

# **Patterning the geographies of organ transplantation: corporeality, generosity and justice**

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## ***Abstract***

Organ transplantation is now an established treatment for patients with end-stage organ failure, yet there are spatial inequalities in access to this procedure. This paper explores the uneven geographies of kidney transplantation in London, arguing that inequalities in access to organ transplantation are created through interlocking spatialities of corporeal difference, enacted through global movements of populations, national organ transplantation protocols and the internal immunological spaces of the body. The combination of these processes, operating at different scales, has produced a distinctive configuration in the embodiment of risk in relation to kidney transplants, particularly born by London's Black and Asian communities. Two ethical dimensions to this geography of organ transplantation are explored here: the ethical responsiveness to others shaping the generous practices of organ donation, and the medical practices categorising difference through techniques of blood typing, tissue matching and the spatial organisation of organ transplantation. In concluding, I argue both are critical to understanding the links between ethics and justice in the geographies of organ exchange in London. Further, I suggest geography is central to political debate about the exchange of biological material elsewhere, for it is only through tracing the intersection of ethical, corporeal and technological practices in situ that we can fully reflect on questions of justice within the developing bioeconomy.

## ***Keywords***

Organ transplantation, Health inequalities, London, Ethics, Corporeal generosity, Difference

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'I take tentative steps, consider everything as only a tentative understanding, a lost cartographer with no maps. [...]. We are left to invent a new way of being human where bodily parts go into each other's bodies, redesigning the landscape of boundaries in the habit of what we so definitely used to call distinct bodies' (Varela, 2001, 161)<sup>1</sup>.

## ***Introduction***

The emergence of modern organ transplantation can be traced to experimental procedures in kidney transplantation from the 1950s onwards. The first successful kidney transplant took place at the Peter Bent Brigham Hospital in Boston, USA, in 1954, with the donation of a kidney by Ronald Herrick to his brother Richard, who was dying of kidney failure. Ronald and Richard were identical twins, and for the first time the organ was not rejected, confirming contemporary speculations about the importance of immunology in graft survival. However, it was not until subsequent advances in understanding human immunology, developments in tissue matching and the discovery of drugs to suppress immune responses that transplantation between genetically diverse individuals became possible and survival rates began to improve.

Organ transplantation is now an established treatment for patients with end-stage organ failure. Globally, over one million people have received an organ transplant, and, as Lock suggests, 'organ transplants have been routinized with apparent ease and become part of the health care systems of virtually all countries in the world able to support the necessary technology' (Lock 2002a, 1406). Kidneys remain the most frequently transplanted organ. Continuing improvements in surgery and immunosuppression have extended kidney transplantation from a pioneering experiment between identical twins, into a medical procedure that enables the commonplace crossing of boundaries between self and other, life and death, and individual and society, in the extension of human life through the organs of others.

However, the extension of the technologies of organ transplantation, and the model of a dualistic and severable body in which they are located, has not been even. The procedures and discourses around organ transplantation have encountered resistance, leading to different

practices in different countries. Furthermore, they have produced inequalities evident at different scales. It is medical anthropologists and sociologists who have written most extensively on these topics and there is now a rich vein of cross-cultural work on organ transplantation. There are ethnomedical studies of different cultural attitudes to organ transplantation (Daar 2000; Gordon 2001; Lock 1999 2002b; Sanner 2001), investigations into the organisation of organ transplantation in different national contexts (Hogle 1995; Ikels 1997; Lock 1995; Ohnuki-Tierney 1994) and increasing information on the legal and clandestine trade in biological material and human organs (Scheper-Hughes 1996 2000; Nguyen and Peschard 2003).

The extension of organ transplantation has also led to organ shortages and the future of organ transplantation is increasing framed in terms of crisis: a mismatch between the increasing numbers eligible for transplantation as technologies improve and populations age, whilst rates of organ donation remain static or decline<sup>2</sup>. Discussions of organ scarcity raise further questions of interest to social scientists: the growing commodification of human body parts (Joralemon 1995; Lock 2002b; Scheper-Hughes 2000; Sharp 2000; Tilney *et al* 2001) and the acceptability of new sources to address this shortfall, for example, through the use of animal organs (Brown 1999; Davies *et al* 2003; Einsiedel 2002; Woods 1998). All raise profound political and ethical questions over who donates bodily material, who receives it and how these decisions get made (Parry 2004; Waldby and Mitchell 2006). As Scheper-Hughes asks 'under what social conditions can organ harvesting and distribution be fair, equitable, just and ethical?' (2000, 210).

The aim of this paper is to explore these political and ethical questions through the geography of organ transplantation in London. There are several reasons for this focus. There are empirical questions regarding the differential access to kidney transplantation in London, which resonate with geographers' long-standing interest in health inequalities (for recent discussion see Smith and Easterlow 2005). In the Greater London area, patients on transplant waiting lists south of the river Thames are twice as likely to receive a kidney transplant as those registered north of the river. Statistics for 2004 indicate 709 people on the active waiting list in the North Thames Alliance area, with 226 transplants carried out (UK Transplant 2005). For South Thames, the figures were 409 and 220 respectively; whilst donation rates in the two areas were identical at 20 people per million population (UK Transplant 2005). Moreover, members of North London's Black and Asian community experience particular difficulty finding a match amongst the pool of donated organs (Randhawa 1998 2000; Rudge *et al* 2003). National figures suggest median waiting times on kidney transplantation lists for Asian and Black patients are 1496 and 1389 days; for white patients, median waiting times are 722 days (Rudge *et al* 2004).

