

## Genetics of Childhood Disorders: XLI. Stem Cell Research, Part 5: Ethical Questions

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Scientists claim to have made remarkable progress in isolating and culturing an indispensable and unique cell type found in animals, the stem cell. The general public accepts that stem cell research is scientifically significant and clinically promising. It also knows that this research has generated ethical questions. No consensus has yet emerged on which answers are the right ones. We must therefore describe the controversies that surround questions like the following: What value judgments are at issue? Which of these collide? Where collisions occur, which judgment should trump?

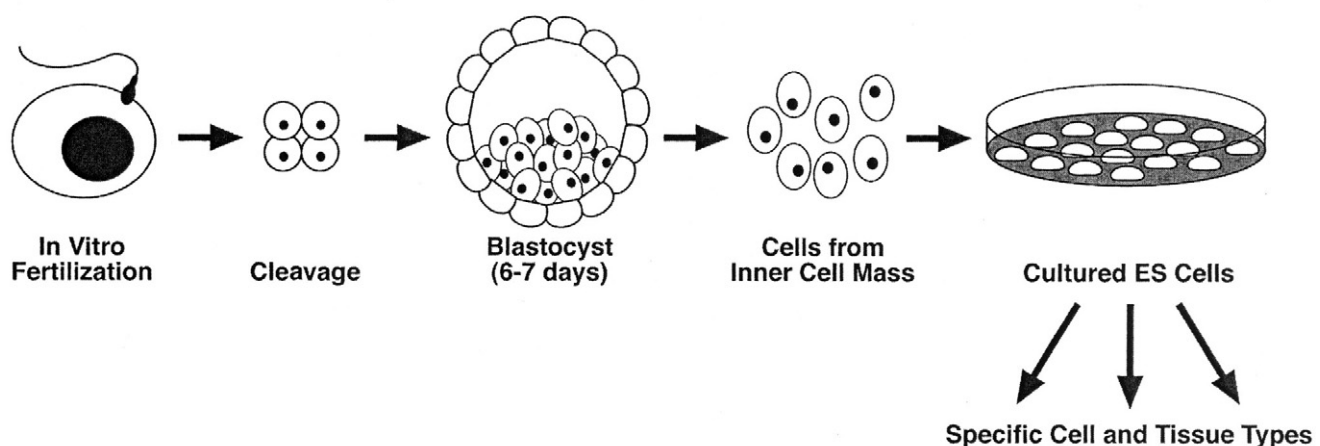
Before we look at the controversies involved, let us review some of the basic terminology to set the stage. Stem cells are best described in the context of normal human development. When an egg is fertilized by a sperm, a single cell is created that has the potential to grow into an entire organism. Thus the fertilized egg is termed totipotent. After several days of dividing, the totipotent cells begin to specialize and form a group of cells termed a blastocyst (Fig. 1). Prior to that point, any of the totipotent cells could be implanted into a uterus and give rise to a fully formed organism.

The blastocyst consists of an outer layer of cells that give rise to the placenta, and an inner mass of cells cluster together at one pole that give rise to the organism. A single cell from

the inner mass has the potential to give rise to virtually all tissues in an organism and is termed pluripotent. However, it is not totipotent as it is unable to generate the placental tissues and cannot be implanted into a uterus.

Pluripotent stem cells have been derived from two sources. The first is embryos. In vitro fertilization clinics usually fertilize more eggs than are necessary for eventual implantation. These fertilized eggs are allowed to grow to the blastocyst stage before being frozen. If cells from the inner cell mass are obtained and pluripotent stem cells are isolated, these cells are more commonly known as embryonic stem cells. The second source is discarded fetuses. In this technique, fetal tissue is obtained from pregnancies that have been terminated and cells are isolated from the germ lines before they are plated onto culture dishes.

