

Parents' Consent to the Post-mortem Removal and Retention of Organs

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ABSTRACT *Parents of children who died following complex heart surgery have recently discovered that organs were removed and retained in post-mortem investigations to which they consented. It has been established that many of these parents did not give informed consent to the retention of organs. The Bristol Royal Infirmary Inquiry which examined these practices drafted codes of practice to govern future post-mortem activities. It is argued that these codes of practice may be onerous to some parents, yet effectively disbar them from dissenting to their application whilst they might otherwise agree to the post-mortem removal and retention of organs for purposes of medical audit, research or training. This consequence arises from employing an over-rigorous concept of informed consent in the immediate circumstances of bereavement. That concept is discussed in detail. An alternative proposal is canvassed which improves on the status quo but does not impose a practice of consent which may be burdensome and distressing to many.*

Consent

The concept of consent operates in interesting ways in moral and political philosophy, and, associatedly, in jurisprudence and medical ethics. Its most familiar practical role is that of a defence to the imputation that one has wrongly caused injury — *volenti non fit injuria*, as they used to say. But its evident role in justifying what would otherwise be wrongful conduct has led, with greater and lesser success, to arguments based on the notion of consent being deployed to vindicate coercive government and, more narrowly, the infliction of punishment. The force of arguments from consent has seemed so strong that philosophers have introduced a concept of *hypothetical* consent in which a distinctive form of practical reason models practices of consent in circumstances where actual consent is entirely absent. The applicability of the concept of consent has been contested, to the point where the concept itself has had to be refined before it can be put to good use. Philosophers and jurists have argued that genuine consent (or the type of consent that can properly vindicate) must be fully informed, rationally guided, uncoerced and attested by parties of equal bargaining strength. No doubt there are other conditions that must be respected, and certainly the adjudication of whether these conditions are, or need be, met in typical or particular cases can give rise to serious controversy.

Against this background, the importance of the concept of consent in medical ethics and practice should seem initially puzzling to the philosopher. In many of its applications, the concept of consent works as a magic ingredient, its operation transforming assault and battery into the noble art of boxing, rape into lawful sexual intercourse,

coercive commands into law-making, the forcible sequestration of income into legitimate taxation, incarceration (and worse) into just punishment. Something otherwise evil or wrong is judged to be morally innocent, permissible or required, once the element of consent is attested. In the case of medical attention, what is it that is otherwise impermissible that is legitimated by consent? Treatment for ill-health looks to be an unalloyed good, the promotion of which is the specific duty of the profession of medicine. If it was the task of surgeons to break legs rather than mend them, it would be easy to see why (the improbable ascription of) consent would be necessary to render their practice legitimate [1]. Medicine does not standardly involve practices that are otherwise harmful, but which are redeemed by the successful imputation of consent. So why does the practice of medicine standardly require the consent, actual or proxy, of the patient?

It would be a mistake to suppose that there is a uniform answer to this question, given the variety of medical practice that my *faux naïve* query conceals. In double blind trials, it is anticipated that some patients will gain nothing. In specific and controversial cases, some may judge that they are harmed by the receipt of a placebo rather than the available drug (and some may be harmed by the drug). Other considerations arise with medical treatment that is risky or known to be damaging in respect of side-effects. But let us put these cases to one side and concentrate on the paradigm of the provision of treatment that is well-tested and efficient, and procures an unquestioned good. Why should the consent of the beneficiary be required in these latter circumstances? The only answer I can think of, that is supplied by the philosophical literature and (modern, Western) ground-level unreflective ethical practice alike, lies in an anti-paternalist principle, grounded in the liberal belief that all moral agents are free and equal. In its more technical Kantian formulation, this is a principle of *autonomy*, which assumes that persons are capable of rational decision-making and action, and requires that they be left alone in the governance of their own lives to pursue their own good as they conceive it. Compulsory medical treatment infringes the moral status which autonomous agents demand for their own part and recognize in others. A practice of requiring consent, even to interventions which produce only and non-controversially the patient's own good, respects this minimal moral status.

Because the principle is open to challenge, it, like the various articulations of the practices of consent which are derived from it, needs to be clarified, elaborated, qualified and defended. The principle of autonomy is not philosophical hard currency; it is not indubitable. But since I believe all parties to the practical problem raised by this paper accept a version of it, I can safely treat it as gospel. So, in this argument, I want to put it in place as the most familiar, most widely accepted (because most plausible) justification for requiring consent before one actively serves another's interests. I shall argue later that the principle of autonomy, in an extended form, justifies the requirement that parents consent to the post-mortem use of the bodies of their dead children.