Theoretical questions thus emerge about the importance of both location and identity in understanding the implications of the increasing exchange of biological material in modern economies and health care systems. Rather than delineating identifiable cultural attitudes or national approaches to organ transplantation, this paper uses London to explore how different moments in the procurement and distribution of organs, underpinned by different ethical considerations and spatialities, pattern complex relationships between organ donors and recipients within the social and medical communities in London. In tracing these relations, corporeal difference appears critical to organ transplantation in a material, as well as cultural, sense. In organ transplantation, as in other contexts, 'the body is produced through concepts, while, at the same time, demonstrating a materiality well beyond the limits of such concepts' (Keane and Rosengarten 2002, 271). Practices of immunology are crucial to crossing boundaries between genetically dissimilar bodies in organ transplantation; yet they simultaneously provide the basis for the further categorisation and embodiment of difference, through procedures of blood typing and tissue matching used to allocate scarce donated organs amongst large numbers of potential recipients. The implications of these corporeal differences are further situated, through the specific operation of kidney transplantation protocols in the UK and the location of different ethnic communities within London. In this context, as in others, a technology based on crossing boundaries between self and non-self, between life and death, ends up reasserting divisions between those whose desperate needs are met and those whose bodies remain at risk. However, as I explain below, attention to the ethics of organ allocation, as well as organ donation, suggests this could be otherwise.

Prior to exploring these patternings in more detail, I want to evaluate two ideas central to organ transplantation from the outset: the idea of the 'gift of life' and a particular construction of property rights in relation to the body. These discourses are important, but they offer a limited account of the complex encounter between self and other, individual and society, that is enacted through transplantation technologies at different scales. Furthermore, they are questioned by participants in this process. Drawing on three moments in the collection, allocation and distribution of organs for transplantation, I explore the imaginaries of self and other that constitute different forms of relating within the geographies of organ transplantation in London. Drawing on in-depth discussion groups, I first introduce the way citizens explore the contexts in which they feel capable of donating bodily material to those in need. Following this focus on the openness to another suggested through support for organ donation, I explore how boundaries between self and other are reasserted in the routine medical practices of organ matching; seeking to take the biology of organ transplantation seriously, but also to 'address material embodiment in ways which undermine rather than give credence to biological determinism' (Nash 2003, 644). Finally, the institutional practices of UK organ transplantation link potential donors and recipients through

geography, through holding in tension communities defined through both generosity and corporeal difference, leading to questions about the operation and embodiment of justice in the distribution of human organs. In concluding, two ethical dimensions to this production of corporeality and difference are reviewed: the responsiveness to others shaping the practices of organ donation, and the calculative practices framing the embodiment of difference through techniques of blood typing, tissue matching and the organisation of organ transplantation. Both are critical to understanding the patterning of organ exchange in London, and I argue their operation here offers insight into the importance of geography when considering the political implications of tissue exchange elsewhere.

### ***The ethics of the impossible gift***

Alongside the development of drugs to ease the acceptability of transplanted organs to human immune systems, the creation of public discourses around organ transplantation has secured the cultural acceptance of this technology. For organ transplant professionals, the Frankenstein metaphor forms a strong cultural narrative to be overcome by other, equally powerful discourses. The medical anthropologist Joralemon identifies these as 'the ideological equivalents of immunosuppressant drugs, designed to inhibit cultural rejection of transplantation and its view of the body' (1995, 335). Discourses around the gift of life and altruistic giving, the dualistic separation of the human body from personal identity and a rationalistic view of individual personhood, normalise the surgical removal of organs from one body and their replacement into another, underpinned by protocols of personal informed consent. The institutionalisation of such discourses within international and national bioethics conventions has facilitated wide social, cultural and religious support for organ transplantation. Yet, at the same time, there is growing awareness of the limitations of these bioethical formulations, which privilege abstract universals over localised concerns (Levine 1991; Bosk 2000; Evans 2002; Hedgecoe 2004). This is increasingly enriched by theoretical and empirical work, which explores the particular, embodied and spatialised nature of the ethical negotiations characterising relations between self and other within everyday life (Valentine 2003; Popke 2003; Barnett 2005), and in the contexts of organ transplantation (Fox and Swazey 1992; Sharp 1995; Waldby 2002).

Two culturally potent scripts – gift giving and property rights – are routinely used to provide support for organ donation and transplantation. In both cases, transplantation advocates make use of the culturally familiar to legitimise a profound transformation in the way we think about and act on the body and its parts, at the boundaries between life and death. To conceive of organs as gifts is the orthodox position, central to transplant surgery from the outset (Fox and Swazey

1978). References to the 'gift of life' are found repeatedly in popular and medical accounts, and underpin the terms donor and recipient, linking the medical procedure to complex notions of generosity, altruism and selflessness. Discussions of organ transplantation simultaneously draw on notions of personhood and property ownership vis-à-vis the body, allowing body parts to be freely given. The use of the two concepts is linked, resolving a tension within modern conceptions of the body and selfhood. To consider the body as constituting the self renders the human body inalienable: the possession of a body by another an unacceptable commodification of the person. Yet, insofar as the body is considered to be an individual's property, the right to do with it what one will should allow its alienation (Diprose 2002). The conflict between these positions is, for the purposes of organ transplantation, resolved through a mixture of informed consent based on personal autonomy over one's own body and the selfless generosity of the 'gift of life'.

When used with donor's families, it is assumed the gift assuages feelings of grief, allowing them to know someone chronically ill has been helped, transforming a sudden death into something meaningful. For the recipient, the theme of gift giving aids acceptance and alleviates feelings of guilt (Sharp 1995). For both parties, the metaphor circumvents the commodification of the donor body and organ transplantation process. Thus, even within clinical contexts, the gift achieves several, apparently contradictory, ends. The gift of life obscures the surgical removal of vital organs from cadavers, encouraging families to donate organs as giving 'life' to another, thus conferring the organ with essential properties. Simultaneously, the gift helps recipients accept as theirs a severable organ, given selflessly by another. The gift thus accommodates contested notions about what is exchanged. As Sharp writes, 'a dead woman's transplantable heart may simultaneously embody the essence of a loved one, be transformed into a gift for a recipient in need, and be the coveted object of a surgeon's desires' (Sharp 2000, 290).

