

## **Medical Marginalisation of Aboriginal Australians: Renal Transplantation and Xenotransplantation**

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### **Abstract**

The suffering of end-stage renal disease in Aboriginal Australians is significant. The demand of Aboriginal Australians on renal replacement therapies such as dialysis and transplantation however, does not equate to this need. This can be partially attributed to institutional racism, which perpetuates health marginalisation by embracing dominant value and belief systems. In this light, new technological developments such as xenotransplantation need to be addressed with consideration of not only their own inherent complexities, but also within existing institutionalised cultural assumptions. Therefore, this highlights a need to consider existing health disparities and transplant outcomes in Aboriginal community, in order to effectively develop xenotransplantation guidelines. In turn, the Australian community as a whole should be aware of such cultural issues in order to make informed decisions, and to provide informed consent.

### **Introduction**

It is well established that Aboriginal Australians suffer significantly more health and welfare problems than non-Indigenous Australians. This disproportionate suffering can be evidenced in the rising rates of end-stage renal disease. Renal replacement therapies, such as dialysis and transplantation, can combat end-stage renal disease and provide an extended life of improved quality. While health disparities between Aboriginal and non-Aboriginal Australians would suggest Aboriginal Australians place more demand on renal replacement therapies, this is not the case. This can be attributed to numerous factors, including selection processes that might be influenced by subjective and institutional discrimination. This raises questions on existing medical knowledge, and the promise of novel medical technologies such as xenotransplantation. Xenotransplantation can potentially increase organ supplies, but it must be examined in the light of existing health disparities, transplant ethics and differing human-animal relations. Such considerations can be facilitated by sociological research, and subsequently built into public consultation and policy

design. As a result, this paper seeks to address some of the issues requiring attention in regard to transplantation technologies and Aboriginal Australians.

### **Renal Replacement Therapies and Aboriginal Australians**

The kidneys act as the body's filtration system by removing unwanted products from the blood, and reabsorbing substances required for the body (Porth 2004: 401). These functions can be impaired by conditions such as diabetes and hypertension, which might lead to chronic renal failure (Porth 2004: 402, 437). If allowed to progress, chronic renal failure can cause end-stage renal disease (ESRD), which alters the functioning of physiological systems, creates waste accumulation, and further health problems (Porth 2004: 437, 443).

Renal replacement therapies (RRT), such as dialysis, are required for the survival of ESRD patients. In Australia, 7674 people were receiving dialysis treatment in 2003, with 1953 new patients commencing therapy (Excell and McDonald 2005: xxvii, 8). Dialysis however, is not a desirable long-term renal program. The ultimate RRT is kidney transplantation, which eliminates the need for dialysis, reduces healthcare cost, and potentially provides an improved quality of life (Bennett et al. 1995: 610; Cass et al. 2004b: S144; McNatt 1999: 213). It is therefore not surprising that renal transplants are in high demand, but in short supply. In 2004, 1399 renal patients remained on the waiting list after 406 transplants were performed (Excell in Excell et al. 2005: 22).

While ESRD has been increasing throughout the Australian population, a higher incidence occurs in Aboriginal Australians (McDonald and Russ in Russ 2001: 95); who enter ESRD programs at eight to ten times the national average (Bennett et al. 1995: 610, 612; Cass et al. 2004a: 768; 2004b: S144). This health disparity is heightened in remote and northern Australia, where ESRD is up to thirty times the national average (Cass et al. 2004b: S144). As many Aboriginal communities reside in rural/remote Australia and do not have regular access to health care services, diagnosis can be delayed (Lowe et al. 1995: 357), meaning these figures could be higher. While this high ESRD incidence may suggest Aboriginal Australians place high demands on the renal transplantation, this is not the case. Aboriginal Australians

consisted of 5.5% of patients on the waiting list at 31<sup>st</sup> March 2001, and 7% at 31<sup>st</sup> December 2003 (Excell and McDonald 2005: xxii; Russ 2001: 63). Thus, despite the prevalence of Aboriginal Australians on dialysis, only a small number will actually receive a transplant.

The transplantation process, which involves evaluation, waiting, receiving and living with a transplant, is stressful on the patient, their family and the health professional, regardless of racial-ethnic background (Bennett et al. 1995: 610; McNatt 1999: 214). The individualistic focus of the Australian healthcare system, however, places significant difficulties on the communitarian nature of traditional Aboriginal Australians (Henry et al. 2004: 518). For example, the compulsory relocation of rural/remote Aboriginals to urban centres for RRT creates a separation of body, land, spirit and familial ties; all of which are considered vital for their health and quality of life (Bennett et al. 1995: 614). Therefore, leaving one's community is not only alienating (Lowe et al. 1995: 357), but makes little 'health' sense. When accompanied with communication and language difficulties - whether they are between doctor-patient and/or hospital-community clinic - compliance to treatment regimes can be highly problematic. Such non-compliance may result in transplant exclusion. For example, without the social support and contact with their extended family, adhering to dialysis and post-transplant regimes becomes disheartening (Devitt and McMasters 1998: 75). At the same time, wider lifestyle influences on health, such as the availability of suitable food and clean water, can hamper and defeat a commitment to RRT (Devitt and McMasters 1998: 76). Thus, poor or non-compliance cannot simply be interpreted as going against medical regimes. For Henry et al. (2004: 517), such misunderstandings and reactions pose significant barriers to improved health, and serve as evidence of discrimination and "institutional racism". Aboriginal ESRD patients do, however, desire a renal transplant, as it allows freedom from dialysis and an ability to return to their community. In this light, transplantation is not simply about quality of life and health for traditional Aboriginal Australians, but is perceived as a means to return to health and quality of life within the communitarian culture of their homelands.

