

A laboratory setting with petri dishes and a pipette. The background is a soft-focus blue and white, with a petri dish containing a yellowish liquid in the foreground. A pipette is positioned above the dish, with a drop of liquid about to fall. The overall tone is clean and scientific.

MODERN BIOETHICS

FRAMEWORKS FOR A CRITICAL THINKING APPROACH

FRAMEWORKS FOR BIOETHICS

Frameworks	Issue
Future of Medicine and Humankind	Genetics, Genomics, Cloning, Reproductive Technology
No Natural Disasters Syndemic Framework	Pandemic, Public Health, Environmental, Climate Change
Modern Privacy Framework	Big Data, Black-Box Medicine, Data Storage, Cybersecurity, Modern Privacy Law
Dignity-Based Framework	Person-Centered Care, Older Adults, Refusals, Doctor and Hospital Setting, Nursing Homes, Managed Care
Justice of Access	Allocation of Publicly Provided Goods, Vaccines, Social Determinants, Healthcare Policy, Clean Air (minimums in healthcare, education, wages)
Justice of Opportunity	Social Determinants of Health, Environmental, Healthcare and Educational Extras
Oversight and Empowerment Framework	Conflicts of Interest

Future of Medicine and Humankind Framework	Genetics, Enhancement, Complex Genomics and Precision Care	Example: Designing children to ensure extremely strong intellect, strength, and height.
Background	Science and technology move quickly. CRISPR, Chinese twins HIV resistance, cloning on the horizon.	I love this quote: “...a common response to the disquieting feeling that science is accelerating beyond our capacity to comprehend it -- let alone control it -- is to declare oneself fervently, if confusedly, on its side.” -Margaret Talbot
Stakeholders	Society (will this change humanity), individuals suffering from genetic conditions, individuals finding success w genetic conditions (what becomes of their community), future people, any autonomous person choosing for themselves	We do not want to stifle science, especially when so many discoveries can have dual purposes. Regulating the use may be better than banning a practice. If no purpose other than enhancement and it is a germline change, stronger argument against. If it can also cure a disease or prevents something with no other prevention tool, then analyze and regulate HOW IT IS USED.
Ethical Issue	Dignity, humanity, larger scope than justice or creating biological classes, who can access it. How do we weigh the interests of people who do not yet exist. The many views on what it means to be human—value of status quo. Autonomy to do for oneself—but should the enhancement be legal. Role of government in oversight.	Approving something with a safety concern (not at issue here) inversely related to the necessity (maybe take a bigger risk to prevent every future person from getting cancer than to prevent a cold. (Really, would target only those with genetic mutation certainly at first.)
Think Critically Considerations	Broad societal changes are not really regulated by the FDA. Yet the President’s Commissions may not represent people. Referendums or elected officials could inform regulatory body.	There is tension between deciding for oneself, one’s children, and society

No Natural Disasters: A Syndemics Framework

Protecting those vulnerable to climate change, weather events, and pandemics (as well as chemical spills and manmade environmental disasters)

Fact Pattern: Cyclone Amphan in India and Bangladesh kills 85 in 2020. Pandemic in India 238,000 deaths.

What We Know

Poverty creates vulnerability due to living conditions. Public policy contributes to climate change, increasing weather events. Public policy contributes to pandemic response.

Human suffering, sickness, vulnerability to storm and virus, commonalities. Rural villages are ill-equipped a year in to COVID-19 global pandemic.

Stakeholders

Broadly analyze who could be affected by the problem and the solution.

Global organizations (parties Paris climate accord), global interest in sustainability, vulnerable people, vulnerable indigenous groups, socioeconomically disadvantaged groups, those with sickness due to environmental exposures, corporations, governments.

Ethical Issue

Does the international community have an ethical duty to care for the vulnerable globally? How should countries weigh caring for their own citizens against providing humanitarian aid? Do corporations that pay less for labor in foreign countries have a moral duty to create fair pay and improve living conditions? Individual responsibilities. (Largescale actions like the Montreal protocol and Paris Climate Accord)

Who is empowered and who are the decision makers? Solutions recognize synergistic negative effects and how one can spiral downward when vulnerable to multiple events or circumstances. Climate change and the pandemic act synergistically.

Objective and subjective components. Anthropology. Public policy. Upstream and downstream. Do not isolate the variables.

How have the global community, local policymakers, incorporated prevention of suffering into policies?

Think Critically

“A syndemics framework examines the health consequences of identifiable disease interactions and the social, environmental, or economic factors that promote such interaction and worsen disease.” (Lancet) Identifying multiple contributing factors is necessary to solving largescale vulnerability.

Analyze policies that affect corporate behavior, protect indigenous people, corporate land use in other countries, broaden the context, then narrow to local actions, policies, and innovations. Biosocial.