Yet further, as anthropologists and philosophers from Mauss (1967) onwards have argued, the gift connects the exchange of organs to the negotiation of social identities and communal relations. For Mauss, the gift shapes social relations through demonstrating the status of the donor, whilst bestowing on the recipient a moral obligation that cannot be repaid except through maintaining a social bond. Yet within organ transplantation any relationship between donor and recipient is deliberately avoided, with transplantation organisations concealing the identities of donors and recipients, preventing contact between the two. Sharp suggests both donors and recipients are often confused by this theme of the gift, with donor families wishing to integrate recipients into their social world to maintain links to the essence of deceased relatives, and recipients troubled with a confusing and ultimately impossible desire to reciprocate (Sharp 1995; Ohnuki-Tierney 1994). Moreover, for donors and patients the human tissue exchanged is not

impersonal matter, and identifications and disidentifications between donors and recipients are central to attempts to make sense of the transformations of the body and self this procedure involves (Sharp 1995; Waldby 2002). To protect individuals and the anonymous operation of organ distribution protocols, attempts by either donor or recipient to construct a social relationship is viewed by professionals as pathological, something to be treated through counselling.

These observations about the complexity of the gift in organ transplantation resonate with alternative readings of the relationship between identity, difference and generosity, informed by Derrida, and developed in feminist work on corporeality (Diprose 2002) and geographical work on ethical relations to others (Barnett 2005). Both Diprose and Barnett start from Derrida's writing on the *aporia* of the gift (Derrida 1992): that the conditions Mauss assumes are necessary for generosity to be possible, an individual virtue deliberately chosen with no expectation of return, are the conditions that make it impossible. Diprose and Barnett both turn to Levinas' phenomenology of care (1969 1981) to re-examine the nature of the encounter between the self and other, as the basis for the generous relation to the other, locating this prior to the calculative exchange of the gift.

For Levinas, generosity operates at the level of sensibility, it is not wholly cognitive, rather it is based in a notion of subjectivity as 'the always-already responsibility to and for the Other, prior to any calculation or reflection by a self-conscious subject' (Barnett 2005, 9). In this perspective gift-giving cannot be separated from being. The sovereign individual, owning property which can be given, is not *a priori*; rather the process of gift-giving constitutes both identity and difference, both ideas of self and of other. In place of the contractual exchange of bodily materials between isolated individuals, Levinas thus offers a relational understanding of subjectivity, emerging from a sensibility to the other, in which the affective and ethical relation to the other can be relocated (for discussion of ethics and intercorporeality see Diprose 2002 and Waldby 2002). Thus some of fundamental tensions embodied in the ethics of organ transplantation can be identified. The gift both evokes but also negates questions of identity and being. In part, organ allocation is dependent on a Rawlsian notion of considering ethics under a 'veil of ignorance', occluding information about age, sex, or ethnicity, to pursue justice within the social contract of organ transplantation (Rawls, 2005). Simultaneously, appeals to organ donors resonate with a Levinasian ethical sensibility to and identification with the other, to secure the willingness to gift bodily material<sup>3</sup>. Furthermore, both ethical positions are necessarily surpassed in the practice of national organ allocation protocols, whose task it is to match donated organs to suitable recipients. In this processes both the multiplicity and materiality of corporeal difference have to be negotiated.



In organ transplantation, questions have to be considered about responsibility to multiple others, and thus to issues of comparison, measurement and calculation, which Barnett (2005) argues Levinas excludes from the purity of the relation to the other constituting ethical responsibility. In exploring the geographies of organ transplantation, Barnett's observations raise questions about the acknowledgement of and responsibility to others, not only through the ethical relation to the imagined other that may inspire individual act of generosity in organ donation, but also through the ethical dimensions to these processes of comparison and calculation that are critical to distributing donated organs to multiple others. Diprose (2002) further elaborates on this relationship between ethics, justice and difference through an emphasis on corporeality, which takes seriously the materiality of the body and the construction of bodily differences in clinical and other settings. For Diprose, the self is a corporeal cultural artefact, also constructed in relation to the other, but through the affective capacity of one body to respond to the bodies of others. This adds a corporeal dimension to arguments in Levinas about generosity, identifying the potential of a sensibility to the other in the inherent openness of being, through the corporealization of traces of the other already in the self.

Moreover, for Diprose, corporeality is central not only to generosity, but also to justice. Bodies are differentiated, normalised and discriminated at the intercorporeal level through encounters taking place in clinical contexts, economic transactions and social relations. For Diprose, both generosity and justice are thus located within this corporeal ethical register; 'judgements that would efface or devalue differences arise just as much as within the affective and transformative dimension of intercorporeality as any generous welcoming and production of difference' (2002, 9). These insights have the potential to link questions about justice and ethics in organ transplantation, extending concern about the ethics of organ donation from a focus on the generous practices of donation, to consideration of justice and the construction of corporeal difference within the multiple spaces of organ transplantation. This potential is explored below, with particular reference to ethnicity and the unequal geographies of organ transplantation in London.

### ***Organ donation and the politics of generosity***

In the UK, organ transplantation only takes place within the National Health Service (NHS), organised under the auspices of UK Transplant. Under the Human Tissue Act 2004, it is illegal for anyone to obtain human organs for transplantation commercially. Thus, the only criteria for the collection and allocation of organs in the UK should be clinical need. Nevertheless, the ethics of organ transplantation, especially in relation to ethnicity, are increasingly visible, as two recent

news stories illustrate. In July 1998, the BBC's *Newsnight* programme revealed the case of the family of an organ donor, who requested their son's organs only be used for white recipients. Three major organs were removed from the donor, and the kidneys subsequently transplanted to a white patient in another hospital; though it was unclear whether the organs had been allocated according to the donor's wishes or through ordinary allocation protocols. Attaching conditions to organ donation was strongly condemned by the Department of Health, the British Medical Association and the UK transplant community, and an inquiry ordered. The then Health Secretary, Frank Dobson, quoted doctors saying there were no racial barriers to transplantation and promised to rid the NHS of racism. Yet, starting in 1999, UK Transplant has launched several major publicity campaigns to boost the number of ethnic minority donors, especially from Britain's Black and Asian Communities. Pointing to higher risks of diabetes and high blood pressure within Black and Asian populations, exposing individuals to higher levels of organ failure, they argued this need could only be met by increasing levels of donation from within these groups<sup>4</sup>. There are thus two significant questions about the relevance of ethnic identity to organ transplantation: firstly, in relation to corporeal generosity and the motivations of individuals to donate, but secondly in relation to corporeal difference and access to donated organs. I explore the first of these below.

