Viewpoint

What's wrong with "retained organs"? Some personal reflections in the afterglow of "Alder Hey"

A primary wrong

Let me acknowledge at once that, whatever my other concerns in this discussion, a disturbingly large number of individuals, predominantly parents, sense that they are victims of a betrayal of trust. In particular, those whose deceased children's bodies have been substantially eviscerated or otherwise dissected, but who were given no solid opportunity to know about or object to this, and who moreover were allowed to believe in a contrary state of affairs, have suffered a grievous wrong. Nothing said here is intended in any way to obscure, to diminish, or still less to attempt to justify that primary wrong.

My concern is rather to explore, as dispassionately as I can, the basis upon which the postmortem removal of tissue is taken to be so sensitive a matter.

An unusual introduction

It may be instructive to begin with some historical peculiarities. In their various colonial wars in India, the British hit upon a form of capital punishment that would deter the most fanatical of their religious opponents from terrorist acts. They executed their victims by tying them over the mouth of a cannon, and firing it, sending fragments of the body to the four winds and defeating all possibility of successful reincarnation of the deceased. This was non-consenting tissue distribution, rather than organ retention, but to my mind it seems to strike at some of the same anxieties.

When John F Kennedy was hit by the sniper's bullets, fragments of his brain were sprayed over the boot of his car; the famous Zapruder cine film of the incident apparently shows Jackie Kennedy leaning over the back of the car trying to retrieve them. They were collected for the presidential necropsy, but these fragments and indeed the major part of the president's brain were—for obscure reasons dear to the hearts of conspiracy theorists—somehow spirited away by the authorities before the rest of the body was released for burial. Mourners of a free society, rather than specifically of the presidential deceased, continue to feel that they have been robbed of something they cherish, although no doubt it is the tissue's forensic rather than intrinsic value that they pine for.

Some years before this, Evelyn Waugh, wrote that: "Randolph Churchill went into hospital ... to have a lung removed. It was announced that the trouble was 'not malignant' ... it was a typical triumph of modern science to find the only part of Randolph that was not malignant and remove it." (Evelyn Waugh, *Irregular notes*).

And Shakespeare puts into Sir John Falstaff's mouth this humbling thought: "Thou seest I have more flesh than another man, and therefore more frailty.".

So between these four examples we seem to have most if not all of the ingredients of the Alder Hey syndrome: the "therapeutic" or investigative removal of suspect tissue as seen by those engaged in the removal; its retention for the purposes of gaining unspecified knowledge; a decided lack of interest in consent; and a kind of veneration of human flesh on the part of those who feel they have been wronged.

Some analogies

It often seems to me useful to try and think my way through some analogies, albeit in this case rather crude ones. Here are three:

- I voluntarily take my motorbike to the repairer because I need what he can do for me and he (yes it is indeed a he in this case) mends the bike, replacing some wiring in the low tension circuit to the coil. He keeps the wiring, without asking me, and may later look at how it corroded or fused. When asked, he shows it to other mechanics and they discuss its faults, its material quality, etc. Years later someone tells me about this. Am I distressed? Should I be?
- I voluntarily sit an exam paper in the history of pathology (because I want to obtain a valuable qualification), and the marker (who uses anonymous marking) copies out some of the mistakes from my exam script, and she circulates them among subsequent students—in an anonymous, unlinkable form—for their instruction. "Don't do it like this!" She does this without my knowledge or consent. Years later someone tells me about both of these disclosures. Am I distressed about either? Should I be?
- My barber covertly secretes away the hair cut from me and sells it to a wig maker for monetary gain. Years later someone tells me about both her secrecy and her commercialism. Again, am I distressed about either? Should I be?

What is "essential" to me?

The point of an analogy depends on whether its relevant similarity to the question at issue is more compelling than any relevant differences. I have tried to think about things that are to varying degrees separable from me: my material property; my thoughts, committed to paper; and that portion of my hair that remains worth cutting.

Part of what is at stake in each case is how important to me—or to my legitimate property—are the components, defective or otherwise, which are removed from me (or my property), in these cases, with my agreement and to help me. None of the items in these examples seems particularly important to me. And certainly none of them seems remotely essential to my sense of myself or my identity.

Could we change the examples slightly, so that the items were more important to me? Imagine the motorcycle mechanic removes a defective part that I myself had modified to give better performance (say it was a success for several years but has now failed). Or imagine I have authored, not wildly inaccurate examination answers, but a rather embarrassing sonnet.

