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Forgotten Fetuses - A Sociocultural Analysis Of The Use Of Fetal Stem Cells

This two-year project is a socio-cultural analysis of fetal stem cell focused on Britain. It is the first social science project to investigate the following: 1) how aborted fetuses are collected in the abortion clinic for research; 2) the concerns that might influence women's willingness to donate an aborted fetus to stem cell research; 3) the ethical, legal and policy frameworks governing the collection and use of aborted fetuses in research and therapies; 4) the extent to which fetal tissue is used in stem cell science; 5) why stem cell scientists value fetal tissue as a biological resource and research tool in stem cell science; 6) how fetal stem cells are being translated into standardised therapies. The research methods used include: participation observation of more than 30 scientific meetings, extensive documentary analysis, 29 interviews with stem cell scientists, clinicians, tissue bankers, sponsors of research and activists, and six focus groups with 41 women, the research develops a detailed analysis of four key areas outlined here but discussed in our publications.

The first relates to features of what we call the 'fetal tissue economy' and the work involved in reconfiguring an aborted fetus into the 'right tool for the job' in the stem cell laboratory. Seven stem cell laboratories using fetal tissue were identified. We found that although most abortions take place in the independent sector, most fetal tissue for research is collected in NHS hospitals under local arrangements. Each research team has established a chain of custody between two independent institutions – abortion clinic and laboratory – which is fragile and dependent on the goodwill and co-operation of clinic staff. In most cases a research nurse seeks women's consent to donate. Fresh fetuses are collected following surgical or medical abortion. Modifications to the method of abortion in order to collect the material have been approved by Research Ethics Committees. A variety of methods are used to transport, store and process aborted fetuses and the kind of fetal tissue used in different laboratories varies. Aborted fetuses are sometimes imported by the commercial sector. There are striking differences between the abortion clinic and the IVF clinic (where pre-implantation embryos are collected) as sites for collecting human material for use in stem cell research but much less is known about the former largely because collections of aborted fetuses for research are caught up in the controversy around abortion.

Secondly we found that regulations covering how the aborted fetus should be treated are contradictory and ambiguous, and that the use of fetal tissue in stem cell science lacks transparency and public accountability. On the one hand, the fetus outside of the woman's body is regarded as clinical 'waste' and can be handled like other tissue removed by medical professionals. On the other hand it is singled out as tissue deserving of respect. Although there are guidelines on the use of fetal tissue in research, the Polkinghorne Guidelines drawn up in 1989, some research teams do not comply with these. We argue that 'sanctioned non-compliance' characterises current practices and we make a case for the guidelines to be reviewed. We see stem cell science in the UK as less strictly regulated than is frequently claimed.

Thirdly, many women who took part in the focus groups initially expressed

willingness to donate an aborted fetus to medical research. However, some changed their mind as the discussion around stem cell research developed. What troubled them was the idea that the aborted fetus might somehow continue to exist, albeit in a different form, in the laboratory, for example, if it were used to produce 'immortalised' stem cell lines, or in transplantation, where some connection with the source of the fetus is maintained. They saw these applications as undermining the very reason women seek abortion which is to terminate the fetus' biography. They voiced concerns about what scientists might do to fetuses which suggests that the rule in the Polkinghorne guidelines that women must not be given detailed information about research using aborted fetuses should be reviewed.

Fourthly the fetus emerges as an unstable and highly contingent scientific object with both use and exchange value and as an important source of a range of cell types with different potential therapeutic applications. However we find that there is discursive management of the notion of 'fetal stem cells' as scientific and policy discourse frequently obscures the fetus as a source of cells by using terms such as 'adult stem cells' or 'non-embryonic cells'. This we suggest relates both to ways in which scientific objects are materialised in stem cell science but also to political and commercial concerns to distance stem cell science from abortion politics.

The research team has engaged widely with academic audiences with backgrounds in law, ethics, politics, history, science and social science through presentations at eighteen international and national meetings and participation in workshops. Two papers have been published in the clinical press, one in an interdisciplinary journal and four other journal articles have been submitted. The research has attracted media interest and coverage in both electronic, print and broadcast media. Its findings are topical and contribute to current debate around the new Human Tissue and Embryo Bill and implementation of the European Tissue and Cells Directive.

The research makes an important contribution to the development of a sociology of the biosciences by expanding on ideas around the gendering of global tissue economies and investigating the donation by women of aborted fetal tissue to the biological and medical sciences. It provides a strong foundation for further comparative work looking at the relationship between abortion and fetal tissue research policy and stem cell science in other countries. Pfeffer will be developing this work further in her forthcoming book on the history of human tissue banking and in her international fellowship exploring related developments in the USA. Kent's translational fellowship will enable her to build capacity for further research in Europe and develop her analysis of the findings in her book on regenerative medicine.