities caused by emphasis on the wealthiest few.
The disparities between wealthy and poor patients have many contributing factors. Physician perception and treatment of socially disadvantaged groups can significantly impact health outcomes. The way physicians form perceptions about their patients has been shown to have heavy influence from the patient’s socioeconomic class, with physicians associating socioeconomic class with perception of a patient’s personality, ability, behavioral tendencies, and role demands. This means that a physician may treat a patient differently based on perceptions of how they will behave – even if these perceptions are not based in any evidence of the individual patient’s characteristics. This can affect outcomes for patients who are treated unfairly based on provider bias.

Absolute socioeconomic position has a great influence on health outcomes, but so does relative socioeconomic position in terms of income inequality. Income inequality has also been shown to negatively impact infant mortality, low birthweight, and mortality in people aged 1-14 years, although these outcomes are not universally applicable and are most clearly correlated within the United States where income inequality is overwhelmingly associated with unequal distribution of health. The correlation between income inequality and negative health outcomes is another factor related to socioeconomic status that affects outcomes for all individuals – not just those who are economically disadvantaged. Mortality has been shown to be reduced with more equal distribution of income, with benefits weighing toward the poor and smaller benefits shown for the wealthy, which may be explained by the socially corrosive nature of income inequality. Income inequality, in other words, is not good for any member of society – although the poor are impacted the most severely.

Poor health exacerbates and perpetuates poverty through social marginalization, disadvantage, vulnerability and discrimination, but can be addressed operationally by
institutionalizing systematic and routine application of human rights perspectives, strengthening and extend public health functions, implementing equitable health care financing, ensuring adequate response to major causes of preventable ill-health among the poor and disadvantaged, and monitoring implications of development policies. Health care organizations, leaders and providers can foster improved health outcomes by addressing social determinants of health and improving economic equity for all individuals within the multicultural society.

Further, socioeconomic status is closely related to the ability of an individual to meaningfully access health care. In addition to race, culture, ethnicity, and socioeconomic status, barriers to healthcare access are a significant social determinant of health.

**Barriers to Access**

Access to health care is essential to good health outcomes. Most importantly, health care access is related to core American values of equality of opportunity, justice, and compassion which lead to the following ethical obligations: Every member of society must have adequate health care benefits; The contents and limits of health care benefits must be established through an ethical process; The health care system must be sustainable; and Stakeholders must be accountable for clear responsibilities. Because health care access is intrinsically tied to core American beliefs about opportunity, justice and compassion, it should be emphasized when looking at ways to reduce social disparities of health care.

Health care providers and organizations should work to reduce disparities experienced by racial and ethnic minorities – such as lower quality and quantity of preventative, diagnostic, and therapeutic services –by addressing and monitoring the contributing financial and structural barriers. These financial and structural barriers effectively equal barriers to access when they prevent a patient from obtaining meaningful care. Racial and ethnic minorities disproportionately
experience inadequate access, which goes against the core American belief of equality of opportunity. When a person does not have access to care that can help them achieve optimal level of health, their opportunities to effectively participate in society are significantly diminished.

Financial barriers are one of the most significant barriers to access faced by those in disadvantaged groups. Financial barriers can include insurance status or ability to pay for health care services. This is especially important because the uninsured do significantly worse in both quality and satisfaction outcomes than the insured. When a patient is not able to pay for health care or health related goods, this means that they do not have access to this care or these goods, regardless of how geographically easy they would otherwise be to obtain. When patients are not able to pay for health care, they are prevented from accessing health care services they need, including preventative and diagnostic services. In addition, they may not be able to receive care for chronic or disability-causing conditions. This could have serious consequences for long-term health outcomes.

Barriers to access can be especially stark for minority populations in the United States. Minorities are less likely to have a regular doctor, to feel like they have a choice in where they go for care, or to have a regular doctor. This can be due to various reasons, but the outcomes for minorities show that access can be a significant social determinant of health closely related to race, ethnicity, culture, and socioeconomic status.

Language can also be a significant barrier to access, causing disparities in health outcomes for minorities. Disparities in access to health care among Hispanic children have been shown to be largely related to language ability. If a person is not able to speak or understand
the language used by the health care system they have access to, they will not have effective access to health care.

Effective communication between patient and doctor is critical for good outcomes, yet many patients who need a language interpreter still go without one. Providing patients with adequate interpretation services and ensuring that they understand key elements of their health, including their care plan is crucial to reducing health disparities among minority populations. Some ethnic disparities, especially for Hispanics, have been explained at least in part by differences in English fluency. Understanding language is the first step that a person must take before they can even begin to understand messages of health care providers and ultimately gain meaningful access to health care services.

Full access to healthcare includes cultural, linguistic, and financial access. This means that health care should be culturally and linguistically appropriate, as well as affordable for all groups – including ethnic, racial, and cultural minorities, and those in low socioeconomic spheres of society. Only when these three conditions are met will all patients be able to meaningfully access care.

The goal of access to health care is for it to be equitable. Equitable access means equal access for those in equal need and unequal access for those who have unequal need and are influenced by factors on the supply side – including geographical availability and proximity, resource distribution; and the demand side – including individual’s ability to pay for health care, knowledge, information, cultural beliefs, indirect financial costs, opportunity cost of patient’s time, and preferences. Patients with equal need for certain services should have the same or similar access to those services, provided that ensuring access is financially and logistically reasonable.
This notion can further be explained through human rights principles, which should guide policy to address the ethical challenges stemming from social determinants of health.

**4a1i Developing Normative Ethics in a Multicultural Society through Human Rights Principles**

*Secular and Religious Bioethics*

Secular and religious bioethics are offer competing theories of how to define “right” or “good” in health care. Many secular philosophers rely on reason – believing that reason can deem certain behaviors ethical or unethical through thought process or negotiation in social contracts – or experience and senses – believing that the human body can weight moral benefits and harms to self and others through sense and perception. Religious theories are also common when approaching ethical theory in health care. Religious theories tend to rely on revealed truth or natural theology. Revealed religious truth or “faith knowledge” means that members of a particular religion have knowledge of true morality that has been revealed to them through their religious doctrine. Natural theology is a theory of religious ethics that states that there are natural ways of knowing moral norms, and that these norms are revealed by reason. These varying and often conflicting theories offer a confusing array of approaches to health care ethics in multicultural societies.

*Human Rights*

Choosing one of these normative moral theories – secular or religious – is not possible because, in a multicultural society, there are conflicting values, backgrounds and cultural beliefs that keep individuals from agreeing on theories outlining specifics of what is right and what is wrong. In other words, a multicultural society such as the United States faces moral pluralism, or morally diverse individuals and groups, which can attempt to engage with each other through
bridging foundational differences, but should keep in mind that agreement about moral a
philosophy does not necessarily mean that it is justified, i.e. consensus can arise out of pressure
from power structures or mindless conformity rather than true moral justification.35 Using
methodologies of bridging theories and justifying actions can be helpful when navigating
through differing moral beliefs within a multicultural society, however there are foundational
principles that should be started with and used as a foundation for these justifications. These
foundational principles are under the umbrella of human rights.

Human rights principles are principles that apply to everyone simply for the reason that
they are part of humankind. Human rights can and should be applied to health care ethics
because of its universal application and ability to create a guideline or framework for ethical
decision-making.

The United Nations’ Universal Declaration on Human Rights provides common
standards for fundamental human rights to be universally protected, and includes articles
outlining these established rights.36 Especially important for the right to health care are the
human rights principles outlined in the declaration of respect for human vulnerability and justice.

To be vulnerable has been defined as “… a means to face a significant probability of
incurring an identifiable harm while substantially lacking ability and/or means to protect
oneself.”37 All humans are – or are at risk for – being vulnerable at some point in their lifetime,
although some individuals facet a greater risk for vulnerability than others. In health care, and
often in terms of medical research, some patients are considered to be more vulnerable than
others. The International Ethical Guidelines for Biomedical Research Involving Human Subjects,
prepared by the Council for International Organizations of Medical Sciences (CIOMS) in
collaboration with the World Health Organization (WHO), defines vulnerability as “a substantial
incapacity to protect one’s own interests owing to such impediments as lack of capability to give informed consent, lack of alternative means of obtaining medical care or other expensive necessities, or being a junior or subordinate member of a hierarchical group.”38 A person is vulnerable when they are not able to protect themselves and are at a higher risk for harm.

All humans face vulnerability making it a shared trait of humankind and one in which incurs social and moral obligation. Societies have an obligation to protect their most vulnerable, and those within a society can feel comfortable that if they ever develop vulnerability, they too will be cared for.

Human vulnerability is closely related to social determinants of health, including race, ethnicity, culture, socioeconomic status and health care access. Vulnerable populations face critical barriers to care associated with multifactorial risk, including minority race, low socioeconomic status and lack of health care access, which predispose and enable poor access to care, and result in unmet healthcare needs associated with cost.39 Certain groups are more vulnerable than others and therefore need more social protections than others. These social protections extend to the protection of health for vulnerable populations. An ethical framework for addressing ethical issues in a multicultural society begins with the acknowledgement of human vulnerability and effort to address and protect vulnerable individuals and groups. Those that are socially disadvantaged deserve special protection, consideration and prioritization based on their vulnerable status.

Health care is often touted as being unbiased, as shown in the emphasis on evidence-based medicine; however, evidence-based medicine often inherently excludes benefits to vulnerable populations. Evidence-based medicine’s implicit promise is a commitment to objectivity and fair distribution, but vulnerable groups are often excluded from these benefits and
inequalities are often actually increased due to low socioeconomic status, ethnicity, age, gender, and mental ill health.\textsuperscript{40} If the focus on medical research that forms the foundation for evidence-based medicine is based on wealthy and advantaged populations only, these evidence-based interventions will be inherently designed to serve advantaged populations and may ignore the needs of vulnerable populations altogether.

In consideration of the nature of human vulnerability, the principle of justice should be applied to ensure that health care is fairly provided to those who are disadvantaged, with health care resources prioritizing those who need them the most.

Justice is important in health care especially because of the implications that injustices could incur on society as a whole. Health care deserves special protection because of its special moral importance founded in social obligation to protect of opportunity, meaning that health care helps to protect normal functioning of individuals and thus protects their ability to participate in political, social, economic life of society.\textsuperscript{41} Health is necessary for people to reach their basic functional capacity and most importantly to realize opportunity to meaningfully participate in society.

In a multicultural society, justice must be approached from a human rights perspective. Moral norms differ culture to culture which sometimes leads to a gap between is/ought, meaning that a society’s moral norms can explain why a norm is present yet these norms may still not be morally justified.\textsuperscript{42} Human vulnerability combined with justice shows that those who are most vulnerable should be protected and resources provided should coincide with need. In this model, one group will not necessarily be prioritized over another because once a persons’ need is gone, they will enter back into the group receiving the fewer resources. One group or type of individual
will not always get more resources unless they always need more resources, which would be unlikely or very rare.

Among many approaches, ethical decision-making can be based on utility (the greatest good for the greatest number,) deontology (nature of duty,) or consequentialism (decisions based on their consequences,) but a just outcome balances these approaches, as well as accountability and learning.\(^43\) Most importantly, these approaches should be founded in respect for human vulnerability, with the specifics of decisions made based on applicable theories. The basis for which goods and services should be prioritized should be based on human rights.

Justice involves priority setting – including how to use resources, which outcomes should be emphasized, to what degree to give priority to those who are worse off – which can be achieved through a model with four conditions: a publicity condition, a relevance condition (reasonable explanation of priorities), a revision and appeals condition, and a regulative condition.\(^44\) In health care, this priority setting is and should be very closely related to human rights, specifically respect for human vulnerability.

This definition of justice couched in respect for human vulnerability is necessary in order to respect the multicultural layers of society and needs of specific groups within a multicultural society. There is cross-cultural variation in understanding of morality including what is “reasonable” and “normal,” attitudes toward health and healing, beliefs about illness and suffering, beliefs about death, family obligations and what constitutes norms, leading to and contextualized patterns of social life accounts of moral reasoning.\(^45\) These variations in specifics about what is reasonable and what needs to be done can still be respected within the confines of respect for human vulnerability and justice.
Human vulnerability and justice will determine when there is need for intervention and the amount of resources society is willing to contribute to that intervention. Once this has been decided, strategies of cultural competency can and should be used to determine details and nuances of providing those resources. Organizational policy focused on cultural competency and based on human rights principles of respect for human vulnerability and justice can therefore alleviate effects of social determinants of health and ultimately improve health care quality.

4aiii Organizational Policy focused on Cultural Competency to address Social Determinants of Health & Improve Quality

Human rights serve as a foundation for ethical policy within health care organizations. In order to begin addressing the ethical challenges presented by a multicultural society – including race, ethnicity, culture, socioeconomic status, and barriers to access – health care organizations should develop a policy of cultural competency. When founded in human rights, this organizational policy can impact social determinants of health and ultimately improve quality of care.

Organizational Policy Focused on Cultural Competency

Cultural competency is the tool structured by organizational policy that can begin to address the ethical challenges facing multicultural societies. It can help to address the social determinants of health including race, ethnicity, culture, socioeconomic status, and access. It is well-founded in the human rights principles of respect for human vulnerability and justice, and can help organizations achieve their goals of improved quality of care.

Cultural competence falls into three buckets – organizational cultural competence, systematic cultural competence, and clinical cultural competence, each with their own unique challenges such as problems with lack of diversity in health care leadership and workforce, poorly designed systems for diverse patient populations, and poor cross-cultural communication.
between providers and patients. Organizational policy can address all of these buckets. Organizational cultural competence involves the health care organization having structures in place for a culturally competent environment for employees and patients. Systematic cultural competence means culturally competent systems within the organization that facilitate culturally competent care. Clinical cultural competence is at the provider and staff level for providing culturally competent clinical care for patients.

Health care organizations can approach cultural competence using many strategies. Health care organization interventions can include evidence-based cost control, improving financial incentive structure, providing meaningful interpretation services, using community health workers, incorporating multi-disciplinary teams, and improving patient education and patient empowerment. The organization can use evidence-based cost control as a justification for enhancing cultural competence policy and training within its organization. The health care organization can improve the financial incentive structure for providing culturally competent care. It can provide interpretation services for all patients who need them. It can incorporate community health workers who understand the cultural nuances and language of the patients who live within the same community. The organization can also incorporate multidisciplinary teams to emphasize the importance of cultural competency. In addition, organizations can improve patient education by including elements of cultural competence, thereby empowering the patient to participate in their health-care decision-making with cultural sensitivity.

Organizations face many challenges when creating policy based on human rights and cultural competency. Legal, regulatory and policy interventions can create systematic challenges to a multicultural society – creating defragmentation of healthcare financing and delivery and policies to that affect doctor-patient relationships. Organizations must work within the confines
of the legal, regulatory and policy environment in which it is entrenched and create complementary organizational policies to improve cultural competency. This is not to say that organizations should be the only level concerned about cultural competency.

All levels of the health care system, including payers and regulatory bodies, should emphasize cultural competence at a system level, striving to provide culturally and linguistically appropriate health care services, which will ultimately impact access, utilization, and health status of minorities. Health care organizations such as hospitals and health care systems should work together with payers and regulatory bodies to create policy that provides the most benefit for the patient population.

One way to structure this can be implemented is through continuing medical education (CME,) which can provide cultural competence training, guide providers to develop skills for culturally and linguistically competent health care, and foster self-reflection, critical thinking, and cultural humility. Continuing medical education is an excellent avenue for training staff and providers on cultural competence. Since there is expectation for ongoing training and learning, cultural competence education can be a consistent part of continuous learning.

Residency training is another important avenue for improving cultural competence in health care. Pediatric residents who have experience in cross-cultural care have felt more prepared to care for the diverse needs of children in the US – although more attention is needed to address patients who have limited English proficiency, are new immigrants, or have differing religious affiliations than their provider. Academic health care organizations can provide and encourage residents to participate in training related to cultural competence. This is important because resident physicians have self-reported that their preparedness for cultural competency lags behind their technical and clinical skills. In order for residents to be able to fully realize
their abilities to care for patients, they will need to know how to provide culturally competent care. Since this training is often not adequately provided in medical school, resident training programs should provide aspects of cultural competence education. Including cultural competence in resident training programs early on could have long-term effects of culturally competent care throughout the rest of a resident’s career.

When providing cross-cultural training, whether it be for residents, clinical faculty or staff, cross-cultural education can use interactive, experiential, practical, case-based approaches to teach these attitudes, knowledge and skills. These techniques will help cross-cultural training have a high level of impact as intended by the organization.

Cultural competence training should be multidimensional, addressing all of the aspects that may affect a patient’s ability to access culturally competent care. Organizational, professional, and individual levels of cultural competence can be conceptualized through a three-dimensional model including race and culture-specific attributes of competence, awareness of personal beliefs, and skills. Employees of an organization – including administrators, physicians and staff can follow this model to improve cultural competency in their area. This can and should begin with an understanding of race and culture-specific issues facing employees and patients.

The cultural competency training can then migrate to an analysis of one’s own personal beliefs about culture. Last, employees and providers should develop skills for addressing cultural issues within the health care setting. These three levels of cultural competence will build on one another and should all be included in a cultural competency training policy.

A system of cultural competency should provide a structure that facilitates organizations and providers in their development of cultural awareness, cultural knowledge, interpersonal
communication skills, cultural collaboration, avoidance of stereotyping, cultural experience, and conviction. The awareness and knowledge of cultures will help the provider or staff member understand the issues, and then use interpersonal communication skills and cultural collaboration to share in decision-making with culturally diverse patients. Cultural competence programs should also emphasize avoiding stereotypes and having cultural experiences. This will lead to conviction about cultural understanding and acceptance, which will be the ultimate goal of cultural competence training.

Cultural competency training is only one part of organizational policy focused on cultural competency. Culturally competent health care organizations provide culturally and linguistically appropriate services, recruit and retain staff who reflect cultural diversity, provide interpreter services or bilingual providers, facilitate cultural competency training, and offer linguistically and culturally appropriate health education materials. The organization must take steps in addition to cultural competency training to ensure a culturally competent organization.

The organization should provide services appropriate to its population and also ensure that their staff and providers reflect the cultural diversity of the population they serve. In addition, patient education materials developed and available to patients should be culturally and linguistically appropriate for the patient population/s served.

Organizational policy to cultivate cultural competency should not stop at understanding diverse cultures. Cultural competency, including linguistic competency, goes beyond cultural awareness or sensitivity though and requires the cultivation of cultural knowledge, development of skills to apply cultural knowledge, and policies that provide a structure for providers to deliver culturally competent care. Employees of a health care organization should not only understand
what cultural competency is, they should continue to cultivate knowledge and develop skills to apply their training in the clinical setting.

