SYMPOSIUM ON CONSENT AND CONFIDENTIALITY

Organ retention and return: problems of consent

M Brazier

Correspondence to:
Professor M Brazier,
School of Law, University of Manchester, Oxford Road, Manchester, M13 9PL, UK;
shirley.tiffany@man.ac.uk

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This paper explores difficulties around consent in the context of organ retention and return. It addresses the proposals of the Independent Review Group in Scotland on the *Retention of Organs at Post Mortem* to speak of *authorisation* rather than consent. Practical problems about whose consent determines disputes in relation to organ retention are explored. If a young child dies and his mother refuses consent but his father agrees what should ensue? Should the expressed wishes of a deceased adult override the objections of surviving relatives? The paper suggests much broader understanding of the issues embedded in organ retention is needed to provide solutions which truly meet families' and society's needs.

Consent is such a simple word. Since I gave my less than fully informed consent to chair the Retained Organs Commission, I have heard on thousands of occasions that consent is the key to the problem. Other papers in this edition of the journal amply demonstrate the complexities of this seven letter word, consent, in many contexts of medical practice and research. The particular difficulties generated by organ retention and return reveal a host of practical problems around consent. As a lawyer I tend to look for practical and pragmatic solutions. An examination of practical problems, however, uncovers questions of principle and if we do not attempt to address those questions of principle, any practical solutions are likely to be, at best, partial solutions.

I am not alone in being troubled by the language of consent in this context. The Scottish Independent Review Group on the *Retention of Organs at Post Mortem* (chaired by Professor Sheila McLean) has proposed that, rather than speaking of consent in the context of organ retention, we should speak of *authorisation*.[1] They offer a number of reasons for their rejection of the term, consent.

Two principal reasons stand out: (1) there may be families content to allow the retention of organs taken from their relatives at postmortem examination who will not wish to give fully informed consent. The family are prepared to permit the removal and retention of body parts. They either do not wish to or do not feel able to participate in a process akin to giving fully informed consent to medical treatment in life. The family's fundamental values are not offended by removal of organs or tissue. They will authorise others to do what others think beneficial for science or education; (2) in relation to children, the Scottish Independent Review Group argue that parental powers to consent on behalf of young children are limited to consenting to procedures in the best interests of the child. The mutilation (my emotive word not theirs) of a child after death does not fit into the framework of parental consent as it is applied in life. Nonetheless, a deceased child's parents (given no suffering is caused to the child) may authorise hospital autopsies and retention of organs.

The first of the Scottish concerns is of great importance. How consent in any real sense can be given in the context of bereavement, especially sudden bereavement, must be addressed.[2] In this short paper, however, I focus on other problems of consent illustrated by the second question raised by the Scottish Independent Review Group.

Underlying the group's specific discomfort with the notion of parental consent is a broader question of how far analogies derived from consent to medical care in life are applicable after death. To quote the Scottish report, is " . . . the use of the word 'consent' as currently legally understood . . . inappropriate and misleading in the context of postmortem examination and the removal, retention, and use of organs/tissue?"[3]

WHAT IS CONSENT FOR?

A previous Master of the Rolls, Lord Donaldson, took a straightforward view of consent to medical treatment by living patients. He likened consent to a *flak jacket*.[4] Once consent is obtained, the doctor is protected from legal gunfire. Consent protects his back. He cannot be sued. Academic lawyers, those rather precious creatures, dislike the analogy, ignoring as it does any analysis of the interests consent protects, avoiding even any mention of autonomy. Moreover, whether you like flak jackets or not, the crucial question remains of *who* has the requisite authority to provide the flak jacket to the doctor?

Consent by conscious competent adults is often said to protect fundamental rights of self determination and safeguard bodily integrity.

Kennedy and Grubb put it this way[5]:

> The ethical principle that each person has a right to self determination and is entitled to have their autonomy protected finds its expression in law through the notion of consent. [A]ny intentional touching of a person without lawful justification or without their consent amounts to battery.

