

Attitudes of women to fetal tissue research

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Authors' abstract

The use of human fetal tissue for scientific research has enormous potential but is subject to government legislation. In the United Kingdom the Polkinghorne Committee's guidelines were accepted by the Department of Health in 1990. These guidelines set out to protect women undergoing termination of pregnancy from exploitation but in so doing may significantly restrict potential research. Although the committee took evidence from a wide variety of experts they did not seek the views of the general public.

We asked 108 women about to have a therapeutic abortion; 167 women who had had a pregnancy terminated in the past, and 419 women who had never had an abortion, their views on research using human fetal tissue. Regardless of their past experiences the women were overwhelmingly in favour of research using fetal tissue (94 per cent). They made little distinction between basic research and research with obvious clinical relevance and supported the concept of using transplanted fetal tissue for the treatment of adult disease such as Parkinsonism. Women about to undergo an abortion were significantly more likely ($p < 0.001$) to approve of all types of research including that aimed at improving methods of abortion and research using live fetuses in utero.

Introduction

The use of human fetal tissue for research purposes is a subject which arouses strong feelings. Although there is no doubt that scientific research using fetal tissue has enormous potential, different governments impose very different restrictions on its use (for review see *British Medical Journal* (1)). In the UK an advisory group was asked in 1970 'to consider the ethical, medical, social and legal implications of using fetuses and fetal material for research'. The resulting Peel Report, published in 1972 (2), recommended that research should be allowed on fetuses weighing less than 300g, provided there was no objection on the part of the mother and the

research had been approved by an ethical committee.

In the late 1980s, concerned principally about experiments in which human fetal tissue was being grafted into the brains of patients suffering from Parkinsonism, the British government invited a second committee, led by the Reverend Dr John Polkinghorne, to review Peel's guidelines. The Polkinghorne Committee took advice from organisations involved in medical research and in the provision of abortion services and also from a significant number of religious organisations and groups campaigning against abortion. The recommendations of the committee were published in 1989 (3) and accepted by the Department of Health in 1990.

One of the principal concerns of the committee and of opponents of fetal tissue research was that women might be pressurised into terminating a pregnancy in order to provide fetal material. To safeguard women from exploitation the new recommendations included a recommendation that doctors involved in obtaining fetal tissue, ie those who agreed to a woman's request for abortion or who performed the termination – called in the report 'the source' – should be totally separate from doctors and scientists carrying out research – 'the user'. Indeed the two parties were specifically prohibited from discussing the proposed research. Women from whom tissue was obtained should give a general informed consent to the research but should not be told what the research was about or even whether the tissue was used.

Although the committee sought the views of many relevant bodies, no attempt was made to seek the opinions of women of reproductive age and in particular of women about to have a termination of pregnancy.

In this study we have sought to investigate the attitudes of women to fetal tissue research by a questionnaire based on the points brought out in the Polkinghorne Report.

Subjects and methods

Thirty questions were devised to investigate the attitudes of women to a variety of aspects of fetal

Key words

Attitudes; fetal tissue; research.

tissue research and to the main recommendations of the Polkinghorne Report. The questionnaire was designed to be completed by women while waiting at clinics. Effort was made to simplify the questionnaire by providing explanatory paragraphs where appropriate, giving examples of relevant research areas. A pilot version of the questionnaire was given to 30 women attending a family planning clinic, minor modifications were made and a final version prepared.

Two groups of women were selected in an attempt to identify differences of opinion that might relate to different reproductive experience. Five hundred and twenty-seven consecutive women attending a large family-planning clinic in the centre of Edinburgh (The Dean Terrace Centre) were given the questionnaire, 108 of these women had a history of termination of pregnancy while 419 women had never had an abortion. A second group of 167 women attending the Royal Infirmary of Edinburgh who were pregnant and requesting termination of pregnancy were also asked to complete the questionnaire. One hundred and fifty-eight women did so; two women were short of time; two said they found the subject too upsetting, while five refused to participate as they felt that they held no strong views. None of the women were given the questionnaire until after the gynaecologist had agreed to the request for abortion and the woman had left the consulting room. The person who asked the patient to complete the questionnaire was not involved with the consultation. It was made clear that women were not being asked to participate in the sort of research being discussed nor was any part of their treatment dependent upon their responses to the questionnaire. The study and the questionnaire both received the approval of the Paediatric/Reproductive Medicine Ethics of Medical Research Sub-committee of the Lothian Health Board.

