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# Learning Activity 1: Teaching Notes for Creating a Market for Eggs to Support SCR Eggs & Blood: Gifts & Commodities

by Katayoun Chamany Updated July 2018

In this activity, students model the first two steps of the <u>7E model of learning</u> proposed by Arthur Eisenkraft (Engage, Elicit, Explore, Explain, Elaborate, Evaluate, Extrapolate). Students *engage* in discussion and *elicit* prior knowledge from one another by reviewing secondary literature and tracing the evolution of policies regarding compensation for oocyte provision as it applies to basic scientific research, medicine, human rights, and business. The perspectives presented in the articles invite students to enter the compensation debate from multiple points of interest. The material reviews existing and proposed policies that emerged as a consequence of advances in reproductive technology and basic science. The arguments for, or against, any given policy include concerns about the moral status of the embryo, health of providers, commodification of marginalized bodies, reproductive access for LGBQT, and equity in pay.

This activity is designed as a form of engagement and formal assessment or evaluation is not necessary. Rather, the assigned articles cover a broad range of topics that provide a cursory review of the need for oocytes for human embryonic stem cell research (hESCR), stimulating students to ask questions about current practices and future research directions. The activity can serve as segue to lectures on basic cell biology topics such as cell signaling, cell differentiation, nuclear reprogramming/genomic imprinting, cloning, and gametogenesis and embryogenesis.

For students with limited biology background in biology some of the topics above can be introduced using the *ZoomGraphics* and *Animated Slide Sets* associated with the <u>Stem Cells Across the Curriculum</u> project (See **Media & Infographics** pull down menu). Instructors may choose to place more emphasis on the social context of the investigations and explore the relationship between science and other disciplinary areas such as politics, cultural studies, disability studies, and gender studies. If the latter case, then all materials in the <u>Module for Eggs and Blood</u> should suffice.

This assignment *elicits* alternative conceptions or understandings of stem cell research, health policy, and eggs as commodity. The level of discussion and the complexity of questions will vary depending on academic background and interest. The activity is designed to have students frame the discussion through reflection and the generation of a set of questions that can be answered in future class sessions. The divergent stances taken by New York and California regarding compensation for oocyte provision is contextualized by reviewing arguments for and against compensation by scientists, feminist scholars, sociologists, patients, race scholars, and ethicists.

## STUDENT LEARNING OUTCOMES:

- · Recognize the intersection of reproductive technologies, stem cell research, and cloning
- Gain familiarity with the various arguments presented by scientists, feminists, policy makers, social justice scholars regarding compensation for oocyte procurement for stem cell research and to be aware of the diverse points of view *within* these stakeholder groups
- Explain how choice, autonomy, agency, exploitation, and labor inform health and science policy
- Distinguish between different sectors, public and private, and identify ways in which they are interdependent.
- Recognize the influence that advances in basic science, law, business, human rights, and medicine can have on one another
- Develop a set of questions about the social impact of compensation for bodily goods
- Generate questions about the unique biological role that eggs play in human development and subsequently stem cell research

## FORMAT:

Portions of this case have been used in a cell biology course, a non-majors stem cell course, and a University lecture course for liberal arts and design students at The New School. It has also been adapted for a medical anthropology course at Fordham University.

## Timing

As described below, the activity can take between 1-3 class sessions using a progressive disclosure approach in which the class is split into two large groups with even-numbered resources reviewed by one half and odd-numbered reviewed by the other half.

In this scenario, all students read the <u>Embryo Project web entry for the Dickey Wicker Amendment</u>, which explains the emergence of an egg marker for ESCR, and the *Lancet* editorial, <u>Eggs Shared</u>, <u>Given</u>, <u>and</u> <u>Sold</u> which provides a succinct overview of the evolution of assisted reproductive technologies since 1978, when the first IVF baby was birthed. The last two references review the necessary biological processes required for cell differentiation during embryogenesis and in somatic cell reprogramming. Both processes are dependent on proteins and RNA factors in the egg.

