

A photograph of a kitchen area. In the foreground, a wooden table holds several items: a large silver pot, a smaller orange pot with a black lid, and a brown bowl. Underneath the table, a large metal basin is filled with laundry, including a white shirt and a red garment. On the table behind it, there is a blue thermos, a green bottle, and other kitchen items. The background wall is a textured, reddish-brown color with some green paint visible on the right side. The floor is made of light-colored tiles.

CRITICAL MEDICAL ANTHROPOLOGY

Perspectives in and from Latin America

Edited by Jennie Gamlin, Sahra Gibbon,
Paola M. Sesia and Lina Berrio

EMBODYING INEQUALITIES perspectives from
medical anthropology

 **UCLPRESS**

Critical Medical Anthropology

EMBODYING INEQUALITIES: PERSPECTIVES FROM MEDICAL
ANTHROPOLOGY

Series Editors

Sahra Gibbon, UCL Anthropology

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This series charts diverse anthropological engagements with the changing dynamics of health and wellbeing in local and global contexts. It includes ethnographic and theoretical works that explore the different ways in which inequalities pervade our bodies. The series offers novel contributions often neglected by classical and contemporary publications that draw on public, applied, activist, cross-disciplinary and engaged anthropological methods, as well as in-depth writings from the field. It specifically seeks to showcase new and emerging health issues that are the products of unequal global development.

Critical Medical Anthropology

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Sesia and Lina Berrio

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7

The ethno-racial basis of chronic diseases: Rethinking race and ethnicity from a critical epidemiological perspective

Melania Calestani and Laura Montesi

An engaging five-day workshop on critical medical anthropology organised by CIESAS and UCL was coming to an end. It was a sunny Friday in January and the Central Valleys of Oaxaca promised a spectacle of beauty and historical heritage to a group of anthropologists. We were about to visit Monte Albán, an archaeological site, testament to the Zapotec civilisation and its power over the region. We were still riding the wave of the workshop debates when we met our tourist guide. We introduced ourselves to him and when Laura said that she worked with diabetes patients, the guide observed that diabetes is the largest epidemic in Mexico, caused by an unhealthy food system and by wrong eating behaviours triggering defective genes: ‘We, Mexicans, are genetically predisposed to diabetes.’

We looked at each other and immediately understood that we were thinking along the same lines. We had been talking about racialised societies and health during the last few days, having found parallels between our respective works on social representations of diabetes in Mexico, and on chronic kidney disease and kidney transplant listing in the UK. We were wondering about the growing explanatory power of genetic aetiologies in health discourses and about how and why certain social groups, often detected on the basis of ethno-racial differences, end up being described by researchers, physicians and public health workers as genetically prone to many diseases and conditions, including type 2 diabetes (hereafter diabetes) and chronic kidney disease. We had also

discussed the ways in which such representations and medical and scientific practices become part of the public imaginary, intersecting with popular notions of race, ethnicity, fitness and weakness.

In the 1990s, Lippman introduced the term 'geneticisation' to describe 'an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviours and physiological variations defined, at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health' (1991: 19).

The term geneticisation is resonant with 'medicalisation', which indicates processes 'by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses and disorders' (Conrad 1992: 209). Although medicalisation can have beneficial impacts, it has traditionally been seen with suspicion by medical anthropologists in light of the tendency by societies to label deviance and use medicine as a means of control, punishment or marginalisation. Finkler (2000) expressed concern about the mushrooming growth of beliefs in genetic inheritance because they are instrumental to the individualisation of health problems and the technification of solutions. Kinship and ethno-racial genetic explanations and solutions sit easily within the current global neoliberal climate and the growing 'economisation' of 'heretofore noneconomic spheres and activities' (Brown 2015: 17). As Marks (2013) highlights, genetic and genomic research projects usually promise solutions, mainly diagnostic tools, which are easily privatised (2013: 257). This raises more than one question about the interests behind scientific research, an issue that is becoming of paramount relevance as public funds diminish and corporations are increasingly being subsidised by state governments to promote research and provide health services (Clarke et al. 2003: 167).