Pluripotent stem cells continue to divide and undergo specialization. The next type of stem cell is termed the multipotent cell. These cells are unable to give rise to all tissues but can differentiate to a number of different cell types within a particular tissue. Examples would include skin stem cells that give rise to the majority of skin cells and the blood stem cell that gives rise to the various cells found in our blood. These multipotent cells have been found in child and adult tissues. If in fact we could isolate all the different types of multipotent stem



**Fig. 1** Isolation and culture of human embryonic stem cells from blastocysts. This procedure derives cells from the inner cell mass of a blastocyst stage embryo obtained from unused embryos obtained from fertilization clinics. Cells from the inner mass are disaggregated and grown in tissue culture. These cells are termed embryonic stem (ES) cells. It is a more controversial technique than the one that derives cells from precursors of germ cells from a fetus. The status of the embryo and the act of intentionally disaggregating it are subjects of moral controversy.

cells from adult tissues, then there would be less urgency to use embryonic tissue and considerably less controversy.

It turns out, however, that to date a relatively small number of multipotent cells have been discovered in adult tissues. For example, it has proven difficult to isolate multipotent cells from the pancreas (to treat diabetes) or from the brain (to treat degenerative disorders). It is easier to obtain these types of cells from either fertilized eggs or aborted fetuses.

I sketch four areas where rival value judgments present themselves. Three of these concern the “sources” of stem cell research. The first centers on the “status” or “moral standing” of embryos and aborted fetuses. Are these morally licit sources for such research? The second centers on questions of “complicity.” Should researchers confine themselves to embryos and aborted fetuses that the genetic parents themselves elect to donate for research? Or may researchers themselves create embryos in order to disaggregate them for research? The third concerns adult stem cells. Inasmuch as no one doubts that research on adult stem cells is morally licit, should this sort of research receive priority in the allocation of funds? Indeed, should they be the only source of permitted research? Or should they remain one of several acceptable sources, without ranking any single source as preferred? The fourth area shifts to the political and legal contexts in which stem cell research proceeds. How should moral judgments of what is desirable mesh with political judgments of what is viable?

I will describe the controversies but will not try now to evaluate them. Let us consider a spectrum of value judgments in contention. To compare them increases understanding of where disagreements lie.

First, *the status of fetuses and embryos*. Those on the “right” side of the spectrum extend the prohibition against murder as the “direct and intentional killing of innocent life” to fetuses and embryos. To regard early, indisputably innocent life as a “mere means” to other, perhaps laudable ends (benefiting third parties) makes fetuses and embryos “instruments.” It also may jeopardize, sooner or later, our ability to welcome children into the world and to care for them. Those in the “middle” often distinguish conception and individuation, and permit certain sorts of research on embryos at the earlier stages (before the “primitive streak” develops or implantation occurs). They believe that the embryo is a form of human life and entitled to a certain level of respect, e.g., we should not be allowed to buy it or sell it. Those on the “left” deny that we should accord value to pre-viable fetuses and to embryos. They assert that we do not harm embryos by disaggregating them for research if there had been no expectation of transfer to the uterus.

Second, *complicity*. Those on the “right” grant that a researcher who uses fetal tissue does not necessarily support the decision to request or perform an abortion. They do believe, however, that a researcher who either derives or uses stem cells from embryos is directly complicit in destroying an embryo. In the

latter case, the research protocol itself requires an act of destruction. Those in the “middle” judge that it is morally relevant to distinguish the destruction of embryos that already exist as “spares” in in vitro fertilization clinics from the creation of embryos in order to destroy them solely to benefit third parties. Complicity in the former instance looks morally less ominous. Those on the “left” hold that once we permit the obtaining of cells from spare embryos in in vitro fertilization clinics, we may also permit the creating of embryos for the purposes of research. In both cases, we permit embryos to be a means to address the needs of others. The key decision is to permit their use in research, whatever their origin.

Third, *the alternative of adult stem cells*. Those on the “right” accent the advances that researchers have made in their work on adult stem cells. Everyone agrees that one advantage of using adult stem cells is that we avoid the risk of tissue rejection when we treat a patient with his or her own cells. Those in the “middle” are disposed generally to accept (though sometimes reluctantly, particularly as research on adult stem cells shows increasing promise) a verdict that many scientists have reached. It is that adult stem cells are necessary but not sufficient for obtaining the various cell types that clinically important areas of research require. Those on the “left” insist that we have not definitively established the case for limiting research to adult stem cells, when we consider all of the likely consequences. Research that is free to use any one of the three “sources” will maximize the possibilities.