For instructors teaching non-science based courses, they may forego the Schatten and Schatten article and instead assign an article authored by feminist anthropologist Emily Martin. While Schatten and Schatten criticized those that describe the egg as "passive" and "welcoming," Martin and others extended this criticism through their analysis of medical and biology textbooks, identifying numerous portrayals of gendered stereotypes in basic biological processes. Martin argues that because science is a male-dominated field, men are the creators and perpetrators of patriarchal stereotypes about women and men, and subsequently, the egg and sperm (Martin, 1991).

Using progressive disclosure, students then read the references during class in pairwise sets such that (1,2) are read and discussed before receiving the next set (3,4) etc. Using this approach would require 2-4 class sessions to move through the remaining references.

Alternatively, reading can take place outside of class with each half of the class only reading odd (1,3,5,7,9) or even-numbered references (2,4,6,8,10) and again this can be broken up over a few days to achieve partial progressive disclosure.

It is important to note that the references span blogs, news for the general public, news for scientists, and conference proceedings. Students should consider who has access to what types of information, the purpose of the communication, and the timing of publication. Additionally, one academic article can be assigned to compare the situation in the US to that of the UK (see optional article) either before this class session or afterward.

## Readings & Constructed Discussion

The assignment can involve small group work, where each group of students is responsible for reporting out the findings of a particular news piece or video clip. The articles can be read in, or outside of class, depending on the course structure. If articles are to be read prior to the class session, the class can be divided in half where one half reads the odd-numbered articles (1,3,5,7,9,11) and the other half reads the even-numbered articles (2,4,6,8,10,12).

By splitting the class in half, the subdivision creates a situation where the two groups can discuss the same topic from different perspectives. Each group will hear from feminists, social justice scholars, and scientists, but the complete story must be put together through structured discussion. As one example of policy perspectives, the O'Reilly news piece and the Roxland report (#1, #2) discuss the rationale behind compensation using public funding in New York, while the Crowley piece (#3) challenges the rationale by presenting a lawsuit brought against New York and the Egli et al. (#4) article backs up the NY stance with evidence about altruistic egg provision. Another example involves scientific analysis of the existence of ovarian stem cells as described in the Powell piece (#5) and challenged by stem cell researcher Lovell-Badge's blog post (#6). Issues of economic equity, health risks, and commodification of things considered sacred are covered in this short list of news and editorial features. Though at first glance it may seem that there is too much overlap, the collection teaches students the value of investigating multiple layers and narratives of the same story. Each feature highlights a significant perspective: Gutierrez (#7) explains why extranumerary embryos in fertility centers can not be used for SCR and is the only one to introduce the patient perspective (Breast cancer patient infertile from chemo seeking assisted reproductive technology champions research in this area); Benjamin (#8) specifically addresses exploitation of vulnerable populations in a context of economic inequity; Miles (#9) is the only news items to explore how egg compensation can expand reproductive access for the LGBTQ+ community, presents an argument for gender equity in payment for gametes, and raises the issue of commodification of the body within the context of bans on compensation in three states; and Darnovsky (#10) is the only news item to clearly outline potential cancer risks associated with oocyte provision and claims that the procedures for gamete acquisition are more risky for those with ovaries than those with testes. Reference #11, raises this issue of gender in a different way, by discussing the removal of ovaries from individuals seeking gender reassignment and the isolation of ovarian stem cells, which the researchers claim could eliminate the need for continued egg provision, as they could not be created in a petri dish using cell differentiation protocols. Instructors may find that some students will focus on social justice/ethics while others tend to support innovation as important endeavor for which to take some risk.