To disentangle how political and economic forces shape scientific research and medical practice, we draw on Breilh's critical epidemiology (CE), which serves a double purpose: it supersedes the limits of conventional epidemiology with its multi-causal (yet still lineal) model of disease and rethinks 'health as a complex, multidimensional object, submitted to a dialectical process of determination' (Breilh 2008: 747). By dissecting two case studies, social representations of diabetes in Mexico and ethnic minorities in transplant medicine in the UK, we analyse how science, considered in its broadest sense (as it is practised and communicated), reinvents race and ethnicity and can inadvertently contribute to deepening racialised inequalities in stratified societies. We examine how this over-emphasis on ethno-racial genetic aetiologies in chronic diseases

diverts attention and resources from more important influences on populations' health, such as embedded health inequalities exacerbated by colonial pasts, neoliberal capitalism and institutionalised racism. In line with recent discussions in the anthropology of epigenetics (Lock 2013; Thayer and Non 2015), we draw on Kuzawa and Sweet's work to suggest how 'social influences can become embodied, having durable and even transgenerational influences' (2009: 2). Ethno-racial differences in disease patterns are then embedded in pathways of power, characterised by a somatisation of racial tensions (Guthman 2014) that profoundly affects local biologies (Lock and Nguyen 2010). We argue that CE permits us to move some of these discussions forward in specific ways: for instance, identifying how biologies are moulded within their larger ecological contexts, or webs of relationships, and how social systems, ways of life and health are inextricably linked.

Ethno-racial discourses and health

Concepts of race and ethnicity are among the most controversial and contentious classifications in our social and scientific landscapes. In health research, genotypes have often been associated with ethnic/cultural identity, showing poor consistency in terminology and reinforcing ethno-racial stereotypes (Sheldon and Parker 1992). Race and ethnicity have then become mere statistical categories, denying the complex interactions among political-economic processes, lived experiences, societal ways of living and human biologies (Goodman 2000; Krieger 2001).

In this chapter, rather than engaging with race as a physical or phenotypical category, we draw on Gilroy's and Ahmad's understandings of racialisation. The former talks about it as the existence and hegemony of 'raciological' thinking that affects the world and provides differential access to resources for members of different groups (Gilroy 2005: 39), while the latter conceptualises it as a process that 'assumes that "race" is the primary, natural, and neutral means of categorization, and that the groups are distinct also in behavioural characteristics, which result from their race' (Ahmad 1993: 18).

We argue that race and ethnicity are polysemic terms, acquiring a plurality of meanings according to the (inter)national and local circumstances in which they are employed. Moreover, their use responds to ideological and political propositions grounded in power unbalances. The rise of the race concept in the fifteenth century as part of the European conquest and as a means of legitimisation (Smedley 1998; Ahmad and Bradby 2007) reveals its political and colonial genesis. Historically, the

involvement of health within racial representations has been instrumental, not incidental (Keval 2016). Arguments on health and hygiene were (and still are) racially coded and have been central to (post-)colonial practices of inclusion and exclusion (Mawani 2003; Shah 2001; Gilman 1988). Nineteenth-century health and hygiene movements were concerned with maintaining the boundaries between populations.¹

In tandem with biological depictions of race, ethno-racial differences in health have also been explained in terms of cultural inadequacies, mobilising essentialised notions of 'culture' (Ahmad 1993). According to Menéndez (2001), since the 1950s, we have witnessed an expansion of biological understandings of everyday life and the rise of the concept of lifestyle as a signifier for (un)healthy behaviour, working as a mechanism of differentiation, stigmatisation and subalternisation. Likewise, in health research, racial and ethnic-group comparisons of health indices frequently are presented without stratifying or adjusting for socio-economic conditions that could affect the interpretation of the data (Lillie-Blanton and Laveist 1996).

CE provides a criticism of dominant biomedical and epidemiological explanations of health and illness, unveiling their reductive biological orientation and shedding light on how large-scale political economic processes 'get under the skin' (Leatherman and Goodman 2011): for instance, how racism and chronic stress affect local biologies through processes of somatisation (Kuzawa and Sweet 2009) or how the ever-growing reproduction of capital under market rules reduces the spaces 'for the fulfilment of life and health' (Breilh 2008: 747).

