Organ donation, genetics, race and culture

The making of a medical problem

Ciara Kierans and Jessie Cooper

Ciara Kierans is a medical anthropologist based in the Division of Public Health and Policy at the University of Liverpool. Her research interests include medical practice, inequality and the biopolitics of transplant technologies. Her email is c.kierans@liverpool.ac.uk. Jessie Cooper is a PhD student in the department of Public Health and Policy at the University of Liverpool. Her research interests include organ donation, minority ethnic health inequalities and the study of science and technology. Her email is j.c.cooper@liverpool.ac.uk.

A recent BBC Radio 4 programme, Blood for blood (2010), told the story of a young black man who died waiting for a bone marrow transplant. The programme emphasized the need for increased organ and blood donation from Britain’s black and Asian populations, and looked at why these groups are far less likely to come forward as donors than their white counterparts. Is it because of fear and suspicion of the medical profession; is it because of culture or religion; is it simply a lack of awareness? The programme asked: ‘Just what is behind the conundrum of Britain’s black and Asian population’s disinclination to volunteer as blood and organ donors?’

In this article we argue that this ‘conundrum’ acquires its force from a complex interweaving of biology/genetics and ethnicity/race within transplant medicine, an interweaving that both modifies and reinforces ideas of culture and responsibility. As we will show, low rates of organ donation among what are routinely referred to in healthcare domains as ‘black and minority ethnic’ (BME) ‘communities’ (here denoting people of African, Caribbean and South Asian backgrounds) are a problem that emerges within the professional matrix of UK transplant medicine and the organization of the health service to which it connects. At the same time, we show that, despite this, the problem is one that is increasingly viewed as the responsibility of those groups that transplant medicine collectively defines as being affected by it.

Our aim in what follows is to examine how ethnic populations have come to be problematized in relation to kidney donation. We will show that transplant medicine, in trying to work out a solution to this ‘problem’, has culturalized the issue by treating it as something that falls outside its own domain of practice and that, in doing so, it has entrenched racialized responsibility by mapping donor pools to cultural difference. We will also show how this problematic coupling of biology and ethnicity, two domains that have come to be treated as coextensive for the practical purposes of transplant medicine, works to deflect attempts to trace the complex genealogy of this ‘problem’.

We chart the materialization of this problematic in three stages. First, we examine how inequalities in access to kidney transplantation are translated into social and cultural distinctions, as low organ-donation rates are viewed through the lens of ethnic and racial classifications; secondly, we trace the construction of ethnic difference through transplant practice and policy, with a particular focus on blood and tissue matching, and how these practices interplay with understandings of ethnicity. Finally, we discuss the work of the discursive technology of health-promotion campaigns in placing the moral imperative on specified ethnic groups to solve this problem for themselves.

Kidney transplantation: Inequalities of access and the ‘problem’ of organ donation

In the UK, inequalities in access to renal-replacement therapies, in particular transplantation, are frequently broken down statistically in terms of ethnicity (Randhawa 2010). The problem is conventionally portrayed as follows:

- **BME groups** are three to four times more likely than their white British counterparts to die on the transplant waiting list, and only 4 per cent of deceased organ donors (NHSBT 2011).
- As blood and tissue matching requirements mean that transplant practices in the UK favour organ sharing within ethnic groupings, this translates into longer waits for suitable organs (Rudge et al. 2007).
- **As a result**, individuals from ‘South Asian’ and ‘African Caribbean’ ‘communities’ wait nearly twice as long for a kidney transplant than their white counterparts (1,368, 1,419 and 719 days respectively) (ODT 2008), and thus have a greatly reduced chance of receiving a transplant.

While responding effectively to health inequalities is of course important (Karlsen & Nazroo 2010), the relationship between low donation and ethnicity that is used to define this particular area of inequality is not, however, as straightforward as it might appear in light of the statistics. We might be tempted to conclude that low organ donation is a free-standing problem, that is, that BME groups simply donate less than their white British counterparts. However, we argue that this would be unwarranted: when we look at the matter in more detail, we see that low donation rates among certain populations have become a problem as a consequence of the specific ways in which
transplant medicine in the UK has been configured so as to recognize and respond to genetic sameness and difference by translating biological markers into membership of social and cultural groups.