In addition, organizations can use various techniques to address cultural competence include interpreter services, recruitment and retention of minority staff, training, coordinating with traditional healers, use of community health workers, culturally competent health promotion, including family and/or community members, immersion into another culture, and/or administrative and organizational accommodation.58

When an individual staff member or employee approaches a culturally diverse population, they should take steps to ensure that they are facilitating cultural competence with all patients. Steps toward cultural competence should include cultivating attitudes, developing awareness of impact culture has social values and health beliefs, obtaining background information about patient’s cultures, performing a cultural assessment, planning culturally sensitive care, and avoiding defensiveness.59 The provider or staff member should understand that each patient may come from a culturally different perspective than their own and not assume that they know about the patient’s cultural background and preferences.

Getting background about the patient and performing a cultural assessment will help the provider to avoid harmful stereotyping and ultimately provide culturally appropriate care. The provider should avoid begin defensive during this process and learn from their experiences and mistakes. Providers and staff should identify cultural patterns, develop individualized care plans, and engage in cross-cultural communication (considering all types of communication including meanings associated with eye contact, touch, silence, space and distance) by adopting attitudes, developing awareness, and performing cultural assessment.60 In addition, guidelines for approaching cultural competency can include listening with sympathy and understanding,
explaining perceptions of the problem, acknowledging and discuss difference and similarities, recommending treatment, and then negotiating treatment.61

Understanding one’s own cultural perspective is an important part of cultural competency training. Physicians and health care staff must acknowledge their own potential biases when approaching a culturally diverse population. If a provider is unable to introspectively look to see how their biases may affect their care for a patient, they may inadvertently favor patients who are most culturally, ethnically, racially, or theologically like themselves.

A cultural competency curriculum should focus on examining and understanding attitudes, gaining knowledge of existing disparities, acquiring communication skills, understanding one’s own racial and cultural background, understanding the concept of cultural diversity, identifying types and cause of disparities, familiarity the community where practice is, ability to conduct cross-cultural and cross-language clinical encounters, and use of patient centered approach.62 These techniques and approaches will help the provider to navigate through a culturally competent episode of care and should be an emphasis for cultural competency training.

Health care organizations can look to the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards) for guidance on developing cultural competency policies. The CLAS standards include provisions for governance, leadership, workforce, communication and language assistance, engagement, continuous improvement and accountability – with the goals of decreasing health disparities, enhancing health equity, and improving quality.63 These can be used as a foundation for policy
development and implementation within health care organizations to foster culturally competent care.

Justification for organizational policy focused on cultural competency is based on human rights – specifically justice for patients and respect for their vulnerability. Patients facing disparities related to social determinants of health – race, ethnicity, culture, socioeconomic status, and access – are in particular need of culturally competent care as vulnerable populations.

Social Determinants of Health & Quality of Care

Social determinants of health can and should be addressed through cultural competency programs within health care organizations. Factors that affect social determinants of health such as culture, ethnicity, and race will be more adequately addressed when an organization has an effective cultural competency program.

Cultural competency begin with a cultural assessment. Cultural assessment should include demographic characteristics such as age, education, occupation and income, culture-specific epidemiological and environmental influences, and general and specific cultural characteristics – such as cosmology, time orientation, perceptions of self, and norms, values, customs, and general and specific health beliefs and practices such as explanatory models, response to illness, and health behavior practices, and western health care organization and assessment – such as examining one’s own cultural competence and sensitivity, organizational policy and mission, and facilities and program preparation. This cultural assessment will help the health care provider determine potential social factors that may affect their patient’s health. It will also help to keep the provider from making overgeneralizations or having prejudices based on patient’s demographic characteristics by learning about the patient’s unique background and risk factors. Cultural assessment will also help the provider learn specifics about the patient’s
culture that they may not have been aware of but could affect the care the patient receives. With an effective cultural assessment, the provider can tailor the patient’s assessment and course of treatment to their individual needs, considering their background, values and beliefs.

Patient-centeredness, or focus on the patient’s specific needs and goals is another tool that providers can use, although a patient-centered approach is not an adequate replacement for cultural competence. Cultural competence focuses on the needs of minority and disadvantaged groups while patient centeredness does not inherently address these issues – although these two concepts should work together jointly to deliver high-quality care and addresses issues of quality, equity, health disparities, and care for disadvantaged populations. Cultural competence is needed specifically to address social determinants of health that may give certain groups or individuals a disadvantages in achieving optimal health or accessing health care.

When a provider is working through cultural differences with a patient, they can use justification to determine the best course of action. Justification can include aspects of time, place, and culture, with a claim justified without necessarily admitting its moral truth and carried out using “bridge concepts,” inter-comparative dialogue, ongoing consensus, and maximizing respect for diversity and pluralism. This does not mean that the provider needs to agree with the patient’s point of view, but if the two parties can understand each other’s’ justification for certain decisions, it can help to come to a decision that both can accept.

Providers can also use techniques of cross-cultural communication to address disparities caused by social determinants of health. Cross-cultural communication can be improved by addressing health literacy, focusing on messages, becoming bilingual, understanding language nuances, understanding of nonverbal interpretations, and using interpreters. These techniques
can help patients who are in disadvantaged social, ethnic, or cultural groups to understand their care and how to navigate the health care system. Cross-cultural communication skills are important for understanding between providers and patients who may have very different backgrounds, beliefs and education. They can help to give providers a foundation for addressing issues with their patients that they may not otherwise understand without careful consideration.

It is also important that organizational policy and employees within an organization understand patient literacy and, more specific, health literacy of patients. Health literacy indicates the degree that an individual is capable of obtaining, processing and understanding basic health information, and directly influences their capacity to make good healthcare decisions, and to communicate about their health.68 Even if a patient can read, they may not be able to read and understand critical health care information. Making sure that verbal and written communication tools are in a level of health care literacy that patients can understand is a crucial step for providing adequate, appropriate, culturally competent care to patients and ultimately addressing the health disparities caused by social determinates of health related to these factors.

Similar to cultural competence, cultural humility is a commitment to self-evaluation and self-critique, addressing power imbalance between patient/physician, mutually beneficial advocacy partnerships, and patient-focused interviewing and care as a lifelong commitment.69 Providers can use cultural humility on an ongoing basis to improve their communication with culturally diverse patient populations. This technique provides an opportunity for continuous improvement and self-reflection for health care providers and has the potential to enrich the provider-patient relationship.

Based on the effect of sociocultural background on beliefs and behaviors, residents and medical students should be especially participate in cultural competence programs, including
analysis of individual patient social context and belief system, avoidance of generalizations, improvement in ability to understand, improvement in communication, and exploration of meaning of illness within the patient’s social context. Residents and medical students are learning the skills that they will take with them throughout their career, so emphasizing cultural competency and giving future and young physicians the tools to provide culturally competent care will have long-term positive effects.

Cultural competence is critical for addressing social determinants of health. Providing culturally and linguistically appropriate services in healthcare can help to respond to demographic changes, eliminate health disparities, improve quality, meet regulatory mandates, give a competitive edge in the market place, and decrease risk of liability for health care systems. Through cultural competence, social determinants of health can be addressed and health care quality will improve.

Culture, environment, socioeconomic status and healthcare access contribute to disproportionate adverse health outcomes experienced by minorities in the United States, and are strongly related to the physician-patient trust relationship, workforce opportunities, public health, costs to the economy, and overall quality. These key social determinants of health are closely related to health care quality outcomes, and can be improved by interventions included in cultural competency training.

Cultural competency is crucial for addressing social determinants of health to improve quality. It is justified based on human rights principles, especially the respect for human vulnerability and justice. Respecting certain aspects of a person’s culture, race, ethnicity, or background that may cause them to be vulnerable is a key tenet of cultural competency. Using cultural competency to improve quality is founded in justice because it is creating a fairer
environment of opportunities and social involvement which people can only achieve if they have a baseline level of health. Factors that are out of a patient’s control like their culture and ethnicity should not be a penalty for a patient to receive top quality care.

Health care outcomes can be improved for providers and organizations that emphasize social determinants of health, implementing cultural competency programs to address disparities they cause. For example, pain management could be improved through better communication because racial and ethnic disparities in pain perception, assessment and treatment call for education and treatment approaches that are more targeted to individual patient needs. Approaches to creating better understanding between provider and patient will help to facilitate these improvements.

Disparities in health care quality can be addressed by recognizing them as a significant quality problem, improving collection of relevant and reliable data, defining performance measures stratified by socioeconomic position and race/ethnicity, examining population-wide performance measures that are adjusted for socioeconomic position and race/ethnicity, and approaching relationships between socioeconomic position and race/ethnicity in relation to morbidity. The disparities caused by social determinants of health must first be recognized before they can be addressed. Next, data to monitor these disparities and show specific areas of improvement can help to focus goals of quality improvement through cultural competency.

These goals can be interpreted through definition of performance measures that are stratified by key socioeconomic factors. Socioeconomic group-specific data can then be compared against overall outcomes to see where there are disparities and which groups have the biggest gaps in outcomes. Importantly, an analysis should also be completed on the intersection of socioeconomic status and race/ethnicity disparities since these factors are intertwined and
analyzing their relationship may provide key insights on how to address them to improve quality. Cultural competency techniques can then be used to address any issues found between different ethnic, racial, cultural, and socioeconomic groups.

Cultural competency to improve health disparities is increasingly important as these disparities become more acute and more prevalent. More than 30% of medical expenses can be attributed to disparities in health experienced by minorities, which means that eliminating disparities could reduce costs to the US health care system through the reduction of direct expenses associated to providing care to sick and disadvantaged population as well as indirect costs including lost productivity, absenteeism, lost wages, family leave, and quality of life.75 With limited health care resources, resource allocation and cost is an increasingly important aspect of health care quality. Eliminating or reducing the disparities in health experienced by minorities could have a huge impact on not just the quality of life, but also the costs to the healthcare system, which has a limited amount of resources.

Additionally, increasing recognition of cultural influences can improve quality in healthcare and also improve a health care organization’s bottom line by appealing to minority customers, competing for private purchaser business, responding to public purchaser demands and improving cost-effectiveness.76 This means that implementing cultural competency programs can not only reduce costs for hospitals and health care systems, but could also help to bring in more revenue. Minority populations are growing in the US, and health care organizations should recognize their importance in growing market share for their organization. Appealing to minority populations is then not only the right thing to do, but also the approach that makes the most sense from a financial perspective.
Cultural competency is important because it can cultivate an understanding between providers and patients and help them to understand and participate in their own health care. Cultural competency is a crucial tool that allows providers and patients to cultivate knowledge, awareness and respect, thus leading to a satisfactory understanding between provider and patient, maximum patient compliance, and good outcomes. Patients who understand their providers would be more equipped to follow instructions than those who are facing miscommunication with their provider based on language or cultural barriers to communication.

Cultural competency and quality health system level factors, such as access to care, should address key determinants of health that contribute to disparities and even though evidence base has not been fully developed, expert opinion has indicated that cultural competency is imperative to improving quality and eliminating health disparities. More research is needed on the true effect of cultural competency on health outcomes, but it is shown as a promising, easy and cost-effective way to address disparities in health care that reduce quality outcomes. Cultural competency can improve these outcomes by improving a patient’s effective access to health care and facilitate compliance and satisfaction through mutual understanding.

Evidence to support cultural and linguistic competence programs are in early the early development phase, although the literature provides examples of benefits in terms of quality and effectiveness of care, health outcomes and well-being with early promising but not conclusive early results. Research supporting a relationship between cultural competency and patient outcomes has been limited in depth and scope, so there is a need to increase resources to look at cultural competency education to improve health outcomes. Future areas for research include mechanisms for how cultural competency improves quality, which aspects of quality are most
affected by cultural competency and to what degree does cultural competency improve quality outcomes.

Cultural competency is an important part of hospital policy to improve quality outcomes. It can help to alleviate disparities caused by social determinants of health. It is based on a sound ethical foundation of human rights – specifically respect for human vulnerability and justice.

Although cultural competency is extremely important, it still cannot work on its own in a silo. In order for cultural competency to fulfil its full potential, it must be include a multi-faceted approach. It must be a multi-level, coordinated effort with the role of patient, provider, and context and as equally important in achieving the goals of eliminating racial and ethnic disparities in health, improving health care quality, and achieving financial imperatives. \(^{81}\) With this type of approach, cultural competency as part of an overarching organizational policy to reduce health disparities will effectively impact quality outcomes in health care.

Determining how to approach ethical issues and justifying decisions within a multicultural society is challenging. Justification is relative to time, place and culture, and necessitates inter-comparative dialogue, ongoing consensus and idea of bridge concepts to maximize respect for diversity and pluralism. \(^{82}\) Justification for health care decisions should be based on human rights in order to decrease health disparities that result in negative outcomes caused by social determinants of health. Cultural competency can help providers and patients arrive at a mutually-agreed upon decision through these approaches. This mutual decision-making can help to improve quality by increasing the patient’s understanding, compliance and satisfaction. It can also help patients to make decisions based on their specific health goals and
goals of care. Cultural competency is a tool to navigate decision-making in a multicultural environment.

Health care leaders can begin to address some of the challenges arising from health care disparities by increasing interdisciplinary involvement, balancing universalism and particularism, improving education and training of bioethicists to analyze these issues more deeply, and creating distance from the divisive ideological politics. In a multicultural, pluralistic society different perspectives on ethical decision-making should be considered, but human rights should be considered the most basic foundation for this decision-making, specifically the human rights principles of respect for vulnerability and justice. These human rights principles are key to addressing the social determinants of health that lead to poor health care outcomes – including race, ethnicity, culture, socioeconomic status and healthcare access. When addressing issues within a multicultural society specifically, cultural competency can be used as a tool to decrease health disparities caused by social determinants of health and therefore protect human rights. This approach will ultimately improve quality outcomes.

4b Social Determinants and Shared Decision-Making

4bi Applying Clinical Ethics within Health Care Organizations through Shared Decision-Making

Shared decision-making describes a process where physicians and patients can collaborate to determine a course of action that is founded in the patient’s values and goals. It should be carried out through organizational policy related to informed consent and ethics consultation. The roles of the organization, the physician, the patient, surrogates when necessary, and ethics committees are integral components of the shared decision-making process.
What is Shared Decision-Making?

Shared decision-making can be used by health care providers and patients to determine the best treatment option based on the patient’s values, beliefs and goals. The essential elements of this process are: recognizing that decision needs to be made, understanding the evidence, and incorporating patient values.84 First, the patient and physician must discuss the decision that they are facing and determine the options available. Second, evidence related to the risks and benefits of each option must be reviewed, including the likelihood and severity of each risk and benefit. Third, the patient and physician should discuss the options, along with their evidence-based risks and benefits in terms of the patient’s values and goals. This process can facilitate significant positive outcomes for the patients.

Shared decision-making can improve care quality, improve patient experience, and reduce costs – including the cost of surgeries and hospital admissions – through low-cost interventions such as telephone health coaching.85 When patients have a chance to consider the options along with their risks and benefits as they relate to their personal values, beliefs and goals, they have the information that they need to make a truly informed decision.

Some patients and physicians face barriers to shared decision-making which should be addressed. Issues that can cause patient reluctance to engaging in shared decision-making, such as perceived vulnerability to physician’s good will and authority, time pressures, and fear of being categorized as difficult, can be addressed through multifaceted structural approach including provision of adequate reimbursement, implementation of decision-support tools, reorganization of care, addressing differences in perspectives, and working at the organizational level to facilitate a supportive culture and policy.86 Organizations can institute polices based on
this structural approach to facilitate shared decision-making between the physicians and patients who interact within their system.

In addition, organizations can provide physicians with the education and tools to help patients participate in shared decision-making. Barriers to shared decision-making can be addressed at the physician level by making patients feel supported, empowered, and emotionally safe, by using verbal and non-verbal cues of respect, addressing health literacy barriers, engaging family members, and asking patients about fears, and sending affirming messages.87 Physicians should be aware of the barriers that patients may be facing and proactively address these potential barriers. At the same time, the organization should work to create a system and structure that supports the shared decision-making process for both physicians and patients. In other words, the systematic barriers to shared decision-making should be addressed through a participatory, collaborative approach at the organizational, practice and physician level.88

Specifically, the organization should focus on policy related to informed consent and ethics consultation to support shared decision-making and reduce barriers that physicians and patients face when making decisions.

_Informed Consent: The Roles of the Health Care Organization, the Physician, the Patient and the Surrogate_

Informed consent is a crucial component of shared decision-making. Informed consent encompasses legal rules, ethical doctrine, and an interpersonal processes based upon rights and duties, as well as consequences of actions, and is intended to protect bodily integrity and autonomy.89 It is the mechanism in which patient autonomy and right to make decisions about one’s own body and health are fulfilled. Legal or institutionally effective rules and requirements of informed consent are intended to create conditions that enable autonomous authorization and promote shared decision-making.90 The health care organization, the physician, the patient have
important roles in this process. When the patient is incapacitated, the surrogate has an important role as well.

Informed consent is the practical application of autonomy in the health care setting and is carried out when the patient is informed of benefits and risks, understands the relevant information, can comprehend the information given to them, and gives documented consent.91 It is crucial for shared decision-making since it supports and protects the patient’s right to make decisions about their health care. The organization’s role in this process is to create policy that supports a robust informed consent policy that supports an ongoing process of physician-patient collaboration.

Policies that support his process should promote shared decision-making, protect a patient’s right to self-determination, promote well-being through discussion of pertinent information and facilitate the patient’s voluntary agreement with their treatment plan.92 The organization creates the policy and culture which facilitates this process. Importantly, informed consent should be a process rather than an event, with medical decision-making as continuous process throughout course of physician-patient relationship, where information is disclosed as it becomes available, and receive information over time.93 The organization will create the environment in which this process is possible, impossible, encouraged or discouraged. This environment includes support for physicians to spend time with the patient throughout this process.

The organization’s role is important in facilitating the physician-patient relationship, and also when a patient is incapable of making their own decisions. A healthcare institution can have a formal procedure to govern the process of choosing a surrogate, especially for cases when patient does not have an advance directive or has not expressed their wishes related to a
surrogate decision-maker. The health care organization should have a structure and policy in place for when these difficult questions arise. The organization’s policy should therefore consider the role of the physician, the patient and the surrogate related to informed consent.

The physician’s role within the context of shared decision-making is to partner with the patient, providing the patient with all relevant and necessary information needed to make an informed decision. An essential element of informed consent is the disclosure performed by the physician. Disclosure should include information about nature and purpose of proposed treatment, risks, benefits, and available alternatives. The physician should provide all pertinent information and make sure that the patient both understands and voluntarily consents to the proposed course of treatment. Importantly, legally valid consent must include understanding and voluntariness. Truth-telling is also an important part of this process.

Arguments for truth-telling include respect for others, respecting right to self-determination, promoting fidelity and promise keeping, building trust-based relationships, allowing a patient to make choices consistent with goals and values, promoting feelings of self-control, and preparing for the future; while arguments against disclosure can include culture-based comfort with disclosing medical information and acknowledging the importance of hope. The physician should weigh these considerations, but always prioritize the patient’s right to have all relevant information and make autonomous decisions. With informed consent as a process rather than a discrete event, the physician can share the information as it becomes relevant to prevent a burdensome, overwhelming flood of information to the patient. In the shared decision-making process, the physician can provide information to the patient as it becomes important.

