

EDITORIAL

PERSPECTIVES ON ORGAN TRANSFER AND BIO-IDENTITY

Medical and scientific advances in the twentieth and early twenty-first centuries have transformed the boundaries between the human body, other forms of life and technology. Our moral, ethical, and legal institutions and values have consequently come under increasing pressure to respond. We need new ways of understanding these changes, as well as new models to interpret and adjudicate the moral bases these changes hold for the future of social relations and human life. In different ways the articles in this volume respond to this call, scoping out a philosophical anthropology of organ and tissue donation and transplantation in light of biomedical and technological innovation.

There is an established international tradition of empirical research in medical anthropology and the sociology of health and illness on organ donation and transplantation (see Fox and Swazey, 1992, 2009; Healy, 2006; Lock, 2002; Sanner, 1994, 2001; Scheper-Hughes and Wacquant, 2002; Simmons *et al.*, 1977). Until recently, however, little empirical research on the topic has been undertaken in New Zealand. The articles in this special issue of *Sites* seek to remedy the dearth of local research in this area, grounding discussion about organ and tissue donation in burgeoning interdisciplinary debates around embodiment, identity and relatedness and against the backdrop of public health initiatives to share and exchange corporeality.

In so doing, each article presents research highlighting some of the central analytical themes that have dominated social science work on tissue donation and organ transplantation over the course of the last two decades. These themes include concerns around death and bodily integrity, constructions of bio-identity, corporeal hybridity and kinship, altruism and gift-exchange, and the ever-pressing problem of commercialisation and organ trafficking. The contributors to this volume explore how people make sense of bodily exchanges when donating and receiving tissue from various others, including non-human animals, as well as the impact of tissue exchange on understandings of kinship categories. For social scientists, the nature of tissue donation

and organ transplantation as a transformative experience and the new relatedness it brings about is often overlooked in the bioethics literature on this topic. It is nonetheless pivotal to comprehending the complexities of peoples' decision-making around participation in organ and tissue transfer procedures.

In this issue the term organ transfer, coined by the American anthropologist Lesley Sharp (2006) whose work features in the volume, describes the links between organ donation, 'procurement' and retrieval, and transplantation as interconnected processes. The term is useful because it enables us to think beyond transplantation as an end point to consider what Waldby (2002) refers to as the 'relational and social' construction of bio-identity in the course of organ donation and transplantation. It also prompts us to take seriously the movement of body parts and tissues across local and global sites, and the adverse impact of organ exchange processes for some of the world's poorest and most vulnerable populations. How we address issues concerning organ donation and transplantation in New Zealand thus has global consequences.

Several of the contributions to this special issue are based on papers presented at *The Future of Organ and Tissue Donation* Conference held at Victoria University of Wellington on 7th April, 2010. This multi-disciplinary symposium, funded by the Royal Society Marsden Fund (NZ) and SPEaR, the Social Policy Evaluation and Research Committee, was designed to bring together social scientists, health professionals, transplant physicians and surgeons, organ donor and recipient coordinators, policy makers, living organ donors and recipients, and the general public to discuss organ donation and transplantation in New Zealand. The aim of the symposium was to engage people in dialogue about organ and tissue donation and to encourage debate about the topic in the New Zealand media. There is no doubt we were successful on this front, with articles appearing in the *Weekend Herald* (10/04/10: B4), the *NZ Herald* (8/04/10: A1), *Dominion Post* (8/04/10: A1), *Sunday Star Times* (28/03/10: 10), and in local print media elsewhere, up to and after the symposium. A number of speakers received radio and television coverage, including our keynote speaker, Lesley Sharp, who was interviewed about her ethnographic research on organ transplantation in the United States of America with Kathryn Ryan on the National Radio 'Nine to Noon' programme (9/04/10). The real success of the symposium, from my perspective as convener of the event, rests with raising awareness among New Zealanders to a fuller understanding of why demand for organs outstrip supply.