There is another way of articulating the intuition that compulsory medical treatment does wrong to the unwilling patient, one that invokes a direct citation of persons' rights. Thus if you set the fracture of the injured person without their consent you violate their right to physical integrity (or some other such right). This language (of rights) will be as familiar, if not more familiar, than the principle of autonomy. I shall avoid using it, because I think even the most basic rights stand in need of justification.

This would not be troublesome if basic rights, in their turn, were justified by application of the principle of autonomy, as many believe. But I think, controversially, that rights are more perspicuously derived from considerations of utility, and so will deprive myself of the unexamined use of rights-talk in the argument that follows. If the reader sees no problem in the derivation of rights from the ascription of autonomy as a matter of minimal personal moral status, he or she may reproduce the argument in these terms [2].

The Bristol Royal Infirmary Inquiry: Interim Report on the Removal and Retention of Human Materials. [3]

Following the disclosure that children's hearts and associated organs had been removed in post-mortem investigations subsequent to these infant patients' deaths after complex heart surgery at the Bristol Royal Infirmary, it was revealed that most of the parents of these children had not been given the opportunity to give their fully informed consent to the removal of organs from the dead children and to the retention of these organs for a range of purposes, including those of medical audit, archiving, research and teaching. Parents of dead children were informed as and when coroner's post-mortems were required; other parents were asked to consent to hospital post-mortems. It is not easy to discover from the transcripts of the Inquiry what reasons were offered to parents for the conduct of these latter investigations. On the evidence given to the Inquiry, most parents believed that the hospital post-mortems were intended to discover the cause of death, and falsely believed that the bodies of their children were delivered to them complete, for burial or cremation.

The parents of dead children who offered evidence to the Inquiry had a range of complaints. Some parents objected that the practice of removal and retention of organs violated spiritual injunctions. Others believed that they had been deceived. Still others, who accepted the legitimacy of the purposes of the practice of removal and retention of organs, believed that they should have been consulted, and their consent solicited, before these post-mortem activities had been carried out. The volume of complaint evidently affected the report of the Inquiry.

The Inquiry recommends (May, 2000) a Code of Practice governing the post-mortems of dead children which requires that senior medical staff seek parents' consent for hospital post-mortem investigations, that they explain the purposes of the investigation, that they ask for parents' consent to the removal and retention of human material, specifying the material to be removed and retained and the purposes of such removal (e.g. for audit, teaching or research). Further, they should state the length of time for which the organs will be retained and ask the parents how they wish the organs to be disposed of once they have served the specified purpose [4].

The detailed protocol recommended as a code of practice amounts to a practice of consent that ideally engages the co-operative activity of medical staff and children's parents. The practice of consent is deemed to respect the interests of the parents in the condition, use and disposal of the body of the dead child, and these interests are acknowledged to outweigh the public interest in, e.g. medical research and education, since consent to a hospital post-mortem may always be refused, however weighty the case for research or however useful the tissues may be for medical education. The

interests of the child's parents do not outweigh the public interest in determining the cause of death if this information is required for a coroner's inquest, but even where such investigations are required, parents' consent is required for the removal and retention of organs for purposes beyond those necessary for the conduct of the inquest.

The Rationale of the Code of Practice.

It is worth asking why the consent of parents to the removal and retention of organs is necessary in the first place. To put the question bluntly: should not the corpses of dead children be regarded as a medical resource to be employed in *bona fide* research and training (supposing in fact that the tissues will be thus employed, and not e.g. be deemed to comprise a unique collection: doctors, in turn, being supposed to be as interested in collecting things as other mortals)? [5] This question is easy to answer: they should be so regarded. Corpses are indeed a uniquely valuable resource for a range of medical purposes and the profession of medicine does not need a philosopher to spell out the reasons for according this value to pathological investigation. So the question really is one of priorities: why should the interests of children's parents be thought to outweigh the public interest as registered by the interests of those who practice medicine? (I cannot see how the interests of the dead child can figure in the matter in the absence of parents' attribution of interests to them.)