This process of consent in the clinical setting should be carried out by establishing the relationship, defining the problem, ascertaining goals of treatment, selecting an approach to
treatment, and follow-up. As a patient’s condition or context changes, their informed consent for specific treatment options may change as well, so informed consent should not occur as a discrete point in time, but continuously over the course of the physician-patient relationship.

The physician’s role is to provide the relevant information and to partner with the patient to determine the best course of treatment. A patient does not have the right to receive any treatment they demand, but they do have the right to reject a physician’s recommendation, even if the physician considers their recommendation to be in the patient’s best interest, especially because the patient is ultimately the person who can make a final judgment on quality of life goals. The partnership created through shared decision-making mediates differing opinions that may occur between the physician and patient. The physician ultimately is providing the information and options, but the patient ultimately makes a decision on whether they want the offered treatment or not.

One of the physician’s primary roles is to disclose information. Although there are arguments for nondisclosure – such as when it is employed to avoid serious harm, perform culturally appropriate care, or if it is in response to a patient request – disclosure generally can do more benefit than harm because it allows patients to make informed decisions. Only when the patient has all of the relevant information can he or she make an informed decision about health care.

The patient’s role in informed consent is to provide values and goals for decision-making. The major goals of informed consent include protection of the patient’s well-being and promotion of autonomy. The patient is the central piece to informed consent since only he or she can define what well-being means to them. The patient’s autonomy, based on their values and goals, is central to the informed consent process.
Respecting a patient’s autonomy requires that patient preferences - based on patient’s own experience, beliefs, and values – be respected, acknowledging the patient’s right to self-determination, including the right to accept or reject recommendations of physician. The patient’s role is to weigh the information and options against their own values and decide a course of action.

A patient’s right to refusal is fundamental to concept of informed consent and patients should be permitted to refuse treatments even if the treatment is high benefit and low risk. The patient can refuse based on their own personal values and goals of treatment. The health care organization, physician, nor any other member of the patient’s care team can make the decision for the patient since the patient is the expert on their desired outcome – even if their desired outcome is not what someone else would want. As long as the patient’s decisions are based on clearly articulated values and beliefs founded in logical reasoning, the patient’s wishes must be respected.

The patient’s autonomous choice should be protected to the extent that is possible. That being said, complete autonomy can be difficult to achieve in a practical setting. This is because all actions have some degree of both internal and external influences, including pressure, possible fear of retribution, and emotional or mental weakness – although these influences should be avoided as much as possible on the grounds of avoiding fraud and duress, promoting of rational decisions, preventing abuse, promoting health benefits, improving doctor-patient relationships, demystifying medicine for patients, and reducing miscommunication. External influences to the patient’s decision-making process should be avoided if, when and to the extent possible; However, it is also important not to narrowly define self-interest since a person’s interests include their social relationships that are closely related to their values and sense of
The patient has a right to take their social context into consideration when making decisions about their treatment.

The patient also has the right to waive consent if they desire to do so. This is morally acceptable because a properly given consent waiver maintains the values of self-determination, placing the patient as the ultimate decision-maker and letting them decide if they will experience harm resulting from disclosure, such as anxiety from the decision process. The patient can delegate decision-making process to a proxy if they wish to do so. Not all patients have the same decision-making preferences. Some patients do not want to make their own or prefer to entrust decision-making to others for reasons such as the emotional, intellectual and physical weakness from being sick and psychological barriers to understanding.

A patient may choose to delegate decision-making for their care even when are competent to make their own decisions. If a patient is not competent to make decisions, then someone will be chosen to make decisions for them as well. This necessitates the role of a surrogate decision-maker.

The role of the surrogate is to make decisions for the patient if he or she is unable to make decisions for him or herself. The role of the surrogate becomes necessary if the patient does not have or loses capacity to make decisions. Incapacity can be determined by the patient’s health care team, specifically their physician. Capacity is most commonly determined by the attending physician, and can be related to patient characteristics such as intoxication, developmental disability, dementia, psychosis, or anything that would not render a patient unable to understand or make rational decisions. The patient can be temporarily or permanently unable to make health care decisions.
In addition, the patient could be incapable of making certain decisions about their health care, but able to make other decisions. The process of determining competence should include defining what is meant by incompetent patient, and who should make decisions for patient if they are incompetent so that, at a minimum, the goals of informed consent can be pursued on their behalf.\textsuperscript{109} This can be a complex task, because the continuum of decision making capacity is multifactorial, including the degree to which a patient can engage in discussions, understand pertinent information, appreciate relevance of information, and use reasoning to make and communicate a choice that is consistent with their values and goals.\textsuperscript{110}

The process of determining competence begins with the informed consent process. Competence can only be determined once consent and disclosure process has begun since it requires that a patient must be able to make and communicate a decision, understand the factual basis for their decision, appreciate the nature and consequences of treatment, process information logically.\textsuperscript{111} Only when the patient begins engaging in this decision-making can their capacity can be assessed.

Health care providers should look for evidence of a patient’s incapacity, whether the patient is mentally capable to make decisions, whether they are legally competent, whether they have capacity to refuse and consent to care, if they have the ability to understand relevant information, can appreciate consequences of the proposed course of action, and can communicate a rational choice in accordance with their values.\textsuperscript{112} Organizational policy should clearly outline the process for determining capacity of a patient. A patient’s level of competence determines moral authorization for health care decisions and moral validity of consent based on the patient’s ability to exercise autonomy in processing and understanding information, weighing
consequences, applying values, making consistent decisions over time, and communicating preferences.113

If a patient is incapacitated, it should be determined whether they have expressed prior preferences through advanced planning – including establishing a durable power of attorney for health care or an advanced directive – and if they need a surrogate, who would be the appropriate surrogate to make decisions for the patient who can make a substituted judgement for the patient.114 If a patient has freely and clearly expressed their wishes previously, these should be honored if and when possible. It is especially useful if the patient has documented an advance directive and/or who should be their surrogate, though wishes that were expressed in advance of serious illness have limits since these decisions made may not have been informed, patients can change their minds, directives can be open to interpretation, and expressed wishes may conflict with patient’s best interest.115

When a patient has not previously expressed their wishes, health care providers should avoid purely paternalistic approaches and consider what is known about patient’s wishes, what can be inferred about patient’s wishes and what is the best interest of the patient.116 A patient’s autonomy should be maintained to the degree possible by making judgments about what the patient would have wanted for him or herself. This can be performed through a surrogate decision-maker.

Surrogates – whether court-appointed guardians, non-relatives selected by the patient, or family members – can be problematic when there are emotional barriers to decisions, decisions made are inconsistent with the patient’s values, there are conflicts of interests, and when there are disagreements among potential surrogates.117 Nevertheless, a surrogate is the best tool that health care providers have to provide information and guide decisions based on the patient’s
values. Surrogate decision-making using substituted judgment is solution that is closest to maintaining the patient’s autonomy.

A surrogate should avoid bias and use substituted judgement, taking the place of the patient in the informed consent process through collaborative decision-making with physician while placing the patient’s values, goals and preferences into the decision-making process to the extent possible and attempting to replicate the decision that the patient would have made for themselves.\textsuperscript{118} The surrogate should decide as though he or she was the patient with the information that is available about the patient’s values, beliefs and goals. The surrogate acts as the patient in the shared decision-making process when the patient is not able to participate him or herself.

When conflicts or ethical dilemmas arise from the individuals directly involved in the shared decision-making process, ethics committees can help to mediate decisions through ethics consultation.

\textbf{4bii Addressing Social Determinants of Health through Organizational Policy focused on Shared Decision-Making}

Shared decision-making as supported by organizational policy can reduce health disparities related to social determinates of health. Informed consent and ethics consultation can help to alleviate disparities caused by social determinants of health. Coercion is not always overt, and instead is often structural, meaning that societal, cultural, economic and/or political realities can make it so that an individual can only realistically make only possible choice.\textsuperscript{119} Shared decision-making can be used to alleviate some of these structural barriers and support the patient in making decisions based on his or her values, beliefs and goals for care. This includes socioeconomic status, race, ethnicity, culture, language and geographic barriers to health.
Socioeconomic Status, Race, Ethnicity, Culture and Language

Patients are influenced by risks and resources in their physical and social environments often related to multiple dimensions of race, ethnicity and socioeconomic status, which combine and accumulate to influence health outcomes. Socioeconomic status is one dimension that significantly affects a patient’s ability to effectively interact with the health care system. Patients with a disadvantaged socioeconomic status tend to have worse outcomes compared to those in more advantaged situations. For example, long term breast cancer survival outcomes could be improved by targeting patients with low socioeconomic status.

Through shared decision-making as carried out through the informed consent process and ethics consultation, the burdens of health disparities related to disadvantaged socioeconomic status can be ameliorated.

The mechanism of how socioeconomic status affects health outcomes is not definitive. Interpersonal interactions and experiences, such as exposure to social dominance expressed by others and perceptions of low relative status, may be one mechanism linking socioeconomic status to poor health outcomes such as cardiovascular disease. Other possible causal links or correlations between socioeconomic status and poor health comes may include education level and ability to pay for health care services.

The informed consent process as part of shared decision-making can begin to address some of the barriers to health related to socioeconomic status. Through the informed consent process based on shared decision-making, health care providers can determine the gaps in the patient’s needs to be addressed through their interaction with the health care system. Health care
providers should recognize that those who face burdens of disadvantaged socioeconomic status may face unique challenges compared to those with a more advantaged status.

Informed consent requires decisional capacity, disclosure and understanding of information, voluntariness and clear communication of consent or refusal. Understanding and voluntariness are key pieces of informed consent when addressing patients with disadvantaged socioeconomic status. The informed consent process should be used to ensure that patients are able to understand and voluntarily consent to treatment or care options regardless of their socioeconomic status.

Ethics consultation can also help to address issues related to socioeconomic status and shared decision-making.

When an ethical question requiring ethics consultation is presented, the patient’s socioeconomic status and potential associated barriers should be considered as part of the consultation process. This is aligned with the goals of ethics consultation, which are to clarify the facts of a case, identify and analyze ethical uncertainty and conflict, and to build consensus among stakeholders. Since the patient’s socioeconomic status can have such a significant impact on these goals, the ethics committee or consultant should consider ways in which socioeconomic status could be influencing the case. For example, social support systems could have an influence on the patient’s beliefs, values and goals related to socioeconomic status.

Optimistic self-belief and social support could help to explain the considerable variation in health across the socioeconomic continuum, meaning that some individuals and groups could be more resilient based on psychological or social resources. Considering these factors during an ethics consultation can help to facilitate shared decision-making among health care providers
and patients since it can help with understanding of the context in which the patient is making decisions.

Closely related to and often overlapping with socioeconomic status, race, ethnicity, culture and language can also have a significant impact on the effectiveness of shared decision-making in the health care setting.

**Socioeconomic Status, Race, Ethnicity, Culture and Language**

Race, ethnicity, culture and language can also have a significant impact on health outcomes and shared decision-making. Although often intertwined with socioeconomic status, race, ethnicity, culture and language present unique barriers to shared decision-making within the health care setting. For example, a high socioeconomic position may not necessarily alleviate the toxic effects of discrimination related to the psychosocial conditions and stresses tied to minority status. These factors should be considered as presenting unique challenges to clinical ethics and the shared decision-making process.

Race, ethnicity, culture and language can significantly influence a patient’s ability to engage in the informed consent process. Therefore, informed consent needs to be addressed within the context of culture, with a patient having the right to autonomously decide who will be involved in decision-making related to their health. People with different cultural or ethnic backgrounds may have different expectations or perceptions that affect their health-related decisions and basic assumptions of informed consent may not be culturally relevant for some individuals or groups, necessitating a culturally responsive process for decision-making. Shared decision-making can facilitate a culturally sensitive informed consent process via organizational policy that allows for flexibility and cultural understanding within the process.
Language barriers can also be addressed through shared decision-making and the informed consent process. Addressing language barriers to informed consent is a crucial aspect of shared decision-making and clinical ethics since a patient cannot begin to understand treatment options, risks and benefits if they do not even understand the language in which the information is presented. Patients with limited English proficiency have been shown to have low rates of documented informed consent in the United States. Policy that provides the structure for the informed consent process should take language proficiency into consideration and provide support for patients who do need support related to language skills, up to and including interpretation services. Interpreters are essential for patients who do not understand the language of their physician. When no trained interpreter is available, serious communication problems such as misinterpretation, inaccurate or incomplete information, and loss of privacy, can occur so low cost strategies such as translating key documents into Spanish, testing and training clinicians and staff for bilingual and interpretation skills, and training of how to effectively use interpreters, scheduling extra time for consulting requiring interpretation should be implemented by health care organizations whenever possible.

Improving the informed consent process as based on shared decision-making is one way to address health disparities related to race, ethnicity, culture and language. Ethics consultation should also take these factors into consideration, supporting the goals of shared decision-making.

Race, ethnicity, culture and language should be considered when performing ethics consultation since these factors can strongly influence a patient’s understanding of key issues, as well as their values and goals of care. Although racial or ethnic difference do not necessarily constitute cultural differences, not all conflicts between people of different cultures are cultural conflicts, and some cultural differences are not obvious, cultural values, beliefs, and behaviors.
do often determine an individual’s reaction to illness and death. In order for ethics consultants to make decisions based on the foundations of shared decision-making, these factors should be considered when analyzing and making recommendations on any case.

Quality of life perceptions can be influenced by these factors as well. Quality of life, or degree of satisfaction a person experiences with their own life, should be discussed between the patient and physician to determine the most desirable and attainable outcome, how it can be achieved, risks and disadvantages associated with each decision, and potential long-term consequences. A person’s race, culture and ethnicity can significantly influence their perceptions of quality of life. Quality of life assessment raises questions about changes in treatment plans, like foregoing life-sustaining treatment, and how to care for patients who face severely or profoundly diminished quality of life. These decisions can be heavily influenced by a patient’s background and current context.

In addition to socioeconomic status, race, ethnicity, culture and language, a patient’s physical location or proximity to accessing health care services can significantly affect their ability to engage in shared decision-making.

Geographic Location and Access

The location in which a patient lives can significantly affect their ability to access health care and engage in shared decision-making. This can be especially true for individuals and groups who live in rural areas. Barriers to receiving health services in rural areas can include lack of knowledge of available resources, cost of services, difficulty navigating the system, difficulty finding qualified providers, and proximity to services. These factors can all influence a patient’s ability to engage in shared decision-making.
A patient’s geographical location can affect their access to health-related services as well. For example, a neighborhood food environment can have a significant impact on health and accessibility to healthy food can be affected by physical distance from food sources, personal mobility, and environmental barriers such as safety concerns, and facilitators such availability of public transit service. These factors influence health outcomes for groups and individuals in disadvantaged geographic areas, including many rural areas. In addition, health care needs such as housing and transportation can be affected by geographic location and availability of health resources. For example, adults with multiple sclerosis, can face barriers to obtaining specialized housing, transportation, and resources needed to manage their progressive and episodic illness.

Socioeconomic factors could also act in concert with geographical barriers to health care from both individual and neighborhood level factors. Informed consent and ethics consultation solutions could help to alleviate some of these barriers to accessing health care and achieving quality health outcomes through shared decision-making.

A patient’s ability to engage in the ongoing informed consent process can be significantly affected by their geographic location. For example, if a patient has limited transportation to access health services, they may not have continuous or consistent interactions with a health care provider, even if they have a condition or disease that would benefit from consistent health service access. This transportation vulnerability can occur when transportation is a barrier to accessing ancillary services, including availability, accessibility, accommodation, affordability and acceptability of transportation.

Technology could help to alleviate some of these barriers to shared decision-making and access to information. For example, online health communities could help to alleviate
geographical health disparities by facilitating sharing, dissemination and creation of health information between urban users (as net suppliers) and rural users (as net recipients.) Health care organizations could incorporate the concept of information sharing via the internet to improve the informed consent process for those who have difficulty physically accessing health services.

New approaches to ethics consultation can also help to address geographical barriers to health care access. For example, health care organizations can institute web-based consultation system for rapid dissemination of cases, on-call team with a clinician and a non-clinician, adding cases to secure ethics website with space for ethics committee comments and discussion, allowing for timely participation from committee members at different locations. This could help to provide consultation resources to patients who cannot access a hospital with a robust ethics consultation service.

Health care organizations can alleviate the burdens caused by health disparities by addressing social determinants of health, including socioeconomic status, race, ethnicity, culture, language and geography. This can be accomplished through organizational policy supporting shared decision-making, focused on two key features: informed consent and ethics consultation. Informed consent is a process that supports autonomous decisions of patients, and ethics consultation helps to address particularly difficult ethical conflicts.

Organizations, physicians, patients, surrogates, and ethics committees all have important roles in practical applications of clinical ethics through shared decision-making. The organizational role is to facilitate and provide structural support for these elements of clinical ethics. According to the American College of Healthcare Executives, Health Care leaders have moral obligations to professional codes, patients, the organization, employees, the community
and society with the fundamental ethical objectives of creating an equitable, accessible, effective, and efficient system that maintaining or enhancing quality of life, well-being, and dignity of patients. Through effective organizational leadership support for shared decision-making, patients can have improved outcomes with fewer disparities based on social factors.

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Chapter 5: Medical Futility and Rationing

Health care resources are finite, yet demand for needed health resources are virtually unlimited. This means that some people will not be afforded the resources for the care they need. In the United States, the highly politicized, often ill-informed debate about health care rationing has prevented proper critical analysis of health care resource distribution. With little guidance from federal or state governments on health care resource allocation, health care delivery organizations are left to determine how these limited resources can be distributed to patients in an ethically sound and/or efficient way.

In the past, the basis for discourse surrounding health care delivery resource allocation has focused on two key concepts: medical futility and rationing. These two key concepts will be examined as background concepts for ethical resource allocation at the level of health care delivery. Resource allocation will then be explained as a concept which transcends the existing understandings of futility and rationing. Based on obligations to protect and promote the human right to quality health care, health care organizations have an obligation to develop ethically sound ways to distribute their limited resources. These decisions should be founded in justice, and should not be influenced by non-medically relevant patient characteristics such as race, ethnicity, culture, socioeconomic status and geographical proximity to health care providers.

5a Medical Futility

Futile medical care can be defined as a treatment or medical intervention where there is no benefit, or where the amount of benefit achieved is judged as not worth its costs. When unpacking this broad definition, however, flaws with applications for the medical futility concept emerge. Ambiguity remains in terms of which expected outcomes are relevant and how likely those outcomes are to occur. This can lead to drastic differences in opinion among stakeholders.
making assessments based on different assumptions of risk and outcomes. In addition, the acceptable probability threshold for achieving the patient’s goals has not met consensus. These factors can lead to equity violations when medical futility disagreements are influenced by bias, especially when these biases are related to social determinants of health. Opinions of futility are susceptible to opinions on whether specific patients are worth of a perceived high-cost, low-benefit treatment. When these judgements are made based on any non-medically relevant criteria, they unjustified and in violation of the right to quality health care.