Modern Privacy Framework	Harms and Benefits of Big Data	A company stores children's health records for many schools called Magnus Health. Parents prefer records in paper form stored only at the school.
Stakeholders	The public and all individuals (privacy as well as suffering when infrastructure is hacked like pipeline, shipping, state department, large Target credit card breach), corporations (reputation), government entities (role of hackers; national security)	The child, the child as a future adult, potential for extortion and discrimination.
Ethical Issues	Navigating the weighing process of benefits to individual and public health against possibly privacy violation, is privacy sacrificed once data is entered,	Is there a narrow solution—some parents submit paper documents. Are parents aware that Magnus aggregates and shares? Is the school obligated to tell the parents? Is the deidentification enough. Why are the families not paid if the data can be used commercially?
Macro to micro issues	Policies like California Consumer Privacy Act, role of HIPAA, European Union General Data Protection Regulation (GDPR) Individual's ability to keep things private.	From the Magnus website: "Magnus may aggregate your information with information from other users and share aggregated information with interested third parties." https://magnushealth.com/18-2-28-privacy-policy/
Considerations	Deidentification, Discrimination, Privacy, Black-Box method of clinical care, Cloud computing, edge computing, hackability, bad actors, future extortion, political manipulation, vulnerability of children,	Is there a data-generating patent allowing one company to use the data. Children are vulnerable and not decision makers with any control over their data.
Think Critically	Can convenience be put in ethical terms. What are the benefits beyond convenience? Are other substantive benefits ethically necessary?	Is there really a public or private health benefit to outsourcing data storage for children. (There is still a school nurse...)

Dignity-Based Framework for Person-Centered Care

Protecting those vulnerable to infractions of dignity

Fact Pattern: An older person refuses an invasive treatment for a disease with an 80 percent cure rate. The doctors challenge her capacity to decide for herself.

The Issues

Disagreements in care decisions. Ethical dilemma often stems from physician viewpoint in the care. Capacity is challenged in older adult populations often.

An autonomy violation is possible. Four principles approach could fail the person. Dignity-based considerations.

Stakeholders

Broadly analyze who could be affected by a solution. A person seeking, receiving, or refusing care. The public.

State interest, person, hospital, doctors

Ethical Issue

Is it appropriate to challenge her capacity if it has not been challenged before and she has been handling her own medical decisions? How do we weigh control over decisions surrounding lie and quality of life? How should be the decision maker?

Autonomy challenge based on paternalistic beneficence and avoidance of liability. Evaluate the importance of self-sufficiency to this individual and to the broader demographic.

Personal preferences can differ from a medicalized viewpoint. Doctors might feel authority to question. Is that proper?

The refusal itself could trigger the capacity assessment. Is there ageism? (Note that sometimes the law has a role in refusals—e.g. religious refusals for care for a child or Baby Doe laws.)

Think Critically

Autonomy, legal rights, humanism, micro-subjective, teleology. What is the “happy ending” and how much harm (to autonomy and physically from the treatment) should be required on the road to the ending?

Life at all costs, respect for autonomy, moral and legal rights, is the care paid for— justice and access to care. Interpretive sociology, context of culture, world, priorities.

Justice of Equal Access	A Framework for Equal Access to Equal Public Goods (clean air, education, living wages, global, police treatment)
Is the problem in the public sphere?	Identify it as a public problem. Justice of equal access acts as a floor but it does not apply to certain arguably private goods. It is difficult to use it to justify things seen as “extra”. For example, should it apply to a laptop for every student or just access to public school. It seems to apply to the COVID vaccine in the US.
Stakeholders	To identify the stakeholders, who is deprived; who provides; taxpayers. How detrimental is the deprivation to the party deprived?
Ethical Issue	Is it ethically permissible to fail to provide certain “public” goods? Is scarcity or a lack of funding a permissible excuse? How to identify which public goods are ethically compelled or merely permissible. That can identify which goods fall within the narrow fully public domain and which society is split about or may see as extras.
Learn the Causes and Solutions	Role of the power structure; politics, political will, philosophy, communitarianism, or social programs within capitalism, Economic structures producing the most wealth (capitalist countries with safety nets for the poor –some redistribution, welfare) Will private contributions fill the gap? How much will it cost and then what government entity must budget for it.
Think Critically	Are resources scarce? consider voting power, labor unions, political power, use of media to draw attention to deficit. Is there an issue of fiscal federalism—identify the role of federal government in providing even if the benefits flow to a state or locality.
Solutions	Public policy, identify the deficit, financial analysis, determine costs. Identify macro policy and benefits to individuals.

