

Conversations in the Future Tense

Ethical Issues in Ovarian Tissue Salvation and Egg Generation

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First of all: what is Bioethics?

- ❑ Ethics ask the question: What is the right act and what makes it so?
 - ❑ Classically, a conversation about acts whose entire consequence cannot be foreseen
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First Ethical Premise

- ❑ Therapies of the late 1990s had reconfigured the disease “cancer” not only as a crisis at the end of life, or hospice but also as a life-threatening event that then called for rehabilitation.
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Next Ethical Premise

- ❑ Second, the research looked carefully at the assumption that a critical part of a human life is the ability to bear genetic children and the loss of that is a medical problem with a medical solution.
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Third Ethical Premise

- ❑ The development of egg banks from frozen ova will impact on stem cell research as well as fertility research.
 - ❑ Thus potentially changing the constructs of physical human existence in fundamental ways
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Ethical Problems: a selection

- ❑ Not exhaustive
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Ethical Issues I: Cancer and childhood consent

- Idea of child as sexual beings
 - Death and its confrontation
 - Risk above minimum
 - Consent vs assent
 - Therapeutic misconception
 - The problem of theoretical futures
 - Is this a permissible way to create families?
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Standard issues of informed consent and refusal/ or pediatric assent or refusal

- ❑ should the time and kinds of treatment for the cancer be altered by the harvest of the ovary?
 - ❑ For whom is the risk of surgery justified? For whom is the risk of treatment delay justified?
 - ❑ What percentage of the stored tissue should be kept for private use, what for the research needed to see if the procedure actually can work?
 - ❑ Who decides and how does the decision making process change as the child grows?
 - ❑ How do we protect (can we protect?) against the stress of decision making itself, the stress of infertility newly acquired? Or unfairly coerce a choice for enrollment in the research, or offer false hope for either the fertility or the cancer therapy research?
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Ethical Issues II: “Comes the Dreamer”

- ❑ Joseph project and its implications
- ❑ That is a doubled consideration, for in addition to the undercurrent of anxiety that the child will not survive, there is the need to simultaneously hold and abandon the sense of innocence of children with the violation of surgery and the thought of the child’s future sexual preferences, plans and reproductive life.
- ❑ How can a family make the calculation as they struggle to see the child both as herself and deal with the meaning of the imagined and sexual and adult person that this work implies that child will be?

Trading in Futures

- ❑ What is the nature and meaning of asking for permission to do research that is not at this time possible and whose parameters are constantly mutable as the technology itself is developed?
 - ❑ Given the fact that humans beings are unique in our ability to imagine and plan for a future but rather bad at actually predicting what will make us happy? (Daniel Gilbert, Harvard)
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What is the providence of the gametes if the person cannot or does not use them—

In the event of death—can others use them and with what constraints?

In the event of changing one's mind?

Could they be used for research?

Ethical Issues III.

❑ Egg donation and its discontents



<http://www.ronsangels.com/index2.html>

❑ “There are 6.1 million infertile women in America some are looking for eggs so that they can have children. Many are opting for eggs from dissimilar donors. There was even an Asian couple who chose an egg from a blue-eyed blonde Scandinavian woman. Or you could choose the girl who most resembles you. A better looking version of you.”

Political

- ❑ Eggs are a 20th century “sign” of many things
 - ❑ Function as the “homunculus”
 - ❑ Close to The Neighborhood of America’s most contentious debate—abortion
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Ethical Issues IV

- ❑ Yuck factors and slippery slopes
 - ❑ Cascade of issues raised by Kass Council:
end of history, threat to family, post-human
future, etc.
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Deconstruction and its discontents

- ❑ post-modern reconsideration of the meaning of the body as a set of parts—and such a reconsideration of the body impacts on the meaning and value of each part and of our sense of the whole of the self.
 - ❑ Parts and chassis notion is core to all synthetic biology
 - ❑ Synecdoche for modernity itself
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Ethical Issue V: Social Justice

- ❑ Some standard issues mirror organ donation policies
 - ❑ Other are de nova: violation of two classic “bright lines” in human genetic research (“Points to Consider” Splicing Life, 1982)
 - Somatic vs “germ line”
 - Disease treatment vs enhancement
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Justice issue I.