Discussions, which took place in North London in 2002 as part of a project developing a new form of participatory technology appraisal piloted using organ transplantation, offer valuable insight into the way imaginaries of self and other are evoked by citizens exploring corporeal generosity through their views on organ donation. In a seminar room in North London, eight women who have never met sit in a circle discussing the issues associated with different kinds of organ donation. The women are of different ages and occupations; they have been recruited to reflect the ethnic diversity of the North London Borough of Camden; they have also been screened to exclude people with immediate experience of kidney problems or organ transplantation (for discussion of methodology and results see Davies et al 2003; Davies 2006a; 2006b). Following initial introductions from researchers and participants, the women spend time searching for a common basis on which to develop discussion around the apparently abstract issues of giving and receiving organs. Many of the women find these subjects difficult to discuss. They seem located outside the range of everyday experience, set in contexts so unique and precarious that normal frames of reasoning may not apply (Sanner 2001). They are tentative about what it is appropriate to say, uncertain about how to explore collaboratively sensitive issues that are personally difficult to articulate.

Amidst the first hesitant exchanges, one woman remembers she has in the past signed up as a bone marrow donor. She had forgotten this, and reflections of her past generosity erupt,

apparently to her surprise, in the midst of this initially reserved discussion. Immediately, another woman recalls she did the same. The conversation becomes more animated, and as the concrete details of these personal recollections emerge, the rest of the group finds a way to enter the conversation around the motivations for the often extraordinary moments of bodily generosity that puncture everyday relations.

Bianca (salon manager, 40s, Black Caribbean): I became a bone marrow donor two years ago, only because they were appealing to the black community. There was a cute little black boy, absolutely gorgeous; he was dying and desperate for bone marrow. It was near me, the Willesden Library. So I actually went, because he was so cute and it was such a big thing. And then went and had a blood test. Waited for my results and everything, and I didn't match him. I thought "okay, never mind". Then they wrote back to me saying, 'doesn't matter your bone marrow is on our list anyway for anyone else' ...

Daniella (company secretary, mid 30s, white): I did that as well ...

Bianca: Then I thought, but what if it comes up? I only did it because he was a kid. I thought 'God, anyone else?'

Daniella: Because I did it as well, I did the same thing as you, I saw a sob story, I went along and donated, and ...

Bianca: I waited for ages before he got matched. I didn't feel as though ... If someone asked, I don't know. I don't feel like I could be bothered to go through all that for someone else.

Daniella: You just think somebody else's child. God forbid if it was your own. You're automatically there aren't you, because you're a Mum.

The conversation that follows draws lines of personal ethical responsibility, based on the affective and corporeal dimensions of responding to the needs of individual others, and the capacity people felt they had to give their own bodily material to family, to the families of others, to strangers, and thus towards a sense of a reciprocal social good. Discussions also move quickly from bone marrow to living kidney donation. Many agree they would consider donating a kidney to family or friends, and sometimes to strangers. Yet the considerations in giving such intimate bodily material rarely start from abstract notions of altruism. Rather, each expression of care for others is a singular response to their suffering, arising within and limited by personal capacities of sensibility. The sense of responding to a named person, whose face can be pictured, is an important part of making this personal connection. The person envisaged is often a child, to whom lines of affect and care can be drawn through the willing sacrifices of family life, the shared experiences of parenting and the relief of innocent suffering.

Bianca is able to envisage the process of donating bone marrow to a child with whom she has been asked to identify, but cannot countenance this generosity for just anyone. This is not to say she would not, but that she does not know, without being in that position, faced with that individual need. In this case, Bianca has responded to a specific appeal to the black community for a matching bone marrow donor, and this is an important part of her motivation to donate. Yet, in general, for this urban multi-cultural group, the idea that transplantation should be constrained by markers of ethnicity was anathema. However, the reliance of donor campaigns on establishing an emotional connection between donor and recipient does raise this possibility. As Diprose argues, 'corporeal generosity is grounded in affect rather than conscious reflection, so also is prejudice. Affectivity is thus the domain of politics' (2002, 75).

A week later, a group of men occupy the same seminar room, and struggle with the same opening conversations. Many similarities emerge in their discussions about donation, and many of the lines of ethical connection traced from the individual to a broader social need are the same. Pierre (civil servant, 30s, Black Caribbean) echoes Daniella's comments above.

'You can see a bigger picture just from that point, sort of seeing your child onwards, the picture just gets bigger, because you realise just as your child could be in need, somebody else's child could be in need and it just broadens out, it gets global'.

Thus, for both these groups, corporeal affect does appear to underlie the personal ability to consider organ donation. The citizen discussions reveal that issues around personal ethical responsiveness, affectivity, the opening of the body to another, and the imaged encounter with those in need, are central to the consideration of organ donation. At times, this affective ethical relation runs counter to professional discourses around altruistic giving in organ transplantation, with their demands of anonymity, their rejection of directed donation and their emphasis on abstract principles of medical efficacy in allocating donated organs. Yet affect appears vital to secure a willingness to donate and, in other contexts, it is exploited by transplant professionals, as in personalized appeals to particular donor communities.