At this point we should not look to the law for guidance; as the Bristol Inquiry Interim Report makes clear, and the Report of the Scottish Independent Review Group confirms, there isn't much of it; and what there is, is contested. On the other hand, one may fairly enquire about the assumptions made by law-makers about the positive morality which their uncertain prescriptions encode. My belief is that such a sociological investigation would unearth an ancient and modern confection of factual error, quasi-religious superstition and moral misjudgement (of the sort that holds that parents have property rights over their children's bodies), together with some ancient and elementary moral truths concerning the prime responsibility of parents for the respectful disposal of children's remains. Parents' evidence to the Inquiry comprises a useful resource for those who are curious about the range of such beliefs. Whatever the aetiology of the rights which parents demand concerning the bodies of their dead children, we should recognize that they have both an interest in and a responsibility for whatever constitutes respectful disposal. This is basically a domestic duty, more naturally ascribed to children than to parents, and holding for siblings, too, in the voice of Sophocles' *Antigone*. In defence of such a duty, and its priority, parents may cite an appropriate and plausible extension of the principle of autonomy. This is a matter for *our* governance of the lives of *our* family members [6].

I cannot see any principled and uncontroversial way of assigning priority to one or other interest (public or domestic) as represented in the case, although I acknowledge that it is politic for a public inquiry to assign such a priority to the interests of parents, however inchoately expressed, who in any case may have real grievances concerning the quality of the medical treatment given to their children. I regard it as an open philosophical question as to whether patients in general, or by proxy, the parents of child patients, have an imperfect duty to promote the research and training of the profession of medicine from which they seek benefits or whether they have a perfect

duty to do so — a duty that may be exacted from them. Or, one may judge, patients (or their parents) have neither of these duties, such service to the ends of medical science being supererogatory. I can think of reasonable arguments that suggest each of these contrary conclusions. Nonetheless, I shall take it that the priority assigned by the Bristol Inquiry to the interests of parents should be respected for the purposes of working out and drawing up a code of practice.

The code of practice that is commended by the Inquiry is remarkable in its specificity. Thus, as we have seen, before consent is formally acknowledged, parents must be told which bodily material will be removed and retained and for what purposes [7]. There is a politic, protective reason for this: to prevent the opportunistic use of organs in research or training projects which bear no relation to the condition which caused death. But there is another reason, too. It is felt that the consent which is solicited from parents is not real, well-grounded, consent unless the parents are fully informed concerning the processes which their consent legitimates. There is a proper worry, inside the medical profession as well as outside of it, that the actual practices of eliciting patients' consent may not issue in fully informed consent. There are countless reasons for this, prominent amongst them the fact that consent must often be solicited from patients, parents or other relatives in the most distressing personal circumstances. But it may well also (and associatedly) be that rational patients or their guardians *do not want to know* the full details of the particular case they find themselves involved in. The code of practice drawn up by the Bristol Inquiry ensures that this will not happen. It is designed to ensure that consent to the removal and retention of organs shall be fully informed. I shall say more later about the implications of the requirement of fully informed consent.

Consent to the Operation of the Code of Practice.

Implementation of a code of practice of the type recommended augments the practice of medicine. It itself becomes a component practice of medicine more generally, a practice to which those involved in the sort of case it covers must submit. What begins as a moral demand that parents of autonomous standing should be respected by conceding the necessity of their consent to the removal and retention of children's organs ends as the constitution and prescription of a specific institutional form — a practice that requires the full provision of information and the opportunity to discuss the details of post-mortem processes with available senior medical staff [8]. It is clear that, in the spirit of the recommendations if these are adopted, *pro formas* will be drawn up to record that full information has been made available and consent explicitly given. Where there is good reason to retain and remove organs, as signalled for example by the approval of a hospital Ethics Committee in respect of research, the practice detailed above will be imposed on parents [9].

There is a something of a paradox (or at least a moral conundrum) concealed here. No one should doubt that the practice as described in the code will be onerous to all concerned. It is likely to be distressing to many parents; other parents just may not wish to go through with it, trusting the medical profession to do what is best, wishing to get on with the process of grieving and re-building a life without the dead child. There are many good reasons why parents may not want to know all of the information

that is to be made available to them. Yet there is no way in which parents can opt out of the practice as specified by the code; there is no provision for them to refuse consent to what they may judge to be a cruel rigmarole acted out at a time of severe personal distress. There is no opportunity for them to refuse to give their consent to the operation of the practice of requiring consent, as this practice has been designed. And yet such refusal strikes me as an autonomous decision that an (otherwise) fully informed and rational agent may wish to make. That principle of autonomy which requires the practice of consent is itself undermined or violated if the practices which it seemingly requires are of a kind that an autonomous agent may repudiate.

