Learning Activity 2: Teaching Notes for Hope v. Hype & Care v. Cure

Disease, Disability, & Immortality: Hope & Hype Module

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In this activity students move through the 7E model of learning proposed by Arthur Eisenkraft (Engage, Elicit, Explore, Explain, Elaborate, Evaluate, Extrapolate) by *exploring* secondary literature, infographics, and animations and *explaining* what they have learned about relationship of stem cell derived therapies and those that live with disease and disability. In Part I, students learn that a diversity of opinions exist among disability rights scholars and activists as well as stem cell researchers regarding the utility of SCR and its applications for those that live with disease and disability. In Part II, the resources invite students to consider advantages and disadvantages associated with different kinds of stem cell therapy considering the procurement processes and scientific and therapeutic potential. This activity is designed to encourage students to *explore* the material on their own and *explain* what they have learned through *discussion and presentations* that combine images and text. This approach to teaching and learning is constructivist because the presentations reveal what is most important to students and can then serve as reasoning tools in discussing policies for regulating stem cell therapies. As students construct their knowledge they become more self-aware of their own learning. With respect to Blooms Taxonomy, students acquire and remember content knowledge, connect specifics to broader concepts, and synthesize mental models of the information at hand.

Students should reflect back on the sets of questions provided in the assignment and the specific resources assigned to them or a small group. Because the activity draws on personal interest, each group or student will respond to the questions differently, highlighting those aspects that are most relevant and meaningful to them. Through class discussion and viewing oral presentations students will come to realize the diversity of responses even within their own class environment. The activity can serve as segue to lectures on basic cell biology topics as cell signaling and cell differentiation, and can also be used in seminar courses to explore the relationship between science and other academic disciplines and activist movements.

Because many different kinds of resources are listed, the activity can be customized for a variety of courses. In courses where primary scientific research articles can be read, instructors should be aware that primary literature is not included in this set of resources in Part II and only one such article is listed in Part I. The decision to omit these resources from the assignment was intentional as the field moves quickly and thus, the instructor should select an appropriate and current research article for each therapy category represented in Part II. Alternatively, instructors can choose from the articles listed in the Essential Resources associated with this module.

STUDENT LEARNING OUTCOMES:

- Recognize the difference between the biomedical and social models of health.
- Map the dichotomies of medical v. social, cure v. care, and hope v. hype to the arguments made by members of the disability rights and the stem cell research communities.

- Provide evidence for a diversity of viewpoints *within* communities that share common identities (those living with disability, disability rights scholars, stem cell researchers, bioethicists).
- Generate questions about the types of disease and disability that could be best addressed by either the biomedical or social model of health.
- Describe how advances in stem cell research can both challenge and confirm stereotypical views of those that live with disease and/or disability.
- Recognize the influence that advances in basic science, law, business, human rights, and medicine can have on one another and how this informs an address of disease and disability.
- Gain awareness of the ethical, legal, and social issues tied to various stem cell sources and stem-cell related therapies that are developed as a consequence of research using embryos, cord blood, fetal tissue, and fat.
- Understand how basic science reveals the underlying cell signaling pathways necessary to stimulate regeneration in the body and how this work informs the development of transplant and drug therapies.
- Describe how the value of various bodily tissues has shifted from waste or unwanted entities to useful resources for stem cell research.
- Compare the ethical issues associated with procurement processes for each type of stem cell used in therapy. Is the source contentious? How easily can cells be retrieved; are they numerous or a minority population? How invasive is the process? Are there any health risks associated with the procurement process? Are there any other scientific manipulations of the source material? Is any money exchanged? Are the processes legal, and are regulations in place?
- Compare the scientific and therapeutic potential of stem cells derived from embryos with those derived from fetus and adult tissue. Which source proves more immunocompatible? Which source has a wider range of possible cell fates? Which therapy has less potential for the development of unwanted outcomes such as tumor formation?

INSTRUCTOR PREP: For instructors unaccustomed to introducing disability perspectives or the social model of health in their courses, it would be prudent to read the Garland and Stull Chapter 9 from the *Ethics and Public Health Model Curriculum* (pp. 241-251) published by the Association of the Schools of Public Health, The Health Resources and Service Administration, and the Hastings Center Institute as well as Tom Shakespeare and Nicholas Watson's article published in 2002 reviewing the history of this model as it emerged in the UK to address a form of oppression experienced by those living with disability ("The social model of disability: An outdated ideology" *Research in Social Science and Disability*. 2: 9-28).

FORMAT:
A version of this activity has been used in a non-majors seminar course designed for liberal arts students at Eugene Lang College and in a University Lecture Course serving art, design, and liberal arts students at New School University.

Because the assignment is not explicit in its directive, instructors should clarify which **Parts** of the assignment are to be completed, and what students need to do: participate in class discussion, write a response essay, and/or provide an oral presentation. These choices will play a role in the number of class sessions required to move through the assignment.

Instructors of science-based courses may choose to use both **Part I** and **Part I**I of this assignment or only **Part I** and ask students to dissect the following scientific research article which is in the collection of resources titled *Kessler Lab Terra Incognita + Follow Up,* as the first author is one of the main characters represented in the *Terra Incognita* documentary film. This particular research article was chosen because students often don't recognize that many stem cell based advances will not involve transplanting stem cells

into patients, but rather stimulating patient's bodies to regenerate upon exposure to cell signaling molecules identified through stem cell research.

