

bioethics commentary

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A great many events of interest to bioethicists may occur in the passing of any year, and 2002 was no exception. Some are clear cases of wrongdoing whose interest lies in identifying what has gone wrong and why. More interesting are those which engage us in moral debate because it is not so clear that wrong has been done, or what kind of wrong it is. These are most interesting when they challenge and extend our understanding of moral concepts and principles. I will comment at some length on issues raised by the Green Lane Heart library, and mention some others more briefly.

Green Lane Heart Library

In February 2002, the media revealed the existence of a 'heart library' at Green Lane hospital, containing over 1300 hearts mostly taken from babies and children at autopsy.¹ The collection was started in the 1950s, for research and training purposes, and was a significant factor in the high quality of heart surgery and understanding of congenital heart defects at Green Lane. The scandal of the library was that a great many of the parents of the children from whom these hearts had come were unaware that such a collection existed or included their child's heart.²

Initially, it was suggested that failures to obtain consent from parents for including hearts in the collection were a historical phenomenon, with all proper procedures being observed from the 1990s. This might leave us in some doubt as to whether a wrong had been done, because the legal requirements and professional standards of 50 years ago arguably did not require consent. Though one might argue that the ethical reasoning which supports contemporary consent requirements is not limited to this moment in time, it is difficult to blame those who acted in keeping with the conscience and legal requirements of their time.

In the following weeks, it became less clear that current ethical requirements for consent had been followed even in all recent acquisitions. The New Zealand public seems firmly of the view that, as expressed in a *New Zealand Herald* editorial

(*New Zealand Herald*, 2002a), 'organs could not be taken for any medical purpose without the family's consent'. Bioethicists might be more cautious about so categorical a claim, but the general consensus is clearly that consent of family/whanau/next-of-kin is necessary for the removal and use of human organs for research and teaching purposes (see for example Cole and McCabe, 2002). But the library presented some more complex issues.

One major issue was whether or not those who had not given consent should now be asked for it.³ Opinion in New Zealand, and in discussions of the similar overseas situations, was divided about whether or not parents should be contacted and informed. *The New Zealand Herald* editorial on 1/3/02 noted that

Families who lost a child 10, 20 or 30 years ago have come through the normal ordeal of years of grief. The last thing some of them might want is a notice from the hospital advising their child's heart has been in storage all these years and is now available for burial.

That some hearts had been acquired at abortions gave further reasons why contacting the mother years after the event might be problematic.⁴ This issue presents a classical moral dilemma. On the one hand, principles of respect for autonomy, informed consent, and respect for human remains, would entail that the hearts cannot be held without consent. On the other hand, to approach families at this point to ask for that consent is likely to cause serious distress and possibly other harms. While it is difficult to ascertain what consequences are really likely, some argue that the risk of suffering and harm from contacting families at this point would be morally unjustifiable. It would not remedy the initial wrongdoing, just add another. Others are firmly convinced that, however painful, families have a right to be told and to decide what should now happen to hearts which had been taken without consent. If the hearts were to be retained without securing consent for each one, then an acknowledged wrong would be continued. If the hearts for which consent is lacking were disposed of, then a valuable

resource would be lost (and the form of disposal might not accord with what those who have the right to decide would have wished). Not contacting parents also risked being interpreted as a cover-up, or a refusal to face the consequences of past wrong actions. From what has been done, it seems that in the end greater weight was placed on protecting people from harm than on recognizing rights and obtaining consent now. The public has been informed about the library and opportunities provided for concerned individuals to make contact and seek information should they wish to, at which point consent for continued retention, return, or other disposal can be obtained. Requests for return have been honoured and ceremonial burials held. However it is likely that this process will leave some hearts still without consent for their retention.

A second issue was determining what the informed consent requirements for taking and retaining organs or tissue should be. The situation for living donors is clearly spelt out in the Code of Health and Disability Services Consumer Rights, 7[9] and 7[10]; informed consent is required. For dead donors, the situation is complicated by what seems to be a gap between the law and ethical expectations (as Warren Brookbanks notes in his Law Commentary). Further complications arise from the fact that there are two different processes requiring consent – removal, and retention for research (or other) purposes; that different professionals (clinicians, pathologists) are involved in different parts of these processes, and may not be able to provide the information about all aspects necessary for consent; and that consent requirements arguably differ for different kinds of tissue.

