THE ELEPHANT IN THE ROOM
BIOETHICAL CONCERNS IN HUMAN MILK BANKING

MOTHERS’ MILK BANK, SAN JOSE

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The Elephant in the Room: Bioethical Concerns in Human Milk Banking
derives from a bioethics consultation paid for by Mothers’ Milk Bank, San Jose, through a contract with Ninth Month Consults: A Bioethics Consultation Practice for work from December 2016—May 2017.

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Learning Objectives

1. To understand how the definition and history of modern bioethics applies to matters of breastfeeding.

2. To acquire tools to identify bioethical conflicts related to breastfeeding.

3. To learn how a paradigm utilizing the three principles of Beneficence, Autonomy and Justice can direct actions when faced with bioethical conflicts in breastfeeding.
“The Lancet series 115 reports specific outcomes of breastfeeding as improvements in: 1) lifetime benefit for babies health increasing with the duration of breastfeeding over two years, and 2) ameliorating or eliminating major diseases including gastrointestinal and lung problems for full term, early for dates, and low birth weight infants. When mothers are able to breastfeed it decreases their risk and incidence of chronic disease, obesity, diabetes, and cardiovascular illness for themselves and their babies as they age.

Additionally, mothers who have breastfed have lower incidences of breast and other reproductive system cancers. The World Bank estimates that the deaths of 823,000 children and 20,000 mothers each year could be averted through universal breastfeeding. Breastfeeding also provides economic savings through health promotion estimated at US $300 billion per year.”
WHY DID MOTHERS’ MILK BANK SAN JOSE WANT A BIOETHICS CONSULTATION?

Breastfeeding \(\alpha\) Health

The next best thing in the absence of breastfeeding is breast milk.

MMB needed to double the amount of donated milk to meet the anticipated needs of babies in 2018 resulted in Mothers Milk Bank, San Jose (MMB-SJ) seeking a bioethics consultation to help with the organization's strategic planning. How did they get into this reactive position focused on the daily deficit of available breast milk to meet ever-growing needs—and how can they get out of it?
WHAT IS BIOETHICS ANYWAY?

BOTH A BRANCH OF PHILOSOPHY and a PROFESSIONAL DISCIPLINE, Clinical Medical Ethics, Pediatric ethics, Environmental Ethics, Neuroethics…

IT’S ALSO AN ORGANIZED WAY OF CONSIDERING MORAL CONFLICTS
What Prompts A Bioethics Consultations?

“NARRATIVE CHAOS”
WHAT’S THE STORY? Narrative Conventions Clarify Ethical Questions

1. Decreased availability of human milk because of for-profit milk banks and products?
2. Hospital Accreditation & World Breastfeeding Trends Reports?
3. Medical Association Policy Against Unregulated Breast Milk Exchanges?
4. Tiny Babies (24-22 week Gestational Age)?
5. Increased Premature Baby Survival means increased hospital and community need for breast milk?
6. Inadequate Political, Regulatory, and Community Support for Nursing Mothers and especially working mothers.
7. USA Infant Mortality and Breast Milk inequity?
CLARIFYING THE QUESTION:

“SHOULD WE LET BABIES STARVE?”

CASUISTRY: Uses cases or stories to help clarify moral questions and answers.

MORALITY is the ability to know right from wrong.

ETHICS is the step by step approach to actualizing morality.

My apologies to real theologians and philosophers!
FEELING OVERWHELMED?
THE CATCH IS TO LOOK AWAY
FROM THE LIGHT to find—
“The Eyebrow Raising Event”

The Good News is: Most children over the age of seven have a basic sense of the difference between good and bad, right and wrong—or morality.

START THERE.
Yet, a peculiar characteristic of the human experience is that ‘good’ is almost always clarified by the challenge of facing that which might be ‘bad’.

If You HAVE AN ICKY FEELING FIGURE OUT WHY.

The impression of injustice lassoes the desire for justice, whose need for promotion might not have been noticed without a potential violation having occurred.

The intuition of a possible ‘bad’ thing having happened is often referred to in bioethics as ‘an eyebrow raising event.’