These changes do indeed make some difference to how I feel about their unauthorised use. But the changes rely on my being in some sort of special and above all intentional relation with them. I modified the cylinder head, or I penned the sonnet, so I have some stake in what others think of my efforts.

This matter of creative effort seems definitely not to apply to bodily tissue removed from me and these analogies do not seem to offer much of an explanation for why people might feel so strongly about "ownership" of pathology specimens.

Still, such specimens could feel important to us for other reasons. Gross surface or external anatomical specimens could be important because of their morphology—imagine how one might feel about an amputated limb, perhaps a hand. Or they could be important because of their former function. Imagine how the pianist Paul Wittgenstein might have felt about his amputated right arm, for instance. But cases like these would, I take it, be pretty rare, and not at all representative of the material retained at Alder Hey and elsewhere. They would fall somewhere on a spectrum between, for instance, an entire abortus at one end, and a few stained oncogenic cells at the other.

So difficult questions arise about exactly where we place specific tissues on such a spectrum. And of course this is probably a highly individual matter—different people will value different kinds, even extents, of tissue very differently. They might also value them differently in different circumstances. I personally find it hard to make sense of someone who so highly values, say, a preserved biopsy specimen from the pancreas of their deceased loved one as to wish to bury it with the panoply of a funeral service. On the other hand, I can fully understand someone feeling that a substantial organ—a heart, perhaps, or a brain—is not to be treated lightly or disrespectfully. And I think I can make sense of the idea that someone might agree to the harvesting of organs for therapeutic transplant purposes, although not agreeing to the harvesting of those same organs for educational purposes.

Is consent really central in our ethical judgements?

The usefulness of the above analogies to the problem of retained organs and tissues is, let us be clear, only partly a matter of whether the organs and tissues are in any sense essential to me—or to the person from whom they are removed. It is also partly a matter of whether the removal of something is itself a necessary part of helping me—or whether, by contrast, it is exclusively a matter of helping somebody else. And then the key question is: "Who is helped?". Our society takes the idea of consent very seriously, and a substantial part of what distresses so many of the relatives of the deceased in the present case is the thought that they were simply not asked how they felt about the tissue removal or retention. Perhaps if they had been asked, they would have said: "Yes—if it's for transplantation.". And maybe they would have said: "No—not if it's just to be put in storage, or for educational or research purposes.". At any rate, we cannot know because the whole point about the cases in the current controversy is that they were not asked.

But now I have to be a little controversial myself. Because although consent has been widely taken to be the central issue here, I can think of three reasons why it might not be decisive.

First, there is, I think, an ideal of collective solidarity underlying the collective provision of health care free at point of use. It is a matter of what sort of a society the National Health Service stands for, or expresses—indeed a matter, arguably, of what any civilised system of providing medical care represents. Enjoying the benefits of free health care brings responsibilities, and perhaps these extend beyond simply contributing through your national insurance payments. We do not (any longer) coerce people into taking part in medical research. And yet those who refuse to be research subjects while still enjoying the benefits of the best currently available treatment are, in effect, standing on the shoulders of research subjects in the past, but refusing to hold up the feet of patients in the future. Obviously, in arguing like this I am relying on a kind of ethics of consequences, whose extreme form, utilitarianism, I would not support, against an ethics based on rights. But questions of how the good is done are important as well—generating questions of duty (concern for the parties most affected) and, with the clinician personally in mind, questions of virtue.

Second, we have noted that the current clamour is centred on a lack of consent, but consent is not the only serious consideration in moral life. We are, perhaps, at risk of degenerating into a culture so wedded to individualism of a highly consumerist kind that we may witness a decline in the very meaning of the word "society". It seems a sorry road to travel—yet the litigious culture of blame facing professionals of all kinds shows how far we have moved along that road. Consider the seemingly bizarre nature, scope, and scale of the some of the compensation claims lodged by specialist lawyers offering their services on a no win no fee basis specifically for the purpose. Are these claims (for huge sums) not intensely individualistic? How much may the collective purse be raided for the satisfaction of the individual, however aggrieved?

Third, it strikes me that it is possible to become somewhat precious with regard to some deceased tissues about whose very existence in the living body one may never even have heard, still less cared. Is not the reverence for such tissues, after removal, a kind of vitalism? But perhaps we should be cautious here—not least in reflecting on where some of this vitalism might come from.

