Submission
National Health and Medical Research Council
Supplementary Note 5 – the human fetus and the use of fetal tissue 1983

Selena Ewing
Research Officer
Southern Cross Bioethics Institute
1E/336 Marion Road
North Plympton SA 5037

Monday 29th August 2005

Introduction

This submission concerns the use of tissue from foetuses obtained through induced abortion, not through spontaneous abortion. The use of tissue from spontaneous abortion is not problematic provided appropriate consent has been given *by the parents.*

My main concerns are about separation between the research and the abortion, particularly in relation to gaining the consent of the woman.

The fact the fetal tissue is a 'scarce' resource[1] means that care must be taken not to allow attempts to expand access to this resource at the expense of women. This is particularly relevant in the light of public concern over abortion, and the public's strong desire for a reduced rate of abortion, which were both identified in opinion polling research recently conducted by Southern Cross Bioethics Institute.[2]

(1) The guidelines must eliminate the influence of the possibility of research on a woman's decision to abort.

It is possible that the very process of obtaining informed consent from the pregnant woman is in fact an inducement to terminate the pregnancy for the purposes of research.[3] Therefore the question of procedure in gaining the consent of the woman is of great importance. The guidelines need to clarify this.

Gaining consent for the research *before* the abortion has taken place, even though it is done *after* she has given consent to the abortion, may influence a woman's decision.

This is because she may still withdraw consent at any time before the procedure is underway. The abortion decision is highly complex and there is clear evidence that

[1] Tuch BE et al. Use of human fetal tissue for biomedical research in Australia, 1994-2002. *MJA* 2003;179:547-550.
[2] Fleming JI and Ewing S. *Give Women Choice: Australia Speaks on Abortion*, Southern Cross Bioethics Institute 2005.
[3] Childress JF. Ethics, public policy, and human fetal tissue transplantation research. *Kennedy Institute of Ethics Journal* June 1991, p93-121.

many women are ambivalent when making the decision to abort[4, 5, 6, 7] Among 1446 women applying for abortion in Sweden, almost one in ten changed their minds.[8] Another Swedish study, involving 854 women one year after abortion, found that 19.8% were still undecided as to whether they had made the right decision. [9]

A related issue is that there is a possibility that the existence of fetal tissue research may *in general* influence women's decisions to abortion because they may see at least some good coming from the abortion. Reports of success from aborted fetal tissue may cause the public, and women considering abortion, to think more favourably about abortion, perhaps with comparably less regard for the well-being of the mother and baby involved, and more emphasis on the 'greater good'. An example is the article in the SMH reporting on successful skin grafts from aborted fetal material.[10]

It seems clear, however, that approaching a woman about using her aborted fetus for research may compound her trauma, whether it is done before or after the abortion. It must be done with utmost sensitivity to her loss and grief.

(2) The guidelines must eliminate any influence of research on the method and/or timing of abortion.

One clear omission from the current guidelines is the separation of the institution in which the abortion is performed and the institution which carries out the research. Carrying out research is usually beneficial to an institution as a whole, and therefore a doctor is likely to benefit indirectly from the advancement of the institution. There should also be a requirement that there be no financial or legal relationships between researchers and abortionists.

There must be no change in abortion technique, or in the timing of the abortion, related to the research. This is crucial both for women's health (later abortions increase in risks for the mother) and for more humane procedures for the fetus (the foetus is more likely to feel pain at later gestations).

It is of great concern that some procedures may be allowed once the abortion is irrevocably in train. This is highly problematic because it requires that consent be given *before* the procedure, and may therefore influence the woman's decision. It also may impact on the technique of abortion. It is also highly problematic that in this

[4] Allanson S and Astbury J (1995). The abortion decision: reasons and ambivalence. *J Psychosom Obstet Gynecol* 16:123-136.
[5] Törnbom M et al (1999). Decision-making about unwanted pregnancy. *Acta Obstetrica et Gynecologica Scandinavica* 78:636-41.
[6] Alex L and Hammarström A (2004). Women's experiences in connection with induced abortion – a feminist perspective. *Scand J Caring Sci* 18:160-8.
[7] Allanson S and Astbury J (1996). The abortion decision: fantasy processes. *J Psychosom Obstet Gynecol* 17:158-167.
[8] Söderberg H et al (1997). Continued pregnancy among abortion applicants: A study of women having a change of mind. *Acta Obstet Gynecol Scand* 1997;76:942-947.
[9] Söderberg H, Janzon L and Sjöberg NO (1998). Emotional distress following induced abortion. A study of its incidence and determinants among abortees in Malmö, Sweden. *European Journal of Obstetrics and Gynecology and Reproductive Biology* 79:173-8.
[10] Robotham J. Skin from foetus is a balm for burns, *Sydney Morning Herald* Friday 19th August 2005, p3.

case it is almost certain that the researcher would be present and involved during the abortion, thus contravening these guidelines.

Some abortions, particularly medical abortion techniques at later gestations, may take hours, and the current guidelines appear to leave a window of opportunity for experimental procedures to take place during this time. It should also be clarified in the guidelines that this does not replace the requirement that the fetus be dead before any research can take place.

(3) The guidelines must consider those in the Australian community who would have ethical concerns about therapies which originated in induced abortion.

A general concern is that the Australian government and private scientists should not invest in research using techniques which a significant minority of Australians might find unacceptable.