I have been assuming that the practice has been designed with total prescience, but such an assumption is not warranted. There will be many practical difficulties in its operation and we should not grant that all deleterious consequences have been anticipated and discounted for. Thus one might ask just when the code of practice should become operational. Would it be better to begin the solicitation of consent to the removal and retention of organs before operations or treatment or after they have failed? If before, how long before? One can read in the evidence brought to the Inquiry very different answers to these questions, all of them, of necessity, put hypothetically to relatives. The code of practice is silent on the issue. It does not follow that some time is better than no time. For many, we can assume that there is no good time for the practice to be engaged.

One might further ask, as the Inquiry asked: which hospital staff should conduct the practice? It is recommended that consultants or other senior doctors should be involved, together with some third person, probably a nurse. It is insisted, in particular, that this not be another short straw for junior doctors to pick up (and especially not a practice to be delegated entirely to clerical staff or clinically assigned social workers or counsellors). Since consultants have not generally been appointed on the basis that they possess the sensitivities and sympathies required for an inoffensive practice of the code, it is recommended that they undergo the necessary training 'in breaking bad news' [10]. This is an illuminating if not unfortunate turn of phrase to describe the employment of the code following an unsuccessful operation. The child is dead. The parents know this. The innocent phraseology captures the truth: that the practice of consent as specified imposes a further burden on parents which no amount or quality of training can enable medical staff to shoulder on parents' behalf. As for the prospect of successful training programmes with even more modest objectives: no comment [11]. I suppose doctors to be typical members of the human race, rather than saints whose potential can be tapped by approved training courses. Many doctors, far from being paternalistic manipulators, will be timid and hesitant in the face of grieving relatives, and, daunted by the prospect of completing a lengthy and distressing *pro forma*, will jib. The practice of medicine will suffer.

Having heard the evidence of many parents who felt that that they ought to have been consulted and who believed that their consent ought to have been obtained before their children's organs were retained, the committee acknowledged that it could not square the circle of designing a code of practice which suited both those who said, retrospectively, that they ought to know all of the relevant facts and those who do not wish to know. The issue was decided in favour of imposing the code of practice summarized above. It is not hard to see why this was the case: the Inquiry did not pursue all the available options.

The Available Options.

The Inquiry seemed to believe that there were two clear alternatives: the first practice amounts roughly to the *status quo*: the removal and retention of organs is permissible if the parents do not object to the procedures being effected. This places the onus of seeking information which might ground an objection firmly on the parents. The alternative practice is that of fully informed consent. This places the burden of providing information on the medical staff. The first practice is deemed to be manipulative, paternalistic and possibly self-serving by the medical profession. It seems now to be accepted that nothing less than fully informed consent will serve and hence that the full body of information must be communicated to parents as a basis for their decision-making (despite the fact, as we have seen, that many will just not want to know, and thus will be prevented from sanctioning post-mortem practices which they would otherwise approve).

Interestingly, a third option is available, and the Inquiry recognized this in its discussion of the *Guidelines* published in March 2000 by the Royal College of Pathologists. These envisaged a code of practice which sought the 'agreement' of the parents. But this proposal is mauled by the Bristol Inquiry as representing 'the worst of all possible worlds' [12]. The philosophical basis of their criticism is, however, unclear. So let us review the options.

To my mind there is nothing in the concepts of 'consent' and 'agreement' that favours use of the former but disables the latter. The conceptual apparatus of consent is well-understood, though its application conditions are contested. Thus one might try to argue, for example, that the first, 'no objection', procedure attests tacit consent. There are plenty of occasions when tacit consent is witnessed, as when those who accept a round of drinks consent through their action to reciprocate in turn. The question is then whether or not those who do not object in specified circumstances thus tacitly consent. My answer would be: no, in the case of the whole range of post-mortem practices. What guides the ascription of tacit consent is an established rule or convention that is well known to all the parties. If one thing is clear from the evidence brought to the Inquiry it is that many of the parents were ignorant of the implications of their decision to approve a hospital post-mortem. By contrast, explicit consent in the context of medical practice has come to signify fully informed consent with a maximal understanding of 'fully informed' to mean just about as much relevant information as the brightest and most focused patient can be assumed to digest.

