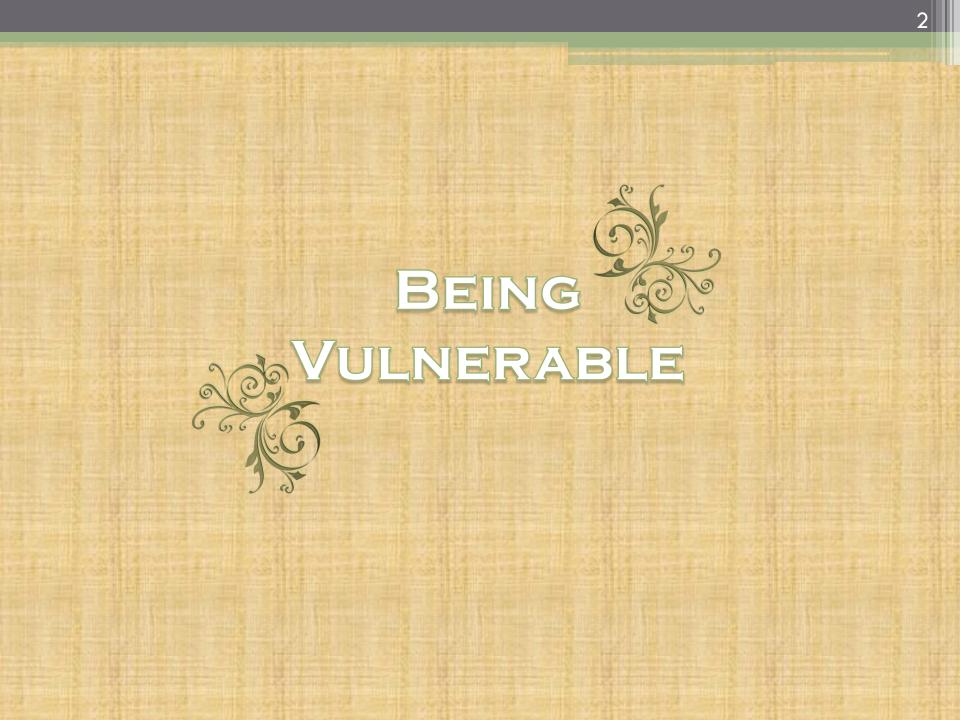


VULNERABILITY IN BIOETHICAL CONTEXTS

Ethics: Bioethics (Fall 2014) Laura Guidry-Grimes



STARTING POINTS

- What is the significance of identifying vulnerable persons and groups?
 - Justice concerns
 - Material inequities inequitable distribution of resources, lack of access, barriers to inclusion
 - Historical oppression recognition of the marginalized and silenced
 - Might be in need of additional protections against exploitation, coercion, harms
 - Belmont Report: "When vulnerable populations are involved in research, the appropriateness of involving them should itself be demonstrated" (17)

Vulnerability as a Label: The Problem & Challenge

"the concept of vulnerability stereotypes whole categories of individuals, without distinguishing between individuals in the group who indeed might have special characteristics that need to be taken into account and those that do not"

nose that do not" – Carol Levine, Ruth Faden, Christine Grady, Dale Hammerschmidt, Lisa Eckenwiler, and Jeremy Sugarman

FRAGILE HANDLE WITH CARE

Worries about Vulnerability Label

*Naturalizing" vulnerability
 Vulnerability as inevitable or common state...so not worth noticing or protecting against?
 Especially in bioethics...

'Vulnerability' becoming watered down, useless term

Rigid designation
 Essentializing vulnerability in virtue of fixed trait
 Feeding into stereotypes

 LAYERS OF VULNERABILITY
 ♦ Economic, political, and social exclusion & barriers → layers of vulnerability

Different **types** of vulnerabilities (many layers possible)

Vulnerable to different degrees (weight of layers vary)

 As a flexible, relational, dynamic term
 Accommodate particularities, circumstantial details – highly contextual

 Not looking for necessary and sufficient conditions or categories of populations

WHO IS VULNERABLE?

Not one homogenous group
 Can change over time

 Someone can have some layers of vulnerabilities in some circumstances and not in others.
 Medical intervention, research protocol can take advantage of, reinforce vulnerabilities

Situations render someone vulnerable (not group affiliation, sex, etc.)

Historically vulnerable groups are potentially being targeted, de facto or de jure, by social institutions and power relations.

Example: HIV and Women in SOUTH AFRICA Vulnerabilities in virtue of... being a woman? [category] being of reproductive age? [category] being poor? [broad category] relative sexual powerlessness as a result of confluence of environmental factors?