Organizing accounts of the problem according to classificatory schemas that distinguish the white population from BME populations has been central to this translation process (Bowker & Star 1999). In order to be able to explore how such schemas have been made to bridge clinical, policy and public domains in response to organ-donation issues, we need to examine where and how the donation-rates problem itself has been in large part forged (i.e., within transplant medicine itself), as much as where and in what terms it has been fixed in place (i.e., through being linked to black and minority ethnic groups). One concern is that a focus on low organ-donation rates among BME groups has the effect of making the ‘engines’ involved in their formulation within transplant medicine recede from view (Hacking 2006). In what follows, we suggest some reasons why these engines should be brought back into the analytic light.

Marking the boundaries of race and ethnicity within transplant policy and practice

Anthropologists have tracked crucial developments in transplantation practices for much of the past 20 years, investigating the complex interplay among developments in transplant technology, a variety of social, cultural, political and economic arrangements, and the different kinds of relationships that link both the technologies and the arrangements at different moments in time (Das 2000; Cohen 2002; Hodge 1995; Lock 2001; Schepers-Hughes 2002; Sharp 2006). Anthropological research has thus followed the ways in which different publics have been progressively implicated in the ‘transplantation story’ (Cohen 2002), highlighting how transplant medicine has served to underwrite privilege and power by exposing already marginalized populations to new forms of biotechnical intervention grounded in new kinds of knowledge claim. Here, we want to explore such processes as they have played out in the context of British transplant medicine.

In the UK, organ-donation rates among BME populations have been restricted by an explicit orientation towards cadaveric donation and an ‘opt-in’ system of participation. For anyone classified as a ‘BME’ patient, these structural constraints on organ availability have been compounded by allocation policies that favour blood group and tissue, or HLA (human leukocyte antigen), matching (Davies 2006; Rudge et al. 2007). Until relatively recently, kidney recipients and their donors were strictly matched by blood group. While Group O is the most common blood type in the UK, 38 per cent of ‘Asian’ people are Group B, compared with 24 per cent of ‘black’ people and 10 per cent of ‘white’ people (Rudge et al. 2007). Although it is possible to allocate Group O organs to patients of any blood group, Group O recipients can only receive O organs. With allocations organized in the context of a mainly white (and therefore mainly Group O) donor pool, standard practice was to only offer recipients exact organ-blood group matches. This put ‘Asian’ patients waiting for transplant at a disadvantage (Davies 2006). It was not until 2002 that the matching of O organs to recipients with blood group B was permitted, in recognition of the inequalities the previous policy had created (Rudge et al. 2007).

The practice of tissue matching, in which the HLA groups -A, -B and -DR are used as the basis for identifying suitable donors, carries similar implications. As are present in all human bodies, and are essential to immune-system functioning and the maintenance of a healthy body. They work by recognizing foreign matter entering the body, and rejecting it through the production of antibodies. Foreign matter includes new organs – a central concern for transplantation. Because of this, the closer the HLA matches, the better the outcome. HLA as varied in humans and their distribution can be mapped to the geographic ‘origins’ of different populations, and to population ‘mixing’ (Marsh et al. 2000). However, in the transplant literature, what are highly complex variations are typically represented in sim-


Transplantation 89(4): 387-394.


plified, analytically unstable racial terms (Gordon 2002), with ‘black’ and ‘Asian’ populations routinely described as having different HLA distributions from ‘white’ groups.