The role of medicine in a misplaced vitalism?

For one source of it might, perhaps, step from the very signposts put up by modern medical science: fixing its gaze towards the hidden structures, the supposedly superior reality represented by the bodily substrate as compared with the "mere" exterior surface appearances—the greater explanatory power of the unseen, the underlying, the invisible. And haven't you pathologists played your part in this, intensively and extensively? Your craft, your "sullen art" as Dylan Thomas might have called it, consists of making hidden structures visible. You make the unseen parts seen. Perhaps the public understand this. Perhaps they have read the implicit message—that the mind is the brain, that the person is the (neurological) organism, that the organism is the genetic code, etc.

Let me elaborate this a little further. Why are the tissues of the dead taken and stored, for inspection now or in the future? Surely because of what they may disclose in the form of knowledge—knowledge of the body pathological, no doubt, but knowledge of the human, nonetheless. Implicitly, these tissues are among other things the knowledge they might disclose—organic, perhaps genetic. And perhaps this contributes to why not only you pathologists but also the bereaved value these tissues. What was taken without consent was not only the tissues, but also the possibility of knowledge of the deceased. Such knowledge seems dark enough to the lay mind already—the fact that it was obtained covertly seems only to confirm the darkness. So perhaps the bereaved also—subliminally, maybe, tacitly, but in response to the reductionist claims of medical science and of its attention to the unseen and the underlying—perhaps the bereaved sense the knowledge these tissues represent, regarding it as "stolen". Perhaps they wish first to recover and then to bury that knowledge along with the tissue.

All of which leads me to the irony of thinking that the present extent of such reverence for deceased human tissues is in part a fiction of medicine's, of pathology's, own

making. The attention lavished on the tissues by pathology is part of the focus upon the organic which medicine proclaims. Coupled with the promises of medical technology, and the potential proclaimed for the genome, comes an extension of the traditional popular reverence for the body as a whole, the sacred frame and form, into a corresponding reverence for its parts—a reverence that in extreme cases extends to solemn rites for a hitherto unacknowledged morsel of diseased and formalin drenched tissue.

Which constraints are ethical? A modest proposal

Such vitalism may not be a sufficient basis for giving those who practise it a veto over medical science's use of those same tissues—intended, after all, to pursue knowledge aimed at serving the collective good.

However, even if I am right in my argument so far, this would not license the unlimited harvesting and retaining of bodily specimens before and after death. What limits then should we consider? Here are some possibilities; they seem to me to be modest, constructive, and transparently obvious. Indeed, I suspect that they tacitly underlie the practice of most pathologists already.

First, there is the reason why such tissues are taken. What uses and purposes has medical science in mind? There must be some; endless and aimless duplicative storage with a view to possible future trawling is not good enough, even though we should acknowledge the sometimes serendipitous nature of scientific progress. In effect, if—in the legally appropriate context—I want to take and keep part of someone's body, my reasons for doing so must be capable of sounding plausible to someone not sharing my particular fascination.

Second is the question of how I obtain the tissue: certainly not in wilful or reckless opposition to or neglect of the views of the patient or his/her relatives; and certainly never by deception. Does this then give them a veto over an honestly and compassionately expressed request? Currently, in our individualistic society, it does—so far as diagnostic and therapeutic purposes are concerned, although not, importantly, in the case of forensic and judicial purposes. Now is not a comfortable time to say so, but the balance between individual consent and the public good needs constant, and above all sober, review.

Third, we should consider the methods of storage and subsequent retrieval of the specimens. Arguably, they should not be stored casually, nor publicly on show; and not in a manner reckless of the dignity of donors or even the dignity of the specimens themselves—as in the case of whole abortuses, for instance. I think we need not ourselves stray into vitalism when simply asking whether any non-sentient thing can attract considerations of dignity. We almost certainly accept that deceased humans can. And maybe this is also, in a "thinner" sense, true of images of human beings, such as some portraits, or the memories or traces (including photographs) of real people.

Taken together, these considerations point to moral limits on the retaining of organs and other tissues, whether or not we are persuaded that consent is the litmus test—or the holy grail—of moral life. Because I find myself quite unable fully to join in the popular scandalised reaction to organ retention as such, I run the risk of myself scandalising those who are offended by the practice, simply by the reasoning I have just run through. This is perhaps unavoidable, suggesting that, just like clinical pathologists, we philosophers too must face our own professional and occupational hazards.

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