

new developments

The Use of Human Tissue: An Outsider's View

Donald Evans

Bioethics Centre, Dunedin School of Medicine, University of Otago

Introduction

Professor Jones provides us with an interesting account of the role of consent in scientific and medical research on human tissue. He correctly asserts the importance both of such research and of the maintenance of respect for human tissue and the donors of tissue, but notes that the tension between these considerations poses threats in each direction (p.9). After offering some tentative proposals for dealing with this tension, he encourages teasing out the ethical issues by means of discussion. This note offers a start in this direction in the form of an evaluation of some of his proposals.

Symbolic and Ethical Significance

One route by which the tension might be resolved is to make the distinction between body parts which have considerable symbolic significance and others which do not (p.10). There are two comments called for on the usefulness of this distinction. The first concerns its scope and the second its character.

First, is there a secure boundary between what is symbolically significant and what is not? In the Alder Hey case complete heads were retained, whereas a recent research application sought permission to retain veins from an umbilical cord for research into a human model of angiogenesis. How do these compare on the scale of symbolic significance?

It is certainly the case that the head is especially significant in a number of respects – for example: everyday recognition of others is usually connected with the head and face; in certain situations the head is covered as a mark of respect; people are sometimes honoured after death by means of a bust (a sculpture or mould of the head and shoulders); touching the head of another can be a mark of disrespect in some societies such as

Maori society. Each of these, and others, might be said to be expressions of the symbolic significance of the head.

It is not possible to see the other candidate in any of these lights. But that is not to say that such tissue does not have symbolic significance, nor even that it has less symbolic significance. The symbolic significance, which it may be thought to have, might simply be different. For example, the proposal to place the DNA from the umbilical cells into a cow would give rise to considerable controversy. Conservatives might describe the procedure as undermining the dignity of human life. The minute elements of tissue involved nevertheless symbolically stand for the whole of human life in this context and to proceed would not be simply to damage the dignity of one person, whose head might be retained, but of human life *per se*.

It is thus the context rather than the intrinsic character or function of the body part which determines its significance. This is easily demonstrated in the case of the head by remembering Frazer's account of head hunters of Borneo returning in triumph and lifting the head of the enemy on a pole when 'the most dainty morsels of food are thrust into its mouth, delicacies of all kinds and even cigars'. Freud proposed that there could only be one significance of the head in this setting (Freud, 1962, p.37). But it has been shown that there could be various accounts of significance offered here and, furthermore, that the significance of the head for those warriors could only be understood in the context of their lives, not by means of some claim to its intrinsic properties or to fundamental attitudes which human beings must have to them (Phillips, 1976, pp.74-75). Both reverence for and ridicule of the enemy are possibilities here, and which of these descriptions one is moved by determines what symbolic significance pertains to the head.

This observation leads us to the second point at issue (p.11). Is it the case that the symbolic significance of the body part determines the ethical significance of what we do with it? On Professor Jones's account this would have to be the case. But on reflection we might come to think that the opposite is true. It is, of course, the case that we would make a distinction between the use of a severed head as a football and the use of a pig's bladder stuffed with human hair for the same purpose. And this would not be a matter of squeamishness; it would have ethical significance. But why would this be so? It is partly because the face reminds us of a person, with all of the range of feelings and emotions which the face can express, and clearly it is wrong to play football with persons or to denigrate their memory. Again it reminds us of the ways in which we can show disrespect to persons. In polite society we cannot show respect for a person by slapping him across the face, but we can by slapping him on the back. But this is not a matter of the intrinsic significance or function of the head. It is not because we might cause serious injury that face slapping is disrespectful. Kicking the severed head about relates to such an expression and is thus ethically unacceptable. If the head is symbolic in this sense, its significance arises out of the role it plays in ethical discourse rather than the reverse.

The Research Intent

The second interesting suggestion to resolve the tension is that there may be different levels of consent applied to the donation of the range of tissues referred to above, so that failing to obtain consent for the donation of unwanted tissue removed at surgery would be of minimal ethical significance. Once again the distinction is based on the functional significance of the tissue.

