Regenerative and Cellular Sciences

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RESPECTING / PROTECTING WOMEN

Women are central to embryonic stem cell research as they are the source of the primary tissue. Whether the sourcing eggs for derivation of embryonic stem cells is leftover IVF embryos, egg-sharing schemes, or altruistic for-research donations, there are ethical issues with which women (and society) must grapple.

Given that women are often asked to donate embryos in the fertility treatment context, they are more likely to be vulnerable and could feel coerced.

Given that the embryonic material is needed for cell line derivation and future research, can informed consent ever truly be achieved?

Treating egg donation like blood or bone marrow donation supports women’s autonomous right to choose and make decisions for themselves, but can their consent be justified if the health risk is too high (or unknown – the full consequences of which are not well understood)?

‘… If you actually look at informed consent, there’s no such thing because you can never be fully informed because there’s always another question … . In a true sense … there is no such thing as informed consent. [Rather] they’ve been given enough information that allows them to make a decision they’re comfortable with, I think.’

[UK Policy-Maker]

‘[A]fter the scandal … with Hwang … it was a great discussion in my group … [They said if [she gave] informed consent, what was the problem, because if one doesn’t want [to do] something, then they shouldn’t do it. [But] if it’s your chief asking you if you want to take part … it’s just always abuse of power.’

[Argentine Ethicist]

RESPECTING / PROTECTING EARLY LIFE

Embryonic stem cell research, more than any other type of stem cell research, raises important ethical and social issues relating to the beginning of (socially valuable) personhood and how to respect early life.

• Is the early embryo human life or a collection of cells?
• What makes human life valuable?
• Is using leftover IVF embryos a means of showing them respect because they will otherwise be discarded (which is disrespectful)?
• Is using embryos however obtained going too far down the instrumentalisation road?

‘In the broad sense … the discussion about the ethical use of embryos … goes to the very root of our experience as a society. … [W]hat’s life worth in the beginning? How far can we go in manipulating that? The different religions [approach it differently]. It’s a very interesting discussion.’

[Argentine Researcher]

RESPECTING / PROTECTING PATIENTS

Patient safety is a key issue and many agree that much more basic research is required before most stem cell practices legitimately reach the clinical trial stage; premature clinical trials could set the whole field back (although some still think that the emphasis should be on disease-specific and translational research).

‘[U]sing these early cells, you don’t know what they might do … . The dangers of viruses and other things in animal cells also another [risk].’

[UK Interfaith Group]

‘[Y]ou have got to make sure the [originators of the stem cell] are healthy … especially if they are taken early in life. You have to monitor the person they came from to make sure nothing crops up later that would raise issues.’

[UK Clinical Stem Cell Scientist]

‘[Y]ou have to deal with safety concerns … . You need clear-cut safety measures that have to be implemented … so we are not going to allow people to put things [in people].’

[Argentine Researcher]

The hype around stem cell research can make it difficult for scientists and can be harmful to the long-term future of the research by prompting people to take risks and sign up for dangerous trials:

‘I was reading something … about some scientists … that had just taken a load of embryonic stem cells and injected them into patients without doing proper controls or anything. … [S]ome people tend to think it is like a magical cure for everything, so go straight ahead with some things which a lot of preliminary work should [precede].’

[UK Stem Cell Scientist]

‘[S]ome people think this is like a magic tree [and] that we are going to heal all diseases, which is [pure] fantasy … . We don’t have even one patient who can work with this technology and have to be extremely careful.’

[Argentine Researcher]

‘[I] have concerns about the tone of the discussion of stem cells within the public. There must be a general statement to say this could be the future, but don’t put this in the everyday life of people because this creates a lot of uncertainty within patients which is absolutely unfair.’

[Argentine Researcher]

Research and new treatments must not be at the cost of public health. Scientific funding is important but it should ideally be directed at objectives that can be delivered to populations and are not so expensive as to be restricted to elites.

‘[S]pending more money on research does not get the waiting list times down.’

[UK Stem Cell Scientist]

‘[D]oes money go into something that may initially help a few people or do you spend it on having someone’s blood pressure checked frequently and … treated well … ?’

[UK Nurse]

‘At present time it is only cost, there is no benefit. In neurological diseases, this is just the future, and I think we are far from having this as a useful therapeutic option for patients.’

[Argentine Researcher]