Amerindian genes and the Mexican susceptibility to diabetes

Diabetes in Mexico has become a top health, social and economic concern. Its prevalence rate ranges between 9.2 and 14 per cent, making it one of the highest worldwide (world prevalence in 2014 was 8.5 per cent of adults aged 18 and older (WHO 2016)) and the highest among Organisation for Economic Cooperation and Development (OECD) member countries (OECD 2015). In only 30 years (1980–2010) diabetes has gone from being the ninth to the second cause of death in the Mexican general population (Secretaría de Salud 2012: 38). People with diabetes often have to endure suffering and pain due to severe disability. According to a recent report (Secretaría de Salud 2015: 20), in 2013, 30 million disability-adjusted life years were lost, especially among two age groups, adults between 35 and 60 years of age and the over-80s. The statistics are indisputable. What is questionable is how this epidemiological panorama

is portrayed and addressed by a number of institutional actors, from state representatives and public health workers to researchers and journalists.

State representatives say the diabetes epidemic is a national threat. The Mexican ex-Minister of Health, Mercedes Juan, described diabetes as a 'health emergency [...] capable of jeopardising [Mexico's] viability as a nation' (Secretaría de Salud 2013: 7). In 2013, President Peña Nieto launched the National Strategy for the Prevention and Control of Overweight, Obesity and Diabetes, designed to promote behavioural changes, increase epidemiological surveillance, make health services more accessible and regulate the sale of high-calorie food and beverage products. The strategy, contained in a 105-page document, showed a limited understanding of the role that social inequalities play in disease distribution. While launching his national strategy, President Peña expressed the need for citizens to be 'informed, active and healthy' and lamented the fact that the Mexican population 'suffers from overweight problems and lacks healthy habits'. He exhorted people to interrupt their sitting time with at least one hour of exercise per day (Presidencia de la República 2013). Discourses like these tend to frame diabetes not only as a Mexican problem but also as one that reflects *Mexicanness*, constructed around stereotypes of laziness, a propensity to over-eat and focus on the present, and the lack of a culture of prevention. In conjunction with behavioural/cultural explanations, the diabetes epidemic is also narrated in terms of ethno-racial predisposition, due to genetic variations that are 'exclusive of *mestizo* populations, whose *Amerindian* component is under study' (Secretaría de Salud 2013: 77; our emphasis). Although no national diabetes indicators by 'race' and/or ethnicity are available,² Mexico has taken a leading role in genomic research, searching for 'a genomic haplotype commonly found in Mexican and other Latin American *mestizo* populations and linked to *indigenous genetic ancestry*' (Saldaña-Tejeda and Wade 2018: 2733; our emphasis).

This scientific endeavour has spurred public interest and widespread media coverage, particularly after the foundation of the Instituto Nacional de Medicina Genómica (INMEGEN) in 2004 and the start of the Mexican Populations Genomic Diversity Project in 2005. In 2008, scientists at the National Autonomous University of Mexico (UNAM) inaugurated the Genoteca Indígena, a project that aims to form a DNA bank from Mexican native populations. The objective is to know more about frequent diseases in Mexico, particularly diabetes, 'from their origin' (El Informador 2012). The investigation aims to detect the genetic polymorphisms associated with diabetes, which are said to be more frequent among indigenous peoples and, consequently, in Mexicans, depicted as a

mestizo population with a high percentage of indigenous genetic ancestry (El Informador 2012).

Interviews and reports on the Genoteca Indígena released in Mexican media indicate that researchers give credit to James Neel's thrifty gene hypothesis,³ although it remains unexplained in what ways Mexican indigenous peoples might have had a more nomadic life in the past than other populations. The biochemist leading the Genoteca Indígena project argues: 'In the past, more than 6,000 years ago, when communities were nomadic, Mexican genetics allowed [Mexicans] to survive. This genetic make-up is today fattening them and making sugars harmful' (Menjívar Iraheta 2009).

Even though Neel's thrifty genotype is still an unproven hypothesis, its explanatory power has been astonishingly great (Fee 2006: 2990), as it provides an appealing answer to the high prevalence of diabetes and obesity among disparate ethnic groups, from the Pima of Arizona and the Oji-Cree of Ontario (Hegele et al. 1999) to Samoans (Minster et al. 2016) and Mexicans. Montoya (2011) underscores the fact that Neel's hypothesis remains elusive in at least two ways: the hypothesis rests upon disputable assertions about feast and famine cycles among populations, and the population groups deemed diabetes-prone are not biological but social groups (2011: 48). Thus, both minority groups and large national populations (but ones with strong links with indigeneity) end up lumped together because they share genetic 'ancestry'. In this regard, Ferreira and Lang ask: 'How can a genetic cause be applied across the borders of 300 million people divided into thousands of ethnic groups, living across the planet under strikingly different circumstances? What do these people have in common? Their genes?' (2006: 12).