5 ai Defining Medical Futility

The purpose of medical futility assessment is to determine the probability of achieving desired outcomes from a medical intervention, then possibly limiting or eliminating the intervention based on this assessment. While the virtue of this type of assessment may be rational on some level, there are many arguments against the use of medical futility as assessment criteria for patient interventions. First and foremost, there is no established normative criteria or threshold to determine how to limit treatment for the critically ill or to determine medical futility.¹ With no normative criteria or commonly accepted guidelines for judging where medical care reaches the level of futility, variation and ethical concerns of bias are introduced into this concept.

While specific normative criteria has not been established for medical futility assessment, relevant ethical principles have been identified. These principles include the equivalence of withholding and withdrawing life support, the difference between killing and letting someone die, the distinction of medication intention to hasten death versus palliate, and the ethics of care or requirement to not only treat for longevity, but also alleviate the suffering of patients and families.² Clarifying these principles may assist in medical futility assessment, although thus far
they have not been enough to develop a commonly accepted normative criteria for medical futility.

Since there are no commonly accepted guidelines for determining medical futility, the U.S. federal government has not instituted policy to support decision-making or how to manage resources when treatment may be futile. Institutional policy developed within the health care delivery organization is thus left to guide this decision making both systematically and at the bedside on a case-by-case basis. Specifically, institutional policy should be put in place to support clear communication, protecting both patient and professional autonomy and addressing the emotional obstacles of medical decision-making. Incorporating communication and organizational culture that facilitates the patient-physician relationship should be at the core of this institutional policy and have special expediency when limited resources are involved. For example, blood products are a valuable resource that should be used judiciously and only when there is a clear connection to achieving the goals medicine. Institutional policy that guides evidence-based decision-making and communication between providers and patients about blood products can be put in place to protect this limited resource. Additionally, institutional policy can support providers and patients to make shared decisions when the decision does not fit into the mold of the general policy. Institutional policy can address conflicts in decision-making that arise between patient autonomy and the authority of clinical experts by providing rules for the decision-making process governing a range of situations and promoting shared decision-making. This policy should focus on the roles of the patient or surrogate, the provider, and the ethics committee.
The Role of the Patient or Surrogate

The role of the patient or surrogate is to provide the values and goals related to the treatment option. When it appears that a treatment may be deemed "medically futile," the provider and patient (or surrogate) will discuss options based on the patient’s values and preferences. These options should allow for consideration of the patient’s values, priorities, life philosophy and background, which can significantly influence their decision-making process.\(^6\) The provider should encourage this shared decision-making that includes the patient’s values and goals.

To engage in this decision-making process, the patient must first understand the key variables for an informed decision. The patient must then take this understanding and relate it to their values, beliefs and goals with relevance to the decision. Patient education is an essential component of this informed decision-making, and can be aided by decision-making tools as well as the provider’s awareness of personal views and biases.\(^7\) A patient must be informed of all information relevant to the decision without bias. Institutional policy should be developed to facilitate this patient education and encourage shared decision-making. This type of shared decision-making may also be called "personalized patient activation and empowerment," which can be used to aid with decision-making through involvement of health care providers, the community and the delivery system to provide knowledge, self-determination and confidence to patient decision-making to improve health and reduce health disparities.\(^8\) The patient must be empowered with an understanding of how all relevant information relates to their values and goals in order to self-determine. Only through an understanding of this relationship between goals and relevant clinical information can an assessment of medical futility even begin to form.
Institutional policy to support this shared decision-making and patient education is especially important to overcome barriers to physician-patient communication. One of the major barriers of this communication involves the power dynamic between physicians and patients. The dynamic between patient autonomy and physician authority can create challenges for identifying appropriate treatment and a shared understanding of prognosis. Although this challenge prevails within most health care delivery organizations, it can be overcome through organizational interventions. For example, the communication conflicts created by the power imbalance between the doctor and the patient can be systematically addressed by using a decision-making matrix including the initial state, the defined intervention, the defined goal of treatment over time, how much gain there will be in net benefit for each treatment, and a declaration of the defined goal in relation to the intervention. Frameworks and tools for decision-making, developed and implemented at the level of the delivery system, can begin to address the barriers to physician-patient communication and decision-making related to medical futility. Also, these decision-making tools should account for the complicated relationship between autonomy and well-being. Due to a lack of stable preferences and/or decision-making biases, patients do not always make decisions in their best interests. Decision-making and communication tools should incorporate ways to address this potential conflict between respecting a patient’s autonomy and supporting their well-being.

The involvement of family and surrogate decision-makers should also be included in these organizational models, frameworks and policy for shared decision-making. Some patients may value family involvement and input in decisions about whether care is futile in relation to their goals of care. In some cases, relational autonomy – rather than traditional autonomy models – may be appropriate when patients value family involvement in decision-making.
Incorporating the potential for varying patient perspectives in medical decision-making will be essential for ethical organizational policy formation and implementation related to medical futility. In addition, the role of surrogates must be addressed for ethical decision-making related to medical futility. Surrogates decision-making is difficult and unique since the surrogate is presuming what the patient would have wanted, or what would be best for the patient. In addition, surrogates tend to have overly optimistic expectations and there can be barriers to quality end-of-life care - such as more invasive treatments and delayed palliative care integration – when surrogates midjudge prognosis of the patient. Providers need the ability to work with surrogates and facilitate their unique informed decision-making process. Importantly, providers should help surrogates separate their own beliefs versus the values and beliefs that the patient would have in the present situation. For example, religious influences can not only impact a patient’s medical decision-making, but surrogates also often invoke their own religious beliefs related to the value of life, religious coping and support, and guidance of their religious community. Organizational policy should support this and other unique aspects of surrogate decision-making. Overall, physicians may be able to better understand patients and surrogates, including how they make medical decisions, by discussion religious and spiritual ideas of the patient and their family. Physicians need the tools and support from the health care delivery organization to understand and address these needs.

The Role of the Health Care Provider

In medical futility assessments, the role of the health care provider is to clarify the goals of care, give patients and families time to comprehend the diagnosis and options, and facilitate patient and family expressions of understanding. The health care provider must accomplish this while demonstrating professional integrity, incorporating professional norms and standards into
communication and the shared decision-making process. In cases of medical futility, physicians should assess whether all reasonable options have been attempted and establish guidelines plus limits for interventions in place. To accomplish this, physicians need to understand the limits of medical care and their own power. In addition, physicians should avoid offering medically inappropriate options while also addressing the emotional needs of patients.

Health care providers can face many challenges when assessing and communicating about medical futility. Challenges to discussions and determinations about nonbeneficial include differences in prognostic estimates, inadequate data about quality of life, unprepared patients, variation in perception of the role of palliative care, inconsistency in weighing patient goals, and time constraints. The uncertainties of these decisions creates major barriers to effectively assessing and communicating about potentially medically futile care. The uncertainty inherent to medicine can affect both quantitative and qualitative assessments of treatment benefits. This uncertainty can affect quantitative risk assessments as well as quality of life predictions for the patient. This uncertainty is the crux of ethical dilemmas related to medical futility.

Some health care providers are better at assessing and predicting patient benefits of care than others. With more experience, physicians can make better decisions about treatment appropriateness and engage in better communication for decision-making. More experienced physicians tend to make better decisions when faced with uncertainties and complexities than those who have less experience. Physician trainees can experience moral distress when asked to provide treatments that they believe to be futile which can lead to decreased job satisfaction, feelings of powerlessness, compromised well-being, burnout, and thoughts of quitting. Those who experience internal ethical conflict and self-doubt over medical futility assessments can experience negative consequences for themselves as providers. It is important for leaders of
health care delivery organizations to recognize this and address barriers and challenges to
decision-making faced by junior or trainee health care providers.

In addition, health care delivery organization policy, leadership and culture should
facilitate healthy responses to the uncertainty of medicine. Physicians should learn to recognize
and tolerate uncertainty and avoid overconfidence to improve the quality of information they
provide to patients and promote informed decisions. In respect to patient autonomy and
informed consent, patients should know the level of certainty of various potential outcomes of
treatment or non-treatment. If there is uncertainty or lack of evidence, the physician should use
professional judgement to facilitate shared decision-making emphasizing patient autonomy.
Patients should be able to consider all relevant information to decision-making, including
probabilities or uncertainties of an outcome occurring.

While providers are not obligated to offer non-beneficial treatment to patients,
they should always offer some option to care for the patient. In many cases the best option for
patient care may be palliative care. Providers who deny non-beneficial treatment should still
provide palliative care as an alternative and give the patient the opportunity to contact other
practitioner or institution. Provider transparency as to what treatment options are available,
their probability, the level of uncertainty in outcomes, and what may be offered by other
providers is all part of the ethical respect for patient autonomy and respect for a patient’s
personal integrity. In addition, physicians should have a commitment to trustworthiness, showing
attitudes and behaviors that gain the patient and family’s trust. The relationship that the
physician cultivates with the patient is essential for smooth and morally sound shared decision-
making about a patient’s care. Health care delivery organizations can help to facilitate this
decision-making by creating an organizational culture and policy that supports transparent,
compassionate, and respectful communication between the provider and the patient. Patient-physician interaction can be improved through more open communication and a mutual recognition of topics where there is no clear and present expert on the matter.24 Health care delivery organizations can help physicians to recognize topics and situations where there may be a high level of uncertainty. In addition, organizations can help physicians to develop cultural competency and understanding of potentially diverse patient perspectives on medical decision-making. This can help the provider to understand the patient’s values and goals of treatment. For example, an understanding of patients’ and families’ religious beliefs can help a physician to better understand the patient perspective, including their values and preferences.25 The provider should recognize the diverse perspectives and experiences of the patient that will affect their goals of care, and thus help determine whether a treatment option is futile in terms of the patient’s goals. In addition, the provider should use introspection to analyze how their own background, values and biases may affect decision-making with the patients. In other words, a physician should consider their personal views versus professional norms.26 A physician should understand which opinions on the best course of action for the patient come from their own, potentially biased, beliefs versus evidence-based medical management and professional values.

Organizational policy and provider decision-making can use approaches and innovations of patient-centered care to achieve effective shared decision-making. Health care delivery organizations have a significant role in facilitating these interactions since patient-centered care innovations depend on leadership development, incentives for experimentation, and cooperation between delivery systems, health plans and policymakers.27 This leadership development and cooperation will depend on programs and policies at the health care delivery organization. This is especially important in the United States as the population continues to become increasingly
diverse, creating serious challenges for health care administrative leaders and providers. Because of this, health care organizational policy needs to balance of homogenization (building common ground) and customization (addressing individual uniqueness) to adequately address diverse patient populations. In addition, recognizing this common ground as well as the unique needs of patients will be essential for conflict resolution in medical decision-making. When disagreement occurs between a provider and patient, or any stakeholders in the patient’s care, other support may be needed to make an ethically sound conclusion to address the uncertainty. Decisions about medically futile care should not be unilateral and instead be based on a foundation of rapport and trust between the physical and patient with mediation from outsiders such as ethics committees when needed. Even provider-patient communication is effective and the patient’s autonomy is fully respected, there still may be disagreement or conflict between the provider and patient.

Institutional policy and provider decision-making may also consider the costs of futile care toward other patients that they serve. Providing futile care - or care to prolong life without achieving meaningful benefit to the patient - is associated with delays in care to other patients. Therefore, balancing the spread of resources is an associated outcome of medical futility assessment. When resources are used to give treatments not aligned with the patient’s goals of care, other patients who would benefit from the treatment may lose out on the resource. Medical futility may then be useful as a starting point or foundational concept for a resource allocation framework to emerge.

Social Determinants of Health - Bias & Influence on Futility Assessments

Social determinants of health can further complicate the ethical application of medical futility concepts, especially if related bias is introduced into medical futility assessment. Justice should
form the foundation for ethical futility assessment to prevent undue bias from influencing futility-related decisions. When conflict arises in futility assessment, ethics committees can mediate problems at the beside. Ethics committees can also preemptively identify potential biases through the development of ethically sound organizational policy related to medical futility assessment.

Justice

Justice in terms of modern ethical discourse, is "the moral principle that relates to proper 'balance' or allotment among persons of groups."31 Justice then explains how to incorporate fairness into resource allocation within health care organizations. Justice creates a foundation for ethical distributions of benefits and burdens.32 Incorporating solidarity into justice-based analysis of organizational policy can help to elucidates key concepts related to fairness in health care. Solidarity can provide important relational aspects that can complement rights-based justice approaches to health care by promoting a sense of belonging, recognition, reciprocity and support.33 Solidarity supports justice, and justice supports the human right to health. The right to health includes the right to pursue flourishing where one can make sense of oneself and one’s own identity including one’s past, present, and future, and the ability to act in accord with one's own nature.34 This includes the rights of all persons, regardless of their culture, religion, ethnicity, race, gender, or age. All persons have a right to justice in support of the human right to quality health care.

In practice, this right can be difficult to carry out when policy leaders and health care providers hold personal biases. Even physicians face limitations in decision-making that may be influenced by either implicit or explicit bias. Limitations of cognitive capacity can lead physicians to make systematic errors in judgement, such as estimation of subjective, rather than
statistical, probabilities related to diagnostic decision-making, based on a patient’s belonging to a minority group. These limitations can place unjust burden on marginalized individuals who are the subject of this biased decision-making. A health care professional has the same level of implicit bias as the general population which can impact the clinician-patient interaction and lead to biased treatment, level of care, and diagnosis decisions. When bias is introduced during the clinician-patient interaction, there is a potential for serious, negative consequences for marginalized individuals and groups. Racism, ageism, and sexism are just a few examples of how this bias can manifest into unjust treatment of patients.

Structural racism can have a serious negative impact on health outcomes for those afflicted. Structural racism is manifested in economic injustice and social deprivation, environmental and occupational inequalities, psychosocial trauma, targeted marketing of health-harming substances, inadequate health care, state-sanctioned violence and alienation from property and traditional lands, political exclusion, maladaptive coping behaviors and stereotype threats. This means that, even beyond the physician-patient interaction, patients face discrimination and bias that can put them behind in terms of health outcomes. For example, structural racism, especially that which results from inequalities in education, professional opportunity, and income, is correlated with an African-American infant mortality rate that is double than that of white Americans. There are a litany of negative outcomes like this that are the result of this structural racism. When making decisions about medical care, and especially about futility of care, providers and organizational policy should ensure that structural racism is not causing unjust harm toward minority patients.

Ageism is another way in which bias may manifest itself in medical decision-making. Ageism involves bigotry and discrimination from one age group to another, and is embedded in
social cognition and prejudice in a variety of fields – including health care. Ageism has many implications for health care decision-making. Ageism can impact autonomy in health care decision-making, especially in terms of its impact on an individual’s self relations, including one’s self-worth, self-esteem and self-trust. A patient may internalize ageism when facing systematic unfair treatment. This can ultimately affect the patient’s capacity to make autonomous decisions and participate in shared decision-making.

Gender is another area where bias may occur in medical decision-making. Gender inequality exists in health care access, where there is a gender bias that negatively impacts females in both clinical practice and research. This demonstrates that root of bias can go even deeper than bedside interactions and result from structural inequalities such as unbiased inclusion in medical research.

Provider bias does not always have to be based on demographics, and can also be based on certain clinical conditions. For example, negative attitudes held toward overweight and obese patients include blaming the patient for their weight, disrespectful treatment, inappropriate treatment and, in health care, can lead to less empathetic communication from providers. This type of bias toward overweight patients can lead to negative health consequences for patients and create barriers to effective shared decision-making.

These types of bias and discrimination - racism, ageism, sexism and others - can act independently but also can be compounded when a patient falls into multiple marginalized groups. Bias can also be intersectional, where multiple patient factors impact the bias of a health care provider. For example, gendered racism and its related microaggressions can negatively impact the mental and physical health outcomes of black women. This and other types of bias and discrimination can be either conscious or unconscious.
Health care delivery organizations can create policies that address both conscious and unconscious biases. Health disparities that result from implicit bias of providers can be mitigated by experience and expertise. Institutional policy that promotes experience and knowledge about treating marginalized groups can help to mitigate implicit bias. Explicit bias can be addressed more directly through training and management techniques. Provider education should focus on self-awareness of cognitive, emotional end ethical responses to uncertainty and using decision aids or diagnostic guidelines to assist with decision-making. Creating a systematic framework and tools for decision-making can reduce or eliminate bias by creating a fair process for all patients.

Leaders of health care delivery organizations should use caution, however, when removing too much physician autonomy in decision-making. Bias can also occur when physicians over-rely on clinical decision-support. This type of bias can lead to omission when clinicians do not find errors when they do not receive an alert and commission bias when clinicians do not verify the veracity of an alert before acting. Organizational policy should focus on making ethical decision-making easy and create barriers to biased, unethical decision-making. Removing bias from decision-making related to futility assessment is especially imperative due to the potential for grave, life-or-death consequences in medical futility cases. Bias or unequitable treatment related to medical futility decisions opens the possibility for gross injustice.

The Role of Ethics Committees
Ethics consultation developed as the complexity of modern medicine advanced, including the development of organ replacement therapy and life-prolonging measures in the ICU, due to the need for shared responsibility for difficult decisions, support for physicians, and difficulty in
The ethical complexity of modern medicine has created a need for ethics committee intervention on both bedside and policy decision-making.

The roles and obligations of ethicists and ethics committees include creating and updating organizational code of ethics, enforcing professional conduct, anticipating and addressing ethical issues from scientific developments, contributing to public discourse, conducting ethics research, producing or contributing to policy statements of the organization, and providing education and training. Ethics committees can identify biases related to social determinants of health when facilitating medical futility discussions by focusing the ethical dimensions and clinically relevant information of the decision-making process. Ethics committees also play a crucial role in clinical guideline development, policy advisement, and case review.

Ethics committees should be trained in identifying both explicit and unspoken, implicit bias in health care decision-making. Including representation from marginalized groups could help to alleviate distrust of the decision-making process, as well as improve understanding of the burdens and benefits that each unique patient may be facing. Eliminating unfair decision-making bias at both the organizational policy level and at the bedside is a crucial role of the ethics committee.