In English law, my right to decide what is done to my body is paramount. However bizarre, irrational or repugnant my reasons may be, I can (save in very limited circumstances defined by statute) refuse any proposed medical intervention. That does not mean that I can mandate that any treatment that I desire must be provided for me. The English courts will not compel a doctor to provide treatment which s/he considers contrary to his or her clinical judgment.[6] Certain forms of mutilating treatment may constitute criminal assault, even if performed with the full consent of the patient.[7]

In relation to my children, I am empowered to give a proxy consent while they are too young to decide for themselves, but only to treatments or procedures which at least do not violate their interests. I could not—for example, authorise surgery to alter my child's sex because I suddenly decided that I wanted a "boy" not a girl. In relation to mentally incapacitated adults, in English law, no proxy can consent on their behalf. Treatment in their best interests is lawful so that the ultimate decision makers are often doctors themselves,[8] or in controversial or disputed cases, the courts.

How can these principles be extrapolated to organ retention? Can this usefully be done? Let me begin with some

practical problems. They fall into two principal categories. *Whose* consent should have been obtained for organ retention? *Whose* consent ought to be obtained for organ return?

Current legal principles expressly addressing "consent" after death give us little help. We will alas learn little from the current law. As the Bristol interim report[9] forthrightly put it: "the complexity and obscurity of the current law will be manifest to all".

The Human Tissue Act 1961 is a toothless tiger imposing fuzzy rules with no provision for sanctions or redress. Absent directions from the deceased herself, the act provides that the person lawfully in possession of the body (often the hospital where the body lies) may authorise removal of body parts for the purposes of medical education or research providing that having "made such reasonable inquiry as may be practicable", he has no reason to believe that the deceased had expressed objections to such a process or that "the surviving spouse or *any surviving relative* of the deceased objects to the body being so dealt with". Under the Human Tissue Act it may appear that the requisite authorisation, consent if you like, comes from the hospital. Hospitals permit themselves to remove organs and tissue which they desire to put to scientific or medical uses. The Department of Health now advises (or rather mandates) an interpretation of the "no objection" rule to require explicit informed consent.

Does the common, the judge made, law assist us further? Not much. The common law casts on the executors or administrators of the deceased's *estate* the duty to dispose of the body decently and lawfully. That duty confers a right to claim possession of the body for burial, cremation, or other decent or lawful disposal. Note that this right is a right enjoyed by the *estate,* not the family as such[10] Whether or not a body that is less than intact is lawfully returned may be a question of degree. A body virtually stripped of organs would not appear to qualify. A body minus a millimetre of tissue sits at the opposite end of the spectrum. Were the focus of our debate on the legality of past practice we would need to factor into our discussion the Anatomy Act and the Coroners' Act and Rules.[11] My task is to look to the future rather than revisit the past. And so I return to the question of *whose* consent ought to be required for, first, *retention,* and then *return.*

The simplest case may appear to be one where, tragically, a child has died too young to have expressed any sort of choice about the fate of her body after her death. Every official utterance since the Bristol interim report was published declares that parents must decide. Let us assume for a moment there is no question of a case being made that society's interests, or the interests of future children, necessitate and justify organ retention without any consent. Even in this simple case practical problems soon surface. Consider this scenario.

Parents, who were married at the time of the child's death so that both shared legal parental responsibility for the child in life, disagree about whether or not to "consent" to organ retention. The mother wants her child buried intact. The father is content to authorise retention of organs or tissue. Moving from organ retention to organ return, where organs have been retained, what should ensue in this case? The mother is content to allow the hospital to continue to retain body parts from her child. The father wants to re-unite those parts with his dead child.

Let us add another layer of complexity to these two scenarios. The parents were not married, and did not share parental responsibility for the child in life. Maybe that is not another level of difficulty but the answer to the problem? It could be argued that only the mother who was legally entitled to make decisions for her child in life counts. Her word is absolute?

In searching for answers, return to my first scenario involving married parents (or unmarried parents who nonetheless share parental responsibility). In that scenario, the mother wants her child buried intact, but the father would authorise retention. If we have to determine whose *wishes* take priority do we review the reasons for those wishes? Might we reason as follows?

Assume that the mother is an Orthodox Jew. Her religion requires burial intact. The child's father, while also Jewish, is not religious. He has no special reason to authorise retention. He is simply keen to help science. Does religion trump science in this scenario? But what if we alter the facts a little and the child died of a rare genetic disease? The father's motives are to promote research to try to ensure that his other surviving daughters will not themselves be at risk of giving birth to similarly affected children. Do we (or some appropriate authority) weigh the parents' motives? Who makes that judgment? Or do we reason differently and conclude that unfortunately as the parents disagree a *partial* consent is insufficient? Must both parents agree to retention, or retention is unlawful, as the Scottish Indpendent Review Group proposes?[12] In life, normally only one parent's consent is required to authorise medical treatment of the child.[13] What (if any) is the rationale for *dual key consent* after death?