There are interesting comparisons to be made as well. Instructors can highlight the cross talk between the private industry of IVF in the US and the publicly funded ventures of SCR in California (7,8,9,10) and New York (1,2, 3,4). How human eggs migrate across these two spaces can lead to further class discussion . If the Roberts and Throsby article is assigned, discussion about how public funding can warrant movement of cells and embryos destined for reproduction towards stem cell research. The overall effect of the assignment is to highlight the moral dimensions of compensation/bartering/exchange for oocytes for stem cell research using many different vantage points.

Instructors may also choose to give students time in class to form small groups of 3-5 to discuss among themselves before providing a consensus overview to the remainder of the class. For small group work, see the resources at this site (<u>Resource One: Group Role Profiles</u>) for role responsibilities that ensure equity in groups, or assign an "equity monitor" who must ensure that all voices are heard in the group and that any missing voices are raised.

During the class discussion, the instructor acts as note taker, guiding the discussion by posting the groups' questions as they are posed and asking if another group can answer the question or challenge the points made using a different perspective. By asking the groups to consider how their resources "talk to one another" the discussion can move from group to group rather seamlessly. The note taking can take the form of a concept map, making explicit the connections, pushes and pulls in narratives that may appear to be in conflict, and help students synthesize a complex story from many vantage points.

#### Videos

Depending on the number of video clips and articles assigned, the activity can be completed within 1-3 class sessions. Showcasing videos after the class discussion can illuminate more complexity. The Lines that Divide documentary clips are only 1-2 minutes in length, but grapple with a range of issues including health risks, moral status of the embryo, commodification, and economic inequity. For legal perspectives, showing the video clips of President Bush's Veto of the congressional bill that had bipartisan support (one vote shy of override), President Obama's executive order, and Colorado Representative Diane DeGette's interview illustrates the shifting landscape of public funding for embryonic stem cell research. Adding these videos can clarify the reason that states have moved forward and why federal law would prevent reversals of funding rules by presidential executive orders. Additionally, President Bush's video includes images of "snowflake babies" that resulted from the adoption of frozen embryos via Nightlife Adoptions. If only one of these legal videos is used, I would suggest the DeGette interview with Chris Matthews on MSNBC as it reviews both presidential executive orders and the annual Dickey Wicker appropriations rider. The clip from Democracy Now highlights the need to consider compensation policies within the context of existing economic inequities. The stark contrast in average wealth between Caucasian women and non-Caucasian women addresses the social justice aspect of the controversy. The Benjamin TEDx talk examines economic and health inequity in biomedical research using three cases studies one of which details the outcome of an third party oocyte provider in the reproductive sector. She argues for a new paradigm in designing research studies with community input. The last clip by Dolgin connects to the Powell article assigned to students and highlights the purported identification of ovarian stem cells and in this very short clip, a great deal of biology is covered with an animation allowing an instructor to ask students to outline the experimental scientific method (observations, questions, hypotheses, experiment, results, conclusions, new questions). This clip ends with a provocative statement pointing to a new company, Ovascience, founded by Tilly, designed to produce "billions" of eggs for those who seek reproductive assistance and also to provide a much needed biological resource for stem cell researchers. An instructor could use this clip alongside this set of questions:

- 1. What aspects of the video did you find most ENGAGING; provide comments and questions?
- 2. How does the video ELICIT prior knowledge and create cognitive dissonance?
- 3. Which **BIOLOGICAL** concepts and principles did you recognize in this video?
- 4. What are some ETHICAL/SOCIAL JUSTICE challenges that may emerge as a result of this work?
- 5. Does the video prompt you to become involved in SHAPING POLICY or activism?

Two teachable moments emerge,

#### Regulation

Students may believe that egg providers in the private fertility sector are viewed as research subjects since IVF is considered an "experimental procedure" and is not approved by the FDA. Though this may seem logical, it is not the case. The long-term health of oocyte providers is only beginning to be tracked and primarily through grassroots efforts. The "We are Egg Donors" project and the "Egg Donors Project for the Alliance of Humane Biotechnology" are two such efforts advocating for the tracking of long-term health of oocyte providers. State funding for hESCR (human embryonic stem cell research) also does not have any provisions for tracking the health of oocyte providers. That said, the New York/NYSTEM model informed consent form is quite detailed in what is known and unknown regarding short and long-term health risks.