The encounter with and acknowledgement of the needs of the other is thus an essential part of the ethical relations of organ transplantation, yet it is not enough to address questions of justice and the distribution of donated organs amongst those in need. As Barnett suggests, 'justice enters the story with the introduction of multiplicity into the dyadic ethical encounter. It is here that responsibilities for generalized others arise, and here too that all those questions of comparison, measurement, synchronicity, equality and reciprocity [...] are readmitted' (2005, 10-11). It is in the procedures for categorising corporeal difference, oriented to the production of

efficacy in organ transplantation, that further inequalities in the geographies of organ transplantation emerge. It is to the specification of corporeal difference, ethnicity and access to donated organs that I now turn.

### ***Organ matching and the accommodation of difference***

The practices of organ transplantation are not only facilitated by affective links between donors and imagined recipients; in other organisational contexts routine assessments are made through which bodily difference and inequalities emerge. The actors here are not the donor families or surgeons, traditional heroes and heroines of the development of organ transplantation. Rather they are the often uncelebrated and unnoticed technicians, matching blood type, calculating tissue compatibility, or transporting organs around the institutions of organ transplantation. Their daily decisions are not the overwhelming personal and family questions of whether to donate bodily material or a loved one's organs, but emerge from the routine operation of medical practices and the required protocols of organ matching, which shift bodies into different categories. The specification of blood group, tissue type and so forth are essential to reconstructing the viability of the transplanted body. For the generous act of donating to others to become effective, some calculation about the corporeal accommodation of difference is essential. For an organ transplant recipient to accept unconditionally an uncategorised organ, the possible results include acute organ rejection and death. Thus, in this case as in others, ethical responsibility to the other is 'necessarily "contaminated" by law, system and calculation' (Barnett 2005, 17). Yet, at the same time, the institutionalisation of such practices have constructed identities marked by differences of biology and ethnicity, giving rise to bodies which experience different kinds of risk and different levels of access to donated organs.

Organ allocation protocols in the UK are based on matching two principal immunological characteristics between donor and recipient: blood type and human leukocyte antigens (HLA phenotype). Considerations of the age, size and quality of organs may also play a part, but the ethnicity of donors and recipients are of no direct significance in established forms of solid organ transplantation. For kidney transplantation, securing the best match can have significant influence on the survival of transplanted tissue, as well as subsequent quality of life through influencing levels of immunosuppression. However, the influence of these characterizations in determining the success of transplant outcomes for individuals is more complex than first appears, for few of these biological differences are simple boundaries.

Blood type in particular is increasingly debated in organ transplantation (Rudge 2003). There are four main blood types found in human populations: O, A, B and AB. These blood types have evolved over millennia as human populations have moved and mixed. The oldest identified is O, and it is the blood type from which all other groups derived; reflected in the fact that anyone of any blood group can receive blood group O. Blood group O is the most common group in the UK. Blood groups A, B and AB emerged subsequently, with increasingly rarity and geographic concentration. B and AB are particularly concentrated amongst Asian, Chinese and Japanese communities, including the South Asian population in London. In organ transplantation, the recipient and donor must be ABO compatible, which means there is some flexibility for individuals with blood types A, B and AB over the blood group of a potential donor<sup>5</sup>. Immunologically and clinically there is no reason why a blood group O organ should not be used for all patients, whether blood group A, B, AB or O.

In the UK, the blood group distribution of cadaveric organ donors broadly reflects that of the general population. Yet differences in blood group emerge as important on transplant waiting lists. Amongst white patients awaiting transplant, 51% are blood group O, 35% are blood group A, 11% are blood group B and 3% are blood group AB. Amongst Asian patients, 37% are blood group O, 17% are blood group A, 39% are blood group B and 6% are blood group AB (Rudge *et al* 2004). These differences become significant because ‘for organ cadaver transplantation a “same blood group” rule is usually maintained, to prevent disadvantaging group O recipients’ (Turner 2003, 1). At present there is fairly rigorous adherence to the allocation of organ along strict blood group lines: 93% of group O organs are transplanted into O recipients (UKTSSA 2000). Yet despite worries that blood group protocols may disadvantage O group recipients, the application of this rule produces other inequalities; in the UK it discriminates against group B recipients and the Black and Asian community in particular, contributing to the national disparities in transplant waiting times for ethnic minorities introduced above.

The application of HLA matching protocols in kidney transplantation further reinforces this process of discrimination. The distribution of HLA antigens similarly differs amongst different ethnic groups, and given that most organs are retrieved from the majority white population, the closer an HLA antigen match is sought through organ allocation protocols, the less likely the kidney will be allocated to an ethnic minority (Churak 2005, 156). Here again, for kidney transplantation, there is scope for a more fluid assessment of the relevance of these biological differences in determining the outcomes of transplantation when different levels of immunosuppression post transplantation are balanced against initial access to organs.

Donna Haraway (1991), in particular, has offered resources for thinking differently about immunology and difference, opening up the medical construction of the body to new ways of thinking about difference that parallel the openness of the body to others suggested through consideration of intercorporeality and relational ethics (Whatmore 1997, see also Martin 1990). Haraway suggests understanding the contemporary 'biomedical, biotechnical body must start from the multiple molecular interfacing of genetic, nervous, endocrine, and immune systems' (1991, 211). She goes on, 'the body ceases to be a stable spatial map of normalized functions and instead emerges as a highly mobile field of strategic differences' (Haraway 1991, 211). Nowhere is this more evident than in the immunology of the transplanted body, which destabilises traditional and localised markers of self and other, normal and disordered, natural and artificial, living and dead.