As we have noted, parental powers to authorise the medical treatment of a living child derive from their responsibility to safeguard the *welfare* of their child. The child's health is the law's priority. Where those interests are disputed, the courts are the ultimate arbiters of welfare. In death does that analysis change? As Lord Mustill somewhat coldly said of Tony Bland as he lay in the coma from which he would never awake[14]:

> The distressing point, which must not be shirked, is that the proposed conduct is not in the best interests of Anthony Bland for he has no best interests of any kind.

So we might say that the dead child has no enduring interests, no more do any of us after death. (I shall dispute that proposition later but for the present may we accept that the child's welfare in its narrowest sense is no longer a moot question.) What *parental* interest do we endorse in granting parents (singly or jointly) *control* of their child's body?

Several interests must be considered, many of which overlap: (1) the child is "theirs". She belongs to them. Her body belongs to them. They are still parents, albeit bereaved parents; (2) they are the guardians of the family's values, be they religious or cultural imperatives, or simply personal convictions; (3) robbed of their child, parents need the means to come to terms with the loss of all the joys of parenthood. They need some means of regaining control; (4) the parents' own mental health and emotional wellbeing are at stake, and (5) the physical body of a beloved child remains fixed in the mind. Rationally parents know the child does not suffer or bleed. In the imagination, nightmares haunt their sleep.

How does recognising such interests assist in arbitrating disputes between parents? Where does it place the unmarried father who did not share legal parental responsibility with the child's mother? Moving the spotlight from children's interests to parental interests makes legal niceties about decision making in life less relevant. It brings into the picture not only a father who does not share legal parental responsibility, but other family members too. The child's siblings, close and loving grandparents, her uncles and aunts all share, if to a lesser degree, the parental interests identified earlier.

Every concern applicable to children relates to adults too. *Who* decides, whose consent is required is as tricky a question where the retention or return of organs taken from adults is considered. Contemplate these scenarios: (1) a young man dies unmarried. His partner of four years is content to authorise retention of his heart to advance research into Sudden Adult Death Syndrome (SADS) of which he died. His parents vehemently object. (2) A woman died 12 years ago of a brain tumour. At the time of her death, she had been separated from

her husband for three years, having lived for the last two years of her life with her lesbian partner. Subsequent to a coroner's postmortem examination, her brain was retained (without anyone's consent) and sent to a brain bank. Her partner seeks information about organ retention and organ return, her husband is remarried in Australia and could not care less; her widowed father wishes her organs to be retained. Whose consent is determinative?

Solutions can be cobbled together—the Retained Organs Commission has given guidance on a pragmatic process to prioritise family interests in such cases, defining family to include partnerships both heterosexual and homosexual.[15] Whether we have worked out an adequate conceptual basis for our priorities I am less sure.

With adults we may discern a glimmer of hope, a way round the problem, a logical answer to practical problems. We could work to use the publicity given to organ retention to promote a culture in which adults would decide for themselves before death what should, and should not, happen to their bodies after death. A culture of donation would encourage us to think beyond the context of organ transplants and consider making an advance donation of organs and tissue even when they may be long past their sell by date for transplant, as I devoutly hope mine will be. *Consent* is given by the deceased person herself exercising an autonomous choice beyond the grave. I define my own interests. The fundamental concept of "advance directives" is well recognised. The law, Lord Mustill notwithstanding, has always endorsed enduring interests which survive our death.

The common law allows me by my will to dispose of property after my death. I may bequeath all my goods to Professor Lachmann, whom who I met for the first time at the conference which resulted in this collection of essays. I need have no good reason for my bequest. I may have bad reasons, simply wishing to spite my husband and daughter. I gain no pleasure but that of anticipating their grievance. No material *good* will be done to me. None of this matters. Just as in life I may refuse consent for medical care, however "bizarre, irrational or repugnant" my reasons may be, so in death the law allows me to dispose of my property by will at *will*.

