

Middle class pregnant women
and cord blood banks.
The Argentine case

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- This presentation examines the ethical and sociological problems of implementing new technologies such as cord blood (CB) stem cells.

Two parts:

- A. Theoretical and ethical about CB banks practices, vulnerability, and their impact on women,
- B. Policy making regarding implementation of CB banks.

A. Theoretical and ethical challenges:

- I want to test a new way of thinking vulnerabilities;
- I will challenge the traditional way of thinking vulnerabilities;
- I wish to analyze an often disregarded vulnerability related to CB banks practices.

B. Thinking on policies:

- I will consider the situation of some developing countries (DC): Latinamerican ones and, specially, Argentina.
- Considerations about DC and new technologies:
 - Heterogeneity among DC;
 - Middle income countries (i.e. Brazil, Mexico, Argentina) face both third and first world problems;
 - Hasty import of technologies without the proper infrastructure and necessary safeguards;
 - Difficulties to issue timely and adequate regulations.

A. Vulnerabilities and cord blood banks

- The traditional way of thinking vulnerabilities is through the concept of "vulnerable populations";
- Generally is associated and reduced to the poor and to people without resources;
- It implies a logic of "all or nothing": one population, one problem hence one solution.
- I wish to consider the situation of middle class pregnant women when asked to collect CB of their future babies.

A. Conceptual analyses of vulnerabilities

- Traditional “vulnerable population” model was strongly criticized because of its labeling and stigmatizing character. It implies stereotyping: putting someone a label that can not be easily taken out. It fixes the content and this cannot be changed.
- I propose an analysis based on “layers of vulnerability”.* It is a relational and dynamic concept.
- We should not think in “categories” or labels.
- Multiple and different layers of vulnerability can coexist.
- It can make a difference in policy design.

* Luna, F, “Elucidating the Concept of Vulnerability. Layers not Labels”, *IJFAB*, vol 2, N°1, spring, 2009.

A. Private cord blood banks practices in Argentina

- They present themselves as the providers of a “life insurance” for the future baby;
 - Advertisements and brochures in private obstetrician offices...
- => TARGET: middle class pregnant women.

A. Some challenges:

- Difficulty to obtain reliable information:
 - highly technical,
 - controversies among scientists regarding auto-transplants and allo-transplants, iPS cells.
- Informed Consent process:
 - lack of neutrality of the provider of information,
 - conflict of interest,
 - possibility of manipulation.
- Emotional pressure to the women/couple:
 - ideal mother paradigm.

A. Revisiting vulnerabilities:

- What about poor women form scarce resource settings?
 - they are not the target of private banks,
 - they can be donors CB at the public hospital,
 - they can have CB available for free for allo-transplant,
 - they have a public system available for free for ill siblings...

A. Revisiting vulnerabilities: Are middle class pregnant women vulnerable?

- **NOT:** for an analysis based in fixed categories that identifies subpopulations in a “essential” way (i.e. all pregnant women);
For the traditional view, vulnerable are the poor, not the empowered middle class women.
- However, the layered analysis of vulnerability allows considering the different problems private banks pose as layers that render a person vulnerable.

B. Controversies over cord blood banks

- The Argentine case:

Until 2009 there was no regulation,

Growth of private autologous CB banks in assisted reproduction centers,

2009: Resolution 009/69 of INCUCAI:

- regulation of standards of tissue banks,
- all CB samples already collected and future ones should be included in the National Registry and be available to whoever needs them.

B. Controversies over cord blood banks

- The Argentine case:
 - Strong reaction on the part of private banks,
 - Cases of lawsuits of parents against INCUCAI for not being allowed to store the samples for themselves...
 - Heterogeneity of answers from Judges.
- It will probably end with the Supreme Court involvement.

B. Controversies over cord blood banks.

Existing infrastructure in Argentina before Resolution 069/09:

- Well established public CB bank at the main Pediatric National Hospital;
- Related Program for the collection of CB at the public level (to allow the collection of families with specific illnesses);
- National Commission on Regenerative Medicine (NCRM): interdisciplinary body for counseling and advice.

A & B. Other possible policies:

Following a layered account of vulnerability there are other possibilities regarding policy making:

* Provision of information:

- Commission of experts providing advice: via internet (website with updated information), hotline (for lay people to ask questions);
- TV programs with information (public channels);
- Requirement that private CB bank brochures or websites refer for more information to the public website...

A & B. Other possible policies (cont):

- Physician` role:
 - Regulation on the fees: not exceed what is charged by delivery,
 - Transparency: disclosure of the role of the physician and of the payment on the informed consent and on the brochures advertising the procedure;
 - Informed consent: updated and reliable information, wording avoiding emotional terms, independent advisor...

A & B. Other possible policies (cont.):

- Endorsing other values:
 - Support of the public bank infrastructure (public and private);
 - Publicizing the existence and functioning of the public bank;
- => Expressing the importance of altruism and solidarity for the society.

A & B. Other possible policies:

Following a layered account of vulnerability there are other possibilities regarding policy making. We can have different sets of policies addressing each layer.

These policies can neutralize some of the problems we saw private CB banks pose. They will not avoid the emotional layer, nor the economic layer but can help minimizing them. They can use and enhance the already existing infrastructure.

As they do not follow the categorical view (which endorses an all or nothing logic: one answer to the whole problem (as such is seen as a whole category)), the answer is multiple and less "authoritarian" than the resolution 069/09.