The Bristol Royal Infirmary Inquiry provided a supplementary paper on informed consent which examined, amongst other things, the concept of informed consent [13]. Unfortunately, the paper does not direct itself to the specific problems which may arise in the context of parents' consent to post-mortem practices on children, or relatives' consent to post-mortem practices taken generally. The question I have raised concerns the *amount* of information that parents must be presumed to digest before their consent is judged to be fully informed. The issue looks hopeless: how much information amounts to sufficient information, short of equating the information communicated to the patient with the body of information possessed by the doctor? But two model answers are suggested by a comparison of British and American law. In Britain, the test for sufficiency is how much 'a "reasonable doctor" would decide to tell in the context of the doctor's relationship with a particular patient . . . In contrast, American

case law defines a “reasonable” amount of information as what a “prudent patient” would want to know in order to make an informed choice’. [14] The second test is judged superior, being less paternalistic and granting more respect to the autonomy of the patient.

Of course, if the reasonable doctor judges matters from the perspective of the prudent patient, this amounts to a distinction without a difference. (And the doctor will have to make *some* such judgement, whether or not the patient requests specific information from her.) The difference between these approaches only comes through if it is thought that a doctor may reasonably withhold information that a prudent patient would require. It follows that a code of practice can settle matters in favour of the prudent patient test by stipulating what information a prudent patient would require. In the context of parents’ consent to post-mortem, I hypothesize that the Bristol Inquiry concluded, on the basis of parents’ evidence, that the prudent (or better, ‘wise’) parent would want maximal information. Hence the detail and specificity of the demands of the code of practice. The doctrine of fully informed consent is given a content by application of what parents giving evidence stated that they would have wished to know, together with the obvious implications of these wishes.

Before we leave the topic of genuine consent, it is worth mentioning two other conditions that are thought to hold for a successful ascription of it. The first is that consent must be given by a rational agent. There is little point here in investigating the assumptions carried by the supposition of rationality, but it should be recognized that permission to remove and retain bodily material will have to be given swiftly following the death of the child patient. The dilemma is obvious. Distressed parents have other things to worry about than the future of medical science, as a senior doctor may conceive this preparatory to interview with the patients. Funeral arrangements cannot be held up until a time when doctors judge that otherwise rational parents might be receptive to their solicitations. A sensible code of practice, which values post-mortem practices of removal and retention of bodily materials, will have to assume a condition of *sufficient* or *minimal* rationality, and accept that decisions are often *not* being taken in a cool and reflective moment by persons fully aware of the goals doctors seek and the means necessary to their attainment. In the context of bereavement, one must either lower the information and rationality threshold of recognizable consent or reject the use of bodily materials following post-mortem. If an impractical code is implemented, i.e. one that assumes more deliberative rationality than is likely to be witnessed in many circumstances, it will be abused because it cannot command respect. It is easy to imagine a kindly doctor telling a couple of distressed parents who wish to get out of the hospital quickly, ‘I’ve marked with a cross all the places where your signature is required’ — and the parents acceding gratefully. In short, I believe the envisaged code of practice requires parents in the immediate circumstances of bereavement to behave in ways in which they cannot universally be expected to behave. Lest this conclusion be deemed paternalistic (the often spurious bug-bear of arguments in this domain), I insist, in my own case at least, that I speak with authority.

The final condition which is thought must be operative before full consent can be presumed is that the parties are roughly equal in power. The evil in the background here is evidently ‘medical paternalism’ once again. This concept is worth a paper of its own, not least since the problem of paternalism quite generally has been regarded as opening up live and difficult questions for philosophers to answer. For philosophers,

at any rate, paternalism should not be regarded as a dirty word. Since paternalistic policies are always intended to secure the good of those judged to lack full decision-making powers, it is a good question who may properly assume the metaphorical standing *in loco parentis*. Politicians universally claim such standing in respect of numerous policy issues, from seat belts to drugs legislation, but citizens would be wise to dispute their credentials. But information is power, and those professionals who possess more information than those they serve will inevitably find themselves in a position of epistemic authority. In these circumstances, and they hold generally between doctors and their patients, paternalism is unavoidable. The issue cannot be fudged by substituting the language of 'shared decision-making' for 'medical paternalism' [15].