One theme of the April 2010 symposium, compensation for living donors and the question of commercialisation of tissue exchange is absent from this

volume, but is currently on the policy agenda for discussion in New Zealand. Under the Human Tissue Act 2008 the commercialisation of any body tissue, including solid organs, is illegal. Likewise, The Human Assisted Reproductive Technology Act 2004, which covers reproductive body matter and services, also prohibits what in legal terms is called valuable consideration for gamete exchange and surrogate pregnancy services. Prohibition against organ trading has been further endorsed by the Declaration of Istanbul on Organ Trafficking and Transplant Tourism (2008), which New Zealand representatives from The Transplantation Society have signed, along with governmental officials, social scientists, and ethicists from around the world. A key question regarding this Declaration is whether New Zealand should send a delegation of social scientists, cultural experts, and policy makers to attend these meetings to represent as many perspectives as possible in the decision-making process. Currently these meetings are attended only by Transplantation specialists.

It is worth commenting on the Istanbul Declaration in this introduction as it has implications for how we think about the future of organ and tissue donation locally. The Declaration prohibits organ trafficking (the illicit sale of human organs), transplant tourism (using one country's resources such as organs, medical professionals and transplant centres and thereby undermining that country's ability to provide organs for its own population), and transplant commercialism (treating body parts as commodities). As part of the Istanbul document, which resolves to protect vulnerable populations in resource-poor countries from exploitation by the organ trade, country signatories are required to develop national self-sufficiency in organ donation. This means implementing programmes to prevent organ failure by ensuring the provision of organs and tissue to meet patient needs within one's own population. While signatories to the document have outlawed unethical organs procurement and transplantation practices as listed under the Declaration, they have also distinguished between the commercialisation of human tissue, which prohibits a legal open market in organs, and compensation for live donors. One suggestion to meet the transplant needs of New Zealand's patient population in the document is the call for financial assistance for those who donate; in particular, live kidneys and liver lobes. The decision to vigorously promote live donation, not without its own attendant risks, has been endorsed by some New Zealand health professionals and politicians. Several politicians aim to provide financial assistance for live donors, targeting financial barriers to donation as a prime reason for our low donation rate. For those working in the field it is certainly important to distinguish between commerce and compensation but an argument also needs to be made for the removal of financial disincentives for living organ donation, a topic somewhat occluded in the social science

literature by over-emphasising monetary recompense as intrinsically exploitative and degrading.

In addition to the debate about financial incentives and inducements to donate, commentators have proposed other solutions to overcome the organ shortage. In an article published in 2004, Ngahoro and Gillett suggested New Zealand's organ scarcity is related to the tentative procurement practices of our health professionals. They maintain the problem is communication, and that critical care specialists (intensivists) and support staff are often unwilling to obtain consent from families in Intensive Care Units where those clinically diagnosed as brain dead could be potential donors. For these authors the law recognises the donor's autonomy in decision-making about organ donation and should therefore override critical care practice and policy. Their proposal, that health professionals receive training to ask the right questions in the right way at the right time, would, they say, bring clinical praxis, the ethics of organ procurement and the law into line by focusing on the wishes of potential donors as registered on their drivers' license. While training workshops for intensivists and support staff such as ADAPT (Australasian Donor Awareness Programme Training) are established to address, among other things, ways of approaching families about organ donation, the authors offer an easy solution to what is essentially a multi-factorial problem. In short, they fail to mention that the so-called organ deficit is relative to advances in intensive care practice and transplant surgery, improvements to road safety and road regulations, the increased incidence of diabetes and kidney failure, public expectations around quality of life, and so on; all of which mean fewer organs for increasingly more patients. Additionally, the view of organ donation as a supererogatory act and ideal to which we should aspire conceals worrisome questions about the ethics of procurement and the distribution of body parts historically (see Richardson, 1998), the spectre of which is deeply embedded in our collective unconscious. As Professor Glennys Howarth from Sydney University pointed out in her presentation at the April 2010 symposium, programmes to promote deceased and live donation can gloss the extent to which historical memory around abuses to do with the retention of organs without consent may impact on the willingness of some groups to donate. We do not have to look that far back into the history of organs procurement and retrieval practices to know what Howarth means. Recall, for instance, the public outcry over the macabre and disturbing Mastromarino case of tissue and organ harvesting that came to light in 2005 in the USA.¹ Closer to home, it is difficult to forget the lamentably well-intentioned Green Lane Hospital saga, which unfolded in New Zealand in 2002. Green Lane Hospital came under public scrutiny when it was revealed more than 1000 children's hearts were retained in a research collection dat-