The data were entered onto a computerised database (d Base VI v 1.1, Borland software) and initial analysis performed by summing the answers for each question and subdividing by group. Statistical analysis between groups was made using

the Chi Square test with Yates correction where appropriate (Epi Inf v 5.01a, Public Domain Software).

Results

DEMOGRAPHIC DETAILS

The demographic details of the women completing the questionnaire are shown in Table 1. Women attending for termination of pregnancy were younger ($p<0.001$) and more likely to be unmarried ($p<0.001$) while women who had never had a termination of pregnancy were less likely to have had children ($p<0.001$) than women in the other two groups. Forty-two per cent of women attending for an abortion had had a previous termination of pregnancy, while only 13 per cent of women who had had an abortion at some time in the past had had more than one.

Fewer women attending with a request for abortion were aware of the existence of research using fetal tissue (28 per cent v 53 per cent, $p<0.001$).

ATTITUDES TOWARDS FETAL RESEARCH

Only 6 per cent of women said they thought it was unjustifiable to use fetal tissue for research. Of the 94 per cent of women who felt that research was justifiable, 88 per cent thought it appropriate to undertake research aimed at improving our understanding of the basic physiology of the developing fetus and 84 per cent said they would allow this sort of research to be done on their own fetus. All women who approved of research agreed with the idea of undertaking research into clinical problems affecting the fetus and neonate, such as investigating the effect of giving drugs to accelerate lung maturation in the event of premature labour. Only 2 per cent of the women felt reluctant to allow their own fetus to be used for this kind of research. Eighty-seven per cent of the total sample approved of research which aimed to improve methods of abortion although significantly fewer of the women who had never had an abortion approved of this kind of research (84 per

Table 1

Demographic details of respondents

Number	Gynaecological. Outpatient clinic		Family planning clinic	
	Attending for abortion	History of abortion	No abortion	
	158	108	419	
% <20 years	20	2	13	
% <20-39 years	74	90	82	
% >39 years	6	8	5	
% with children	29	28	15	
% married/cohabiting	28	50	47	
% higher education	58	66	68	

cent v 92 per cent, $p < 0.001$). Eighty-seven per cent of women felt that research aimed towards using fetal tissue for transplantation was in principle right and 86 per cent of them would allow their own fetus to be used. Overall fewer women felt that research on a live fetus was justifiable but significantly more of the women about to undergo termination of pregnancy found this idea acceptable (68 per cent $p < 0.001$) and more than half of them would have permitted research to be carried out on their own live fetus. Significantly fewer women not currently pregnant would permit research on a live fetus (44 per cent) and even fewer would allow research on their own fetus (32 per cent).

Considering both groups together, women who had had at least one child (regardless of whether they were seeking, or had ever had an abortion, $n = 139$) were significantly less likely to agree, in principle, with research using fetal tissue (89 per cent v 95 per cent $p < 0.01$). However, no differences between parous and nulliparous women could be distinguished with regard to their feelings about the different types of fetal research.

CONSENT TO FETAL RESEARCH

Overall 63 per cent of women said they would wish their permission to be sought before their fetus was used for research purposes, significantly more women who had never had a termination felt this to be important (71 per cent v 53 per cent, $p < 0.001$). Less than half the women in each group would wish to know the exact details of the research but again women who had never had an abortion felt they would want more information (38 per cent v 23 per cent $p < 0.001$) and these women were more likely to want to ask questions of the researcher (54 per cent v 33 per cent $p < 0.001$). Over 75 per cent of all the women would be happy to give general consent to research using fetal tissue.

Separation of doctor and research

Few women felt that the doctor agreeing to and carrying out the abortion (the source) should be separate from the researcher (the user). Only 8 per cent of women about to undergo an abortion said they felt the doctor should have nothing to do with research being undertaken. Of the women not currently pregnant less than 25 per cent thought the source and the user should be separated and less than 15 per cent felt that gynaecologists who were performing abortions should not undertake any research using fetal tissue. Thus women about to undergo abortion felt even less strongly ($p < 0.001$) about the issue of separation than other women and 85 per cent of them compared with 72 per cent of the women not currently pregnant said their decision to consent to fetal research would be unaffected by the knowledge that the doctor advising them about abortion was personally involved with the research.