Benign paternalism should engage the trust of its beneficiaries in the quality of its counsel. Trust may be withdrawn and consent may thereby be refused, but there is no point in claiming that doctors and patients have equal standing in a co-operative enterprise. They have different standing. One party has the power of epistemic authority; the other party has the power of refusal. Epistemic authority may be employed in a manipulative fashion, but the power of refusal may be exercised perversely (as lawyers know well in respect of their clients). Consent between parties thus related is a tricky business, but since the powers involved have different sources, and are not applied in similar fashion in processes of decision-making [16], there should be no pretending that they can be brought into a balance, or the balance of power shifted. Since one of the modalities of unequal power between doctors and their patients is a function of the doctor's knowledge of the practice of medicine, fully informed consent cannot be a procedural substitute for doctors' (epistemic) authority. At the limit, where patients are equal with doctors in respect of their knowledge, there is no distinction of doctor and patient, patients treat themselves, and no consent is needed. Below that limit, patients will never be fully informed, so fully informed consent is impossible; doctors' benign paternalism is a professional duty, so patients' trust is a necessity.

Between the two extremes (the no-objection test and the rational, fully informed consent test, applying the criterion of the 'wise and clear thinking parent') there must be many possible accommodations. In normal parlance, they might all license the application of the term 'consent', but as used in this medical context, that term, as we have seen, has been given a meaning which has been fixed with some rigidity. It now works as a technical term in medical ethics and its meaning has been sharpened in medical jurisprudence. So there is conceptual space for a term designating consent which may be, but is not in fact, fully informed — the type of consent to post-mortem practices which I envisage those being able to give who, for very good reasons which it is not the task of the medical profession to explore, do not wish to be involved in such procedures of informed consent as the Inquiry recommends. I do not see why we should not designate this type of non-specific consent 'agreement'. It avoids conceptual clutter. We can talk meaningfully of agreement which is short of being fully informed consent, but is not to be presumed merely on the basis of persons not objecting to a practice when the onus of objection is placed on them, regardless of their non-culpable ignorance of that practice or its implications.

This is all the conceptual work that is necessary. The upshot is that we have marked off, by legitimate and explicit stipulation, a conceptual space for the application of this, now technical, concept of agreement. The concept of agreement as employed in this

specific context has been clarified, but is it valuable? Which is to say: can we find employment for it?

A Proposal

At this point, some alternative to the recommended code of practice has to be sketched. But I don't think that this is difficult. It only looks difficult if the code of practice has to have the style and standing of a legal document, with every provision needing to be pursued and implemented as a legal requirement, every box filled in, consent attested by signature at each stage. It is at this point that the Bristol Inquiry code of practice becomes oppressive. (I sense that codes of practice which please lawyers do not always suit patients, or their parents, and that the code discussed is an example of this.) The procedure I envisage would go as follows:

Amongst the supportive literature that parents or relatives are given following a death, there should be a statement of the following kind.

The Penwortham Royal Infirmary may wish to conduct a hospital post-mortem on the patient who has died. Post-mortem practices may include further investigation of the condition which was the cause of death. They may also involve the removal and retention of organs and other bodily tissues for the purposes of medical audit, research, and training. If senior medical staff judge that such post-mortem practices will assist future treatment of the condition suffered by the patient [17], they will ask for your permission to conduct them. At the interview where your permission is requested, you may ask any questions you wish about the practices which are envisaged and full information will be given. You may also express any wishes concerning future disposal of the bodily material and your wishes will be respected [18].

When senior doctors seek agreement to post-mortem practices, they should not take such a statement as read, but should ask whether it has been considered. Parents should be asked if they have any questions which they would like to have answered and if there are any conditions they would like to impose in restriction of post-mortem practices. But if they are willing to agree to post-mortem activities quite generally as described in the statement, their agreement at this point should suffice. All of the information which the code of practice recommended by the Bristol Inquiry insists should be disclosed should be made available to those who require it before they signal their agreement. This is information to which they may properly claim an entitlement. But they should not be encouraged or pressed into requesting it, nor induced to feel squeamish or unco-operative if they wish to give a blanket approval without the provision of booklets, videos, or lengthy discussions.

My intention in this section has been to describe a practice of agreement that is more respectful of parents' aspirations to be involved in the decision-making processes which follow the death of a child than the 'no-objection' model, yet does not require them to participate in the grim procedure (to repeat, 'cruel rigmarole') which, I believe, the Bristol Inquiry recommends, if they wish the bodies of their children to be used in the advance of medical science. With further effort, the detail could be sharpened up. In fact I suspect the spirit of my proposal is not far distant from the code of practice

drawn up by the Royal College of Pathology. I have one further suggestion concerning how this matter should proceed.