Legislation has modified that right, so that persons *financially* dependent on me can today make a case for a share in the estate so kindly settled on Professor Lachmann.[16] Nonetheless, providing my daughter does one day acquire an independent income, she cannot on other grounds challenge my will, save to allege that I was not of sound mind.

Using the analogy of disposing of property by will, if it is *my* body I dispose of, should my choice, my *consent*, be paramount? The family interests identified earlier still hold good. I note that the Medical Research Council now advises that[17] even where the deceased has authorised retention and research on body parts his family's consent should still be sought. In a number of countries, including New Zealand, a formal family veto overriding the deceased's directive has been endorsed by legislation.[18] The Scottish Independent Review Group[19] vigorously upholds the rights of the deceased: " . . .the expressed wishes of the individual adult, competently made before death, should take priority over the wishes of surviving relatives". Arguments that others' interests should override my consent, or refusal of consent in life have consistently failed before the English courts. Does an identical analysis hold good after death? We come back to the question of what values "consent" to retention of body parts protects.

A property approach has a superficial attraction in terms of ease of application. My body is mine, therefore just as I may give my money to Professor Lachmann so I can give my body to science. My child is mine so I (with her co-owner my husband) may decide if even a particle of her is used by doctors or scientists. If my mother dies intestate, my brother and I "own" her corpse just as we own her wedding ring.

Property makes it easy to identify who the appropriate donor of the flak jacket may be. It avoids messy emotions. It grants the "owners" untrammelled powers. It might be thought to appeal to families who have been directly involved in organ retention. Families have said to me time after time about their child "but he belonged to us". Widows have said of their husband "they *stole* my husband's brain".

The mantra that there is no property in a corpse is often repeated. Its authority in the mists of history is less clear. I lack time to explore the maze of legal history now. Let us rather consider further the implications of a property model. If my relative's body is *mine,* be she child, mother, or sister, I may do with my property as I wish. I may elect to sell her component parts in public auction. I may donate her for display as a plastinated exhibit.

The "property" debate cannot be shirked. I use it here simply to demonstrate that consent based on ownership—this body is mine—authorises not just a right to say NO but grants untrammelled rights of disposal to the "owner". Despite the language of *ours* and *mine,* it is an option most of the families I have met abhor. The sense of continuing relationship, of still being parents, sharply distinguishes their child, or their husband, from *their* house or *their* car. The interests which families perceive centre on the integrity and welfare of the family of whom the deceased is still a part, and will remain so for decades, if not generations.

How the mortal remains of that person are laid to rest (or otherwise disposed of) is of overwhelming importance for the health and future of that family. The injury done to a family whose religion requires burial of the body intact, or cremation of every speck of bodily material, when organs are taken without their permission is a violation of religious freedom. It is not just that. It harms the surviving relatives, whose ability to work through the gradual process of bereavement is impaired. They believe that they have (albeit through no conscious act of theirs) let that relative down. They failed to safeguard his and their fundamental values. The injury done to families whose *personal* values require burial or cremation intact is no different.

A New Zealand anatomist and bioethicist,[20] recounts the experience of a mother who discovered that her 19 year old son's (Timothy) brain had been retained after his death in a road accident. The parents made this discovery two years after Timothy's death. In a conversation with his mother before he died, Timothy had made it clear he would not want his organs used for transplantation: "he wanted to leave the world intact and by cremation". His mother spoke of "outrage" in relation to the removal of the brain. They had been denied the chance to honour Timothy's last wishes. She said that the hurt will remain with them for the rest of their lives.

> It was my son's heart and brain that made him what he was and I am sure most parents would feel the same.

Timothy, you may reflect, is an easy case, not one of the problem cases I identified earlier. His wishes and his family's co-incided. Nonetheless, Timothy's case illustrates what is at stake: "*respect for private and family life*". It stresses the importance of granting dignity to others' values, not imposing our own.

In exploring more complex cases analogies with consent to medical treatment are not much help. Death is rarely an autonomous choice. After death the principal visible effect of what happens thereafter to our mortal remains is not on us, but on those who loved us in life. Where does that rather trite statement lead us in practice? I suggest that the following issues need debate.