Practicalities of research

Less than half of the women felt that abortions should be especially timed to allow research to take place. However, once again women about to undergo an abortion were more likely to feel this would be acceptable (41 per cent v 27 per cent, $p < 0.001$). Few of the women felt their decision to allow research on their fetus would be affected if either they (8 per cent) or their fetus (7 per cent) had to be tested for HIV infection. Only 45 per cent of women felt they would be more likely to take part in research were it likely to produce information which might be of direct relevance to them as individuals (for example, the discovery of an inherited disease).

Discussion

In the introduction to the Polkinghorne Report the authors stated that 'it is evident to us that there is much concern over any use of fetal tissue, whether it is described as research or therapy'. The women who took part in this study did not appear to show much concern - 94 per cent of them believe there is nothing wrong with research using fetal tissue. They made little if any distinction between pure research and that which had obvious clinical relevance, including the use of fetal tissue for treating adult diseases. It must be remembered that the bulk of research uses tissue obtained after the abortion when the fetus is already dead. The women - particularly those not pregnant at the time - were less likely to approve of research involving a fetus which was still alive, perhaps out of some concern for the moral status of the unborn child, albeit a child destined to die.

Although it is possible that the women may have responded differently had they been asked to donate fetal tissue, we did try to approach this question by distinguishing between approving of research in principle and allowing tissue from their own fetus to be used. For each type of research no more than 20 per cent of the women felt unable to offer their own fetus for research which they had approved in principle. Moreover, the women who were about to have an abortion were more likely to approve of all types of fetal research and to offer their own fetus for use - at least in theory. The women about to undergo an abortion were younger and less likely to have had children than the women in the other group and 41 per cent of them had had an abortion before. It is possible therefore that they had less regard for the unborn child; alternatively they may have agreed with the idea of research using fetal tissue because they felt relieved of some of the anxiety associated with an unwanted pregnancy and received some comfort from the idea that a fetus which they did not want might be put to good use. Whatever the reasons for their overwhelming approval these are the very women that

Polkinghorne thought might be pressurised into participating in research of which they did not approve.

In an attempt to reduce any possibility of pregnant women being exploited, Polkinghorne recommended that the source of fetal tissue and the user should be separated and suggested that the best way to achieve this separation was to involve an intermediary. However, the separation of source and user imposes constraints on the design of certain types of research which could be directly beneficial to women of reproductive age and their babies. For example, research on the effects of corticosteroids on the maturation of the fetal lung would require careful timing of the abortion procedure and would therefore involve the source. Most of the women in our study did not feel it was necessary to separate the doctor who was counselling or treating them from the person who was doing the research. The decision to have a pregnancy terminated is almost always made before a woman reaches a gynaecologist (the potential 'source'), whose role in the counselling process is to make certain she understands the procedure involved and its attendant risks and that she is absolutely certain of her decision. It seems unlikely to us that a woman would deliberately embark upon a pregnancy in order to have it terminated solely to provide tissue for research purposes, since for the vast majority the decision to have an abortion is painful and difficult and not undertaken lightly. The termination of a pregnancy expressly to provide tissue for research would appear to be already illegal. The 1967 Abortion Act states that two doctors in good faith should have reason to believe that a woman has grounds for having a pregnancy terminated and the permitted grounds do not include terminating a pregnancy in order to provide tissue. If the main concern of the Polkinghorne Report was to prevent an act which was already illegal it seems superfluous. It could be argued that there would be a greater risk of abuse of the existing abortion law by women wishing to provide fetal tissue for treatment of relatives or friends suffering from a disease (for example, Parkinson's) which might thus be alleviated. It would be sufficient to add an amendment to the existing Abortion Act, regulating the circumstances under which fetal tissue could be used for treatment.