Having read the evidence presented to the Bristol Inquiry, I judge that the recommendations were over-influenced by the representations of distressed parents, some of whom who were seeking to identify wrong-doing and are currently seeking legal remedy. But that is a subjective view. What I find harder to comprehend is that the Inquiry did not widen the informational basis of its deliberations by seeking the opinions of members of the public who have *not* been involved as parents and whose deliberations have *not* been affected by the contingent and shocking discovery that organs had been removed and retained without their knowledge or consent. I have argued that the major weakness of the code of practice that the Inquiry recommended is that it is impossible for parents both to approve a range of post-mortem practices and dissent from the process whereby that consent is elicited. This suggests an obvious question to be put to a forum of disinterested members of the public, organised as focus groups or through an exercise of deliberative democracy: would you wish this code of practice to be implemented were you the parent of a child so situated or would you prefer a process which can legitimately stop short of requiring your fully informed consent, a process such as I describe above?

It is important when thinking about questions of such delicacy and practical moment that deliberations be as detached as possible from the circumstances of medical incompetence which formed such a disfiguring backdrop to the Bristol Inquiry. It is important that the views be sought of parents who have not experienced tragedy, but who are willing to consider what their reactions might be to the aftermath of it and how they would wish to be dealt with were they to suffer it. Neither a committee of inquiry nor the politicians to whom it reports should believe that they alone embody such an impartial and dispassionate stance when the opportunity is available to seek a wider view. Alternative procedures and codes of practice should be drawn up, tested against a wider public opinion than was represented at the Bristol Inquiry, and the results fed into the political decision-making procedure.

The procedure I suggested is less formal, and, I hope, less distressing in its impact on parents than the one the Inquiry recommends. I accept that two things are necessary for it to gain the confidence of those who will work within it. The first, obviously, is a more general appreciation by members of the public of the purposes of pathological investigations in the service of medical audit, research and education. Given that the interest taken by newspapers and television is likely to be an accurate indication of the public's interest in the practice of medicine, this task should not be impossible to accomplish. The aim should be to achieve a culture wherein parents are not surprised, shocked and distressed to learn that the post-mortem procedures to which they have agreed may have included the removal and retention of organs, even when they were too distressed in the circumstances of bereavement to understand the agreements they have made. The second necessary element of such a culture is that the medical profession recovers in the public mind the authority which its expertise should confer and the concomitant trust that this expertise will be employed for the public good. This element of trust must have been damaged by recent and well-publicized cases of arrogance, incompetence and lethal malevolence.

These things will be hard to achieve, though I stress again that they should not be regarded as hopeless tasks. Above all, the profession of medicine should not be rushed

into accepting codes of practice detailing procedures for the acquisition of fully informed consent which take patients' and parents' consent to be a necessary and satisfactory alternative to a culture of public trust and confidence, however distressing the implementation of such a code may prove.

Postscript

Since this paper was first drafted, reports have been published by the Scottish Executive Independent Review Group (January 2001) and the Royal Liverpool Children's Inquiry. The report of the Scottish Review Group is notable for its acceptance of the claim that '[N]aturally, there will be some relatives who wish neither to receive information about the post mortem nor to be told what may become of the organs after post mortem, and their right not to receive this information must also be respected' [19]. I am not sure that this right *is* respected in the detail of the template for a hospital post mortem consent form given at Appendix 5, so far as concerns parents who wish *both* that the organs of their children be available for medical science *and* wish (rationally, autonomously, if evidently not fully-informedly) to be spared the detail. It is the practical purpose of the philosophical argument of this paper that this option be available. I cannot believe it is beyond the wit of legislators to make practically available this philosophically reputable possibility, though I grant that the difficulties of drafting are appalling. At present, codes of practice are being drawn up that will almost certainly carry the force of law. All the omens tell me that 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 public deliberation will not be attempted; such is the culture of public policy-making in the United Kingdom. Which is another story [20].