Any autopsy requested by medical staff (for example to assist in diagnosis or audit) requires consent, but where an autopsy is a legal requirement (coroner's autopsy) it is not subject to consent. But whether or not consent for autopsy is required, consent for taking organs or tissue for research or training purposes is. Where it is necessary, as it apparently was in the early days of the heart collection, that organs be sent away for examination as part of an autopsy, then this process should be covered in any consent for the autopsy itself. Anything beyond what is needed for the autopsy will require separate and explicit consent based on information as to the nature and purpose of what is proposed.

The law's attitude to dead bodies is a complication in another way. Ethical arguments can support the legal position that denies

the appropriateness of 'ownership' with respect to the possession of human remains. To treat human remains as property would arguably be a failure of proper respect for humanness and would risk commodification of human bodies and body parts. But where someone has previously agreed to be a donor on her or his death, the law requires only that the person legally in charge of the body should ascertain that the family does not object to this, and this is not the notion of consent which many think should hold. Of course, any requirement for family consent raises issues about who is to count as family for this purpose, and what should happen when there is dissension within a family, or between the family and the views the potential donor has previously expressed. Many would be horrified to think that their competent decision about organ donation can be overridden by a family member. Perhaps equally horrifying is the image of doctors fighting the bereaved family to remove organs, even where the deceased wanted to donate. This is clearly an issue for ongoing public and private discussion.

Further complications lie in the variety of different 'bits' of human beings which might be taken and kept (or disposed of) – from organs (like hearts), and limbs, to tissue samples and fluids. These are not of equal significance ethically, and to apply to tissue samples (or urine specimens?) the kind of consent requirements that are proper for donation of major organs would be hitting a fly with a sledgehammer. But how then to differentiate in a principled (and practical) manner the various requirements?

So the Heart library raised a set of interesting questions as to how we should regard different body parts, and what requirements ethically and legally should be placed on their removal and retention for different purposes (see Jones, 2002; Evans, 2002).

The discussion of the heart library also highlighted the existence of divergent views of what is morally acceptable with respect to the treatment of human remains. New Zealand has to grapple particularly with the need to accord to Maori values the respect which the Treaty of Waitangi requires while resisting the imposition of any particular set of values (whether majority or minority) as determining the limits of actions of all. Where actions and processes can be differentiated according to the different requirements of the persons involved, then individual (or cultural) views can and should be accommodated, as part of what it is to respect human beings

as autonomous. Where practices acceptable to some offend others, we have to work out a resolution at a social level. Where respecting the views of one group would impose significant costs on others, or on us all, we are faced with a difficult ethical (and socio/political) problem (at least for those who are not straight consequentialists).

Mental Health

Warren Brookbanks has mentioned also in his Law Commentary the report of the Health and Disability Commissioner into Southland District Health Board mental health services, following the sad case of Mark Burton, who killed his mother just after being released from the care of the inpatient mental health service. Mental health patients are amongst those for whom as a society we have a particular duty of care. But they are also amongst the most difficult to care for adequately, particularly in a system geared to autonomy as the dominant ethical value. Those needing mental health care are likely not to be able to govern themselves autonomously, in at least some areas, and then conventions of care based on autonomous consent will not apply (or not in the same way as for the autonomous patient). A balance must be struck between the demands of care, and the requirements of respect for individual self-determination (and associated values such as privacy). It is particularly important that misunderstanding of privacy requirements or professionalism should not exclude important non-professional carers (family and loved ones) from treatment decisions. Our understanding of the ethical issues in mental health will need to develop in conjunction with developments in mental health services.

This case highlighted problems of professional and institutional failures. Other events, for example, the Bottrill case (see Peart, 2002) have also drawn clearly to our attention that professional competence at the individual level, and institutional systems for supporting, assessing and maintaining this, are an ethical requirement. Incompetence can harm individuals; and recurrent failures of competence in professionals reduce (rightly) public trust in those professions.

Euthanasia

Issues of euthanasia and assisted suicide have also been salient in 2002. In April the Netherlands decriminalized voluntary euthanasia performed under certain strict conditions (following many years in which, though still a criminal act, an explicit policy of non-prosecution had been in place). Belgium too

decriminalised euthanasia in May. The media also reported various euthanasia issues and cases from Australia and elsewhere, including the unsuccessful attempts of Dianne Pretty in English and European courts to obtain immunity from prosecution for her husband were he to assist her to die (*New Zealand Herald*, 2002b).