The harm occasioned by overriding personal values in relation to the body means that *yes* consent is in a sense the key to the problem. If organs are to be retained with no kind of consent, society should establish strong grounds of public interest to justify such a course of action. Those grounds must be at

least as strong as grounds justifying interference with bodily integrity or security in life. As autopsy itself is the first and perhaps the greatest violation of the body, any policy underpinning non-consensual organ retention must also inform coronial autopsies.

Where retention is *consensual* careful consideration must be given to whether a directive from the deceased, an exercise in "immortalising" autonomy, should ever be subordinated to the welfare of her family. Should a refusal and objection by the deceased carry greater weight than a *permission?* Where no directive has been given by the deceased and close family disagree, ultimately arbitrary choices will have to be made and embedded in legislation. Much greater understanding is needed of how families of all different sorts and kinds react to loss and bereavement, and of cultural and religious understandings of dead bodies. Laws must be clear, but should be society's last resort. Society needs to have in place processes which will minimise the number of difficult cases. Organ and tissue retention ought to rest on a culture of *donation,* of gifts freely given. People need to be encouraged to address the possibilities of donation in consultation with their families. Tissue retention cards should record not just that person's but their family's views.

Lawyers and ethicists have dominated the intellectual debate. I doubt we are best suited to do so. Social anthropologists, sociologists, and psychologists have more to offer. *Understanding* why the controversy surrounding organ retention and return has had such an impact is crucial. Let me make one point absolutely clear in conclusion. I do not fail to recognise the immense importance of organs and tissue in research, in medical education, in audit and quality control or in the extreme case in the process of justice itself. I accept that there are instances where the state must authorise retention regardless of the objections of the deceased or her family. I would personally be content to authorise retention of my organs if good purpose were served by doing so and I was assured my closest family were comfortable with my doing so. In all I say about consent or authorisation, the message I wish to reinforce is that that process must be real, and sensitively pursued, not a cloak for persuading people to sign forms to satisfy legal requirements not based on a proper understanding of what is at stake in this painful debate. In a profoundly thoughtful paper, Dudley Knowles[21] concludes:

> At present codes of practice are being drawn up that will almost certainly carry the force of law. All the omens tell me these will be philosophically incompetent because those responsible for the drafting have not thought through the strict demands of a principle of autonomy to which they so conspicuously subscribe. If one thing is certain, it is that the hard and time consuming work of wide, disinterested, and fully informed deliberation will not be attempted; such is the culture of public policy making in the United Kingdom. Which is another story.

I hope on this occasion to prove him wrong.

DISCUSSION

Peter Lachmann suggested there was much interest in the information which can be gained from retaining one centimetre cubes of tissue from all diseased organs found at autopsy. It would not be possible to tell in advance if this material would eventually be useful. In reply, Margaret Brazier said that in cases where the family's consent to autopsy was required it might be possible to get additional consent for this. The chances were that it might be acceptable. An analogy might be the consent by women about to undergo surgery for student doctors to practise gynaecological examinations whilst they were unconscious. There had been an outcry when it was revealed that this was going on without consent; yet when asked for consent, 97% of women gave it.

Onora O'Neill raised two further questions. She asked how tissue and organ retention fitted in with the current law on coroners' courts and also what was needed to promote a culture of solidarity in society. Margaret Brazier said that as regards organ retention, the law is very fuzzy, inconsistent, and non-uniform in application. The current review of coroners' courts might change this. As for the lack of solidarity and apparent conflict between the needs of me and mine and that of society as a whole, changing this would require political will. Bringing together families and pathologists to see each other's perspective was also desirable as, at the moment, there was a lot of anger and misunderstanding.

John Harris argued that as the deceased is no longer there, the feelings of the families of the deceased needed to be set against the feelings of those families who might gain benefit for their relatives in the future. It was agreed that this was a debate which society should have. You couldn't pretend to give rights to families and then override them or fudge the process. Rules should be laid out.

Martin Bobrow wondered whether focusing on the details and the mechanics of informed consent and tissue retention was really so important. Surely the question that should be asked is who is this for? Is all this worth the effort of your team? Is all this worth it for the professional staff who feel defensive? Can't someone just say what we want as a society?

A final question was raised about how to return organs which were taken a long time ago and which the family had no idea had been retained. The commission advises that unless families contact you, the best policy is to remain silent. Some hospitals and coroners have not done this and have proactively and independently contacted families. The result has been a lot of heartache.

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Notes