Justice of Opportunity	A Framework for Leveling the Playing Field (By Providing Something Additional) (Distinguishable from “distributive”)	Fact Pattern: the extreme cases-- A subset of the population needs extra help with homework. They do not have financial means to finance private tutoring.
Distinguish Kinds of Justice	Justice can require providing something additional to people or groups, In bioethics, justice is stretched to cover a lot of issues. This framework is designed to recognize an additional need and to provide a way to analyze whether it is a public responsibility.	Can we influence this subset’s success in a way that is empowering? Defining success. Education correlates to better wages and is a social determinant of health. They do have access to public school. Check on prevailing beliefs: resources are not always scarce.
Stakeholders	To identify the stakeholders, look to who is not thriving or needs something extra and who (if anyone) should have a role in providing it. Government should provide it if it would address the social determinants of health for a group. The responsibility of government to an individual is difficult to prove. Private, corporate, charitable, family members etc. can be sources of support. Power resource theory provides a backdrop to how political power can shape policy choices.	Government, taxpayers, society, parents, local community nonprofits, volunteers, corporate partners, children, business WHO BEST KNOWS WHAT THEY NEED
Ethical Issue	Should the person in need have access to help? Is it ethically compelled or preferred? Should justice go beyond distributive justice of equal access? Competing ways to be fair, competition for public goods. Is it ethical to fail to devote public resources to solve the problem?	Beneficence, justice, philosophy, rhetorical implications: dignity-based, possibly avoid terms like entitlement, charity, handout
Analyze the origin	Is there a lapse in policy? Upstream tax policy or school management? Is there a breakdown of the family unit? Is the family too busy or financially strapped to help? Objective and subjective components. Do high school kids need to earn money after school? Do parents want help for them—cultural values, religion, psycho-social.	If one hour of supervised homework daily would help, who can provide it? Should the school provide it or should a private tutor trade services with a parent? Is there a corporate incentive to contribute or mentor?
Think Critically	Resources are scarce, consider political will, local volunteerism, fairness, create objective goals	In the short term, innovative mentoring programs. Promote self-sufficiency. Dignity-based.. Strong basis for need for government action.
Solutions	Public policy, nonprofits, private, corporate. Consider long term policy changes. Practical solutions from ethics-driven analysis.	Immediate solutions include local community center using government grants and nonprofit infrastructure to provide group study halls after school. Is a long-term solution more ethical—prevention.

Oversight Framework: Conflict of Interest

Goal: protecting those vulnerable to conflicts, leveling the power dynamic. Discern when to prohibit, when to disclose and manage, financially distance the stakeholders, or when to sanction violations based on behavior, Benefits for stakeholders

Fact Pattern: A doctor who is a researcher worked on a cancer treatment and owns stock in the company that developed it. The person needing care wants to pursue an alternative with slightly lower efficacy and much more data.

Identify the Problem

What is the nature of the conflict—financial, ambitious, ability to influence a care recommendation. Person-centered approaches should protect the person in need of care.

We are uncertain whether there are enough protections in place to negate the conflict. We are unsure whether forgoing the possibly more efficacious choice will be good or bad.

Stakeholders

Broadly analyze who could be affected by a solution. Person-centered care framework applies as well. Any person receiving a drug, the public, companies producing drugs, all people who could benefit from the drug—relationships allow drug development

All of those (currently and in the future) wanting access to the treatment, the pharmaceutical company, the doctor who is also a researcher, the person receiving care

Ethical Issue

Is disclosing the conflict like not having a conflict at all? Does the doctor have a duty to provide the other product? Prevent future conflicts of interest. Is the conflict avoidable—should it be prohibited? Is the conflict manageable? Who decides?

Should she switch doctors and then objectively weigh her options? Practical and theoretical. Prevent big picture problems.

Identify and weigh the Benefits

Objective and subjective components. Are some of the issues also contributors to innovation and quicker pharmaceuticals on the market. Weighing.

Academic medical centers contribute to clinicians doing research. Partnerships with pharmaceutical companies are closer to the patient. An upstream change could end this type of conflict.

Think Critically @ Macro and Individual Levels

Autonomy, right to try, trust and knowledge asymmetry, Is in-house oversight enough? Is there any way to create distance – can research be done by a team that does not do clinical care? Research can then collaborate with pharma. Upstream AMC structure feeds the issues. Remember the value of public trust, trust in the doctor and hospital.

Personal autonomy, corporate freedoms, weigh stakeholder's interests (personal or financial)



HYPOTHETICAL TO ENCOURAGE CRITICAL THINKING ABOUT ISSUES AND FRAMEWORKS

A girl in Afghanistan is in the hospital and has cancer. The hospital in Afghanistan does not have cancer specialists or palliative care and is experiencing scarcity of chemotherapeutic agents. Flash flooding killed 150 people in Afghanistan in August 2020, one of whom was her father. Her cancer might respond to proton beam radiation or high dose chemotherapy protocols, for which she would have to travel to Europe or the United States. She does not have funding to do so.