10 Key Cases Relevant to Bioethical Concerns in Human Milk Banking

- Case #1: Monetary Profit Breast Milk Banks & Informed Consent, i.e. Prolacta-Bioscience Case *
- #2: Buying Cambodian Women’s Breast Milk”
- Case #3: J. Marion Sims, Slave Women, Gynecological Surgery & the Giants of Medicine
- Case #4: Medicine, The Holocaust, Nuremberg Doctors’ Trials, Universal Declaration of Human Rights & the Helsinki Agreement
- Case #5 The USA Public Health Service Syphilis Study (USPHSSS) at Tuskegee, Alabama
- Case #6 Forced Sterilization of Hispanic and Black Women at LA County Hospital Madrigal v. Quilligan”
- Case #7: AZT Placebo Trials to block maternal-fetal HIV/AIDS transmission in Côte d’Ivoire and Thailand
- Case #8: Thailand Human Cadaver Tissue Donation, Harvesting, and Resale
- Case #9: The HeLa Cell Line and Henrietta Lacks
- Case #10: Breast Milk Tissue as Coded Information, STEM cells & Microbiota
BIOETHICAL CONFLICTS ARE BETWEEN RANKED COMPETING GOODS

4 Topic Method of Clinical Ethical Decision Making

- Clinical Indications (Beneficence)
- Autonomy (Patient Preference)
- Quality of Life (Justice)
- Contextual/Geo-social-political (Justice)

Case #4: Medicine, The Holocaust, Nuremberg Doctors’ Trials

THE OBLIGATION TO DO GOOD WITH KNOWLEDGE

Clinical Indications (Beneficence)
Case #1: The Holocaust, Nuremberg Doctors’ Trials, Universal Declaration of Human Rights & the Helsinki Agreement

**THE SEA WATER EXPERIMENTS**

**WORLD WAR II AND THE HOLOCAUST (1939-1945)**
60 MILLION PEOPLE OR 3% OF THE 1940’S WORLD POPULATION
6 MILLION JEWISH PEOPLE
A Theory of Human Motivation/ Maslow’s Hierarchy of Human Needs
A. H. Maslow (1943)
Originally Published in Psychological Review, 50, 370-396
A Theory of Human Motivation
MARION DIAMOND, PhD, Neuro-Anatomists who dissected Albert Einstein’s Brain ALSO PROVED Positive STIMULUS and NUTRITION INCREASE # BRAIN CELLS

How? Do we get our kids from starvation to self actualization

Brain growth i.e. weight and function varies with stimulus and nutrition as was shown by renowned neuro-anatomist Marian Diamond several decades ago both weight.


**Autonomy**
The right of persons to do that which is in their own enlightened self interest.
Prolacta Bioscience stocks warehouse-like freezers full of human milk. Based in City of Industry, Calif., it purchases the milk from some women for $1 per ounce. The company uses it to make fortifiers that are added to a mother’s or donor’s milk to deliver extra calories, proteins and minerals to premature babies. The products are expensive, at $200 to $300 for a one-day supply. But they win praise from NICU physicians like Kim, because they can replace fortifiers made of cow’s milk, which are known to increase the risk of necrotizing enterocolitis and sepsis. (Note a 1.5 Kg neonate would at best use only 24ml/day of Prolacta — not measured in ounces.)
Cambodia bans export of human breast milk after US operation raises concern

Unicef hails decision following controversy centered on Utah-based Ambrosia labs, as activist says Cambodian mothers ‘often have no other choices’

The offices of Ambrosia Labs in the Stung Meanchevy neighborhood of Phnom Penh, Cambodia. Photograph: Tan Chhin Sothy/AFP/Getty Images

AFP in Phnom Penh

BIOETHICAL CONFLICTS ARE CONFLICTS BETWEEN COMPETING GOODS

*What Are The Competing Goods in The Prolacta Story?

*In the Ambrosia Prolacta Story?