Historically, adherence to HLA matching policies in the UK has meant a preference for transplanting organs between those from similar ethnic backgrounds – the effect being to divide donor pools not only along white/non-white lines, but also according to ascriptions of ethnic origin. While the US ended the practice of awarding priority points for HLA-A and HLA-B matching in kidney transplants in 1990 and 2005 respectively, due to rising concerns over inequalities for ‘black’ recipients and in response to advances in immunosuppression (Cecka 2007; Su et al. 2004), policy change has been much slower in the UK. However, alterations to the National Kidney Allocation criteria in 2006 did attempt to rebalance ‘equality of access with utility of transplant outcome’ (Johnson et al. 2010). The policy now is, where possible, to ‘default’ the HLA types less prevalent in the donor population to more common forms. For example, HLA-A36 is present in only 0.05 per cent of donors. In contrast, its more common form, HLA-A1, occurs in 18 per cent of the donor population. By effectively relabeling HLA-A36 as HLA-A1, the policy aims to give kidney patients with the former a better chance of receiving a ‘matched’ organ. The change is expected to increase transplant rates for ‘difficult-to-match patients’ (Johnson et al. 2010: 392), but it remains to be seen how it will work in practice.

However, such relaxations notwithstanding, the key point remains that the criteria that are used to determine who may be matched with whom treat membership of social and cultural groups (understood in terms of ‘race’ and ‘ethnicity’) as proxies for genetic makeup. Blood and tissue matching systems that draw distinctions between the genetically normal and the genetically marginal show that the mechanisms for drawing the boundaries of ethnicity remain tightly bound up with a politics of genetic proximity. Although matching criteria have been modified, the change has not precipitated a rethink of the broader categorizations of the entities across which matches are made. Rather, the change addresses inequalities between those groups already deemed to be close to each other in racial or ethnic terms. Thus we have a remodelling of ideas of genetic sameness and difference that in fact translates straight back into the racial and ethnic categories that shape our understanding of who is ‘like’ whom. The instability of such translation practices aside, what is of greatest interest here, and which we explore in more detail below, is how this turns transplant medicine into an important contemporary site for the production of cultural difference.

From society to cell and back again: Grounding organ donation as a moral imperative

In its attempts to accommodate ‘rare’ HLA types, transplant medicine has fallen back on the same classificatory schemas that were implicated in the creation of the inequalities that recent policy shifts were intended to address – schemas that are based, primarily, on the assumption of a ‘natural’ basis for cultural differences. We suggest that this assumption has two reciprocal components: the claim that biological differences can be mapped to racial or ethnic categories; and the claim that these categories thus pick out real, sociobiologically distinct populations. We want to examine how these claims work in complementary ways to reinforce each other.

The idea that biological differences are conflated with race and ethnicity in this medical context has been the subject of much discussion. Writing specifically about the indexing of race to HLA matching in transplant medicine, Gordon highlights several issues. These include the largely arbitrary character of racial categorizations based on purportedly shared skin colour (‘black’, ‘white’), shared geographic location (‘Asian’), language (‘Hispanic’) or religion (‘Jewish’); the scientific bias that sees ‘white’ HLA types as the standard against which ‘rare’ ‘black’ HLA types are identified; the failure to account for racial mixing in the indexing of HLA types, that is, the fact that people of mixed heritage are not represented in the standard schemas, which leads to the reification of racial difference; and the failure to acknowledge that developments in immunosuppressants make HLA (mis)matches increasingly irrelevant (Gordon 2002: 136).

Though writing nearly 10 years ago for a US audience, Gordon’s work speaks directly to the UK context today. Empirical studies of the ways in which biomedical researchers construct, classify, standardize and analyze race and ethnicity suggest that these concepts are in increasingly wide use, despite the absence of any recognized way of defining, explaining or operationalizing them in accordance with such researchers’ own criteria of objectivity (for recent reviews see Lee 2009; Smart et al. 2008, as well as Rose 2007). Such racial and ethnic categoriza-
tion is not simply an issue of ontological and epistemological (in)coherence, as this classificatory apparatus has serious real-life effects on those subject to it.

Drawing on the work of Hacking, Duster (2005) describes the work of ‘feedback loops’ in such situations where social practices have biological effects, effects which in turn further shape the social practices that gave rise to them. Following Duster, Avera has traced interactions in the context of the search for bone-marrow donors in South Africa. She describes a similar sequential scenario to that found in the UK: HLA types are used to define the boundaries between different populations → patients are more likely to find matches within the population they have been defined as ‘belonging’ to → patients from these groups don’t donate → this generates unequal health outcomes for those Africans, which are immediately cast in racial or ethnic terms → health-promotion campaigns are put in place to increase the number of ‘black’, ‘coloured’ and ‘Asian’ donors, even though it may make little sense in biological terms to divide populations in this way (Avera 2009: 180–181).