> **Research:**Tysseling-Mattiace, V. et al. April 2, 2008. Self-assembling nanofibers inhibit glial scar formation and promote axon elongation after spinal cord injury. *Journal of Neuroscience*. 28(14):3814-3823. Link

Instructors in non-science based courses, or courses in which students' scientific background is limited, may eliminate scientific research articles, or review in class or assign only the abstract, introduction, or discussion of these articles.

Though the film *Terra Incognita* can be watched outside of class, in my experience, students appreciate watching the film in class together as the film prompts much discussion. When I facilitate this viewing I often pause the film to interject connections to various readings, or sometimes allow students to ask for a pause for immediate discussion of the cinematic choices used to represent various characters or to ask questions for clarification. The film is available on NetFlix Instant and can also be purchased for educational use by your campus library.

Part II can involve small group work where each group of students is responsible for reporting out the findings or a particular stem cell transplant therapy approach. The articles and video clips are explored outside of class; students develop their presentations on their own, and develop a collective presentation with their peers once they assemble in groups in class. Depending on the number of student groups and topics chosen the presentations will span a variable number of days. If instructors have a larger class, or want to explore other transplant applications, they can select categories from the Essential Resources associated with this Module.

Should instructors want to extend the discussion of hope and hype more generally in translational research, the last Science STAT Blog Post by Zimmer located under Hope v. Hype in the Essential Resources does not discuss stem cell research but, rather, CRSPR gene editing technology. Lastly, if instructors would like to add an additional category of stem cell based transplants that is quite popular among students, they can add the resources from the "Organoids" section of the Essential Resources. More articles for each topic can be found in the Refworks link at *Stem Cells Across the Curriculum.*

IMPORTANT CONSIDERATIONS:

1. Induced pluripotent stem cells have been found to have different gene expressions profiles and potentials (Hu et al, 2010) and the research literature changes rapidly as new studies are conducted revealing new levels of similarity and difference as compared to embryonic stem cells.
2. In PGD, genetic testing prior to embryo transfer can involve testing oocytes, embryos at the 3-day/8-cell stage, or embryos at the 5-day/150-cell blastocyst stage. Most commonly the latter is used. For some, the genetic testing of oocytes alleviates moral issues connected to the destruction of potential life. Because oocytes are not yet fertilized, any oocytes that are found to have genetic anomalies are excluded from IVF, thus, avoiding any embryos undergoing negative genetic selection and possible destruction. The testing of embryos at the blastocyst stage means that only trophoblast cells are being tested and not those of the developing embryo; it is known that in many animals the developing embryo throws off chromosomally aberrant cells to the trophoblast, so this testing may result in false positives for chromosomal abnormalities leading to extranumerary embryos that could be used for stem cell research. (Kalousek, D. et al 1983). Relatively few studies have analyzed the presence of this phenomenon in human development, and some research suggests this does not occur in humans (Derhaag, J. et al. 2003)

3. Ninety-seven percent of cord blood in US hospitals is discarded, and of the small percentage banked, most is banked privately, meaning only family members can access this stem cell source. In addition, the diversity of cord blood is very low, with those of mixed race having less than 25% chance of a match in some national regions.
4. Adult stem cell sources are heterogeneous in nature making FDA approval challenging.
5. Fetal tissue can be used directly in transplants to address neurodegenerative diseases in adults.

ASSESSMENT: A rubric can be constructed based on the goals of the course and shared with students beforehand. A more generalized example is provided below:

Aspect	**Struggling**	**Developing**	**Mastering**
Source of cells	Not clear; ambiguous; no ethical address	Only indicated with text; ethics is indicated	Clear from either text or image; clarifies ethical issues
Process of Procurement	Cursory address; no temporal or spatial imagery, or what resources needed, nor any address of decisions points	Some attention to sequence of steps and resources needed and temporal and spatial aspects; indicates some decision points	Clearly indicates specific steps, resources needed, their location, and their timing in appropriate sequence; highlights the number of choices/ decisions regarding the creation of by- products or excess and related ethical issues
Laws and Regulation	Does not address policy	Some address of policy	Using text and image indicates where regulation if any takes place and its impact on the process and the product
Biology Characteristics	Not clear if cells must be modified in any way	Addresses the status of the DNA and cellular potential	Indicates with text and image whether cell potential is manipulated and why
Scientific Potential	Not clear how this source and technique could advance science	Some attention to the source providing a resource for scientific investigation	Addresses why source is useful for scientific inquiry (reprogramming, differentiation)
Therapeutic Potential	Does not indicate how useful the products would be for transplant or drug development, or immunocompatibility range	Provides one potential use of the product in biomedicine and its ethical perspectives; addresses some immunocompatibilty issues	Clearly illustrates how product will move from various spaces to a clinical setting, and how it will be developed and administered and related ethical issues (access, informed consent, clinical trial etc.); indicates whether source is universally immunocompatible or indicates needed interventions to address this issue.
Public or Private	Does not indicate whether the procurement and/or the products are coming or ending up in one sector of the other	Indicates either procurement or products location in the private or public sectors	Using text and images highlights the location of procurement, manipulation, and product storage with respect to private and public sector and access issues.

Social Views	Does not address the social views of using this source	Addresses at least one social view of using this source	Using text and images highlights a range of social views regarding the use of this source including f disability rights, religious, or social justice perspectives

FURTHER LEARNING: Instructors and students would benefit from engagement Learning Activity 1 (elaborate, evaluate, extrapolate). A collection of **Discussion Questions, Timelines, PPT slide sets, Essential Resources, and Infographics** tracing the trajectory of technologies and policies related to disability and stem cell therapies are also available in this module. Additionally, the Artworks and Videos section of SCAC offer more resources.