The inversions of a schematic narrative of renal failure bear this out. Initially, kidney damage often follows long-standing diabetes, an auto-immune disorder, in which the body's own immune system destroys the normal insulin producing function of the pancreatic cells, destabilising blood pressure and putting stress on kidney function. Thus, at this level, and 'in the clinical context of insulin-dependent diabetes, the space of the same is already differentiated and acted upon, within, as other' (Keane and Rosengarten 2002, 274). If the resulting stress on kidneys is fatal, proceeding to the point of renal failure, a transplant is the only possible treatment, though dialysis can stabilise a patient. Transplantation means replacing the body's damaged tissue with a kidney from a donor; its existence and function normalised in the body by artificial immunosuppressants, constraining normal immune system responses, which would be to reject the transplanted tissue. Renal transplantation is not the end of a patient's medical problems; it carries immediate risks of surgery as well as long term health implications from taking immunosuppressant drugs to prevent rejection. However, both quality of life and life expectancy generally improve after organ transplantation compared to long term dialysis. Levels of immunosuppression are high immediately following surgery, but often reduce over time, as the immune system adjusts to the new organ. Markers between self and this newly implanted 'other' thus alter. The immune system itself is increasingly understood as a system in a state of constant dynamic internal responding (Haraway 1991, 218). Thus, at this cellular level, the categories of self and other increasingly blur. Alternative models of immunology and difference are possible, which stress instead the plasticity of biology and the flexibility of categorisations in organ-matching and perhaps the openness of the body to the other at a corporeal level.

However, as indicated above, within the organisational contexts of kidney transplantation, routine classificatory systems reify certain claims about bodily difference, and the potential for traversing borders between self and non-self, through the technologies of surgery and immunosuppression.

Blood and tissue matching form an important part of the practices of organ transplantation, but their current application gives rise to inequalities, which are often overlooked as they appear to reside in a static biology. As Gatens and others have argued, such characteristics appear consistent through repetition, the guidance of law and regulatory mechanisms (Gatens 1996; Diprose 2002). Yet they could be otherwise, and in many cases the imaginaries of self and other mobilised at the level of the cell, run counter to the ideas of personal generosity that inspire acts of donation. The need for critical examination of such imaginaries is thus acute. As Diprose suggests, 'attending to the politics of generosity is a matter of attending to the source of any potential transformation of social imaginaries that [...] continue to do damage to difference' (Diprose 2002, 172). Certain utilitarian calculations are essential in organ transplantation to protect recipients from harm. However, here there is no reason to privilege the architectures of organ transplantation around current HLA matching and blood typing when these lead to a burden of risk borne unequally by certain groups. Nevertheless, the current spatial organisation of transplantation services actually serves to accentuate the impact of these biological categorisations in inhibiting those individuals most at risk of kidney failure from receiving a donated organ that can be suitably accommodated. These unequal geographies of organ distribution are explored below in the final empirical section.

### ***Organizing the geographies of organ transplantation***

There are 28 renal transplant units in the UK, which manage local kidney transplant services, including local organ retrieval, local waiting lists and transplantation procedures (Rudge *et al* 2003). Some neighbouring transplant units now organise these services collectively, producing six semiformal local alliances for North Thames, South Thames, North of England, Trent, South West and Wales, and Scotland. Central support is provided by UK Transplant, a National Health Service special health authority. UK Transplant manages the national waiting list, determines the principles of organ allocation and organises transportation arrangements. There is thus a complex relationship between local and national scales in the geography of organ transplantation, which ties together the experience of possible donors and the fate of potential recipients within a local area, creating further variation in access to transplant according to local incidence of end-stage renal failure and the local imbalances between donor and patient blood and tissue types, whose significance is explored above.

Individual transplant units generally retain one kidney from each cadaveric donor they obtain, giving the second kidney to be allocated through national waiting lists. In practice more than 50% of kidneys donated are used locally (UKTSSA 2000). The national point scoring system used for



organ allocation not only weights the biological matching of organs discussed above, but also institutional exchange, calculating centrally allocated organs as a net loss to local transplant units, regardless of variations in local need (Cairns, undated). Thus, whilst the NHS carries out some 1400 renal transplants each year, the numbers of transplants per patient on the waiting list varies widely according to location.

The early development of kidney transplant services established a close link between donors and recipients, through pioneering units in which organs were retrieved for transplant and used within the same hospital. One team was responsible for both organ retrieval and the subsequent use of organs in transplantation, with emphasis on retrieving donated organs specifically for the treatment of patients under their care. Lack of knowledge about organ storage and transport encouraged this localisation of services, thus 'prior to organ preservation methods it was truly a local service for local people' (Cairns, undated). However, kidneys can now be kept safely on ice for around 24 hours and sometimes longer, although extended periods of storage are associated with poorer outcomes, and the same is not true for other organs like hearts and lungs. Further, greater understanding of the issues involved in organ matching has led to some widening of organ sharing schemes from this initially local basis through regional alliances. Yet, current practice still gives considerable importance to the local, such that locally retrieved organs are said to be owned by local centres. As Rudge *et al* suggest 'there is still an understandable feeling that the effort expended in organ retrieval should be "rewarded" by the local use of the organ' (2003, 1398). Thus even centrally allocated organs are weighted towards local use, and in the UK and elsewhere organs not used locally are felt to be 'stolen' from local transplant units (Roudot-Thoraval *et al* 2003, 1388).

The spatialisation of these institutional practices produces local inequalities in access to organ transplantation. As explained above, these are particularly evident for the ethnic minority communities of the North London alliance area<sup>6</sup>. Overall levels of organ retrieval in the North Thames area, at around 20 per million of the population, are generally average for the UK and very similar to organ donation levels south of the river (UK Transplant 2005). Yet there are local differences in the numbers and identity of those in need. North of the river over half of the patients on transplant waiting lists are from north London's Black and Asian community (Rudge *et al* 2004). Both communities suffer relatively high rates of renal failure, due to increased susceptibility to diabetes in South Asian populations and hypertension in the Black community<sup>7</sup>. Due to the spatial and biological practices of organ transplantation protocols, they are disadvantaged in gaining access to donated organs. This compares with the situation south of the river, where 66% of the people awaiting transplantation are white (Rudge *et al* 2004). South of the river waiting lists are shorter and patients are two to three times more likely to receive a

transplant compared to the north (Cairns, undated). In London, the artefactual nature of such differences is particularly striking as these areas are geographically congruent. Yet, in medical debate such disparities are rarely attributed to the outcomes of the organisation of transplantation practices, rather such inequalities are 'transcribed into the body as biological difference and expressed as 'risk' to be managed through the techniques of government' (Nguyen and Peschard 2003, 448). Consideration of these inequalities in terms of the justice of systems of organ distribution have to date been largely ignored, and attention focused instead on measures to reduce the risks associated with diabetes and to increase donation rates in Black and Asian communities.