Hence, Aboriginal Australians can be marginalised at any step towards transplantation. Selection criteria such as 'medical appropriateness' are ambiguous

and subjective (Cass et al. 2004b: S144), and allow value judgements to influence decision-making (Lowe et al. 1995: 358). Personal perceptions of transplant success or failure can thereby influence whether an Aboriginal Australian enters the transplant waiting list. This reveals institutionalised judgments towards Aboriginal patients and their health. Significantly, such an approach is not dictated by perceived individual health outcomes or personal circumstances, but perceptions of Aboriginal people as a whole. In other words: 'These sorts of people don't do very well' (an anonymous doctor on the exclusion of an Aboriginal patient from the transplant list in Lowe et al. 1995: 356).

Further exclusionary tactics are evidenced in the matching of human leukocyte antigens (HLA), which are part of the immune system's defence against foreign matter (Porth 2004: 139, 174). Successful HLA-matching between donor-recipient is a major determinant of kidney allocation (Cass et al. 2003: 117; 2004b: S144; National Health and Medical Research Council 1997: 10). This produces extra obstacles for Aboriginal Australians. Cadaveric organs are mostly sourced from the major ethnic and racial groups, namely Caucasians (Cass et al. 2003: 117; Tait and Russ 2004: 629). Aboriginal Australians have difficulty in achieving HLA-compatible donors due to rarer HLA-types, which limit 'inter-racial' transplantation (Cass et al. 2003: 117; Tait and Russ 2004: 628-629). In general however, only a small amount of kidneys are a complete HLA-match (Cass et al. 2003: 117). HLA-matching has also become less relevant through immunosuppressive pharmaceutical developments (McNatt 1999: 216; National Health and Medical Research Council 1997: 23). Using HLA-matching as a dominant criteria can thereby be regarded as discrimination (National Health and Medical Research Council 1997: 23), as it marginalises access to renal transplantation for Aboriginal Australians. By embedding these socio-biological factors into medical infrastructure, dominant Australian cultural values and beliefs are given validity and, in turn, medically 'justified'. Medical rationality and neutrality is therefore questionable (Henry et al. 2004: 517-518). In addition, while Aboriginal beliefs and rural/remote residence might preclude them from cadaver donation, some physicians believe donation 'refusal' places a questionable 'right' of Aboriginal Australians to cadaver kidneys (Devitt and McMasters 1998: 123). These various

factors thereby reveal significant barriers to improved life chances and survival for Aboriginal Australians.

### **Xenotransplantation: The Solution?**

As discussed, the organ need and supply gap limits the amount of people who can be treated, and leads to subjective decisions on organ distribution. Such disparities have rejuvenated medical interest in xenotransplantation. Xenotransplantation involves transplanting live animal cells, tissues or organs into a human recipient (Xenotransplantation Working Party 2003b: 22; 2005a: 7). By using animals, xenotransplantation can potentially increase organ supplies to treat conditions such as ESRD. In turn, this would suggest the selection criteria for organ transplants, including determinants based on HLA, can be loosened to treat more people.

An increased supply of organs and thus an increased amount of possible transplants would mean more Aboriginal Australians with ESRD could be given a human and/or animal renal transplant. Therefore, xenotransplantation could positively affect Aboriginal healthcare and outcomes. In the Australian xenotransplantation community consultation documents (Xenotransplantation Working Party 2002; 2003a; 2003b), however, no explicit consideration or concern for Indigenous Australians is exhibited. Such indifference and neglect also extends to the Australian population as a whole, with the Xenotransplantation Working Party (XWP) of the National Health and Medical Research Council (NHMRC), deciding prior to public consultation:

...the best option for Australia is to allow research to proceed under guidelines that take account of ethical issues, protect the interests of research participants, ensure that animal welfare concerns are met and safeguard public policy (Xenotransplantation Working Party 2002: xxxv).

By making such decisions prior to any public consultation, it is clear that ethics, interest, welfare and the 'public' are universally pre-defined, and therefore do not necessarily or truly reflect subjective public opinions. Most significantly however, these documents do not provide the Australian population *en masse* with the full information on national health discrepancies and Aboriginal cultural beliefs required to make an informed decision.

In contrast, the New Zealand xenotransplantation discussion document (Toi te Taiao: the Bioethics Council 2005) is explicitly concerned with the cultural beliefs of their Indigenous peoples, Maori. This document also acknowledges the: (a) disproportionate distribution of chronic health conditions that negatively affect Maori; (b) potential for biotechnologies to expand or contract disparities of poor health outcomes; and (c) problems of HLA-matching (Toi te Taiao: the Bioethics Council 2005: 17, 30). Consequently, Toi te Taiao: the Bioethics Council (2005) effectively link existing health conditions and transplant outcomes in Maori to xenotransplantation development, while also calling for a consideration of Maori cultural beliefs.