Positive explicit consent

The report recommends that 'positive explicit consent' should be obtained from the mothers to the use of the fetus or fetal tissues. However, the information on which she is to base her informed consent has to be general (not 'explicit') because it has to embrace all the potential research. It would not be permissible to give the mother any indication of the exact use, indeed it would be

impossible because the doctor who gained her consent to research (the source) is prohibited from communicating in any way with the user. While many of the women we asked agreed to giving general consent, a significant minority (32 per cent) felt they would want some detail about the proposed research and would like the opportunity to ask questions. There seems no reason to deny more specific information to those women who want it. With both the woman and the doctor ignorant of the precise use of the tissue it is hard to imagine circumstances in which consent would be either sought or given.

Notable differences

There are some notable differences between the membership and emphasis of the Peel Committee and the Polkinghorne Committee. The members of the Peel Committee specifically stated that they had tried to maintain a balance between ethical concerns and the important contributions which could be made to medical science and 'to the health and welfare of the entire population' by the use of fetal tissue. In contrast the Polkinghorne Committee did not consider any 'particular contemporary developments' taking place either in society or in science but couched the report purely in terms of ethical principles. The Peel Committee was chaired by a gynaecologist and included, among others, two other doctors, two nurses and a social worker. The membership of the Polkinghorne Committee comprised the president of a Cambridge college, the president of an Oxford college (the only medical practitioner – a general physician approaching retirement), a professor of medical law and ethics and a sociologist. In the letter to three secretaries of state which introduces his report, the Rev Dr Polkinghorne wrote that the members of the committee 'brought with them a variety of experience relevant to this inquiry'. While we do not intend to argue the rights or wrongs of the use of fetal tissue for research it seems clear to us that the women whom Polkinghorne was trying to protect feel very differently about the subject than the members of his committee would appear to. It seems odd to us that it was not considered relevant to include on the committee more people who came into direct contact with women faced with an unwanted pregnancy. The very fact that the committee was seeking to make recommendations to protect women from something which gynaecologists consider to be already illegal suggests that the membership might have benefited from the presence of someone actively involved with the provision of abortion. One could even argue that it might have been even more relevant to seek the opinions of women in general and in particular of those women considering having an abortion.

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References

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News and notes

What do we owe the elderly? Allocating social and health care resources

The Institute for Bioethics, Maastricht, the Netherlands, and The Hastings Center, Briarcliff Manor, New York, USA, will co-sponsor a conference on the allocation of (health)care resources to the elderly on September 16-17, 1994. The conference will be held in Maastricht at the Maastricht Exposition and Congress Centre (MECC). The conference will be organized in co-operation with the Council for International Organizations of Medical Sciences (CIOMS) of the World Health Organization in Geneva.

This conference represents the culmination of a two-year research project carried out by the two institutions. The participants in the project came from eight countries in Europe and North America, and focused their work on five major themes: 1) the meaning and significance of old age in contemporary society; 2) the goals of medicine and health care for the elderly; 3) balancing the needs of the young and the old: intergenerational obligations; 4) resource allocation and social priorities, and 5) families, society and long-term care.

Over the two years of the project an intense investigation of these issues was carried out, drawing not only on the knowledge and resources of the project

participants but also on that of other appropriate experts. The research group itself was a mixture of geriatricians, gerontologists, ethicists, philosophers, demographers and sociologists.

The planned conference in Maastricht will be focused around the five themes cited above and, at the core of the conference, will be papers prepared by the research project participants. In addition, however, other people who were not part of the project will be asked to make presentations as well, as a result of a call for papers. By virtue of additional participants from developing regions of the world, the conference will extend the scope of the original research to look at resource allocation for the old as a growing world-wide problem.

There is a call for papers on one or more of the general topics cited above, or other issues pertinent to resource allocation and the elderly. Abstracts have to be sent before April 1 to: International Aging Conference, The Hastings Center, 255 Elm Road, Briarcliff Manor, NY 10510, USA.

Please write to The Hastings Center for further information and registration, or phone: 1-914-762-8500 (fax: 1-914-762-2124).

News and notes

Euthanasia and Assisted Suicide in the Netherlands

A conference on how and why medical decisions concerning the end of life developed in the Netherlands the way they did is to be held in Maastricht, the Netherlands, on June 10th and 11th this year.

For more information please contact: The Convenor, Euthanasia and Assisted Suicide in the Netherlands, The Institute for Bioethics, PO Box 778, 6200 AT Maastricht, the Netherlands. Phone: 31-43-217575; fax: 31-43-256373.