#### Embryo Protection

It is important to inform students that the desire to protect embryos from destruction during biomedical research is varied across nations. In the UK the Human Fertilisation Embryo Authority (HFEA) has permitted the creation and destruction of human embryos for research. Other European countries such as Italy, bans their destruction all together regardless of funding source. In the US there is an appropriations rider (The Dickey-Wicker) that prohibits the use of federal funds for research that would result in the creation or destruction of embryos. This rider has been in place since 1996 and signed each year by every president ever since (Embryo Project, Dickey-Wicker, 1996). In 2001, President G.W. Bush took this one step further and prohibited the use of federal funds for research using any embryonic stem cell lines created after August 9, 2001 regardless or the original source of funding to derive the cell line. When Obama took office, he essentially reversed Bush's executive order, expanding the number of existing ESC lines that could be researched using federal funding however, he signed the Dickey-Wicker appropriations rider. He rationed that addressing the issue via executive order would mean that with each incoming president, scientists would be left wondering what the rules for federal funding will be. Rather, he recommended that Congress propose legislation, stating that this would be the more democratic and stable approach. To that end, Diane DeGette, a Congresswoman from Colorado, has for ten years pursued a bill that would allow the use of extranumerary (surplus) embryos from fertility centers for ESCR, however it has remained dead in the House. Thus, many states continue to use their right to establish state funds for the derivation of ESC lines resulting in the destruction of early stage human embryos. Instructors may find it useful to play this short DeGette interview with Chris Matthews on MSNBC before embarking on this activity as it quickly reviews the status of funding regulations in the US. Because the Dickey-Wicker Amendment is often incorrectly referred to as a bill, instructors should spend a minute or two explaining the difference between the bill proposed by DeGette (which if passed would become law) and the role of an appropriations rider.

**UPDATE:** Most recently, there have been efforts to circumvent the moral status of the embryo by creating SHEEFS (Synthetic Human Entities with Embryo-like Features) or self organized cells that can skip over developmental stages (<u>Aach et al, 2017</u>). To date, the "14-day rule" prevents research on embryos after day 14 of development. This rule was proposed in the US in the 1980s, deliberated by the Warnock Committee for six years, with Parliament passing legislation in 1990 (see Eggs and Blood Primer for more details). Because SHEEFS are made without the fusion of sperm and egg, they may not be subjected to the same rules (<u>Shen,2018</u>). Given these advances, some countries are revisiting the "14-day rule," and the Nuffield Council on Bioethics held a conference at the end of 2016 to discuss the value in doing so (<u>BBC, 2018</u>).

#### Commodification

A number of the resources address the notion of bodily goods or argue for placing a value on human tissues and cells used in research. This idea is made most clearly in the work by the Tilly lab as seen in the last clip by Dolgin. Tilly has procured ovarian tissue from individuals undergoing gender reassignment surgery in Japan and has founded a fertility company Ovascience to create "billions" of eggs for use in the reproductive sector. Though stem cell researcher Lovell-Badge and others have questioned the authenticity of this work based on inadequate data, muddy results, and the inability to reproduce the results in other labs, the notion that this could be possible would inevitably shore up the need for oocytes in human cloning labs focused on hESCR. More recent research using mice shows promise in this direction. Instructors should spend some time discussing the National Organ Transplant Act, and the basis for bans on sales of tissues that are not regenerative. In this case, because the "donors" were undergoing gender reassignment the tissues would be considered medical waste. This might lead to a variety of discussions. First, did the individuals receive subsidies, or reduced surgical costs, in exchange for their tissues? Second, how does medical waste serve as resource material for lucrative profit making ventures? This last point will be even more relevant given the discussions surrounding Planned Parenthood and the claims that they are "selling" fetal tissues acquired through abortions to various clinics and labs. It is also relevant to the Lancet editorial where egg sharing, the process of providing a portion of one's oocytes to researchers results in reduced costs for IVF. These are murky areas, as it is not entirely clear that excess, or waste material, can be considered one in the same. In either case, the notion that someone downstream is financially benefiting from the bioresource is worth discussion.