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NOTES

- [1] Truth can be stranger than the philosopher's fictional example. It is reported to me that some poor souls request doctors to amputate healthy limbs, and that some doctors have acceded to their requests. It is controversial whether this is the kind of surgical activity that consent can legitimate.
- [2] Notoriously, one difficulty to be encountered by such an attempt at derivation concerns the ascription of rights to infants who are not autonomous.
- [3] In what follows I discuss the issue of the consent of parents to the removal and retention of children's organs, which was the issue raised at the Bristol Inquiry. It should be clear that many of the ethical problems raised in this context also apply to relatives' approval of hospital post-mortem practices quite generally. I am aware that the specific questions raised in Bristol are also the subject of enquiries and discussions elsewhere. In Scotland the matter is presently being considered by the Scottish Executive Review Group on the Retention of Organs at Post-Mortem. This paper had its origins in evidence which I gave to the Review Group, speaking primarily as a bereaved parent rather than as a philosopher with a professional interest. It has been improved by discussion with members of the Group and further reflection on questions they asked at interview. The Chairman of the Review Group, Professor Sheila McLean, referred me to materials concerning the Bristol Royal Infirmary Inquiry available at the

web-site: www.bristol-inquiry.org.uk. I refer to the *Interim Report* of the Bristol Inquiry (BRI *IR*) by paragraph numbers. This web-site also contains information on the March 2000 *Guidelines* published by the Royal College of Pathologists, to which I refer later. These Guidelines can be accessed at www.rcpath.org/news/tissue_retention.pdf. The Scottish Executive Independent Review Group on the Retention of Organs at Post Mortem published its report in January, 2001. This can be accessed at the web-site www.show.scot.nhs.uk/scotorgrev/. Since this paper was completed the Report of the Royal Liverpool Children's Inquiry (The Redfern Report) has been published at www.rlcinquiry.gov.uk. I shall direct my critical discussion at the recommendations of the Bristol Inquiry, though a review of the Redfern Report has convinced me that its recommendations are even worse in point of the burden it places on bereaved parents.

- [4] This is an informal and incomplete summary of the recommendations concerning codes of practice. Full details may be obtained from the web-site. Separate codes of practice are commended in respect of post-mortem practices as directed by coroners, and hospital post-mortems conducted when no coroners inquest is convened. These codes of practice overlap in respect of functions other than those directed by the Coroner's investigation into the cause of death. Henceforth I shall speak as though there is one code of practice governing the removal and retention of organs.
- [5] The disgraceful details are given in the Redfern Report.
- [6] What I have represented as a problem of prioritizing the (public) interest in medical research and training and the (domestic) interests of the parents is represented as a *conflict of interests*, or more generally as a *conflict of moral (or God's) law and the law of the state* in Sophocles' play. I mention this source to remind readers that there is an ancient conflict of views here, which is still (and quite understandably) unresolved.
- [7] BRI *IR* ¶¶163–5, 169, Recommendations 40–2, 45.
- [8] And in the case of the Redfern Report, a 'bereavement adviser'.
- [9] I think this is a fair representation of what the Bristol Inquiry codes of practice will require. Readers should judge for themselves the practical upshot of the recommendations. It would have been helpful if the *Interim Report* had included a draft *pro forma*, so that its horrors would be explicit to all who wish to adjudicate its usefulness.
- [10] BRI *IR* ¶ 157; Recommendation 33.
- [11] On second thought, let me state the obvious. Should the recommendations be adopted, such training courses will be tendered for and will appear. Doctors who need to be taught how to behave with bereaved parents will learn little or nothing. Doctors who do not will judge their content as risible.
- [12] BRI *IR* ¶ 113.
- [13] BRI Secretariat (December 1999) Inquiry Paper on Informed Consent: Concept, Guidelines and Practice with reference to Children undergoing Complex Heart Surgery, at www.bristol-inquiry.org.uk.
- [14] BRI *Inquiry Paper*, 9
- [15] BRI *Inquiry Paper*, 5.
- [16] To state the obvious, decision making processes involving doctors and their patients, lawyers and their clients, philosophy teachers and their students, plumbers and their customers, are not *democratic*.
- [17] This is a restriction which I judge to be prudent in the circumstances of interviews with the parents of dead children. I cannot see that it is otherwise necessary.
- [18] This is a first draft, layman's, document intended to illustrate appropriate style as well as a sufficiency of content. I doubt much of it would survive detailed consideration, but I think my argument requires that I lay down the minimal statement of policy which the 'no-objection' practice is unable to take as understood. Following suggestions made in the Scottish Review Group hearing which I attended, I put the term 'permission' in the draft to signal the importance of the parents' authority in fixing the terms of the agreement.
- [19] Report of the Independent Review Group on the Retention of Organs at Post Mortem, p.4, available at www.show.scot.nhs.uk/scotorgrev/.
- [20] I acknowledge the help given me in the preparation of this paper by Stephen Clark and Anne Knowles.