Preventative techniques are certainly important and may be clinically effective in managing diabetes and reducing risks of kidney failure, if they are carried out with care to engage individuals and communities in dialogue about accessing healthcare (Randhawa 2003, 8). Education campaigns targeted at particular ethnic groups have also been a key part of government strategy to increase donation, including the South Asian campaign in February 1999 and Black campaigns in March 2002 and 2004, and there is preliminary evidence that such campaigns do increase rates of awareness. However, there are dangers that such high profile health campaigns focusing either on prevention or on increasing donation may in fact blame the communities already most at risk, whilst glossing over the way that risk also emerges as a consequence of the biology of tissue matching and biases in regionally organized allocation schemes. Crudely done, such techniques may further subject individuals and groups to forms of discrimination, legitimating stereotypes and reinforcing stigma (Hacking 2001), whilst ignoring the ways in 'which relations of power are embedded within the social organization of race' (Shim 2005, 427). This is especially critical in the development of more equitable outcomes for organ transplantation. Stereotypes may suggest a lack of cooperation from individuals in the British Asian community in the successful management of diabetes, which could reduce the likelihood of their being placed on transplant waiting lists (Gordon 2000); or, alternatively identify a lack of generosity or altruism in different sections of the black community (Alexander and Ashwini 1998), producing further mistrust of a medical system that already appears to marginalise such communities.

Less widespread is medical reflexivity about the nature of these categorisations in creating communities at risk, though such debates are beginning to emerge. Chris Rudge, medical director of UK Transplant, has written about the recent limited changes in allocation practice, allowing some O blood group kidneys to go to blood group B recipients, though he notes that still 'most O blood kidneys allocated to blood group B patients go to whites' (2003, 15). He concludes a further set of changes are necessary in the medical categorisation of human biological diversity

and the principles governing organ allocation to prevent outcomes discriminating against minority ethnic groups in the UK. Such measures include further changes to blood group rules, changing the definition of HLA antigens used for allocation and changing the relevance of HLA for some or all patients (Rudge 2003, 15). In the US, Churak (2005) has similarly argued that less importance should be placed on HLA matching, with Roberts and others going further in proposing that HLA matching should be totally eliminated for kidney transplantation (Roberts *et al* 2004). Furthermore, improvements in both organ storage and transportation, particularly for kidneys, are raising debates about the spatialisation of kidney transplantation. In particular, should kidneys continue to be seen as a local resource determined through local rates of donation, rather than as a national resource which could be transferred between regions according to levels of need (Rudge 2003)?

Such proposals alter the relevance of ideas about corporeal difference, apparently fixed in biological categorisation of the body or the socio-economic characteristics of a community, instead proposing a more probabilistic and fluid calculus of material, spatial and ethical connection underpinning justice in the allocation of organs. A focus on the ethical issues involved in the location and reconstruction of the transplanted patient's body can thus augment the considerable attention given to the ethics and actions of organ donation. Corporeal difference matters to organ transplantation as much as corporeal generosity and ensuring the equitable and fair operation of organ transplantation requires attention to the imaginaries of self and other underpinning both. The resulting models of intercorporeality enable a shift in biological understandings of human difference in organ transplantation further towards the imaginaries suggested by Haraway, in which 'human beings, like any other component or subsystem, must be localized in a system architecture whose basic modes of operation are probabilistic, statistical. No objects, spaces, or bodies are sacred in themselves' (1991, 212).

## **Conclusions**

This paper has explored the complex choreography of organ transplantation as it is enacted in London. I have explored the ethical tensions that exist between abstract notions of the good society and the proximate ethical openness to the other, suggesting both are necessary, but also necessarily surpassed in the relations of organ transplantation. Following Diprose, I have suggested the benefit of rethinking these tensions through an emphasis on intercorporeality, and moreover, through understanding both the material embodiment and biological mutability of corporeal difference. Empirically, I have explored both the responsiveness to others shaping the practices of organ donation, and the calculative practices framing the embodiment of difference

through techniques of blood typing, tissue matching and the organisation of organ transplantation, suggesting both are critical to understanding the patterning of organ exchange in London. In concluding, I want to argue their operation here offers insight into the importance of both biology and geography when considering the political implications of growing rates of tissue exchange elsewhere.

Organ transplantation thus emerges as a productive point from which to explore the way corporeality, justice and difference are constituted through the circulation of the fragmented body in late modernity (Martin 1992). Geography matters in this circulation of human tissue, as human body parts become relocalised in patient bodies. Geography plays a role not only in terms of the imagined national or regional communities that constitute populations for organ donation and transplantation, although these do matter and warrant attention, but also in the biological construction and spatial distribution of human difference. The link between bodily cartographies and spatial inequalities vary from organ to organ; thus an emphasis on different organs would result in different geographies. The relevant characteristics used to match organs differ, with close HLA matching essential in bone marrow donation, but of minimal or no relevance to liver and cardiothoracic transplantation (Rudge *et al* 2003). Corneas can be easily stored and circulated, whilst limiting extracorporeal time is crucial for the survival of transplanted lung material. When considering living donation, gender becomes critical, with more women acting as donors (Biller-Andorno 2002; Kayler *et al* 2002). A similar account of bone marrow, lung or living donation would therefore result in different geographies, and different concerns about justice in these exchanges would emerge. Further, in contexts where there is an alternative balance between the biological characteristics of the majority population and those communities in particular need, attention to inequalities in access to transplantation for the same organ may suggest different protocols. These questions are in addition to the increasing ethical attention given to the global sourcing of biological material for medical research and commerce (Waldby and Mitchell 2006). Yet, to date, they have been relatively overlooked, especially by social scientists. There is concern that to talk about human biological difference is to suggest biological determinism and fixity (Castree 2004) and thus to foreclose ethical debate. Yet here I have suggested it is precisely by attending to the production of corporeal difference that questions of justice in organ transplantation can be reopened.