Ethics committees should also be versed in resource scarcity and the balance between individual and population health outcomes. Ethics committees can help providers to focus on the long-term risks of a procedure, including potential psychosocial conditions, and guide the provider and patient to comprehend the suffering and the dying process. This can be accomplished through either an individual consult or committee consultation. Individual ethics consultation may afford better greater of access, speed, flexibility, convenience, and trust building, while ethics committee consultation can offer diverse perspectives, multiple approaches
and opinions, enriched ethical deliberation, and complementary qualifications. Depending on the situation and decision support needed, either of these approaches could alleviate the ethical concerns presented by an ethically ambiguous case. In either case, the role of ethics consultation is to mediate the process of decision-making. Physicians may tend to expect help with moral distress, avoiding legal consequences, and mediation rather than prescriptive solutions from ethics committees. Rather than offering a conclusive solution, the ethics consultation can assist the provider and patient in communication and in the understanding of ethically relevant information for the decision.

Ethics committees must also navigate through multidisciplinary interactions that may complicate the decision-making process. Different care providers may interact with ethics committees differently, so ethics committees should consider the nuances of multidisciplinary interactions within the care team to improve structured support for the decision-making process. The ethics committee can facilitate understanding not only between provider and patient but between different types of care providers and provider of differing disciplines. In addition, ethics committees may create stronger relationships with providers by providing support to their personal struggles with ethical decision-making. Ethics Committees can engage in moral distress consultation when healthcare professionals are feeling loss of power and perception of compromising their own moral integrity. This can help to build a relationship of trust and understanding between health care providers and ethics committees.

Ultimately, the ethics committee can help to facilitate both policy and individual consultation that emphasizes medically relevant information in decision-making and addresses the potential for both explicit and implicit bias in decision-making.
5b Resource Allocation versus Rationing in Health Care

Medical futility is often incorporated into the health care resource allocation assessment when expensive, non-beneficial interventions create high costs to the health care system. Using resources on non-beneficial treatment means that the same resource is not available for another patient who may benefit. When applied through a lens respect for human vulnerability and social responsibility and when carried out through ethically sound policies and processes, the incorporation of medical futility assessment to health care resource allocation can be justified. This must be differentiated than health care rationing, however, since rationing relies on potentially unjust, inadaptable criteria for determining who gets critical health care resources. A systematic organizational resource allocation framework, however, could adapt to specific patient situations and patient characteristics (including social determinants of health.) Importantly, ethical resource allocation includes considerations for quality of care, patient safety, cultural competence, and shared decision-making. With quality care equitably maximized, human rights will be protected and health care delivery will be ethically grounded.

5bi Rationing

Rationing is based on specific patient characteristics, or group characteristics of patients that are in similar situations. This type of rationing can only be justified when applied to very specific situations in very specific contexts, while overarching judgements applied across types of care are impossible to uniformly justify.

Justifications for Rationing in Health Care

Due to the reality of limited health care resources, justification for systematic rationing of health care has been attempted, albeit in ways that have been strongly contested. Models for rationing care have been developed based on age, disease, treatment, waste, autonomy,
effectiveness, personal responsibility, personal choice, individual behavior and luck but none have reached any overarching agreement. Arguments have been made for these and other criteria with little if any movement toward consensus on how to ration in the United States. For example, age has been used to justify rationing in health care, such as the fair innings distributive principle based on age, with a central focus on maximizing life years. Though arguments have been made for this approach to rationing, policy in the U.S. has not embraced rationing by age. Other examples of approaches to rationing have similarly lacked consensus in the United States.

Rationing can occur both at the policy level and at the bedside. Some specific examples of rationing have been embraced in very specific contexts, although an overarching approach to rationing remains elusive. An example of a context-specific approach to rationing is the management of antimicrobial therapy. Antimicrobial therapy is a beneficial treatment that can be held from an ICU patient in order to protect the outcome of the critically ill population in general. This is an example of rationing that has been accepted in the United States in a very specific context.

A major ethical conflict of rationing is the ethical obligation to the individual patient versus the patient population. Physicians may feel conflict between their fidelity to their individual patient and responsibility toward patients apart from their immediate experience, especially when the chance of a good outcome for their patient is unreasonably small compared to their chance of prolonged suffering and death. Physicians face distress when making these decisions on an individual basis, rather than within the context of policy and structure to support ethical resource allocation.

Delimitation between rationing and ethical resource allocation can be a fine line when facing certain rationing criteria. The difference between ethical resource allocation and unethical
rationing is related to the rationing approach. An example of this fine line is risk and clinical benefit in resource allocation decisions. This type of resource allocation approach would result in decisions such as refusing elective surgeries for patients who smoke or are obese due to evidence that connects these factors with perioperative complications. While similar to rationing, this approach is not fully aligned with traditional rationing as it incorporates the benefit of the patient who is being denied the treatment. When a patient will have a worse outcome based on a behavioral issue that they are able to change, the benefit of withholding treatment until the behavioral issue is fixed can be a justified reason for treatment delay. A secondary benefit to this type of decision would be to re-allocate resources to patients who would have a greater immediate benefit. Once the patient with the behavioral barrier to treatment addresses their behavioral issue, they will receive the benefit. This speaks to prioritizing resources, or ethical resource allocation, versus rationing resources.

Another ethical concern with rationing is the use of rationing when there remains a large amount of inefficiency and waste in the health care system. When resources are being wasted on non-beneficial care, it is difficult to justify rationing beneficial care. This means that an ethical approach to the rationing debate may include parallel efforts to address inefficiencies in health care delivery. Waste avoidance gets more to the point of resource allocation, where attempts are made to avoid using resources that do not add value.

Rationing has been justified for reasons of limited resources in the U.S. healthcare system at the level of health care delivery. It has been argued that specific criteria should be used to facilitate a rationing process in the United States.
The Rationing Process

Health care rationing has been strongly debated and contested in the United States. This includes approaches to explicit rationing through deterrence, deflection, distraction, dilution, delay, or denial of services. Explicit rationing has been attempted based on varying criteria with no consensus. For example, it has been argued that age could be used to explicitly ration health care in the United States. The major concern with this type of rationing is that older patients may be discriminated against and all of the patient’s clinically significant characteristics may not be considered. Although the explicit and rigid criteria of patient age may not be justified, it may make sense to incorporate functional abilities into resource allocation decisions when demand for nursing care for complex, older patients exceeds supply of nursing resources. The distinction here, however, must be made for the ethical resource allocation process through the systematic prioritization of limited resources available to a health care delivery organization. Organizations understand the nuances of limited resources at their disposal and the needs of the patient populations. For example, the differences across specialties may require specialty-based allocation strategies to be used. The process for how this allocation is developed and implemented will be the difference in whether the result is ethically sound or not.

Attempts at rationing are often made to address costs to the health care system but are often short-sighted. Allocation of resources should not only address whom the system can afford to treat now, but whom the system cannot afford to treat considering long term costs for short term gains. When patient are excluded from resource allocation based on short-term gains, the entire system suffers both in terms of patient care and health care costs.

The rationing processes that have received the most negative backlash have been attempts to explicitly ration health care resources. Explicit rationing occurs when specific and clear
parameters are set to allocate treatments or services while implicit rationing occurs without a formalized structure and is susceptible to personal biases. Implicit rationing is relatively hidden compared to explicit rationing, so it tends to receive less publicity and backlash than explicit rationing.

On the other hand, implicit rationing can slip under the radar and may not even be conscious decisions by those who are implicitly allocating the limited resources. Although it may not receive as much attention, implicit rationing may create more problems than explicit rationing since no systematic attempt at ethical justification has been made for the decision. In addition, staff and providers can face moral distress when left to implicitly ration at the bedside. Nurses can face role conflict, feelings of guilt, and distress when they are face moral challenges of prioritizing at the bedside. Physicians can also face these and other challenges when left to implicitly ration. Physicians may implicitly or subconsciously ration by proxy when they are deterred from patient care by paperwork burden and excessive prior authorization requirements. This results in rationing of care, yet rationing that is not transparent or available for public scrutiny.

Both implicit and explicit rationing may incorporate varying situational factors. This may include potential length of life and quality of life, or broad well-being and happiness in addition to life years. These may be part of an ethical justification for some forms of resource allocation processes; However, when used as either uniform criteria for all patients or when decided by opinion on an unstructured case-by-case basis, affronts to patient justice may occur. If explicit rationing criteria is too rigid, for example, patients who have unique needs can be overlooked. If left to opinion-based implicit rationing by individuals, however, individual bias can be introduced to the decision-making process, contributing to unjust health disparities. This
demonstrates how both explicit and implicit rationing are problematic and lack ethical justification.

Systematic allocation of resources is important, but health care rationing – either explicit or implicit – is seriously morally flawed. In addition, the term “rationing” is politically and emotionally charged, making productive discussions about resource allocation in terms of “rationing” difficult to impossible. Attempts to address allocation of resources should move away from the language of rationing to create more productive debate. However, linguistic changes in the naming of rationing are not justified when they are superficial and only serve to hide social visibility, avoid painful social conversations and avert ethical scrutiny. Discussing resource allocation at the point of health care delivery must have meaningful differences from existing debate on health care rationing. There is a need for an ethically justified approach to health care resource allocation.

5bii Ethical Resource Allocation

While health care rationing based on uniform criteria of patient characteristics is unethical, it is possible to carry out ethical resource allocation. Ethical resource allocation is based on a foundation of goals and tolerable costs to the patient and should be organized through a framework for organizational policy.

Goals and Tolerable Costs

Ethical resource allocation should be founded in patient goals and tolerable costs. Goals and tolerable costs should be the starting point for making decisions in health care’s resource-limited settings. This includes but is not limited to cases of medical futility.
A patient’s goals can be identified and defined in terms of the treatment process through shared decision-making and the informed consent process. While the informed consent process is useful, it still faces many challenges, including unknown or disputed risks for serious harm, and determining when this type of controversial risk is serious enough to disclose. These challenges should be addressed through shared decision-making facilitated by the mutual trust developed through shared decision-making. When determining goals and tolerable costs of individual patients, the informed consent process combined with shared decision-making can identify whether the patient’s goals are aligned with treatment benefits and risks, even those which may be uncertain. The shared decision-making process allows for the provider to determine which benefits and risks may be most relevant to share with the patient based on their goals. This is an essential component of identifying goals and tolerable costs, especially when assessing medical treatments that may be new or innovative. While medical innovation is generally considered to be positive for patient care, it can complicate informed consent and medical decision-making. For example, surgical innovation such as new devices, technology, procedures, or applications may have the potential to be either beneficial, ineffective, but foregoing new innovations could also harm the patient by foregoing possible benefits of the novel treatment. Sharing new innovations as potential treatment options should depend on the patient’s expressed goals, as well as the patient’s values, especially values related to the patient’s weight of risks and benefits.

Providers must have the communication skills to help patients navigate the assessment of benefits and risks of treatment. Patients have varying backgrounds, perspectives and values that may influence decision-making so providers must understand and include these individual patient characteristics in patient communication. Importantly, the hope for survival or need for concrete action could create cognitive disorientation during decision-making, so providers need
to navigate between hope and realism. Providers must be realistic in estimation of potential treatment benefit and frame benefits versus risk in a way that patients can understand and assess compared to their values and goals. When discussing treatment options, providers should also consider existential dimensions of patient communication such as evasive maneuvers, the presence of powerful emotions, and attempts to avoid conversations about dying or functional decline before death. Patients may be coping with their disease and the difficult medical decision-making process through counterproductive, possibly non-conscious responses. Providers should recognize and address these potential barriers to effective communication with patients. For example, when prescribing or deprescribing medications, a physician should consider the patient’s individual therapeutic goals, benefits and risks, the needs of the patients related to cure versus minimizing functional impairment, patient age and frailty, and the adverse effects or potential for significant harm from a medication. Different patients have differing needs and benefits versus risks may be weighed differently based on the patient’s goals and values. Health care delivery organizations can facilitate this decision-making through policy and an ethical resource allocation framework to support shared decision-making between physicians and patients.

In addition, ethical resource allocation will include a multidisciplinary approach to meeting patient’s goals of care. For example, hospice may be the best option to meet the goals of care for some patients. Hospice services are multidisciplinary and incorporate physicians, nurses, clergy, social workers, volunteer caretakers, family members, and payers that provide monetary and business incentives for hospice referrals. The multidisciplinary approach to hospice and other patient-centered approaches to care means that the health care delivery organization plays a crucial role in coordinating and incentivizing team-based approaches to patient care.
Organizational policy should also support goals of care discussions through support of patient-centered care. These goals of care discussions can include both short term outcomes - such as mortality and morbidity, and long-term outcomes - such as disability, worsening quality of life, and loss of functional capacity. Discussing goals of care with patients will help to determine what is important to them and to prioritize interventions that are aligned with their values and preferences. Goals of care discussions can follow a four-step patient-centered process that includes establishing a diagnosis, discussing prognosis, defining goals of care and making decisions about treatment. This will help patients to understand the severity of their illness and then align their values with the options available for treatment.

Goals of care discussions should be documented for clarity and accountability. Routine goals of care documentation can help to promote better communication, partnership and clinical decision-making with patients. Documentation of goals of care discussions can create better interdisciplinary communication, and create accountability for physicians to incorporate a patient’s goals of care into care planning. Importantly, improved documentation of goals of care, such as advance care planning for patients with terminal cancer, can improve quality of care. Documentation of goals of care incorporates the patient’s values and preferences into the official care planning process and ensures that the outcomes that are important to the patient are prioritized.

Goals of care discussions are essential for effective patient-centered care, but can create some challenges to providers of care as well as overall policy development for the organization and health care system. Potential challenges or special considerations for goals of care discussions include cultural differences, patients who lack decision-making capacity, and the role of medical technology. These challenges do not stop at the level of the physician-provider interaction. Goals of care interventions create challenges at the individual, organizational and
The provider faces challenges with the patient interaction, and the organization and systems levels face challenges in providing the necessary support for these discussions and documentation to take place. Goals of care discussions require adequate team structures, training and resources for initiating conversations. Health care delivery organizations and health care delivery systems must provide this support for goals of care to be effectively incorporated into patient care plans. This is a worthwhile approach because goals of care communication can improve end of life quality for patients, including palliative care plans. When patients are facing difficult clinical decisions, especially during the end of life, goals of care discussions and documentations can clarify the best course of action for the patient according to their values and preferences.

Patient goals begin the process of ethical resource allocation, then tolerable costs must be incorporated to balance decision-making that is in the patient’s best interests. Health care organizations can help providers to assess tolerable costs by facilitating effective risk assessment of patients using both personal risk and comparative risk to show patients big picture of their personal risk and help with interpretation of options and decision making. When facilitating autonomous patient decision-making, tolerable risks and costs to the patient are equally as important as the probability of meeting a patient’s defined goals. When the costs outweigh the benefits to the patient, it will not make sense to provide that treatment to the patient. This is the natural beginning to ethical resource allocation. Ethical resource allocation should first and foremost begin with aligning beneficial treatments with patient goals and tolerable risks.

Tensions between administrators and physicians can occur when cost-saving measures appear to conflict with physician autonomy. This can be addressed by increasing physician leadership and creating a collaborative atmosphere between administrators and providers of
Including physicians on the leadership team help to alleviate communication barriers and tensions with the clinical providers and staff within the organization.

Tolerable cost assessments should include financial outcomes, quality of life factors, social justice and organizational ethics. This means that the tolerable cost assessment of providing a treatment should not only consider the individual patient’s tolerable financial costs and quality of life factors of treatment, but also social justice and organizational ethics. The assessment should ask not only “is this financially tolerable?” and “will the patient have a better quality of life?” but also, “will this decision be supported by social justice?” and “will this decision fulfill the organization’s ethical obligations, based on its moral agency?”

Health care organizational policy that prioritizes assessment of patient goals as well as tolerable costs (at both the patient and organizational level) is aligned with the human right to quality health care. The human rights framework is not only based on respect for autonomy, but also the value of individual dignity, integrity, and vulnerability. The needs of patients as well as the tolerable costs of decisions should be assessed using a gauge of human dignity, integrity of persons, and respect for human vulnerability. Once the focus on patient goals and tolerable costs has been established, a framework to facilitate justified allocation of resources can be developed.

Until now, there has been inconsistency in definitions of equity and ethical concepts related to allocation and priority setting for health care resources. An effective framework for resource allocation should establish relevant ethical concepts and apply principles of health care equity.

*Developing a Framework for Resource allocation*

A framework for resource allocation is needed for health care delivery organizations to manage available, limited resources. Until now, discourse related to resource allocation in health care has primarily been focused on national and global management of limited health care
resources. Specifically, global health discourse is moving toward a focus on state universal health coverage, including discussions surrounding which services should be included, who should be served, who should be served first, how coverage could be based on need, how the greatest improvement of health could be facilitated, how to require coverage based on ability to pay versus need, and how health care spending will fit into overall national spending. While a global approach is noble, it may be far from consensus. At the national level, resource allocation has also varied and been based on differing priorities and values. For example, in the UK, the National Institute for Health Care Excellence serves as a designated organization to provide ethical justification for resource allocation that privileges cost effectiveness, but also considers other social and ethical values. While some countries have established national health care priority setting, the United States is far from establishing an overarching national policy for health care resource allocation. Even when (and if) a national or global approach is established; health care delivery organizations will still need to make decisions on how to allocate resources available to them since each health care delivery organization in the United States will always face unique challenges based on geographic location and patient mix.

There are many barriers to connecting frameworks for healthcare priority setting and practical policy-making. Health care delivery organizations each face unique challenges to implementing ethical resource allocation policy and procedures. A resource allocation framework must be designed to fit the needs of diverse delivery organizations and patient populations. Within a single health care delivery organization, there is a range of decision-makers, settings, scope and type of decisions, and criteria for resource allocation. An ethical framework for resource allocation should incorporate this organizational diversity while also creating a structured process that can be followed uniformly. This will require a focus on the
process and structure of decision-making that is flexible to fit to different organizational structures in health care delivery.

So far, the most developed published theory that begins to address this need is Norman Daniels’ accountability for reasonableness theory of healthcare resource allocation. Daniels’ theory establishes a process rather than requiring agreement on principles, incorporating elements of decision-making and moral legitimacy through the following key elements: transparency for the foundations of decisions, rational appeals that everyone can accept as relevant to meeting needs fairly, and procedures revising decisions if there are challenges.\(^93\) It attempts to address the gap between national health care planning and local realities within limited resources by applying priority-setting criteria to health systems.\(^94\) The accountability for reasonableness theory is an approach that incorporates some useful elements for resource allocation. This theory addresses legitimacy and fairness of care access based on publicly accessible rationales that are assessed to be relevant for meeting the patient’s needs under resource constraints.\(^95\) Some components of accountability for reasonableness are especially useful for an ethical resource allocation framework. For example, the publicity condition is important for critical care unit bed allocations as direct communication between physicians and end-users can improve fairness of decisions.\(^96\) While this theory has useful elements, it is incomplete in its approach to ethical decision-making within the health care delivery organization.