Should the technology be limited?

- For cancer survivals alone? (Why only for cancer?)
 - Are other uses in other life-threatening events permissible?
 - What of the idea of preservation for social or protective reasons?
 - We are lead to consider the limits of the use of this technology
 - A debate akin to the coincident debates about therapy versus enhancement in general.
 - If such interventions are limited, how could this be done, in the climate of IVF and ART as it now exist, and how should such regulation be defined and maintained?
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Justice Issue II.

How are goods distributed?

- What should be the role of economic factors, incentives and distribution costs in access to trials and trials?
 - How should the project seek to address health care and social disparities driven by race and ethnicity, class or gender?
 - Who should bear the cost of research. Who should profit, if anyone?
 - Who owns the tissue? Patents?
 - Is this research just, given other possible uses of scarce resources?
 - How can vulnerable subjects be assured of continuing access to health care and support?
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VI. How can you really know if it is safe?

- Can it be tried in human tissue even if it cannot be done in non-human primates?
 - How can you actually know that the embryos, stem cells, or babies do not have an inherent problem after complex manipulation?
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What are reasonable criteria for bioethical judgments?

- ❑ In a pluralistic society with competing moral appeals
 - ❑ In international research community
 - ❑ Seeking consensus and “bright lines” for this moment (and not all moments)
 - Four ethical questions raised by a AAAS committee in its September 2000 report on heritable genetic intervention (“germ” line gene transfer) give an example of how we look at the issue:
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1. Are there reasons in principle why performing human germline interventions should be impermissible?
2. What contextual factors should be taken into account and do any of these prevent development and use of human germline interventions?
3. What purposes, techniques or applications would be permissible and under what circumstances?
4. What procedures, structures, involving what policies, should be used to decide on appropriate techniques and uses?

Normative Reflections I: Moral Philosophy

- ❑ Is our primary consideration the liberty of each and the full range of all possible choices? (Kant)
 - ❑ Or is duty prior to freedom? (Levinas)
 - ❑ Can the arguments of natural law be usefully engaged in this most artificial context? (the paradox of intuition)
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Normative Reflections II: Quantitative Data

- ❑ Focus groups were conducted with adult survivors of childhood cancer, who were diagnosed between the ages of 13 and 21 years, and their parents.
 - ❑ Survivors and parents reported that fertility was not the primary concern at the time of diagnosis,
 - ❑ As adults, fertility has taken on greater importance.
 - ❑ Both survivors and parents said that they would have seriously considered preserving their child's fertility if it had been an option and further explained that fertility preservation should be presented to everyone, regardless of age.
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Is the research permissible? Perhaps Imperative?

Standard response in American Bioethics was “yes.”

Why?

What makes it so?

- Healing of the suffering other is at the heart of the medical project
 - Medical care involves restoration of loss of function and its associated research
 - Actual subjects (the Other in question) of discourse support its use
 - Research using oocytes is far better done if eggs could be matured rather than harvested using multiple trials of hyper-stimulation from human volunteers
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Your turn

- What is the right act and what makes it so?
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Cases: Candidates for procedure?

- ❑ Dorothy has cancer, and she is 25 and married but not certain she wants children, but her husband does.
- ❑ Alison has cancer, is 38 and unmarried, wants her “own genetic child” someday.
- ❑ Rachel is 15, has cancer and consents to the procedure but her parents do not approve of the idea.
- ❑ Diana is 8, has cancer and assents, and knows her parents “really want grandchildren.”
- ❑ Lily is an older med student who wants to be a neurosurgeon.
- ❑ Regina is a highly paid supermodel, from a third world country.
- ❑ Song-lee is a Kellogg graduate student who understands the growing market for human tissue.
- ❑ Josie is a stem cell biologist and needs eggs for research