Current debate in the UK around the ethics of organ transplantation has also largely focused on the ethics of organ donation, whether exploring new sources of organs, securing donation from more donors or preventing the commodification of organ donation. This emphasis is taken into attempts to address inequalities, through focusing on increasing donation from communities underrepresented or at most at risk of organ failure. This is also mirrored by the emphasis given

to the active body in constructing the affective ethical relation to the other within academic frameworks, including geography (Harrison 2005). The patient is the one for whom the ethical relation to others is most critical, but at the moment it is the site around which ethical debate is most limited. The figure of the patient awaiting transplantation and the reconstructed body of the transplant recipient perhaps seem unlikely starting points for a consideration of the ethics of organ transplantation. The ethical choices here appear constrained, the body of the patient already decentred, its embodiment dependent upon the intrusive routines of dialysis, in the long recovery from transplantation surgery, or in the bodily erosions of immunosuppression.

Yet the transplanted body already lives with the biological and ethical tensions implied by the remaking of the body in late modernity; enmeshed in an inescapable intercorporeality and intersubjectivity that now constitutes their bodily integrity. In understanding what it means to inhabit this body, phenomenological approaches to the body-as-being, as well as the tendencies to fragmentation and commodification in late modernity need to be brought together, bringing a realisation that whilst 'at times the fluidity of boundaries may threaten the integrity of the body and self; at others it may herald new and celebrated forms of transformation' (Sharp 2000, 290). Consideration of organ transplantation also thus has potential to inform discussions of human subjectivity emerging around the notion of post-human, as well as provide resource for questions raised by geographers about ethics at the boundaries of the human body (Anderson 2001; McCormack 2003; Whatmore 2004).

Debates about corporeal justice in tissue exchange reside not only in explorations of individual motivations to donate bodily material, in those moments of extraordinary generosity that punctuate everyday life, but also in questions about how the outcomes of such generosity may inscribe asymmetries based on the normalisation of certain kinds of difference. In both contexts, I have suggested such corporeal practices may precede reflective reasoning about the ethics and justice of organ transplantation, whether through the affective response of a donor to someone else in need, or in the routinized procedures of blood typing and tissue matching. In both cases these corporeal actions are central, but I want to argue that they are the prelude to, rather than the end of the questions about the ethical geographies of organ transplantation. Understanding the ethical dimensions to the uneven geographies of organ transplantation requires critical engagement with both donors and recipients, with ethics and justice, with the material bounding of bodies and their openness, with the history of biotechnological practices, as well as their futures. As Sharp suggests, 'ethical questioning frequently subsides as clinical technologies become normalised' (Sharp 2000, 317). Yet, to echo the words of Fox this is a 'tragic development' in the realm of organ transfer, and one that has already silenced too many ethical debates (Fox 1996, 260). Geography too is central to these ethical debates, for it is only through

tracing the intersection of ethical, corporeal and technological practices in situ that we can fully reflect on the operation of justice within the developing bioeconomy.

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## **Endnotes**

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<sup>1</sup> These words by Francisco Varela, describing his experience of liver transplantation and its aftermath, were published posthumously. His vivid observations detail the corporeal transformations transplantation involves and the challenges of learning to live a different kind of body, whose boundaries have been altered to incorporate both new intimacies and distances.

<sup>2</sup> Many cadaveric organ donors die from intracerebral haemorrhage or head injuries sustained in road traffic accidents; deaths from both these causes are generally declining in developed countries. At the same time, many of the diseases causing organ failure (e.g. diabetes related kidney failure) are age related and demand for organ transplants increases as populations age. Further, medical technology has further increased the eligible population for transplantation, to include small infants, people over eighty, patients with co-morbidities, or people seeking second or third transplants (Lock, 2002, 1407).

<sup>3</sup> I am grateful to Eric Laurier for framing this tension in this way, although he put it more eloquently than I have been able to.

<sup>4</sup> Historically, ethnic minority communities have been underrepresented as organ donors in the UK and elsewhere. Whilst 7.9% percent of the UK population can be said to be of ethnic minority origin, the proportion of ethnic minority donors was 3.7% in 2004 (UK Transplant 2005). However, the number of ethnic minority donors is growing, especially in relation to living donation, and nationally this disparity is smaller than local effects suggest. Religious, social and cultural reasons are most often cited as the cause of this underrepresentation, but inadequate approaches to procurement may play a more important role (Randhawa 2000).

<sup>5</sup> A person with type A blood can donate blood to a person with type A or type AB. A person with type B blood can donate blood to a person with type B or type AB. A person with type AB blood can donate blood to a person with type AB only. A person with type O blood can donate to anyone. A person with type A blood can receive blood from a person with type A or type O. A person with type B blood can receive blood from a person with type B or type O. A person with type AB blood can receive blood from anyone. A person with type O blood can only receive blood from a person with type O. These immunological relations are the same for kidney transplantation.

<sup>6</sup> Other areas of the UK with particularly low rates of transplants per patient on the waiting list include Birmingham and the Midlands (Cairns undated). For inequalities in other contexts see Morris and Monaco (2003) and Roudot-Thoraval et al (2003).

<sup>7</sup> This susceptibility is itself caused by a complex and indeterminate mix of genetic and socio-economic influences, with access to and experiences of healthcare services an additional factor.

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