## **Questions that May Arise During Discussion**

- 1. What biological characteristics do oocytes possess, making them useful for stem cell research?
- 2. Who are the people involved in moving oocytes from a clinic, to the lab, and the market?
- 3. What are the policies regarding compensation for oocyte procurement?
- 4. Why do we need a diverse supply of human oocytes for stem cell research?
- 5. Are oocyte providers adequately informed about benefits and risks? Is this different for reproductive purposes versus hESCR (human embryonic stem cell research)? Should it be?
- 6. Should people have a choice in how their individual bodies may serve hESCR?
- 7. What kinds of information or data need to be made available for individuals to consider participating in hESCR? Does this information exist, or is it being gathered; should it be?
- 8. Why is human cloning contentious? What are the advantages and who carries the burden and who benefits?
- 9. Do human ovaries possess stem cells and if so, can they be grow in a lab, harvested, and sold?
- 10. Are the claims concerning exploitation valid and, if so, why?
- 11. What are some ethical issues related to egg sharing?

## **CONTEXT and EXTENSIONS:**

If used in a freshman seminar, *People's Science: Bodies and Rights on the Stem Cell Frontier* by Ruha Benjamin could be assigned, as it depicts the ways in which stem cell policy in California is viewed by various stakeholders including those who advocate for disability justice, the social model approach to health, and economic equity. If a shorter piece is needed, an article authored by Benjamin in *Sociology Compass* covers some of these issues. If used in a policy or ethics course, the article published by Beth Roxland entitled "Egg Donation for Stem Cell Research: How New York State Developed Its Oversight and Compensation Policies" provides a thorough review of the lengthy process by which the Ethics Committee for the Empire State Stem Cell Board conceived of their policy and the deliberations that informed the development of their model informed consent forms which are to be used by all NYSTEM grantees and their Embryonic Stem Cell Research Oversight Committees (ESCROs). If used in a gender studies course, the article by Baylis regarding the many kinds of embryonic stem cells requiring human eggs could be assigned. If used in a global studies course the article by Donna Dickenson and Itziar Idieakez entitled "Ova Donation for Stem Cell Research: An International Perspective" could be assigned.

- 1. Baylis, F. 2008. Animal eggs for stem cell research: A path not worth taking. *American Journal of Bioethics*. 8(12):18-32. Link
- Benjamin, R. 2013. People's Science: Bodies and Rights on the Stem Cell Frontier. Stanford: Stanford University Press.272. <u>Link</u>
- 3. Benjamin, R. 2014. Race for cures: Rethinking the racial logics of 'trust' in biomedicine. *Sociology Compass.* 8(6): 755-769 Link
- 4. Dickenson, D. and Idiakez, I. 2008. Ova donation for stem cell research: an international perspective. *International Journal of Feminist Approaches to Bioethics*. 1(2):125-144. Link
- 5. Roxland, B. 2010. 2010 report: Egg donation for stem cell research: How New York State developed its oversight and compensation policies. World Stem Cell Report: 60-67. Link

**FURTHER LEARNING:** Instructors and students would benefit from following this engagement activity with Learning Activity 2 (Explore, Explain) and Learning Activity 3 (elaborate, evaluate, extrapolate) or assigning the Primer associated with this module. A collection of **Discussion Questions**, **Timelines**, **PPT slide sets**, **Essential Resources**, and **Infographics** tracing the trajectory of technologies and policies are also available in this module. Additionally, the <u>Artworks</u> and <u>Videos</u> section of SCAC offer more resources.