

new developments

The Green Lane Heart Library: Ethical and Cultural Implications

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Introduction

'More than 1000 babies' hearts have been kept at New Zealand's top cardiac hospital – many without consent. Lifting the lid on a 50-year cover-up, Auckland's Green Lane Hospital admitted yesterday that hundreds of babies' hearts had been taken for research and teaching without parental permission over a 50-year period.'

These two sentences from *The Dominion* newspaper on 28th February 2002 were the first revelation that children's hearts had been retained in a research collection that dated back to the 1950s. In the months following, this subject has remained very topical. Beneath the pain and emotion that the practice of retaining children's organs without consent elicits, there are a number of ethical and cultural issues that require analysis and which have implications for healthcare practice and research in New Zealand and beyond.

Historical Practices

The debate was in fact not new to New Zealanders, as there had previously been considerable coverage of similar practices internationally. The so-called 'Alder Hey Affair', concerning a Liverpool pathologist, who had removed and stored organs from children without the knowledge or consent of their parents, invoked considerable debate during 2001 in both the British Press and in reputable journals such as the *British Medical Journal*.

Shortly after these reports the Australian media reported that in New South Wales, up to a third of approximately 25,000

body parts removed at autopsy had been kept without the relatives' consent. An audit revealed that Sydney children's hospitals had the biggest collections, with most of the samples in these collections being children's hearts.

Commenting on the international situation, a spokesman for the New Zealand College of Pathologists acknowledged that there were collections of organs, held predominantly in medical school museums. These had been put together over a long period but the more recent samples had been kept only with consent (*Dominion*, 15 March 2001). Historically, if an autopsy had been performed, pathologists took the body parts considered necessary for the purposes of determining the cause of death and frequently retained these parts for future teaching requirements. This approach was regarded as normal practice for the time and was not questioned by the medical profession or the general public.

The Cartwright Report and the Legal Context

Since the release of The Cartwright Report in 1988, there has been a greater awareness of consumer rights and consent issues. A legacy of the Cartwright Inquiry, which had examined issues surrounding treatment and research at National Women's Hospital in Auckland, was the demand that scientific research did not compromise the integrity of the individual and that research and treatment should not be carried out without proper informed consent.

It is well known that the National Cervical Cancer Inquiry focused on the study into the natural history of carcinoma-in-

situ and its relationship to pre-malignant disease. It is less well known that the Inquiry also looked at two supplementary trials. One of these involved the collection of 'the cervixes of stillborn and neonatal infants to do "research work on the morphology and histology of the foetal cervix"' (Cartwright, 1988, p.141). In 1987, a box containing sections of whole baby uteri set in wax was found in the clerical office at National Women's Hospital and were apparently from infants examined at postmortem. The Report noted that 'no permission was sought from any parent and the Hospital personnel cooperated in providing the specimens' (1988, p.141). Judge Cartwright commented that if the uteri came from stillborn babies, then it appeared that the provisions of the Human Tissue Act 1964 had not been complied with. In her view, the ethical safeguards were quite inadequate.

A recommendation of the Cartwright Inquiry was the provision of 'a statement of patients' rights and for ... the appointment of a Health Commissioner' (1988, p.176). The subsequent 1996 Code of Health and Disability Services Consumer Rights helped to change the ethos of healthcare delivery and has also led to a greater sense of partnership between consumers and the healthcare professions. There is now greater emphasis on shared decision making rather than a clinician-directed model.

The Code of Health and Disability Services Consumers' Rights states in Right 7[9] and in 7[10] that 'any consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure' and 'any body parts or bodily substances removed or obtained in the course of a healthcare procedure may be stored, preserved, or utilised only with the informed consent of the consumer'.

Some commentators argue that the Code applies only to the living, and that an autopsy is not a 'health care procedure' while others argue that respect for the individual, as enshrined in the Code, does not end with death. Following a formal complaint from parents whose child's heart was kept without their knowledge or consent, the Health and Disability Commissioner has responded by saying that the Code only applies to the living (Nankivell, 2002).

In the debate surrounding the Green Lane revelations, medical law specialist Professor Peter Skegg has stated that in New Zealand, coroners and pathologists are not legally required to

obtain consent to remove and retain body parts. Legally no one owns the body of the person who dies and neither does the law stipulate who has the right to the possession of retained body parts. Nevertheless, he added, 'regardless of legal requirements, hospitals should ask relatives for consent to take and use organs of dead family members' (*New Zealand Herald*, 28 February 2002). This observation is consistent with the view of many people that while it might not be illegal to take and retain the organs of the deceased without consent, very few would term such a practice ethical.