ing back to the 1950s. Many of these organs had been kept without parental permission (Jones, 2002).

The question of who owns the rights to a body is a very real concern for people making decisions about organ donation. As we take a stance against global organs trafficking and move to encourage live donation as a way around organ scarcity and the limits of geographical isolation in our own region, we would do well to remember the lessons imparted by early social science pioneers researching the field. In a number of recent papers remarking on the moral value of live kidney donation from adult children and grandchildren to elderly parents and grandparents in the US, anthropologists (see Kaufman *et al.*, 2006; Lock and Crowley-Matoka, 2008; Scheper-Hughes, 2007) recall some of the concerns Simmons *et al.* (1977) first raised in their study in the 1970s. This early sociological work drew attention to the fuzzy line between consent and coercion when live kidney donation becomes a compelling obligation for those with strong intrafamilial beliefs about love and the duty to care. Not only do we need to ask serious questions about voluntariness in these circumstances, we also need to reflect on shifts in cultural beliefs about overcoming the inevitability of ageing and death. This latter concern recalls Fox and Swazey's (1992) reasons for 'leaving the field' in the 1990s after several decades of ethnographic research on organ replacement. In their words, the decision to finish up their research in this domain was both a matter of 'participant-observer burnout' and a 'value statement' about the routinisation and profanation of organ transplantation. Their disquiet is best encapsulated by the following quotation, subsequently reiterated numerous times by the authors and by Fox in particular (e.g. see Fox and Swazey, 2008: ch.7). For Fox and Swazey, the dominant biomedical ethos of organ transplantation is 'a bellicose, 'death is the enemy' perspective; a rescue-oriented and often zealous determination to maintain life at any cost; and a relentless, hubris-ridden refusal to accept limits' (1992:199).

Unlike our intellectual forebears from the United States most of the contributors to this volume of essays on organ donation and transplantation are new to the field. Three articles are by authors at different stages of their doctoral research, one of which offers a message from the sector, and three are by established academics, two of whom have been researching tissue transfer for some time. The first essay is based on the keynote address of the April 2010 symposium, by Lesley Sharp of Barnard College and Mailman School of Public Health at Columbia University. Sharp's theoretical paper marks a shift in her published work from an earlier focus on organ transplantation (see Sharp, 2006) in the United States to xenotransplantation. The subject of Sharp's article

on interspecies transplantation is topical, given the rapid expansion of scientific work experimenting the uses and potential uses of human and non-human tissue transfer, and the possibilities of xenotransplantation as an innovative response to the shortage of deceased donors for organ transplantation. Sharp frames her topic through key anthropological concepts of relatedness, kinship and kind, taking the reader through a political history of xenotransplantation and the transfer of non-human cells and tissues into particularly vulnerable groups of humans. If human to human organ transplantation is experienced as personally transformative, as several contributors to this volume suggest, then Sharp extends this question to ask what it means when the boundaries between human and animal 'others' are breached.