Accountability for reasonableness seeks both legitimacy and fairness while considering morally relevant needs and can be a valuable tool for setting limits in health care; however, it still needs to be specified to achieve fair, explicit, limit-setting decisions within health care organizations for treatment decisions about needs versus preferences, and is open to serious
disagreement about ethical legitimacy of choices. Accountability for reasonableness does not incorporate the distributive justice concerns related to social determinants of health and its process does not incorporate the importance of patient values and goals in ethical decision-making. Assumptions are made on behalf of the patient, which may or may not be accurate. The multicultural and diverse nature of the U.S. population requires that an ethical resource allocation framework incorporate the diverse needs of patients that respects the nature of human vulnerability, acknowledges the social responsibility of health care organizations and is ultimately in support of the human right to health care. The accountability for reasonableness theory, on the other hand, includes utilitarian-like cost-effectiveness calculations, disregarding separateness of persons, which could be unfair to individual interests sacrificed for group. A framework for ethical resource allocation should incorporate elements of cultural competency and shared decision-making to adequately address the key factors of individual patient values, preferences, and goals.

The resource allocation framework should give health care delivery organizations the structure and process for basing resource allocation decisions on justice with the goal of promoting human rights. Resource allocation decisions may include both efficiency and equity principles with potential decision-making criteria including health gain, clinical effectiveness, and the ability to provide quality of life improvements. These decisions will be facilitated at the organizational policy level, and at the beside. Ethics committees will play a key role in facilitating these decisions at both levels. Ethics committees will be involved in developing organizational policy and also consulting at the bedside. Clinical ethics consultation should prioritize the conversation and mediation of the decision-making process and look for closure where parties feel a deep sense of completeness in the outcome, rather than a specific
The resource allocation framework will emphasize the process of matching patient goals with treatments that have the best chance of meeting those goals.

The role of the provider is also essential in this process. When delivering care in a resource poor environment (where clinicians and health care delivery organizations have knowledge but not means to carry out beneficial interventions,) ethical decision-making at both the organizational and provider level can be improved through experience, adaptability, cultural sensitivity, situational awareness, beneficence, courage, honesty and fairness. The framework must not only include provisions for transparency and appeals, but also focus on the organizational culture plus leadership and provider competencies that will facilitate ethical decision-making. The role of nursing is also important since ethical conflicts related to healthcare provider and system-level factors can directly affect a nurse’s capacity to address complex clinical situations at the bedside, including skill and confidence in the organization’s culture of ethics. The role of providers and staff should be emphasize in a resource allocation framework within health care delivery organizations. Health care delivery organizations poses a unique role in the facilitation of ethical organizational culture and point of care decision-making.

The resource allocation framework should also include transparency of the decision-making process. This decision-making process should always have the patient-physician relationship as the point of focus. A transparent discussion is needed to determine how comparative effectiveness research can be balanced between physician discretion, patient autonomy and system-level restrictions, with a goal of using clinical data to inform decision-making within a flexible system responsive to the complexity of health care. Decisions about resource allocation at the level of health care delivery should incorporate clinical data and best practices with the flexibility to meet patient-specific values and goals. Cost should also be part of
this discussion where relevant since there is a need for clear, explicit, transparent, inclusive process to determine how costs should be controlled, based on a shared social understanding.\textsuperscript{104} A resource allocation framework will incorporate other related concepts, such as accountability for reasonableness and evidence-based medicine, although existing concepts are not comprehensive and must be supplemented with additional framework elements. For example, evidence-based medicine seeks to generalize treatments, which may not be appropriate for all individuals in an ethnoculturally diverse context such as in the United States.\textsuperscript{105} In general, an ethical resource allocation framework should encompass a structure in which health care delivery organizations can make decisions when facing finite resources, supported by human rights, organizational moral agency, patient care quality, and justice.

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Chapter 6: Organizational Policy Framework for Resource Allocation

Ethical health care resource allocation will promote and protect health care quality and human rights. This can be accomplished through organizational policy that includes fairness in value assessments and response to challenges of nonbeneficial interventions. It can be implemented through a practical, formalized, and cohesive resource allocation framework for health care delivery organizations that includes decision-making process, methods, and evaluation mechanisms.

6a Resource allocation

Resource allocation should focus on patient-directed goals, using cultural competence and shared decision-making as tools to alleviate inequalities caused by social determinants of health. Focusing on assessment of patient goals and tolerable first and foremost will ensure that treatments are aimed at the patient’s values and goals of care. When all desired patient goals can be met, a mechanism must be in place to evaluate and implement prioritization of scarce resources. This will involve assessment of both fairness and value. The prioritization of scarce resources can be illustrated through applications to the medical futility and end-of-life care debate.

6 ai Assessing Fairness & Value

Fairness and value will be the basis for resource allocation assessments. Fairness is explained in terms of equity and justice, and value is explained in terms of quality and cost.

Fairness (Equity & Justice)

The resource allocation framework will be based in fairness and equity on two major levels – the bedside level and the organizational policy level and the. The bedside level will address fairness of the physician-patient interaction including treatment plans made through
shared decision-making while the organizational policy level will address equity and justice for
the population or community of patients that the health care delivery organization serves.

Support for bedside decision-making in the face of scarce resources includes concerns of
justice from the perspective of both the patient and the health care provider. Justice must be
protected at the bedside to protect the patient from provider bias. Many times, physicians do not
even realize that they are making biased decision at the bedside, and it can be a challenge to
bring these biases to light. There is a tendency to underestimate one’s own susceptibility to
cognitive bias, also called intellectual deference, where individuals often fail to listen to advice
on avoiding bias due to their overconfidence about their own intellectual abilities.\(^1\) Physicians
may not realize or think that they are susceptible to bias, and may be engaging in implicit bias
when making bedside rationing decisions. This can create a range of emotional responses from
both the provider and patient level, depending on the perceived fairness of both process and
outcome. Anger and frustration can occur when an unfavorable outcome results from an unfair
procedure, while guilt and anxiety can occur when an unfair process results in a favorable
outcome.\(^2\) The fairness of both process and outcome are essential for the well-being of both
patient and provider. Lack of fairness in process or outcome may lead to moral distress in
providers and staff. There is a significant negative correlation between perceived organizational
justice and moral distress of nurses, illustrating the need for organizations to create appropriate
policies that are transparent and clear.\(^3\) When policies demonstrate procedural and distributive
justice, nurses and physicians will be less likely to face moral distress when facing difficult
bedside allocation decisions.

The fairness of process can be influenced by factors of personal motivation. Individuals
can be motivated toward justice based on rational utility maximization, status and social value
maximization, or personal identity associated with moral priorities. Since there is potential for variation of motivations between patients and providers, a standardized, structured, ethically sound approach to this type of decision-making should be established. This will support unbiased decision-making and also support shared decision-making between the provider and patient.

The provider and patient must also consider goals of care outcomes when determining which decision is founded in equity and justice. Using economic opportunity restoration as the sole justification for care is not enough to explain justice in health care. Palliative care illustrates this point. Palliative care is offered when opportunities cannot be restored and is instead focused on less painful treatment and treatments for those who cannot be cured. If the outcome is not aligned with the patient’s goals, preferences, and needs it will not be based in justice and equity. Both the process and outcome must be based in equity and justice for ethical resource allocation to be established.

The social nature of health care helps to explain the importance of fairness in the process and outcomes of health care delivery. Freedom is situated or socially bound meaning that society has a role in creating the alternatives available for people to choose. In other words, individuals do not exist in isolation and there is a shared responsibility for bad health even if a health outcome seems to be the product of free choice. The social responsibility that results from the social nature of health care, combined with the moral agency of health care delivery organizations, places moral obligations on the health care delivery organization to provide equitable health care. Importantly, those with social disadvantage lack material, social, and/or environmental equality such as: the inability to purchase goods, services, influence; treatment within society based on social factors such as race; and exposure to concentrated poverty. These factors offer a limited amount of control over a person’s social situation, so they have limited
moral relevance to health care justice and equity. The life-course perspective explains that economic and social factors influence opportunities across lifetimes and generations.⁸ Even if an individual pursues opportunity to improve their social situation, social disadvantages from previous experiences, as well as social disadvantages from generations before them can continue to negatively impact their opportunity for health and well-being. This again provides a limited amount of control over social context to the individual. Generational trajectories of health disparities can even be influenced by non-health policies – for example, the historical impact of exclusionary federal government housing policies which continue to affect the housing market today.⁹ When an individual starts life with severe socially-constructed challenges and barriers to health, health is compromised by generational and historical from the day a person is born. These disadvantages are not morally relevant reasons for a person to receive inadequate health care.

Justice related to the outcomes of how health care resources are allocated is called distributive justice. Distributive justice can be based on: the contribution principle, or allocation of resources based on a person’s sum of contributions to others; the equality principle, or allocation of resources as the same for all persons involved; or the need principle of social justice, which allocates resources based on individual needs and desires.¹⁰ Since there are several ways that distributive justice can be calculated and analyzed, it must be clear how an organizational framework will approach distributive justice analysis. The goal of distributive justice is to avoid morally arbitrary discrimination and address social conditions that interfere with one’s ability to develop and exercise their potential capabilities.¹¹ In health care, those morally arbitrary social conditions that pose barriers to health opportunity should be eliminated or corrected to ensure just allocation of resources.
In addition, power differentials can create health inequities that must be met by political support for inclusion and human rights to health. This political support is an essential component of justice and human rights in health care. Health care delivery organizations have a role in addressing this power differential as well. Although political climate of power will have a significant effect on a person’s ability to achieve the right to health, this right will ultimately be carried out by the health care delivery organization. The right to health elicits a right to socially controllable causes of health under budget constraints, as well as a moral duty of those in the position to influence these social causes for the right holder. The health care delivery organization has a moral duty to influence and address social causes that influence access to the right to health, within budget constraints.

The social value established by power dynamics can influence the realization of the right to health care. Social value is determined not just by outcomes, but also by process that individuals are exposed to. This explains the importance of both procedural and distributive justice. There may also be a role for interactional justice in addition to procedural justice, which may function differently in terms of fair process versus equity of social comparison. In summary, fairness includes process, outcomes and treatment of individuals that is based only on morally relevant criteria.

Equity and justice principles are essential foundations for the resource allocation framework since they will ensure that only morally relevant criteria are used to determine processes and outcomes for fair health care distribution. In addition to the essential piece of equity and justice, the resource allocation framework will incorporate value.
**Value (Cost versus Benefit)**

Value can be evaluated through robust comparative effectiveness and evidence-based assessment. Assessment of value at the level of the delivery organization will ensure that priorities are set within the limited resources available to the population that the organization serves. The heterogeneous and fragmented health system in the United States cause difficulty in equitable resource allocation at the levels of national policy and health care financing. This results in health care delivery organizations receiving varying levels of resources compared to the needs of the communities that they serve. Some health care delivery organizations have more resources per patient than others. Those who have the fewest resources to serve their patient population will especially need to consider value to ensure that community needs are being met to the best of the organization’s ability, enacting their role in the human right to health.

Value assessments first need to determine the patient’s individual goals of care. There is a need for an established process that incorporates patient values into decision-making and practice guidelines in health care. Without a full understanding of the patient’s goals, preferences, and needs there is no way to determine whether the treatment is beneficial for the patient or not since health care is value-laden and effectiveness of a treatment depends on the patient’s goals.

For example, cancer treatment is value-laden. Cancer treatment is not just the biology of cancer, but also patient preferences, so treatments should be personalized and determined through shared decision-making. The approach to value analysis must incorporate all effective alternatives. For example, prevention, access to early diagnosis and radiotherapy are key factors to effective cancer treatment, even though funding tends to be concentrated on cancer treatment drugs. Different approaches may be more beneficial or less beneficial for different patients,
depending on their goals of care, preferences, and values. Share decision-making is an essential tool for defining the goals of a patient’s care and developing a treatment plan based on those goals.

The cost of care should be considered by health care delivery organizations when developing resource allocation policy, but should only be one component of the analysis. A middle-ground needs to be found between the benefit principle, or resources toward the maximization and cost-effectiveness, and the worse off principle, which is related to equity. Those who need the care the most, based on criteria that includes goals of care may have some level of weight against others who have less need or where a treatment is not aligned with their goals of care. Purely focusing on cost-effectiveness may violate social values of equity and distributive justice. While addressing cost-effectiveness of care, the value equation adds in the essential piece of patient needs and goals. In other words, cost-effectiveness alone is not enough to determine the ethical allocation of health care resources. Patient characteristics, needs and goals must also have some weight and be incorporated into the decision-making process. In addition, when incentivizing patients to engage in their health care, their personal needs and reasonable options must be clear to them. Health incentives require rational deliberation and must avoid restriction of options through coercive paternalism. The patient’s role in the resource allocation framework will be essential, since patient characteristics are crucial variables in the value equation.

Patient needs, preferences and values should be an integrated component of the resource allocation framework. Frameworks should incorporate a range of patient-relevant outcomes, or the flexibility to create tailored treatment where patient input assigns values to the range of outcomes. There is no way to create a one-size-fits all approach that will address the needs and
goals of all patients, and the framework must incorporate this variable factor. Patient-centered care and shared decision-making are tools that can be incorporated into the framework to ensure that patient variables are adequately incorporated into value assessments. Different options may offer the highest value for different patients since there are a range of treatments that may or may not be aligned with a patient’s goals and preferences.\textsuperscript{24} The treatment that one patient values may be different than that of another patient with the same clinical condition because of the nature of human beings and personal values.

On an organizational policy level, values can be categorized and weighted, but there should still be room for individual patient values to be incorporated into decision-making through shared decision-making and patient-centered care. Health care delivery organizations are may weigh and consider relevant value criteria for the community and population that they serve. This value criteria could include disease severity, potential for health, past health loss, socioeconomic status, area of living, gender, race, ethnicity, religion, sexual orientation, economic productivity, care for others, and catastrophic health expenditures.\textsuperscript{25} These factors may or may not be morally relevant for the health care population and resource constraints of the delivery organizations.

The mix of patient vulnerability that a health care delivery organization serves may also need to be incorporated into the assessment of value. Incapacitated and alone adults are particularly vulnerable, and there is a need for adequately funded and monitored solutions that incorporate a multidisciplinary, collaborative approach to protect their rights.\textsuperscript{26} This highlights the need for and emphasis that should be placed on collaboration among care teams to provide the highest value care that is consistent with patient goals.
In addition to individual patient goals, the organization should consider long-term organizational goals in resource allocation decisions. Short-term costs, long-term cost savings and patient outcomes should all be considered in organizational value analysis, with the ultimate goal of determining the value added by an intervention, then developing evidence-based guidelines supporting high-value choices. While a decision may save money in the short-term, a solution that will be costly in the long-term may not carry the highest value. Those who lead and develop policies for health care delivery organizations can use evidence-based guidelines to determine which decisions might be most cost-effective in both the short and long-term.

Difficult decisions related to value and justice are common in health care delivery organizations in the United States, and especially common when facing debates over medical futility and end-of-life care decision-making.

**Medical Futility and End-Of-Life Care**

Medical futility cases are often brought up at the end of life when interventions are prolonging life but not achieving many or any other goals of care. These cases bring up difficult questions of both justice and value. Medical interventions with little or no benefit to the patient may also be costly and may even be inequitable when they are not aligned with the patient’s goals of care. These issues of non-beneficial care often arise at the end of life when a patient receives treatment that will not achieve any of their goals of care and only prolong their dying process.

*Medical Intervention with Little or no Benefit*

Addressing medical futility related to the resource allocation framework because cases of medical futility are those that offer least benefit and some of the highest human and financial costs. There can be conflict in medical futility cases due to underlying, unrevealed beliefs and
values that are not being addressed in the case. The resource allocation model, facilitated by
health care providers, staff, and ethics consultants, can help to unearth some of these underlying
issues to address the true reasons for conflict.

Based on the variable resources available to delivery organizations in the United States,
the health care resource allocation framework will provide a process that allows for decision-
making within the context of organizational constraints. This process should include
establishment of local clinical practice guidelines, methods for documentation and monitoring,
review and measurement of data, process to provide feedback, education and facilitation of
shared decision-making and the development of an environment that encourages blame-free
discussion of waste.28 These approaches can be applied at all health care delivery organizations,
but the process specifics may differ depending on organizational constrains and needs.

The varying constraints of health care delivery organizations in the United States means
that there must be flexibility to make decisions within the constraints of available resources.
Because of this, a framework to resolve conflicts of nonbeneficial treatment should be process-
driven.29 The process for making decisions about non-beneficial care should be consistent, but
there is some room for organization-specific outcome goals that addresses organization-specific
resource constraints. The resource allocation framework will have major consistencies among
institutions, however. The framework should be consistent in fair and explicit policy to support
consensus, respect and understanding when providers face conflict resolution related to
perceived nonbeneficial treatment.30 Although providers should be given autonomy of clinical
decision-making, they should be given institutional support and guidance on decisions related to
nonbeneficial treatment.
Physicians may face challenges to shared decision-making when patients demand a specific treatment that is not consistent with their goals of care. The physician’s role is not to give the patient whatever treatment they demand, but to facilitate coherent deliberation to support the patient’s autonomy, offering reasoned judgements for what is beneficial and appropriate. Organizational policy can support physicians in communicating this reasoned judgement and providing an environment where they are empowered to make decisions that are most closely aligned with the patient’s goals of care. The process of communication about nonbeneficial care is a critical piece for decision-making related to nonbeneficial care. Proactive communication among all stakeholders is needed to prevent and resolve issues related to nonbeneficial treatment. This includes the physician, the patient or surrogate, the patient’s family, and other stakeholders when relevant.

Physicians need organizational support for shared decision-making, especially when facing diverse patient populations. Physicians need culturally effective strategies for end of life discussions when they face barriers to discussing end of life issues with patients, especially when communicating with patients of different ethnicity. Organizations can provide support for cultural competency and communication tools so that providers can effectively and confidently discuss relevant treatment options with patients. This will also help providers to communicate treatment options in terms of a patient’s values, preferences and goals.

For example, providers may need support in communicating about nonbeneficial CPR. Nonbeneficial CPR occur for many reasons including misrepresentation of CPR efficacy, misunderstanding of prognosis, lack of empathetic and skilled communication, difficulty of patient and family acceptance, cultural rejection of death and dying, and difficulty with meaning-making and connection. In addition, there is also a bias toward action in medicine, which could
be a cause of the overvaluing of CPR. Effective shared decision-making would alleviate these problems and prevent non-beneficial CPR. The efficacy of this intervention should be adequately explained along with empathetic and skilled communication of prognosis. In addition, communication to address potential cultural biases and issues of family acceptance could help to reduce the incidence of non-beneficial CPR. Avoiding non-beneficial CPR can prevent both patient suffering and unnecessary burden on resources to the health care system.

Another example of policy in practice to address non-beneficial care is in the context of the ICU. When considering admission, discharge and triage for the ICU, patients real wishes should be determined through proper advance care planning that includes a discussion of realistic probability of cure, benefit of intervention, and dying despite the intervention, plus options of hospice. Advanced care planning can ensure that patients are getting treatment that is consistent with their goals of care, even if they get too sick to communicate these goals later. This is not only good for patients, but also good for providers. Collaboration and workload are predictors of burnout from ICU staff and providers who perceive nonbeneficial treatment in the ICU. When patients are receiving care that is not perceived as beneficial, nurses and providers can feel an emphasized strain and moral distress, adding to workload burden and burnout.