The New Zealand Culture

In treating the dead with respect the principles enshrined in New Zealand's founding document, The Treaty of Waitangi, are honoured. In signing the Treaty, the Crown made a commitment that within New Zealand society the values and traditions of both Maori and other cultures would be reflected in society's customs, laws, practices and institutional arrangements. The dead are considered sacred by Maori and their memory is very much present in the hearts and lives of the living. Maori consider that all parts of the body are imbued with a life spirit handed down from the ancestors, contributed to by each successive generation, and passed on to future generations. Since Maori view their most sacred role as being the preservation of the dignity of their ancestors, the removal or retention of body parts is sacrilegious to them. It undermines their cultural values and prevents them from carrying out their responsibilities in relation to the deceased (Law Commission, 1999, p.9). The Maori view that post-mortems offer an indignity to the deceased is shared by most Pacific Island cultures.

In 1999, the Law Commission issued a discussion paper *Coroners: A Review*. It looked at issues relating to coronial practice and noted there were two specific categories of concern. One of these categories included the following issues: the insensitive handling of the body and/or body parts by coroners and pathologists despite provisions in the Coroners Act 1988 which require coroners to have regard to cultural values or spiritual beliefs; the failure to inform the family when body parts are removed or samples taken; and the absence of a specific provision requiring the return of organs or limbs removed during a post-mortem examination, and the consequent failure in some cases to return a specific body part with the body or to notify the family that a body part has not been returned (1999, p.v). The review concluded that Maori

concerns that current coronial practice is culturally insensitive in the treatment of the deceased and in the removal and retention of body parts needed to be addressed.

Response from Green Lane and Affected Parents

It must be acknowledged that, following the revelations of Alder Hey and New South Wales, Green Lane Hospital initiated its own review of its heart library collection. It formed a 'heart steering group' which includes parent and iwi representatives to review the management of the collection of the library and to ensure that hearts and other organs were not being kept without the consent of relatives. It was this self-review which revealed the lack of knowledge about the retaining of hearts and the lack of consent from many of the parents. This review also indicates a greater awareness of the importance of cultural values and the need for informed consent in the health care delivery and in research.

Most people accept the need for organs for research and medical training but the process for obtaining these organs cannot disregard important human and ethical values. Several of the affected parents acknowledged that the skill and dedication of the healthcare team at Green Lane Hospital was in part grounded in a history of highly regarded research and teaching. They said they would have been happy to donate their child's heart for research if they had in fact been asked to do so. While 'element' discussions about autopsies and the retaining of organs at the time of bereavement may be time consuming and emotionally difficult, they as parents had already considered and consented to complex medical treatments for their children. They therefore find it puzzling that this further decision was not discussed with them.

Conclusion

A clear and unequivocal outcome from the Green Lane heart library issue is the acceptance now that what occurred was unethical and is certainly unacceptable in today's society. Green Lane, along with most other hospitals have reviewed their practices in obtaining consent at the time of autopsy and their care in the storage of organs.

There is always a danger of judging past practices in the light of today's values and beliefs. While this is tempting, it is counterproductive in nurturing a climate of partnership in healthcare delivery and research. Many patients now view their relationship with healthcare providers in a different way –

they want to be partners in the decision making process. Times and societal values change and medical practice must also change in order to better reflect current social, cultural and legal practice. Consequently, protocols and practices relating to the obtaining of written informed consent for organ and tissue removal and retention at the time of autopsy need to be continuously monitored to ensure adherence to accepted standards.

As yet, there has been no move to introduce New Zealand law changes which would make it essential to ensure consent is obtained for the retention of body parts. Peter Skegg is reportedly of the view that 'we shouldn't rush to change things' (*Herald*, 28 February 2002). Yet concerns about the retention of body parts were raised in the Cartwright Report in 1988, 14 years ago. The Law Commission Report states, 'One of the primary purposes of The Coroners Act 1988 was to address concerns that some of the practices under the 1951 Act were culturally insensitive' (1999, p.3), but it concluded that in 1999, coronial practice remained culturally insensitive and the 1988 Act itself required amendment. These examples indicate concerns dating back over at least quarter of a century and thus any changes to the law could scarcely be termed 'rushed'.

It is undeniable that there is confusion surrounding the current law. When news of the Alder Hey affair broke, a Ministry of Health spokesman said the Human Tissues Act and the Health Act required informed consent before organs could be taken for transplant or research. For babies, consent could only be given by the child's guardian, usually the parents (*Evening Post*, 31 January 2001). The Law Commission however says that the Coroner is 'not required to notify or obtain the consent of the deceased's family if body parts are to be removed and retained from a body'. Further, 'There is no provision in the Coroners Act for body parts removed during a post-mortem to be placed back with the body before the body is released' (1999, p.10).

Given the response of the wider public and Green Lane itself to the revelations about the keeping of hearts for research purposes without consent, there is an acceptance that in today's climate of awareness of patients' rights and consent issues, such practices are neither ethical nor in any other way acceptable. The time has come when the law must be clarified and amended to make it equally clear these practices are also not lawful.

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