In December 2004, Southern Cross Bioethics Institute commissioned opinion polling in a random, stratified sample of 1200 Australian adults. We have solid evidence that the Australian community does not offer unqualified support for abortion.

Our research found that 19% of respondents strongly disagreed that women should have unrestricted access to abortion on demand, no matter what the circumstance (and 15% somewhat disagree). This is a significant minority of people who will certainly object if there is any link between the research and the abortion procedure.

There will also be some in the community who will not accept therapies using fetal tissue, no matter how separate the research is from the abortion. These people must be considered, especially where therapies involve the original fetal tissue (rather than cell lines originally obtained from the fetus).

NHMRC should inform and assure Australians that the guidelines ensure that the abortion and the research are completely separate.

It is also of great importance that research using aborted fetal tissue be only conducted when there is no other way to carry out the research, and when the research is directed towards life and health. For example it is reasonable to suspect that the broader community might be unsupportive of the use of fetal tissue for cosmetic purposes.

Seventy per cent believed abortion is “bad but justifiable in certain circumstances”, and 42% of Australians did not accept the argument that a foetus is not a person (15% were neutral on this question). Therefore many Australians are unlikely to accept the idea that fetuses can simply become ‘research fodder’ without respect for the body and appropriate procedures and consent mechanisms. They are also unlikely to accept this kind of research without seeing that there are objectively good outcomes for life and health.

Despite public support to maintain current legal access to abortion, we found that the community does not have the same high level of moral support for abortion. For

example, when the foetus and mother are both healthy (as is the case in most abortions), only 15% believe abortion is morally acceptable, and 33% believe it should be legal in these cases.

Seventy-three per cent agreed that the current rate of one out of every four pregnancies aborted is too high (14% were neutral and 14% disagreed). Eighty-seven per cent thought it would be a good thing to reduce the number of abortions whilst still allowing women a choice.

While these findings do not directly address the matter of fetal tissue research, they suggest that the community is troubled by abortion, and that the majority are likely to be unsupportive of government policies and clinical practices that may be perceived to encourage or increase the incidence of abortion in any way.

(4) An example of the problems associated with a close link between abortion and research. [11]

Several years ago experimental procedures were conducted at the Swedish Karolinska Institute that involved the injection of foetal brain cells into the brains of patients with a neurodegenerative disease. The women were recruited after they had decided on abortion, and the abortions all occurred at ten weeks' gestation. Because of the importance of transplanting fresh oxygenated foetal brain cells as soon as possible after removal, the usual method of vacuum aspiration was not used, as the foetus would be killed and the desired tissues damaged. So instead the abortions were done using dilatation and evacuation, where the women would stay in hospital overnight while dilatation occurred using laminaria tents[12]. The next day the foetuses were removed live and intact, and immediately preceding the transplant the heads were rapidly removed to access the fresh brain cells.

These experiments took place in the adjacent room to where the abortions occurred, highlighting the collaboration that took place between the abortion provider and the researchers who were directly responsible for killing the foetus and conducting the tissue removal. The whole procedure was undertaken to serve the best interests of the patient being treated experimentally for brain disease – not the best interests of the woman. Equally problematic was the fact that the abortion procedure was changed to enable the removal of a live foetus. Because this procedure was riskier than the one ordinarily used at that gestation, it meant a deliberate choice to place the woman at greater risk to serve other interests.

These experiments serve to highlight the fact that the fetus had no legal rights. As a fetal tissue researcher stated,

[11] Personal correspondence, Dr J I Fleming, August 27th 2005.
[12] Laminaria tents are derived from a marine plant and are inserted into the cervix when dry to dilate it by swelling as they absorb water. Twelve hours is typically required for the dilation to occur.

> Once society's declared the fetus dead, and abrogated its rights, I don't see any ethical problem … Whose rights are we going to protect once we've decided the fetus won't live?[13]

It is also evident that the researchers considered that at least some good would come from the abortions.

The important point here is that experiments of this type have already happened in the past and are likely to happen again, unless decisive steps are taken to ensure they are never permitted.

Recommendations:

- The prohibition of commercialisation of fetal tissue must be maintained.
- Gaining consent prior to the abortion is inappropriate and may unduly influence a woman's ultimate decision to undergo abortion. The guidelines should ensure that consent is gained only *after* the abortion has taken place.
- The requirement for gaining consent, if possible, from the father ought to be retained.
- Research should be carried out in a different institution to the one in which the abortion is performed, and the researcher should not be present or involved during the abortion.
- There must be no change in abortion technique or in timing of the abortion related to the research.
- There must be no delay in the timing of abortion in order to gain a more formed fetus.
- Research procedures must not be carried out once the abortion is irrevocably in train (so that the woman does not need to give consent before the procedure, and so that there is no influence on method and timing of the abortion).
- Fetal tissue should only be used for research directed towards the goods of life and health.
- NHMRC should take great care to ensure that no policies or practices exist which in any way contribute positively to women's individual abortion decisions.

Selena Ewing
Research Officer
Southern Cross Bioethics Institute
August 2005

[13] Post-Abortion Fetal Study Stirs Storm. Medical World News, June 8, 1973, 21. See also Peter AJ Adam *et al.*, Cerebral Oxidation of Glucose and D-Beta Hydroxy Butyrate in the Isolated Perfused Human Head, Transactions of the American Pediatric Society, 309:81, 1973.