In identifying this cyclical movement of unshifting classifications across a shifting biosocial terrain, Avera shines a light on the complex interrelationship between the biologization of race and ethnicity and the politics of health-care rationing in post-apartheid South Africa. Though identity politics are set against a different historical and social backdrop in the UK, the consequences of such cycles are not dissimilar. As in South Africa, those subject to this classificatory two-step are, as a result, increasingly being treated as bearing a general responsibility towards those with whom they are deemed to share a common ethnic identity.

In recent years, the UK has seen a stepping-up of health-promotion initiatives specifically aimed at members of ‘black’ and ‘South Asian’ ‘communities’. These have been characterized by hard-hitting media campaigns that frame organ donation as a moral imperative. They also reflect an expanding research literature that traces the genealogy of low donation rates to cultural differences clustered within religious practices, beliefs, constructions of the body, knowledge, language and so on (Exley et al. 1996; Hayward & Madill 2003; Alkhawari et al. 2005; Razaq & Sajad 2007).

Public-health initiatives in this area began with the ABLE project in 2001, which sought to ‘raise the profile’ of organ donation among ‘South Asian’ and ‘African Caribbean’ groups in Leicester and West London. With backing from the Department of Health, similar initiatives have since then been building momentum through poster campaigns, street plays and faith ‘road shows’ in cities with large ethnic populations (DH 2003; DH 2004; ODT 2008) (see figs 1-6). Examples include the 2007 NHS Blood and Transplant service’s ‘Can we count on you?’ campaign, in which ‘black’ and ‘South Asian’ comedians such as Nina Wadia and Curtis Walker promoted the ‘gift of life’. In 2009, the message of ethnic-group responsibility was reinforced by the targeting of ‘black’ and ‘South Asian’ populations as part of the ‘Prove it’ campaign. In a not-so-subtle reformulation of the campaign’s general message, which was that individuals should ‘prove’ their belief in organ donation by joining the donor register, the BME campaigns focused on collectives first and individuals second, urging people to help their ‘communities’ by registering as organ donors.

These and other campaigns have served to amplify the idea that donation is the collective responsibility of biologically, socially and culturally distinct and distinguishable communities. Taking their lead from transplant medicine’s translation of the genetic bases of blood and tissue matching into ethnic classifications, these campaigns form part of the dynamic production of cultural difference within and across different domains of contemporary British social life.

Conclusion

What we hope emerges from this discussion is a recognition that the problem of ‘low donation rates among BME [ethnic minority] groups’ ca not be understood in isolation from the practices of transplant medicine itself. We must examine the various ways in which the categories of ‘patient’ and ‘donor’ have been worked up and refined in problematic ways over time, with conceptual connections being drawn between biological and cultural differences in response to circumstances such as changes in organ-donation targets and changes to the organization of the transplant services within which those targets are pursued; we must also carefully scrutinize the ways in which these categories and connections are presented to the various publics who are defined by them.

Most troublingly for us, these populations defined by these classificatory technologies may have no significance in cultural or even genetic terms, as individuals who have little in common are grouped into the same awkward bi-cultural space. Given this, it seems inequitable to treat such individuals as the solution to problems which have emerged from within transplant medicine itself. The question posed at the beginning of this article – ‘What is behind the conundrum of Britain’s black and Asian population’s disinclination to volunteer as blood and organ donors?’ – resonates very differently once we see the extent to which this ethnic responsibility is externally ascribed.

Whether or not one takes a particular stance on such issues, there can be little doubt that organ transplantation operates as a major contemporary site for the production of difference, and that in transplant medicine’s own attempts to find a solution to the problems and inequalities that have arisen, we can discern a further entrenchment of such difference. This reflects a wider blurring of the boundaries between race, ethnicity and genetics that can be seen today at work across ever-expanding biopolitical terrains (Smart et al. 2008). Given this, it is of critical importance that anthropologists continue to intervene in debates on these and related issues.