The supply of organs and tissues for therapeutic purposes has been promoted and organised through the metaphor of the 'gift of life'. The problem with this terminology, as Fox and Swazey (1992) observe regarding the 'tyranny of the gift' is that far from being unidirectional most people who receive an organ feel compelled to reciprocate. Gift rhetoric is prevalent in the public domain in New Zealand and is used by organ recipients to frame their understanding of transplantation, as Jensen and Wainwright in this volume note in their respective essays. In his article, Robert Webb shows that the vocabulary of the gift may be out-of-step with the experiences of Maori living donors, transplant recipients and whanau. Additionally, although we need to take into account traditional Maori beliefs and values as influencing decisions to donate and receive body tissue data from Webb's study indicate we risk ethnocentrism by assuming those values represent one homogeneous viewpoint. Webb does conclude, however, that long term wellbeing for Maori transplant recipients and related whanau rests on being able to properly integrate socio-cultural beliefs and individual values about shared corporeality. Institutionally, this may mean putting more thought into health care measures to extend current practices and rituals beyond anonymous Thanksgiving services and letter writing between recipients and donor families. In several places around the world, New York City for instance, donor families and transplant recipients are able to establish on-going connections, often resulting in positive on-going relationships. Webb concludes his article by suggesting there is a case to be made for providing opportunity to do this here in New Zealand, in circumstances where people consent.

In her article, Paula Martin adds perspective to debate on the topic of organ donation and transplantation by considering 'the Maori view'. Working in the area of public policy, Martin considers reasons for live kidney transplantation, arguing for live donation over dialysis as less costly to the health system

and offering better clinical outcomes for those with end stage renal failure in terms of life expectancy and quality of life. Martin notes the increase in rates of chronic kidney disease in New Zealand and the ever growing numbers of people on dialysis each year, particularly Maori and Pasifika populations. To address the problem satisfactorily, Martin suggests a multi-pronged intervention strategy; a proposal in line with Hedgecoe's (2004) work at the intersection of social science and bioethics. In short, the argument is that top-down philosophical approaches to the problem of organ supply have not worked thus far so we should take into account the perspectives of those directly affected in order to shed light on these issues.

The next article in the volume, on the lived experience of liver transplantation is by Bethli Wainwright, a liver transplant recipient herself, who passed away on 25 December 2010 and to whom we dedicate this special issue. Wainwright's paper, which is based on doctoral research she embarked on in 2007 and undertook through 2010, was proofread by her sister, Kylie Burling. A dedicated group of people have also cooperated to complete Wainwright's doctoral thesis, which will be available through the AUT Library. Wainwright's article draws on phenomenology to document the experiences of New Zealand liver transplant recipients. In it Wainwright presents preliminary data from in-depth interviews and a qualitative survey with liver transplant recipients, around the obligations they feel after receiving an organ from a deceased donor and their family. For many transplant recipients Wainwright interviewed this is a transformative experience, and the acceptance of the donated liver as a scarce and precious gift is an on-going moral accomplishment. This is reflected in what Wainwright's research participants say about expressing gratitude, writing thank you letters to their donor's family, doing volunteer and community work. They also talk about how they care for themselves post-transplant, and their views about information and making contact with donor families.

Along with other articles in the volume, Wainwright provides evidence from transplant recipients' accounts to show how bodies are viewed as more than functioning or malfunctioning detachable parts lacking and divested of agency. For those recipients who believe the subjective qualities, traits, life force or spirit of the donor live on in the transplanted organ, the experience of tissue transfer is not impersonal or affectively neutral. On the contrary, for these participants tissue transfer exceeds the closed economy of exchange as intended, regulated and monitored by the health care system. As scholars elsewhere have said (see Vamos, 2010), we cannot know in advance whether the psychosocial and moral outcomes of these exchanges will be experienced as positive or negative. What we do know is that for some donors, donor families, and recipi-

ents, tissue transfer challenges the fiction of a bounded subject inhabiting one identity and one body as an inherently stable entity.

