Prologue

Marquette Beyond National Borders

MU Student in Brazil
Community-Based Global Health Program

Brazilian Students at MU Global Health Program
Marquette Beyond National Borders

Bolivia

Haiti

Uganda

Brazil
Global Bioethics and the Pandemic in Dialogue

1. Global Bioethics
2. New Approach
3. Reality
4. Preparing for a Pandemic
5. Framework
1. Global Bioethics

“We are in the same boat”… “We are all in this together”
This is not truth. We are in the same sea or storm, but not in the same boat.

Vulnerability
Vulnerability in Global Bioethics

- **Vulnerability in the Bioethics of US. Origin**
  It is connected to the principle of *autonomy* – Individual Freedom. Research with human subjects – Marginalized groups and minorities

- **Vulnerability in the Bioethics of European Origin**
  EU – substantive or ‘noun-like’ – US – adjective or ‘adjective-like’. Human being – is a contingent being with a natural vulnerability, a universal condition

- **Vulnerability in the Bioethics of Latin American Origin**
  Vulnerable populations – “process of vulneration”. Political implications – *socioeconomics factors* that make people vulnerable

- **Vulnerability in the Bioethics of African Origen**
  Very diverse – many ways and conceptions based on a wide variety of cultures and religions that influence all moral aspects and topics. “Personality” and corporality (body) – Community first rather than individuals. Principle of harmony

- **Vulnerability in the Bioethics of Asian Origin**
  Diverse – different perspectives, but all marked by values and principles. Special place of family in decisions
Vulnerability as a key principle for Global Bioethics

Although vulnerability appears with different characteristics around the world, they are not contradictory. We must see vulnerability as a continuous dynamic process – open to dialogue rather than a static universal concept. The principle of vulnerability presented in the Universal Declaration on Bioethics and Human Rights might help in this continuous dynamic process.

"Human Vulnerability needs to be taken into consideration in application and advances of scientific knowledge, medical practices and associated technologies. Individuals and groups with specific vulnerability needs to be protected and individual integrity of each person needs to be respected" (art. 08)
2. A New Approach: From Below, from the Reality

- Compassion
- Listening
- Community
- Shared responsibility
3. Reality:
The Drama of Vulnerable Communities in Brazil

Historical Genocide

Current Extermination

The bitter memories of previous epidemics have been reawakened by COVID-19. According to anthropologist Carlos Fausto, “Since the beginning of colonization, [indigenous peoples] had to learn the meaning of ‘epidemic’ in their own bodies”. According to a Kuikuro friend with whom Fausto spoke recently by telephone, “[COVID] ...is like the measles of my grandfather’s time”. According to a deeply traumatic account of the measles epidemic that swept the region in 1954, “[the disease] was sudden and swift, killing entire families without even leaving time to bury the dead properly. With everyone sick, no one was left to provide food, much less tend to the bodies”.

“The crisis caused by the COVID-19 pandemic clearly exposes indigenous peoples’ greater political, social, and environmental vulnerability. Experiencing daily violence and discrimination, indigenous people in Brazil live in precarious housing and sanitation conditions; face invaders and the damage caused to their territories; deal with food insecurity and lack of safe water, high infant mortality, invisibility of the indigenous families living in cities and towns; childhood marked by chronic malnutrition (25% of under-five children), and infectious and parasitic diseases such as diarrhea and pneumonia, the main causes of illness and death in indigenous children.” (Santos at all. 2020)

All this destruction is not our mark, it is the footprint of the whites, your make on the earth

Davi Kopenawa Yanomami
The Drama of the Poor in Brazil: Before and With Covid-19

A Normal Day in a São Paulo Hospital

A Day in the Pandemic in a São Paulo Hospital
Two Different Models of Healthcare Delivery/Systems

Brazil: public, social right, community participation, primary care focus and interconnected

USA: private, commodity, top-down, secondary and tertiary care focus, and independent

How does Catholic health care fit in these systems?
4. Preparing for a Pandemic

- **Context**
  - Urgency, High Demand and Scarcity of Resources

- **Ethics Shift:**
  - From *patient-centered care* (clinical ethics) to *population health centered care* (public health care ethics: distributions of risk, frustrations and benefits)
The Hasting Center for Ethics Suggests:

1. **Plan:** health care leaders from administrators and political leaders to clinicians, to bioethicist and community leaders

2. **Safeguard:** guaranteeing support to healthcare professionals and vulnerable communities

3. **Guide:** policies, protocols, ethics consultations, shared responsibility
5. Framework of Ethics Process of Decision Making

a. External Factors:
   1. Context/Culture
   2. Resources
   3. Values/Principles
a. Internal Factors

1. Diagnostic / treatment

2. Ethical Principles / resources
   
   E.g.:
   
   i. Dignity of the human being
   ii. Option for the poor
   iii. Equity/equality
   iv. Transparency
   v. Proportionality
   vi. Subsidiarity
   vii. …
Conclusion

- Active participation from below
- Consciousness of our limits (personal and resources)
- Awareness of the context
- Shared responsibility
- Transparency
- Compassion with all ALWAYS
Appendix

- New Research…
Participatory Action Research about the relationship between human rights, health-related policies and community participation in Brazil.

**Aim:** understand the impact of the last four years of health-related neoliberal policies on the public health services that low-income people received from the Unified Health System (SUS), the Brazilian public health system.

**Perspective:** from the narratives of the users of the system in a liberating theology approach of social activism.

Apparently, there is a conflict between the Brazilian public health system (SUS) – created after the 1988 Constitution that stated the right to health – and recent health-related policies favoring the private health sector.

**Three phases - project:**

1. Analysis of health-related policies.
2. Engaging with local communities in Brazil through PAR/LTM in order to understand the real impact of these policies in the lives of low-income families.
3. Qualitative analysis of the collected material from semi-structured interviews and community gathering observations.

**Results:** understanding how community members have handled this process of commodification of health, centralization of decisions in higher gov. bodies, and their access to healthcare services, measuring whether neoliberal policies improved or worsen the services they received and their participation of decision-making processes.

**Research Impact:** understanding of the consequences of neoliberal policies on population health; practical implications in the life of communities; community education on the roots of their own challenges to access health care and strategies to acting to strengthen the system.
Confronting bioethical issues raised by Covid-19 and how the pandemic has been addressed

2 Areas:
1. Clinical Practice – (e.g.: decision-making dilemmas, triage protocols, moral stress)
2. Public Health Strategies – (e.g.: quarantine, lockdown, epidemiological control)

Context: Urgency – Tension – Scarcity – Lack of proper information
– Basis of the Health System...

Values and Principles: justifications for decisions in clinical practice and public health strategies

Three Steps-Method:
1. Ethical dilemmas, vulnerable groups, and global principles
   A. Mapping ethical issues that vulnerable populations faced;
   B. Identify disparities in the way these issues happening among different social groups divided by race and class
   C. Identify Catholic social principles applicable to bioethics in a global health context
2. People’s experiences and narratives

a. Selected some people from different social groups identified before
b. How have patients and families been impacted by these ethical dilemmas and decisions?

3. Analysis

a. Compare people’s voices with the ethical issues and the proposal answers to them
b. Compare people’s voices and experience with principles from Catholic tradition

Final Goal:

Provide guidelines and resources to support decision-making processes for addressing bioethical dilemmas in a context of epidemic with the participation of the community in order to provide more efficient and less controversial actions of health promotion.