In addition to advanced care planning for patients, addressing nonbeneficial treatments that are already in motion is also part of the decision-making process for equitable, value-based resource allocation. When a treatment is causing burden and not providing significant benefit to the patient, it could be determined as nonbeneficial care. It is ethically permissible to stop technological impediments to death when the burdens to the patient outweigh the benefits. When a patient is receiving extraordinary interventions that are keeping them alive but not
benefiting them based on goals of care, it is ethically permissible to discontinue the nonbeneficial treatment.

There is a need for organizational policy to prevent unnecessary patient suffering caused by nonbeneficial care, such as incorporation of ethics committee consultation to support physicians when facing conflicts related to nonbeneficial treatment. Organizational policies will set the culture and priorities based on the resources that they have to address the needs of their patients. Ethics committees should be part of the framework structure since they can address specific ethical dilemmas at the bedside, as well as facilitate robust ethical deliberation at the organizational policy level. In addition, organizations should consider the resources available to them and the options that they may provide to patients that will benefit them the most based on their goals of care. For example, organizational leadership should establish strong connections with palliative care services and organizational processes for beneficial palliative care transfers. Even if an extraordinary measure is not appropriate or beneficial to the patient anymore, it will always be appropriate to directly care for the patient’s pain and suffering. Palliative care plays an important role in caring for patients when more aggressive treatments are not appropriate for their goals and preferences.

Organizations can also provide support for providers and staff through education and training. Organizations provide support and training for patient-provider communication to promote conversations about nonbeneficial care before a crisis arises, with the goal of reducing communication barriers such as time constraints, inadequate provider communication skills and training, uncertainty about prognosis, patient and surrogate anxiety and fear of inaction, and limitations in advance care planning. There are many reasons why a provider may have difficulty communicating with their patient and engaging in effective shared decision-making.
Health care delivery organizations play a critical role in supporting providers to give them the tools and break down barriers to effective patient communication. Hospital policy on nonbeneficial care can improve end of life care and resolve conflicts in decision-making.\textsuperscript{42} Policy interventions at the level of the health care delivery organization can give practical support to health care providers and staff when assessing benefits and value of care for their patients. This can be especially helpful when providers and staff are caring for patients at the end of life.

\textit{End of Life Care}

Only patients can define the level of benefit and cost they experience from an intervention, so their values and goals need to be at the center of this process. Although quality of life added may be one goal of care, end-of-life care decision-making processes should examine all benefits of treatment, not just incremental length of life added.

One of the major areas of focus at end of life is adequate and accurate assessment of palliative care needs. There is wide variation in physician survival prediction accuracy and the accurate identification of people nearing the end of life that could benefit from palliative care services.\textsuperscript{43} Organizational policy and resource allocation framework can address this issue by providing evidence-based guidance on how to approach assessment for palliative care referrals. Conversations about transitioning to appropriate end-of-life care should occur for timely palliative intervention when there is a high cost of care with little or no value to the patient.\textsuperscript{44} This is not only considering financial costs, but quality of life costs to the patient. The patient may pay a high price in terms of their quality of life to gain little or no benefit from a treatment. The physician and patient should share the probabilities of costs versus benefits of a treatment and then make a decision based on the value weights that the patient places on both the costs and
benefits. This type of shared decision-making takes skilled communication practice from physicians and staff caring for the patient. Physicians and nurses need effective communication skills to help clarify expectations and end of life care wishes. The physician is the expert on treatment options while the patient is the expert on their values and goals.

The physician should understand the goals of the patient to make appropriate recommendations to their patient. The process of advance care planning and discussion of goals of care should incorporate patient-centered, shared decision-making principles incorporating the patient’s personal values and life goals. When these discussions happen early on in the care, shared decision-making is more effective and patients can effectively communicate their goals and values related to end of life care. For example, when cancer patients have appropriate information about the option for a do not resuscitate (DNR) order at the end of life, their care quality can be improved. Patients need to have a meaningful conversation with their providers about the true risks and possible benefits of an intervention, and providers need to listen carefully to the patient’s wishes and goals of care. Health care organizational policy can help to support this type of communication between the physician and provider by supporting shared decision-making education and other resources needed for effective communication. This is especially crucial at the end of life and is often needed in the intensive care unit (ICU). Due to the variability in end-of-life ICU care, there is a need for need for clinical, educational and policy interventions to encourage the use of informed goals of care. Standardized, evidence-based approaches to end of life decision-making in the ICU can be incorporated into the resource allocation framework. In addition, evidence-based guidance on other types of beneficial care for patients can help to improve outcomes and reduce costs. Timely enrollment in hospice care, for example, can reduce health care expenditures at the end of life. When hospice would benefit
the patient the most, they should be referred to hospice rather than continuing to receive care that is not meeting their goals.

Providers face many barriers to end-of-life decision-making. For example, cultural issues can bring up a conflict between individualism and stereotyping since cultural and religious can be complex and negotiated by context, political, social and existential situation. Providers and staff should receive support and training on how to navigate between cultural and religious differences of patients. Due to the significant impact that a patient’s culture and religion have on preferences and goals of care, a provider needs to understand these patient characteristics for effective shared decision-making. Importantly, a patient’s culture can impact preferences for end of life treatment so the institutional policy should promote an understanding individual needs of each patient before documenting advance care planning. Incorporating potential cultural and religious preferences into advance care planning protocols can create effective support for culturally competent, patient-centered shared decision-making. Spirituality can play a significant role at the end of life for patients, family members and clinicians, since end of life care can bring up questions about meaning, purpose, relationships, and destiny as well as the need to meet spiritual goals of peace, comfort, love, and reconnection. Incorporating an understanding of religion and spirituality into advance care planning can enhance the patient’s experience and likelihood of achieving goals of care. Physicians should ensure that care is aligned with diverse patient goals at the end of life by eliciting the patient's explanatory model of illness, addressing the patient’s religious or spiritual values, determining the patient’s desired approach to truth telling, understanding how the patient's family is involved in care, and negotiating cultural conflicts when they arise. When a provider actively seeks to understand the patient’s
background and values – including culture and religious beliefs – shared decision-making will be improved and care can be aligned with the patient’s goals of care.

An understanding of the patient’s culture and spiritual beliefs can also help the physician to understand important aspects of the patient’s decision-making process. For example, end of life care that is consistent with the patient’s goals and desires is not always consistent with the conventional notion of autonomy when patients do not want to make explicit decisions about their end of life care. In this case, the health care provider may need a background in cultural competence to understand how the patient prefers to make decisions and gain a comfort with shared decision-making in this context. In addition, some patient’s may prefer nondisclosure due to cultural or spiritual beliefs. Physicians in the United States need cultural self-awareness and knowledge of other cultures when patients prefer nondisclosure. Otherwise, they may face conflict due to the professional value of truth telling. Organizational policy can help to support the provider and alleviate any internal ethical dilemmas when there is conflict between personal beliefs and patient preferences. When the health care organization has clear policy on how to address these types of situations, and has support for physicians who face moral distress, the decision-making process can be improved for both the provider and the patient.

Organizational policy should also promote collaboration among disciplines and specialties within the organization. An interdisciplinary approach to communicating about end of life care planning should be used to improve advance care planning and increase effective and timely palliative and hospice care referrals. The coordination of health care delivery and transitions of care will improve the alignment of patient goals with recommended treatments and interventions. A multidisciplinary approach will also help physicians to address end of life care issues in a timely manner by providing support and adequate treatment options for their patient.
Conversations about advance care planning should be ongoing and begin early on in a patient’s illness because patients may lose the ability to meaningfully communicate goals as their disease progresses. These ongoing conversations should incorporate relevant disciplines, and a plan for transitions of care. A well-designed organizational policy will improve efficiency, efficacy and quality of care for patients at the end of life consistent with both equity and value.

6b Resource Allocation Framework: Process, Methods, Assessment & Evaluation

Health care delivery organizations face difficult decisions of health care resource allocation including but not limited to non-beneficial treatment and end-of-life care. Organizations have a limited set of resources provided to them through policy and financing of healthcare and must then determine how to spread those resources among the community of patients that they serve. A resource allocation framework is needed for these organizations to make decisions when facing scarcity of resources based on equity and value assessments. This resource allocation framework should include process, methods, assessment and evaluation.

6bi Process & Methods

The resource allocation framework should be developed at the level of the health care delivery organization based on moral agency of health delivery organizations and associated responsibilities toward protection and promotion health and human rights. The process for resource allocation should incorporate the roles of the physician, patient or surrogate, and ethics committee.

Process for Resource allocation

Resource allocation has, thus far, been primarily relegated to national and global debate on priority setting. National agencies aim to align with the social values of a population into health care resource allocation by fulfilling procedural justice, accountability and transparency.58
Although there has been significant policy debate on these issues, comprehensive policy to address priority setting of health care resources has not been developed yet in the United States. There have been some themes in public opinion surrounding health care priority setting, but none have been established as universally accepted. In terms of national health care priority setting, public opinion tends to favor – in varying weighted distribution – the young over the old, the severely ill over the less severely ill, and those with self-induced illness or high socioeconomic status as lower priority, larger health gain but at a diminishing rate, life extension over quality of life enhancement - although reversed at end of life.\textsuperscript{59} Differences in public opinion and related barriers policy have prevented a national framework for health care resource priority setting.

Although efforts toward national policy for health care priority setting is essential, applied resource allocation at the level of the health care delivery organization is also needed. There is a need for pragmatic resource allocation that fits within the health care delivery organizational structure, aligned with political realities, and reflective of unique challenges that result from the heterogeneity of health care organizations and the patient populations that they serve.\textsuperscript{60} Even if and when a national policy framework to set priorities in health care is developed, health care delivery organizations will still be left to implement these policies within the unique constraints they face based on their patient population, payer mix and geographic barriers. Health care delivery is not value neutral and health care leaders should be expected to carry out national policies while incorporating the moral objectives of the delivery organization.\textsuperscript{61} Therefore, an ethical resource allocation framework is needed for health care delivery organization now and will continue to be needed into the future.

This framework will need to give specific guidance for decision-making processes, but allow for context-specific decisions based on characteristics of the organization’s patient
population. For example, an ethical framework for resource allocation should consider the influence of historical patterns and political pressure, including structures, processes, attitudes, behaviors and measurable outcomes.\(^{62}\) Due to the high level of population diversity in the United States, these patterns will vary between different delivery organizations.

An organizational resource allocation framework should incorporate both bedside decision-making and organizational policy development, as well as a forum where the community and stakeholders can participate in case review. Once community input has been gathered, the resource policy committee will engage in a decision-making process that incorporates analysis, policy development, and education (Appendix B.) The committee will circle back with the community for commentary before implementing amended or new policy. This process will follow a cyclical model based on four key process areas: implement, report, evaluation and assess. (Appendix A.) This model will incorporate the two major levels of the resource allocation decisions – the organizational policy and bedside decision-making levels. Resource allocation falls under two major decision-making levels: microallocation decisions, which are focused on individual persons and macroallocation decisions, such as hospital budgeting of spending that is available.\(^{63}\) An effective health care delivery resource allocation framework will need to incorporate both of these levels.

The policy and bedside level of the framework will be inter-related as bedside decision-making will inform policy and vice-versa. Education will be a significant connector of these two levels. The education piece should include didactic approaches to social and health equality, including the development of empathy and critical self-reflection, that cultivates a lifelong learning process of culturally sensitive clinical interaction with a recognition of the narrative and
history of other cultural groups. Education within the framework will focus on supporting shared decision-making and culturally competent patient-centered care.

The organizational policy level will be essential to provide guidance and support for frontline and bedside decision-making when providers and staff face resource limitations. Organizational guidance can help with ethical front-line decision-making that avoids rationalization and denial and instead uses reason combined with empathy. This guidance can help providers to avoid bias in bedside decision-making. Providers will face a lower level of moral distress and not be forced to rationalize unethical decisions. It will also support effective shared decision-making and focus on patient goals, preferences and values.

Shared decision-making will be a focus at both the bedside and organizational policy level of the framework. Shared decision-making is needed to determine the true needs of patients, and to differentiate between patient needs and desires then comparing benefits and tying decisions to evidence-based medicine. Policy will support providers and staff to engage in shared decision-making through education and communication tools. Physicians at the bedside will implement shared decision-making and provide feedback to policy to improve this process into the future. This feedback loop and connection between the bedside and high-level policy will be essential for the success of the framework.

The connection between frontline or bedside care and the policy component of the framework can be supported by incorporating physician leadership in policy decision-making processes. Physician leadership can help to bridge gaps between clinicians and administrators, create a unified health care agenda, implement patient-centered improvements, and facilitate training for clinicians to appreciate the constraints of financial, political and bureaucratic obligations. Involving physician leadership in policy development will ensure that decisions are
clinically sound and lend credibility to the policy-making piece of the process. It will also assist
with communication between the policy development and implementation of policy at the
bedside. The policy component of the decision-making process will incorporate evidence-based
decision-making shared decision-making processes that provide guidance for physicians at the
bedside. This will include evidence and research to support equity of care. Effectiveness
research can support equity in treatments to those with equal morally relevant needs, and be used
to support education and training.\textsuperscript{68} Policy that is within the framework but specific to the health
care delivery organization will be responsive to specific resources available to the organization
balanced with the morally relevant needs of the organization’s patient population.

Cultural competence will be an important aspect of policy decision-making and
implementation within the framework. Cultural competence can improve effective
communication and quality of care for patients with diverse sociocultural backgrounds, reducing
racial and ethnic disparities that are both unjust and costly.\textsuperscript{69} The incorporation of culturally
competent policy development and cultural competence as part of education for providers and
staff will support equitable value-based resource allocation decisions. Cultural competence helps
providers to understand patient goals and preference and to engage in effective communication
with patients. In addition, beneficial tools and approaches can be incorporated into the
framework as they become relevant. For example, technology tools could be considered, such as
the use of telemedicine, if they can improve the efficiency of resource allocation within the
health care delivery organization.\textsuperscript{70} As new tools such as technology solutions become available,
health care resource allocation policy development can assess and utilize as appropriate.

The connection between organizational policy decisions and bedside decision-making is
essential for an effective resource allocation process at the level of the health care delivery
organization. Consequences of macro-level decisions should be monitored, and professional integrity should be protected.\textsuperscript{71} Incorporating both organizational policy and bedside decision-making into the resource allocation decision-making process will protect the integrity of both physicians and patients. The roles of the provider, patient (or surrogate) and ethics committee will be essential for an effective resource allocation framework process.

\textit{Roles of the Provider, Patient and Ethics Committee}

The provider, patient and ethics committee will all have crucial roles in the resource allocation framework. The physician-patient interaction should be based on shared decision-making and mutual respect and aligned with the goal of patient-centered care. The ethics committee will support and mediate the shared decision-making process when there are significant barriers or value conflicts between the physician and the patient.

The shared decision-making process is at the foundation of the resource allocation framework, from both the bedside and policy support perspective. Shared decision-making can help patients and surrogates more effectively express preferences and understand options more clearly.\textsuperscript{72} Shared decision-making also helps physicians. Physicians may engage in shared decision-making to share uncertainty and avoid interventions or tests with little or no benefit.\textsuperscript{73} There may be many possible options to treat the patient. Without understanding the patient’s values and goals, it will be difficult for the physician to advise on which option would be the most beneficial. It will also help physicians to connect meaning to the treatment that they provide since it will be clearly aligned with patient benefit. When physicians feel that their work is meaningful, patient-physician interaction are improved and physician burnout is decreased.\textsuperscript{74} Both physician and patient satisfaction can then be increased with effective shared decision-making approaches.
Share decision-making is facilitated by effective physician communication. Physicians should elicit patient’s preferences, assess the evidence-based information that patients need, then arrive at a treatment decision together with the patient, based on the best available evidence weighted by the patient’s values and preferences. The physician is the clinical expert on treatment options, while the patient is the expert on their own values and goals. The physician must help the patient to define and express their goals of care, and then match options for treatment to those expressed goals.

Share decision-making is especially crucial in situations where the solution to meeting a patient’s goal is not obvious, or where a patient’s goals are impossible to achieve. When facing ethically contentious decisions, physicians should assess context-specific moral norms then lead a participatory and inclusive discussion with democratic decision procedures, rather than focusing solely on the opinion of traditional elites. The physician, in other words, must incorporate the context of the decision-making for the patient in front of them. Medical ethics, distinct from everyday ethics, incorporates a moral commitment decision-making informed by professional rather than personal moral judgement – meaning that others should not be asked to bear the weight of a physician’s personal convictions. Physicians must incorporate the patient’s values and goals, rather than a paternalistic decision based on the physician’s own personal values. Organizational policy can support physicians in this process through training and development of nonclinical competencies. Nonclinical competencies should be included in physician training and practice-based learning, including communication skills, professionalism. These skills will help the physician to assess the benefit versus the costs to the patient of a particular treatment option by understanding the patient’s goals and how they can address situations of conflict. Shared decision-making is not always easy. Obstacles to shared
decision-making include the inherent uncertainty of most medical decisions, lack of consistency, and strength and quality of clinical evidence.\textsuperscript{79} It can be difficult to match a patient’s goals with a suggested treatment when the outcomes of a treatment are not certain. Health care delivery organizations can support physicians facing these uncertainties by developing evidence-based, decision-making guidelines when possible. For example, physician education and palliative care guidelines can support patient and family-centered end-of-life care.\textsuperscript{80} Support and guidance from the resource allocation framework can alleviate some of the moral burden that physicians may face from decision-making uncertainty.

Frontline staff also play an important role in the development of the resource allocation framework. Nurses require organizational enact decisions that benefit the patients they care for. Nursing requires integrity and courage to advocate for patients, intervene during distressing situations, innovate practices to promote individualized care, question physician orders when needed, and advocate for safe conditions.\textsuperscript{81} Creating a culture where nurses are able to engage with the resource allocation process will benefit patients and contribute to efficient and efficacious patient care.

In addition, hospital policy should support the surrogate decision-making process including life-prolonging decisions that require high-intensity care with a high risk of death.\textsuperscript{82} Surrogates face many barriers and challenges to shared excision-making, especially during difficult end-of-life decisions. Surrogates can face conflict from family dynamics and unspoken filial expectations, so physicians should facilitate communication to address surrogate coping and support surrogate decision-making.\textsuperscript{83} The shared decision-making process can support surrogates in difficult decision-making, and help to clarify goals of care for the provider.
When there are conflicts in the shared decision-making process that the provider and patient or surrogate cannot resolve, clinical ethics committees can provide valuable facilitation and moderating services. Clinical ethics committees can help with resource allocation decisions by raising awareness of ethical aspects of resource allocations, bridging clinical practice with higher-level decisions- and promoting fair resource allocation and stakeholder rights and interests. Clinical ethics committees trained in morally relevant criteria can help to guide patients and physicians to make decisions together when there are conflicts of value.