Several cases in New Zealand in the latter part of the year are worthy of comment. In August, Rex Law pleaded guilty and was sentenced to 18 months in prison for murdering his wife of 54 years, an Alzheimer's sufferer. In September Victoria Vincent was found suffocated with her head in a plastic bag. In October, police were reported to be reopening an investigation into the death of Joy Martin, after her daughter Lesley Martin published a book in which she confessed to killing her terminally ill mother. In December, 89 year-old Frank Brown survived his attempt to take his own life following asphyxiating his terminally ill 78 year old wife Eileen. Vincent and the Browns were reported to have previously belonged to the Voluntary Euthanasia Society (*New Zealand Herald*, 2002c; 2002d; 2002e; Wall, 2002).

The sad cases of suicide pacts and assisted suicide of elderly partners may indicate a lack of assistance for the elderly ill and those who care for them, as Grey Power has suggested (*New Zealand Herald*, 2003b). But it seems also that a growing body of opinion supports the right of individuals not only to take their life, but to be assisted to do so, in extreme circumstances of terminal illness.⁵

Cases such as Rex Law's draw attention to a changing direction of concern with respect to euthanasia. Earlier defences of euthanasia have focused on the right of people faced with intolerable pain and terminal illness to hasten their own death. Increasingly though we need to address the point that loss of dignity and human functioning may be as intolerable to many as great pain, and less open to remedy. The legislation passed in Belgium permits not only those in the end stage of terminal and painful illness to request assistance to die, but also those earlier in a terminal process, and it recognises psychological pain as well as physical pain. However, Law's wife would constitute a further extension from cases where the person must be currently competent to make a request for assistance to die, to cases where it is not clear (because of deterioration of personality) that the person can be said to be suffering from the degradation or loss of dignity their condition entails. While

the personal deterioration of progressive dementia creates a situation which someone finds intolerable in anticipation, it is not so clear that she or he is still present and feels this at the point when those who love and value her or him find the situation no longer tolerable. It cannot then be the individual's pain and suffering, whether physical or psychological which warrants the relief of death.

Bioethics Council

Finally, I would like to comment briefly on Toi te Taiao – the Bioethics Council whose membership was announced in December 2002. The Council is yet to choose which of the multitude of possible issues it will tackle, but one of the major points it will need to address are public expectations that a) it must be involved in decisions on biotechnology and b) that it will provide a missing ethical dimension to public policy and deliberations in this area. Resolution of the ethical issues presented by advances in biotechnology will be far from straightforward. Equally well-informed and reasonable people can and do disagree about what is morally required in particular cases, or in general. The more culturally diverse the society, the more likely such disagreement, and the more likely it is to be identified with divergent cultural perspectives and to accrue from that alone additional layers of political significance. Recommendations following from deliberation on complex moral issues are unlikely to satisfy all those involved, and there is a risk that those whose views are not endorsed take this to mean they were not heard. We are in crucial need of morally defensible, and publicly acceptable, deliberation procedures, where acceptance of the result is warranted by the procedure, not the content of the recommendations. Royal Commissions are an expensive and not necessarily satisfactory process for this, and the constitution of committees is itself something that needs justification as part of such a process. The Council will need a robust sense of its role, a commitment to transparency of process and reasoning, and the capacity to hold a line in the presence of righteous condemnation. I wish it well and am sure that 2003 will see bioethical developments from its reflections as well.

Notes

1. The library included also some lungs, adult hearts, and hearts from aborted fetuses (Johnston, 2002). It should be recorded also that the Auckland

District Health Board had begun to address the issue of the library following publicity in 2001 about similar collections in the UK and Australia, and prior to the media revelations.

2. Some were aware and had given informed consent, as reported in the *New Zealand Herald* (Johnston and Mold, 2002). But consent was sometimes documented only through brief comments in the patient's notes.
3. The Hospital's records allowed the heart donors and their next of kin to be identified.
4. Some who contacted the heart library information number did so to request only that they not be informed should a heart from the family be part of the library.
5. According to a Massey University survey, the public preference is for physician assisted rather than family assisted suicide in such cases, despite the sympathy many clearly felt for actions such as Rex Law's (*New Zealand Herald*, 2003a).

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