Mary Murray's article on xenotransplantation, zoonosis and monstrosity extends these themes to discuss how the inherent plasticity of human bodies and identities is magnified in our relations with biomedical technologies. Like other authors in the volume, Murray suggests that organ transplant recipients may experience their post-operative embodiment as morphologically dubious. She goes further to argue that psychic responses to the incorporation of otherness within one body are exacerbated when corporeal transfers occur between non-human and human animals. Drawing on survey research documenting attitudes to xenotransplantation Murray shows how people conceptualise this procedure as a threat to bodily integrity and their sense of self. Notwithstanding this general perception, the experience of incorporating otherness within the self is not unique to organ transplantation or xenotransplantation. Murray suggests that reflecting on the kinds of intercorporeal exchanges xenotransplantation facilitates may help to critically destabilise other long standing binary constructs such as identity and difference.

In the final article of the volume Anja Jensen presents anthropological fieldwork on organ donor families' experiences undertaken in New York City during 2005 and in Denmark from 2008–2011. Jensen's article looks at the different ways donor families in these respective environments make sense of the decision to donate organs after the brain death of a family member. Her article highlights how cultural values and traditions impact families' experiences and how different attitudes toward death, donor identity and reciprocity are managed by donor families and by the professional staff working with them in the very different institutional and organisational organ donation contexts of Denmark and the United States. Although Jensen refrains from judging either system there may be lessons to be learnt from the coordinated efforts of the Aftercare programme of the New York Organ Donor Network that could be incorporated into both the Danish and New Zealand systems.

Additionally, Jensen draws attention to how donor families in Denmark and the United States cope with the death of family members who are certified brain dead by neurological criteria in intensive care units and the decisions families make to donate the organs of deceased family members. To contextualise; brain death was only accepted into Danish law in 1990, alongside cardio-respiratory criteria after a long period of public discussion and debate (Rix, 1999). In Denmark the legally brain dead organ donor is dead for transplantation purposes and has entered the 'death process' but it is cessation of

cardio-pulmonary function that defines death in everyday terms for Danes – what Jensen refers to in her article as ‘dead dead’. By contrast, the concept of brain stem death was first introduced by an *ad hoc* committee of the Harvard Medical School in 1968, and has been the accepted clinical definition of death in the United States since that time, having been endorsed by a presidential commission on brain criteria in 1981 and formally adopted by most States thereafter (Benjamin, 2001). So, while North American families may think of the donor’s spirit as ‘living on’ in the body of the transplant recipient through the donative act, the Danish experience of deceased donation is somewhat different. Drawing on Lock’s (2002) characterisation of brain death as a cultural and technological artefact, impossible without the invention of ‘life-sustaining’ ventilators, Jensen documents the difficulties some donor families have coming to terms with deceased organ donation given the lack of consensus for criteria for brain death.

Debate over the definition of death was recently revived in New Zealand with the reintroduction of DCD (Donation after Cardiac Death) criteria, after a national protocol was approved by the Multi Region Ethics Committee in 2007 (ODNZ, 2010:14). As Jensen’s article suggests, DCD, which refers to the absence of the circulation of blood and other signs of life, accords better with everyday notions of death for many people than brain stem death. There are, however, questions to be asked around reconsidering criteria for the determination of death in this way. For instance, did the decision to return to DCD criteria in the lead up to the New Zealand protocol involve full public discussion as was the case in Denmark?

I trust this *Sites* special issue will generate further discussion around issues like DCD and organ transplantation as well as other topics raised by contributors to the volume. Our intention, as social scientists, is to engage health professionals, bioethicists, transplant specialists, and the public in the process.²

Rhonda Shaw (Guest Editor)

NOTES

- 1 In June 2008 Dr. Michael Mastromarino, a dental surgeon, was sentenced to 18–54 years in prison for purchasing over 1800 human corpses awaiting cremation from funeral homes in New York and Pennsylvania and illegally harvesting them as tissue, bones and organs. Mastromarino and his firm, Biomedical Tissue Services forged numerous consent forms in order to obtain the bodies, which they purchased at around \$US 1000 and sold for at least \$US 13000 per body.

- 2 Thank you to the authors and anonymous reviewers who contributed to this special issue and especially to Chrys Jaye for her help in putting the collection together.

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