While Australian human clinical trials of xenotransplantation have been temporarily banned (National Health and Medical Research Council 2004: <http://www.nhmrc.gov.au/media/rel2004.comm.htm>), there remains a possibility that, in the future, this may change. The *National Statement on Ethical Conduct in Research Involving Humans* (in Xenotransplantation Working Party 2002: 28) and as reflected in the XWP's (2005b: 12) unendorsed xenotransplantation guidelines, informed decision-making and consent needs to occur prior to any clinical trials. As already evidenced however, it is questionable if existing pre-transplant medical regimes can provide informed consent to Aboriginal Australians. Furthermore, while xenotransplantation requires more regulatory guidelines than human-to-human transplantation, it can be presumed that, at least initially, similar discriminatory criteria will apply.

At the present time, renal patients selected to receive a transplant need to travel to their nearest capital city, while those in the Northern Territory need to travel to Adelaide, South Australia. If xenotransplantation becomes available in the future, it will not be available at all transplant centres in Australia due to its substantial infrastructure costs, which includes a need for specific-pathogen free laboratory environments and significant animal 'stocks'. As a result, it is likely xenotransplantation will require increased pre-transplant workups and further travel. Hence, this would only serve to increase the stress many Aboriginal Australians experience when separated from their community and land.

Preliminary exclusion from clinical trials might benefit Aboriginal Australians by avoiding the significant failure rate caused by human-animal molecular incompatibilities, as well as avoiding the potential of cross-species infection (Gold and Adams 2002: 37). At the same time, this exclusion may result in the technology not being designed to benefit Indigenous populations, thereby further marginalising their access to healthcare services and improved life chances. As the NHMRC (2003: 3) recognises, ignoring intercultural differences places questions upon research conduct, and limits the ability to improve human life.

In not understanding or respecting the diversity of cultural and spiritual beliefs of Aboriginal Australians, it is possible they will be compromised or violated in xenotransplantation. As already indicated, Australian Aboriginal beliefs or geographical location can preclude organ donation and/or adherence to medical regimes, and has influenced some clinician decisions on cadaver organ distribution. If such discriminatory tactics are extended into xenotransplantation, will an Aboriginal Australian who refuses a xenotransplant on cultural grounds, be precluded from receiving a human transplant? For Aboriginal Australians, such cultural considerations may include the source animal used for transplantation. This connects to the Dreaming, which is a timeless connection between past and present. For traditional Aboriginal Australians, the Dreaming intimately connects 'who' or 'what I am' with particular land, plants, animals and/or natural phenomena. For example, an Aboriginal Australian with Dingo Dreaming could not kill or eat a dingo, as this would be cannibalistic, and could lead to community disharmony and a loss of personal identity (Cowan 1992: 39-41). At this stage, however, it is unknown if an individual identifying with Dingo Dreaming would perceive receiving a dingo organ to be cannibalistic. On the other hand, the dingo might be a desirable option for an individual with Dingo Dreaming, as it is 'kin'. This highlights the unknown reaction of Australian Aboriginals to xenotransplantation – are Dreaming animals acceptable, or unacceptable? Furthermore, as the characteristics of Dreaming animals are personalised (Cowan 1992: 41-42), it is possible the source animal for xenotransplantation might symbolically conflict with these assumed characteristics from the Dreaming. In this light, the diversity of the Australian Aboriginal population

indicates that one animal might not be acceptable to the entire Aboriginal population. Universal approaches – including a medical predetermination of a socio-culturally ‘suitable’ animal - cannot be assumed or adopted.

### **Conclusion**

The prevalence of end-stage renal disease is significantly increasing in the Aboriginal Australian community. While renal transplantation is considered the definitive treatment, Aboriginal Australians are less likely to receive a transplant than Caucasian Australians, despite their greater health problems and needs. Furthermore, pre-transplantation and transplantation evaluations currently discriminate against Aboriginal Australians. This can be evidenced in ambiguous selection criteria, which require value judgements for decision-making. Such problems can be exasperated by institutionalised processes and communication problems during healthcare provision. Consequently, such socio-cultural and medical determinants create an inequality in healthcare access and, as a result, negatively affect quality of life. As new medical technologies such as xenotransplantation are built upon and are influenced by existing knowledge and infrastructure, significant re-evaluation of existing transplant criteria and health ethics needs to be undertaken. In turn, public consultation processes need to include an understanding of national health disparities to appreciate health inequalities and to provide informed consent. Such developments would allow a reduction of the medical marginalisation experienced by Aboriginal Australians to occur, while also fostering a mutual relationship of respect between Aboriginal and non-Aboriginal Australians. In this light, sociologists are needed to highlight the social issues that could be embedded in xenotransplantation, including those that affect Aboriginal populations. In this way, a better appreciation of cultural differences and values in Australia – whether ‘culture’ relates to human populations or social institutions – can be addressed from initial policy design and regulation.

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