There are numbers of problems associated with this suggestion which can be grouped together under the heading of research intent.

Prospective/Retrospective Use of Tissue

Professor Jones reminds us that times have changed and that large numbers of tissues were retained in clinical practice for use in research and medical education before the need for the consent of patients became a requirement. The patients are either dead or delinked from their tissue so that consent cannot be sought from them for use of their tissue for research or teaching. Thus it is true that what we would now consider unethical was accepted practice.

Use of this anonymised tissue does not raise the same ethical issues as the Bush recommendation with respect to the use of embryonic stem cells (p.9). In the latter case it is the use of the tissue *per se* which is morally offensive to conservatives, in that it constitutes murder, not the failure to obtain consent for its use. Indeed consent was obtained for the use of the embryos involved, but this does not make it morally acceptable to opponents of embryonic stem cell research.

There is an ethical difference between the use in retrospective studies of anonymised tissue collected before consent was required and the prospective collection of anonymised tissue for research without consent. We cannot know whether the patients in the retrospective studies would have consented to its use or not. We can know whether prospective patients would and it is our duty to discover this. The anonymisation process does not mitigate the duty.

Place of Research

In New Zealand great care has to be taken as to where any research tissue is used, irrespective of its size or function. If it is the purpose of the researcher to send the tissue out of the country for analysis, consent from the patient is required. This is out of respect for the Maori view of their relation to the land and their attitude to bodily integrity. Thus, in this regard, the ethical significance of the consent process has nothing to do with either the amount of tissue involved, or its function, or whether it was tissue removed as part of clinical treatment or tissue collected for research. The notion of stronger and weaker varieties of consent cannot find a foothold here.

Return to Donors

For similar reasons the same is true of the manner of disposal of the tissue in the research process. In the case outlined above the enquiry whether the donors of the umbilical veins desired the return of remaining tissue after the research was completed was a requirement for ethical approval. This was in line with the Maori wish to dispose of the placentas of newborns in the manner of their choosing.

Once again this constitutes a rebuttal of the view that the ethical significance of the tissue is determined by a gradation of the intrinsic significance of the tissue implying the need for varying qualities of consent. For most Pakeha mothers the manner of disposal of the placenta would not be a matter of ethical import.

Nature of the Research

The research objectives for which the tissue is to be used might be the determining ethical factor rather than the nature of the tissues themselves. Given the advent of DNA testing the mass or function of the donated tissue might well be an irrelevance with respect to the consent issue. The kind of information which can be derived from such analysis can have profound significance for the donor and for the genetic relatives. It might be the wish of patients for such information not to be made available to researchers for a variety of reasons. That the tissues are removed from the patient in the course of treatment, where such testing is not a part of the total care package, suggests that a quite separate consent needs to be sought for any additional use to which it might be put. This is in line with the restrictions surrounding the use of health information in New Zealand (Health Information Privacy Code, 1994, Rule 10). Rule 10 makes it clear that where identifiable health information is to be used for a research purpose when it is collected for another reason either the consent of the patient is required or an ethics committee approval is desirable. Such committees would not readily approve studies where the consent issue was not taken seriously. For tissue to be subjected to genetic analysis without the consent of patients would not honour the spirit of the Privacy Act. Such a requirement could not refer to a weak form of consent.

Blank Cheque Consents

For a proper consent to be achieved it must be informed. This

is a logical feature of the notion of consent. For this reason it is unwise to seek consents for the use of tissue for unspecified research. Some research might be unobjectionable to a patient whilst other research would not. Professor Jones's example of the stabbing of cadavers would be such a contestable case. Few patients or their families who bequeath bodies for research imagine that a forensic pathologist might use the body thus to learn about the nature of wounds inflicted by various kinds of instruments from various angles and with various levels of force. Such research might be important for the protection of the public, but many willing donors might wish to draw the line at this point. Ethics Review Committees are therefore sceptical about such weak consents and tend to regard them as not being proper consents at all.

Conclusion

The interesting suggestions offered by Professor Jones to help maintain both levels of research and respect for tissue donors are problematic. However he is right to propose a search for means to achieve this worthy enterprise.

References

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