*Which Good Do you Support and Why
INFORMED CONSENT IS A PROCESS NOT A PAPER TO SIGN

INFORMED CONSENT IS AN OPERATIONAL ARM OF AUTONOMY
Capacity Assessment for Informed Consent

Tier I: Disclosure

a. Benefits of the donation: what is expected to happen to the tissue? What happens to any parts left over?
b. Burdens associated with the donation: what happens if permission for using the tissue is rescinded?
c. Risks associated with donating?
d. Alternatives to donating (other forms of participation in the goals)?
e. Voluntariness of the donation—donor answer ‘no’ when asked if another person, or circumstances beyond their control, is forcing the donation.

Capacity Assessment for Informed Consent
Tier 2 Barriers to Disclosure

Among possible barriers to disclosure are:

a. **Physiological** state: illness, pain, fever, shortness of breath…

b. **Psychological**: stages of grief, fear, anxiety, depression, fiscal, psychological, isolation, poverty, or allostatic load

c. **Educational differences**: including but not exclusive to language, literacy

d. **Institutional Chauvinisms**: racism, sexism, classism, colonialism, racism

e. **FaSSI**: Family, Struggles, Spirituality, and Icons” (WHAT ARE YOU R WORRIES)
Case #3: J. Marion Sims, Slave Women, Gynecological Surgery

Twenty years ago today, America apologized for Tuskegee syphilis experiment

Updated May 16, 2017; Posted May 16, 2017

Herman Shaw, one of the last survivors of the Tuskegee study, raised his arms with praise as President Clinton apologized for the infamous experiment. MUST CREDIT: Washington Post photo by Susan Biddle. (Susan Biddle)
Case #6 Forced Sterilization of Hispanic and Black Women at LA County Hospital

Lack of appropriate informed consent is historically the most common bioethical violation in medical, research and other settings. The history of bioethics is replete with such examples. Among those examples is the forced sterilization of Hispanic, Black and other vulnerable women.

Case #7: AZT Placebo Trials to block maternal-fetal HIV/AIDS transmission in Côte d'Ivoire and Thailand circa: 1997

Welcome to DoSomething.org, a global movement of 6 million young people making positive change, online and off! The 11 facts you want are below, and the sources for the facts are at the very bottom of the page. After you learn something, Do Something! Find out how to take action here.

1. Out of the 34 million HIV-positive people worldwide, 69% live in sub-Saharan Africa. There are roughly 23.8 million infected persons in all of Africa. [1]
Breast milk is a liquid tissue filled with cells that have components with a specific purpose. In some states of the USA it is regulated as so.

NOTA (The North American Transplant Act) does not allow for the buying and selling of organs reasonable. Reasonable cost for the work of donating tissues can be enumerated. Organ retrieval services have been known up profit for $80 thousand for the retrieval.

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- Case #9 & Henrietta Lacks,
- The HeLa Cell Line & Human Genome
- The Stem cells & microbiota

A Family Consents to a Medical Gift, 62 Years Later

Who owns tissues excised in medical procedures?
No Justice below the line until we handle Beneficence and Autonomy above the line.

4 Topic Method of Clinical Ethical Decision Making

Clinical Indications (Beneficence)

Autonomy (Patient Preference)

Quality of Life (Justice)

Contextual/Geo-social-political (justice)

OR PUT ANOTHER WAY — THERE IS NO HOPE OF EMPOWERING WOMEN’S RIGHT TO BREAST FEED WITHOUT ADDRESSING BARRIERS TO OUR AUTONOMY FIRST.
2016 USA
Infant Mortality by race

<table>
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<th>Race</th>
<th>Rate per 1,000 Live Births</th>
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<tbody>
<tr>
<td>Non-Hispanic Black</td>
<td>11.4</td>
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<tr>
<td>American Indian/Alaska Native</td>
<td>9.4</td>
</tr>
<tr>
<td>Native Hawaiian or other Pacific Islander</td>
<td>7.4</td>
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<tr>
<td>Hispanic</td>
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<tr>
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NORMALIZING BREASTFEEDING IN SOCIETY SAVES GENERATIONS
Thank you!

The Elephant…
is Available on Amazon
In Trade Paperback and Ebook

All Proceeds go to
Mothers’ Milk Bank