Fourth, *political and legal contexts*. In the United States, we should demarcate two levels. The first concerns controversies about federal funding of stem cell research. These have consumed the bulk of disputants’ energies. Passions rise highest where taxpayer dollars figure centrally. Disputants perceive that federal expenditures attest to society-wide convictions. Those who occupy particular positions along the spectrum outlined above each champion criteria for federal funding that support their own value judgments about “sources.” The second level concerns the absence of coordination between research permitted in the public and private sectors. Many are disquieted that there is no society-wide oversight of research projects. Others either welcome the status quo or appear resigned to it. Some judge the current arrangements to be satisfactory as long as researchers *somewhere* are free to pursue various possibilities. Liberty from scrutiny allows those in the private sector to conduct research that holds promise of achieving major breakthroughs that societal scrutiny might well forestall. In light of societal pluralism, such scrutiny is likely to be constraining, reflecting compromises. Others judge the present situation to be ad hoc to a fault. They assert that publicly and privately funded research should be somehow coordinated, while the realistic chances of coordination seem to be distressingly slight.

Disputants from all parts of the spectrum have concentrated on what federally funded research should include. Comparatively little has been said about conduct in the private sector, where

currently a thousand research flowers bloom. Some liberals especially look to the private sector for much of the most promising and innovative research. As they see it, for the government to issue and enforce rules that apply not only to federally funded research, but also to all research, including privately funded research, would be a poisonous gift. Such a step would curtail substantially the kinds of research currently allowed in the private sector. They prefer to rely instead on ethical standards that professional bodies most directly involved propound, and on ethics advisory committees that Geron and the Advanced Cell Technology group, for instance, have established. These matters are beyond the scope of our inquiry. I add only that one may entertain certain justified worries without indiscriminately attacking all free market research undertakings. The results of privately funded research may not be immediately or universally available to the general public, in the fashion that federally funded research is. "Commercial organizations" are, after all, designed to make money. Neither in their objectives nor in their management are they designed to balance conflicting interests or to pay homage to the distinctive noncommercial qualities of medical research and medical care. At a minimum, the government should not ignore the lack of coordination mentioned above or permit so many decisions to be made by default.

As we reflect on these four areas, it seems clear that no one engaged in stem cell research can evade such ethical questions. We are bound to weigh arguments about where to place ourselves along a spectrum, how far judgments about abortion and stem cell research diverge, and so on. If we give these enduring moral concerns short shrift, we enter the political fray with undefended assumptions that we merely announce. To avoid such an outcome, we must not grow weary of moral debates. They matter, and views taken exert vast influence. Between those who regard embryos as equally valuable human life and those who regard embryos as only "clumps of cells in Petri dishes," there is no peace. I close by offering one observation that comes from inhabiting a particular region in the "middle."

Is it cogent to claim that abortion and embryonic stem cell research are morally indistinguishable from murder? Posing so blunt a question concentrates our thoughts. Yet it also encourages an unfortunate tendency to restrict evaluative possibilities to a single *either/or*. Either we judge abortion and the destruction of embryos to be treating fetuses and embryos as mere means to other ends, or we judge the case for transparency to omit too many morally relevant considerations, but then rush to the other end, where we judge abortion and embry-

onic stem cell research as morally *indifferent* actions *in themselves*, to be evaluated solely by the benefits they bring to others. Beliefs in the middle lead us to reject this simplifying restriction. Here one engages formidable arguments from the "right" and the "left" and appropriates as much as one consistently can, while retaining a distinctive vantage point. From this point, one finds a position less cogent than many conservatives do that extends without modification (morally, if not legally) the prohibition of murder to the prohibition of abortion and embryonic stem cell research. The middle point ascribes *greater* importance to fetuses and embryos than many liberals do, an importance not reduced to the benefits that research on them may bring to third parties. From this point, one permits research on embryos conceived to enhance fertility, but which will never be implanted. One excludes embryos created exclusively for research, where we directly and intentionally create them, *in order to* disaggregate them. Whether this region is the most fitting place to be, and what dangers lie in locating ourselves there, are matters to be canvassed elsewhere.

#### WEB SITES OF INTEREST

<http://www.nih.gov/news/stemcell/scireport.htm>  
<http://www.stemcellresearch.org/>  
<http://www.nih.gov/about/director/Speeches/healthykids092700.htm>

#### ADDITIONAL READINGS

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