> Identify and ameliorate those environmental factors, so these women are not rendered vulnerable (target each layer)

MITIGATING VULNERABILITY

Focus on changing the situation that renders someone vulnerable, rather than viewing one group as necessarily vulnerable in virtue of a fixed trait.

Identify the multifaceted and changing ways in which a person can be vulnerable, recognizing the numerous contextual factors.

 Give recognition to some of the central barriers experienced by historically marginalized groups.
 Look for multiplicity of answers, not oversimplified solutions



CASE STUDY: REPORTING UNLAWFUL ABORTIONS



IN EL SALVADOR: BACKGROUND INFORMATION

- 1998-present: life at the "moment of conception" protected against abortion
 - No exceptions for rape, incest, fetal malformation, life of the mother
 - Active law enforcement apparatus
 Prison sentences for medical doctors, women, and those who help women with the abortion

Result: "abortion tourism," self-induced, or back-alley
 Frequently report to hospital as attempted suicide

 Ulcer drug commonly used to cause contractions and bleeding, giving false impression of miscarriage

VULNERABILITIES

 Pregnant women in El Salvador (especially those who are not wealthy) are vulnerable along several dimensions:
 Health, security, self-determination

 Legal and medical institutions create additional barriers to health, security, and self-determination.
 Legal punishments, long-term prison sentences

 National Secretariat of the Family and hospitals instruct health care workers to report suspected abortions.

 Women have to seek unsafe or costly options, subject themselves to significant risk, deceive medical staff and/or legal authorities, refrain from taking advantage of support systems.

VULNERABILITIES

- Conflicting legal and ethical obligations
 - Salvadoran Medical College Code of Medical Ethics: "requires health care professionals to keep secret what they see, hear or discover in the context of their professional role" (qtd. in McNaughton 1927)
- Can mitigate some of these vulnerabilities:
 Clarifying professional and legal duties, weight of each
 - Strengthen support systems and services for women's reproductive health
 - Increase options, especially for the poor
 - Educational campaigns to clarify rights and obligations
 - Long-term efforts to make women more secure



FOR CONSIDERATION

When medical research or clinical policies worsen the pre-existing vulnerabilities of certain populations, what moral responses are called for?

What responsibilities do researchers and clinicians have, and what responsibilities do they not have?

What is the line between adequate protection and overprotection of vulnerable persons?

What are the moral concerns with erring either way?

Should vulnerable populations be excluded from participating in clinical research? Should there be additional safeguards?

Other examples of how vulnerability factors into clinical ethics, research ethics, or public health ethics?



ADDITIONAL RESOURCES

Carse, Alisa L. 2006. "Vulnerability, Agency, and Human Flourishing." In Health and Human Flourishing, ed. Carol Taylor and Roberto Dall'Oro, 33–52. Washington, DC: Georgetown University Press.

Carse, Alisa L. and Margaret Olivia Little. 2007. "Exploitation and the Enterprise of Medical Research." In Exploitation of Developing Countries and Biomedical Research, eds. Ezekiel J. Emanuel and Jennifer Hawkins, 206– 45. Princeton, NJ: Princeton University Press.

- Grimes, David A., Janie Benson, Susheela Singh, Mariana Romero, Bela Ganatra, Friday E. Okonofua, and Iqbal H. Shah (World Health Organization). 2006. "Unsafe Abortion: The Preventable Pandemic." The Lancet, Sexual and Reproductive Health Series: 1-13 (pre-print WHO report).
- Guidry-Grimes, Laura and Elizabeth Victor. 2012. "Vulnerabilities Compounded by Social Institutions." International Journal of Feminist Approaches to Bioethics 5 (2): 126-146.

Hitt, Jack. 9 April 2006. "Pro-Life Nation." The New York Times.

Kottow, Michael H. 2003. "The Vulnerable and the Susceptible." Bioethics 17 (5-6): 460-71.

Levine, C, R. Faden, C. Grady, D. Hammerschmidt, L. Eckenwiler, and J. Sugarman. 2004. "The Limitations of 'Vulnerability' as a Protection for Human Research Participants." *American Journal of Bioethics* 4 (3): 44-49.

Luna, Florencia. 2009. "Elucidating the Concept of Vulnerability: Layers Not Labels." International Journal of Feminist Approaches to Bioethics 2 (1): 121–39.

McNaughton, Heathe Luz, Ellen M. H. Mitchell, Emilia G. Hernandez, Karen Padilla, and Marta Maria Blandon. 2006. "Privacy and Conflicting Legal and Ethical Obligations in El Salvador: Reporting of Unlawful Abortions." American Journal of Public Health 96.11: 1927-1933.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1978. The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research. Web.

Powers, Madison and Ruth Faden. 2006. Social Justice: The Moral Foundations of Public Health and Health Policy. New York, NY: Oxford University Press.