The resource allocation framework will need to facilitate a close relationship between organizational policy and bedside decision-making. In addition, assessment and evaluation that incorporates a close relationship with the community that the delivery organization serves.

**6bii Assessment & Evaluation**

The resource allocation framework will include a robust assessment and evaluation component. This component will facilitate community involvement in both initial needs assessment and evaluation of established policy for resource allocation.

*Assessing Resource Allocation*

The assessment process will include defining the patient’s goals, determining the patient’s tolerable costs (such as quality of life measures or complications,) and ensuring stakeholder understanding of patient goals and values. When specific policy needs to be developed based on scarcity of resources, a general assessment will be performed of the benefits of the intervention and which types of patients would benefit from the intervention. The process will be transparent with an appeals process. Resource allocation should incorporate evidence-based care including guideline creation, guideline adherence, assessing quality measures and guidelines, outcomes research and safety. The assessment of resource allocation policy will
focus on the development of guidelines taking bedside decision-making challenges to the policy development committee responding to these challenges.

Stakeholder deliberation is an important part of the resource allocation process since value judgements and preferences may vary between various stakeholders.86 The assessment of policy priorities will incorporate stakeholders and community members that the health care delivery organization serves. Prior to the development of policy, the community and stakeholders will be invited to a designated forum for open resource allocation discussion. Problems that have been identified at the bedside will be presented and discussed at this forum, and community input will be documented. Since health care is – at least partially – a publicly financed community commodity, allocation of resources should incorporate relative social value estimates, social norms, and citizen values.87 The community forum will be a venue for the community to express social values and give feedback on allocation decisions that affect them. Values of the communities that health delivery organizations serve should be incorporated into policy development, although the weight of community input should be carefully considered88 The community feedback will be documented for further assessment by the resource allocation committee. For example, health gains of special interest may be emphasized by the community but not be aligned with equity for the population. Health gains may be assessed based on a reference point where health gains below the reference point are weighted more than health gains above a reference point.89 If incorporating prioritization for the worse off, it is essential to define what "worse off" means, such as preferring those with fewer lifetime Quality-Adjusted Life Years (QALYs).90 Different types of ethics reviews might be needed for different contexts within the health delivery organization.91
The policy committee will deliberate this and other key points, considering community feedback in their assessment. Public engagement will be important to the framework since it can help to create legitimacy, transparency and accountability for resource allocation policy by developing popular support, identifying points of agreement and disagreement, identifying value judgement and normative aspects of the decision, and garnering public trust in the decision-making process. The community of the health care delivery organization will be invited to policy discussions in the assessment phase, and also in the policy evaluation phase.

Evaluating Resource Allocation Organizational Policy

The framework will be evaluated for effectiveness. After the resource allocation policy committee has gathered and assessed community feedback, they will develop an ethical resource allocation policy for the issue discussed. Policy committee assessment will include key ethical considerations of: distributive justice, procedural justice, interpersonal justice, informational justice, social responsibility and respect for human vulnerability. The committee will use the process of accountability for reasonableness when developing the policy and develop associated education necessary for policy implementation. Once this has occurred, policy will be ready for stakeholder and community evaluation.

Evaluation methodology should be transparent and incorporate community input. There is a need for a clear method to evaluate a resource allocation framework, which could incorporate efficiency and health outcome data that maximizes overall health but also addresses distribution of benefits and process indicators for allocation. This resource allocation criteria can be mapped out into buckets of feasibility, health level, health distribution, responsiveness, social and financial risk protection, and improved efficiency. Community feedback will be
assessed within these buckets, and compared to the committees assessment of justice, social responsibility, and respect for human vulnerability.

Community evaluation will be supported by any relevant data that would help in the assessment of the policy draft. In the current climate of accountability, data is needed to provide effectiveness information to consumers and stakeholders. Stakeholders should be given all of the information that they need to effectively evaluate each proposed policy. Involvement of community members and other stakeholders will not only provide perspectives that the policy committee may not have considered, but it will also create an environment of trust between the health delivery organization and the community. Legitimacy of priority setting can be improved by managing external stakeholder relationships, including government, citizens, the media and other external interest groups. By including the community that the delivery organization serves in policy evaluation, the priority setting process will be legitimized through transparency and accountability of the health care delivery organization.

External review is also helpful for the resource allocation committee to establish outcomes that are important to the key stakeholders, which are the community of patients that the health care delivery organization serves. Like other program evaluation processes in health care, the resource allocation committee should be subject to an evaluation process and continuous process improvement. Program evaluation should include a systematic process to evaluate established outcomes and determine the possible need for program revision. Including community evaluation in the cycle of resource allocation decisions will provide opportunity for continuous process improvement. It will also allow the committee to respond to changing community needs and demands when ethically relevant. In addition, program evaluation in health care can facilitate individual, team and organizational learning. The organization can
learn what their community needs, giving a voice to those who are directly impacted by resource allocation decisions.

The community who is most affected by decisions that the health care delivery organization makes should also be privy to the normative allocation criteria developed by the committee. The dimensions of equality that are normatively relevant need to be clearly defined since implicitly unfair allocation will occur without the employment of explicit allocation criteria. When the community is aware of the resource allocation decisions, they can act as their own advocates to protect against implicit bias in decision-making. Decision-making processes will be transparent and patients will be empowered with that information, helping them to become active members in the shared decision-making process.

The community can be given criteria to evaluate resource allocation decisions, and also the committee process itself. The CDC recommends that a program evaluation framework includes standards of program utility, feasibility, propriety, and accuracy through a cycle of describing the program, focusing evaluation design, gathering credible evidence, justifying conclusions, ensuring and sharing lessons, and engaging stakeholders. The committee can incorporate feedback about specific policy decisions but also about the decision-making process of the committee itself, as well as the implementation methodology at the bedside.

An ethically sound resource allocation framework is needed for health care organizations when there are not enough resources to respond to patient demand. This resource allocation framework must focus on the process that can respond to specific resources available as compared to the organization’s patient characteristics, payer mix, and other organization-specific barriers or relevant characteristics. A redefinition of rationing cannot overcome its baggage and this term can create unnecessary polarization and argument about rationing rather than address
root of the problem. Still, an approach to address limited health care resources is needed.

Although an approach at the national policy level is important, a framework at the level of the health care delivery organization is also needed. This resource allocation framework will fulfil the responsibilities that organizations have, based on their moral agency, to protect the right to health.


46 Myers, J. "Measuring Quality of End-of-Life Communication and Decision-Making: Do We Have This Right?" Cmaj 189, no. 30 (Jul 31 2017): E978-e79.


76 Salloch, Sabine. "Same Same but Different: Why We Should Care About the Distinction between Professionalism and Ethics." [In English]. *BMCA Medical Ethics* 17 (2016).


Chapter 7. Conclusion

An organization’s moral agency assigns its ethical obligation to protect the human right to health care, based in the foundations of equity, respect for human vulnerability and social responsibility. This obligation is particularly important to reduce social inequalities within health care, based on social determinants of health including race, ethnicity, culture, socioeconomic status, and access to health care. Health care organizations can start to address these issues by using cultural competency and shared decision-making, but these tools must be incorporated into a larger framework to promote health care equity within the confines of finite resources.

A framework of resource allocation puts the patient’s goals and values first, with recommended interventions presented in response. Resource allocation can also be used be in a broader sense when distributing specific finite resources. Based on obligations of moral agency, health care organizations are ethically obligated provide this framework, guiding the actions of its agents and protecting the human rights of the patients it serves.

The human right to quality health care provides the foundation for this framework. Human rights are based on the dignity of humans and are essential for all individuals to self-determine. Health is essential for humans to act freely and make choices about their lives and what is important to them. The duties to health were further defined through this dissertation as the right to quality health care. The right to quality health care is supported by principles of equity, respect for human vulnerability and social responsibility.

The right to health care includes the availability, accessibility, acceptability and quality outcomes. Realizing the right to health care includes the need for health care to be available. In addition to being available, these resources need to be accessible. All persons need have meaningful access to health care to realize the right to health. In addition to being available and
accessible, these resources must also be acceptable. Acceptability means that health care must include the services that are needed to the level of quality that is needed to promote and protect the right to health. Further, available, accessible, acceptable quality health care must be provide with respect to equity. This involves both horizontal and vertical equity. Horizontal equity explains that those with equal needs should be treated equally, while vertical equity explains that those with differing needs should be treated differently.

Health care is a human right based on respect for human vulnerability and social responsibility in health care. The nature of human vulnerability explains that all humans are vulnerable, which means that all humans are at risk of poor health. Special vulnerability is also an important concept for the respect for human rights. Special vulnerability explains that some humans are more vulnerable than others based on individual or group characteristics. Special vulnerability can be permanent or temporary. Social responsibility also provides support for health care as a human right. Health care is social in nature, and can be defined as a social good. Health care organizations should provide equitable, quality health care based on their social responsibility.

Health care quality is a function of human rights because it is needed for humans to meaningfully exercise other rights and freedoms, and vice versa. This right to quality health care should include care quality, patient experience, patient safety and cost concerns. These facets of quality should be incorporated into human rights protections with the goal of reducing disparities in health care. The human right to quality health care defines standards of care that should be protected, which is a needed clarification to existing human rights discourse. Clarity is needed on roles and responsibilities related to the protection and promotion of the human right to health. The human right to health is carried out by health care organizations since it requires that
individuals have access to the highest quality of health care possible in the context of available resources. The realization of this right to quality health care can be measured quality process and outcomes, plus patient safety, patient satisfaction and costs to the health care system.

Quality health care is essential for humans to thrive and to realize other rights. Standardization and accountability of human rights protections are needed to reduce health disparities and protect health equity. The obligations of health care delivery organizations include responsibilities for creating and sustaining quality health care, including measures of outcomes, process, satisfaction or cost. Health care delivery organizations must also address structures of inequality that influence quality and patient safety.

Social determinants of health – including race, ethnicity, culture, socioeconomic status and barriers to access – have a serious impact on health outcomes in the United States. Addressing these issues in the United States is especially challenging due to the multicultural nature of the US population. Factors such as race, ethnicity and culture can have a significant impact on health care access and outcomes. For example, Asian Americans patients can face barriers to access based on language incongruity and discrimination.1 American Indians and Alaskan Natives face barriers to quality health care as compared to non-Hispanic whites for various reasons including cultural traditions, perceptions of bias, provider communication, mistrust, beliefs and attitudes about care, cost, and continuity of care.2 Racial differences have been demonstrated in breast cancer treatment and outcomes, where black women have experienced worse outcomes than white women.3 In addition, geographical differences can create significant barriers to access. Individuals who live in rural communities face significant barriers to health care access independent of race, ethnicity and socioeconomic status.4 There are countless examples of health disparities resulting from social determinants of health. This issue
will only gain importance as racial and ethnic diversity in the United States will continue to increase over the next 50 years. These demographic trends will place growing pressure on health care systems to address human rights concerns related to the policy, financing and delivery of equitable health care. Although national policy and health care financing have a clear role in addressing these disparities, health care delivery organizations will have a special responsibility to promote equitable access based on their moral agencies.

The role of the health care delivery organization is based on its moral agency. The moral agency of a health care delivery organization requires a commitment to protect the human right to quality health care. The importance of this commitment is related to the finite nature of health care resources and the implication for health equity. Health care delivery organizations can use tools within an ethical framework to promote health equity and protect health and human rights – especially the tools of shared decision-making and cultural competency.

The moral agency of health care delivery organizations requires that they protect the human right to health. This moral agency describes how the organization enacts its goals and values of providing safe, quality care. The mission and values of a health care organization describe the moral identity of a health care organization. The obligations of health care organizations include promotion of quality care and protection of patient safety in respect of the right to quality health care. A health care’s agents carry out and embody its moral identity. Agents enact the moral identity of the organization. Quality, patient safety, and medical error are closely related.

Due to the nature of health care delivery, health care delivery organizations have moral responsibilities to protect the right to quality health care. This is explained by the express moral agency of health care delivery organizations. The moral agency of health care delivery
organizations is based on its ability to take collective moral action, and face collective moral retribution based on those actions. Organizations that can face punishment-as-retribution demonstrate rational agency since responsibility and punishment for corporate actions require the ability to analyze corporate actions as moral.  

Health care organizations can face collective consequences of actions (rather than singular agents blamed for actions of the organization,) due to the collective organization and resources behind those actions. The ability to assess and penalize an organization for collective action demonstrates its independent moral agency.

Organizations have obligations to promote and protect quality health care and patient safety, based on their role in carrying out the human right to health. The organization itself is the driver of quality health care, based on these traits. Organizations should also monitor quality outcomes to promote continuous quality assurance and improvement.

The health care organization should use an integrated approach to addressing issues related to quality in health care. Health care quality encompasses the interconnected components of the health care organization. These components cannot be separated and need to be addressed as at the whole organization level to adequately address health care quality. This moral agency is relevant to health care delivery organizations due to the nature of health care delivery services. A health care delivery organization clearly fulfills duties to the interests of others through organizational actions. In other words, the purpose of the health care delivery organization is to serve the interests of others. A health care delivery organization has collective integrity since it meets the needs of many and not just the few through its commitments, conduct, content, context, consistency, coherence and continuity. A health care delivery organization is a moral agent due to the moral obligations that result from this collective integrity.
Shared decision-making can provide a platform for health care delivery systems to address the common ground between physician and patient while respecting individualized needs. This process can be facilitated through informing and involving the patient and ensuring that the patient has adequate decision-making influence.\textsuperscript{10} This can be difficult for organizations to effectively facilitate. Barriers to shared decision-making can include time pressure, frequent alternation of physicians, and poor coordination.\textsuperscript{11} Shared decision-making requires a conscious organizational commitment and resources to ensure the support and success of this process. Shared decision-making is also closely connected to patient-centered care. The patient, including the patient’s unique goals and values are at the center of health care decision-making. The respect for human vulnerability and the social responsibility of health care share a focus on responsibilities to individual patients, as well as patient populations within health care delivery. Patient-centered care and shared decision-making can also enhance the effectiveness and legitimacy of the informed consent process.

In addition, organizations should cultivate cultural competency at all levels of decision-making to facilitate shared decision-making and health equity. Cultural competency involves an ability to interact with those who are culturally different from oneself with a consideration for cultural beliefs, practices, communication patterns, and health-seeking behaviors.\textsuperscript{12} Cultural competence enables culturally appropriate decision-making processes and encourages dialogue about health behaviors and biases that may adversely affect health disparities. Cultural competency is a tool that can be used by the organization to address ethical challenges of a multicultural society. It can help to address the social determinants of health including race, ethnicity, culture, socioeconomic status, and access. Social determinants of health can and should be addressed through cultural competency programs within health care organizations. Factors
that affect social determinants of health such as culture, ethnicity, and race will be more adequately addressed when an organization has an effective cultural competency program.

While shared decision-making and cultural competency can help health care delivery organizations address the burdens of health inequity, these two tools alone will not fully protect this right. These two tools, instead, should be integrated into a comprehensive framework in which health care delivery organizations can protect human rights and fulfil their responsibilities as moral agents. Presently, health care organizations lack a commonly accepted framework for assessing benefits and prioritizing resources to protect equitable health care access. There is a need for a framework focused on resource allocation with the intent of setting priorities within the confines of limited health care resources. Cultural competency and shared decision-making are important tools to promote health equity and human rights but, especially within the context of finite healthcare resources, health care organizations need additional and even more robust guidelines for addressing inequalities.

Health care delivery organizations have an obligation to protect the human right to health based on their moral agency. This includes an obligation to protect the nature of human vulnerability and honor their social responsibility. More specifically, health care organizations must promote equitable quality health care, but this creates major challenges for health care organizations when resources are scarce or limited, as they are in the United States.

Since health care resources are finite but demand is virtually unlimited, some people may not be afforded the resources they need for health care. There has been much debate on this issue in terms of health care rationing. The definition and arguments for rationing have thus far been inadequate responses to the problem of limited resources in health care. Health care rationing has also caused conflict and barriers to meaningful national policy discussion about the limitations of
health care resources. Because of this, no comprehensive healthcare resource allocation exists at the national level. This creates challenges to health care delivery organizations who are left with little guidance on how to allocate resources.

Even if there was national policy guidance for the allocation of resources, health care delivery organizations would still face significant challenges to implementation based on the variation of patient needs and payer mix that are unique to each delivery organization. Health care delivery organizations have an obligation to engage in ethically sound approaches to distribution of their limited resources. The process for these decisions should be founded in justice with a consideration for value. The process should be equitable for all patients, regardless of medically irrelevant characteristics such as race, ethnicity, culture, socioeconomic status and geographical proximity to health care providers.

The debate on medical futility highlights the need for a health care delivery resource allocation framework. When medical non-beneficial care is provided, resources are wasted and patients suffer. The major purpose of medical futility assessment is to determine whether an intervention should be limited or eliminated based on its lack of efficacy. This could be a helpful approach to evaluating and identifying waste within the health care system but it meets ethical challenge because it lacks normative criteria for assessment.

Shared decision-making and patient-centered care facilitated by health care delivery organizations can help to address issues related to non-beneficial care. When systematically supported and guided by organizational policy, shared decision-making and patient-centered care can be used to identify patient values and goals, and then make recommendations that are aligned with benefit to those values and goals. Through shared decision-making, nonbeneficial medical
care should be eliminated, since the patient and provider will decide on a treatment that is aligned with the patient’s goals and values.

The role of the health care delivery organization is to facilitate policy and practical decision-making to protect the human right to health care through equitable allocation of available health care resources. This is accomplished by instituting a framework that incorporates a resource policy committee, stakeholder commentary on developed policy, bedside decision-making and an option for the community that the delivery organization serves to provide input on future policy development. The resource policy committee should fulfil three major roles of analysis, policy development and education. Analysis should incorporate justice, respect for human vulnerability, and the social responsibility of the delivery organization. Policy development should utilize the accountability for reasonableness framework. Education should support cultural competency, shared decision-making and multi-disciplinary collaboration.

Through this framework, ethical resource allocation will be supported within health care delivery organizations.


## Appendix B

### Resource Policy Committee

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<th>Analysis</th>
<th>Policy Development</th>
<th>Education</th>
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<td>• Distributive Justice</td>
<td>• Accountability for Reasonableness</td>
<td>• Cultural Competency</td>
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<td>• Procedural Justice</td>
<td>➢ Relevance</td>
<td>• Shared Decision-Making</td>
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<td>• Informational Justice</td>
<td>➢ Publicity</td>
<td>• Multidisciplinary Collaboration</td>
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<td>• Interpersonal Justice</td>
<td>➢ Appeals</td>
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<td>• Vulnerability</td>
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<td>• Social Responsibility</td>
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