Montoya (2011) suggests that the targeting of certain bodies as suitable DNA donors for research is made possible by the colonial practices that differentiated those bodies from the dominant ones in the first place, and confined them into poor neighbourhoods, plagued by poverty, neglect and therefore an excessive burden of disease. In the case of Mexico, it becomes clear that the reasoning by which (a) Mexicans are mestizos, (b) their indigenous genetic component is troublesome and (c) contemporary indigenous people should be targeted for DNA sampling is the direct result of Mexico's (post-)colonial history, which created the entire concept of the *indio* (Bonfil Batalla 1972), used it to place *indios* ('Indians') at the bottom of society, and pushed them into regions of refuge (Aguirre Beltrán 1967).

As several scholars have argued, *mestizaje* heralded 'the mixing of races rather than the separation of them, but without questioning the privilege of whiteness' (Saldívar 2014: 94). The proposition 'the whiter,

the better' has structured Mexican racism, which works through 'distributed intensities' (Moreno Figueroa 2010) of white capital. The proposition 'the whiter, the less predisposed to diabetes', which seems implicit in the current scientific search for ancestral genetic backgrounds, sounds like the contemporary rendering of the Mexican *mestizaje* ideology. Indeed, the genomic enterprise – albeit not purposefully – articulates and is infused with racialised meanings that reflect cultural understandings of nationhood and alterity. As Wade et al. have pointed out:

Racialized categories are implied in the use of concepts of genetic ancestry – usually talked of in terms of African, European, and Amerindian components. For the geneticists, genetic ancestry (understood as very specific sets of genetic markers) is distinct from race (which they understood as a set of coherent biological-bodily types). But the constant reference to African, European, and Amerindian ancestries evokes familiar racial meanings.

(Wade et al. 2014: 497–8)

The Genoteca Indígena substantiates the idea of Mexicans as *mestizos* with a double genetic inheritance (the black component is largely overlooked) and of native peoples as the authentic, 'original' key to Mexican biology. Consistent with this perspective, Mexican media explain the Genoteca Indígena project in the following way: 'Indigenous genes: solution to diabetes' (Ocampo 2013). The article details how:

Specialists agree that apart from promoting dietary and hygienic measures in the population, *the only way to know the origin, complications and therapeutic management of diabetes, and to develop diagnostic, prognostic and control methodologies, is to identify its hereditary components.*

(Ocampo 2013; our emphasis)

In order to identify those hereditary components, researchers extract DNA from indigenous groups, the more 'isolated' the better. The logic is that isolated groups, being genetically more homogeneous, make for a good case study. One study on diabetes susceptibility, for example, found an association of genetic polymorphisms with the development of type 2 diabetes in Mayas (Lara-Riegos et al. 2015). Researchers selected participants who 'confirmed a Maya origin, with parents and grandparents born in the same communities, speak their native language and preserve traditional folks' (Lara-Riegos et al. 2015: 69).

It is interesting to note that cultural and ethnic qualities were used as indicators of genetic ancestry. The choice of taking DNA from this ethnic group was justified on the grounds that Mayas are said to have little contribution of continental ancestry (Silva-Zolezzi et al. 2009, cited in Lara-Riegos et al. 2015: 69) and that the region they live in presents a high prevalence of diabetes. The blood samples were later genotyped to confirm Amerindian ancestry. The search for 'isolated' groups recalls ideas of 'purity', which anthropological and ethno-historical scholarship has often demonstrated to be at best imprecise and, at worst, pernicious (Kuper 1988). Thus the isolation of the Mayas of south-east Mexico appears at odds with past and present history. The historical record, for example, demonstrates intense black–Maya relations in Yucatán (Lutz and Restall 2005: 189). Although mixing was much more common in urban than in rural areas, by the eighteenth century (often informal) miscegenation had become commonplace in Yucatán, especially 'between enslaved African men and native or mixed-race women and, to a lesser extent, between female slaves and Spaniards' (Lutz and Restall 2005: 193). Although the study mentions the importance of considering local environmental factors, lifestyles and modes of subsistence (Lara-Riegos et al. 2015: 73), virtually nothing is said about this region's social history and the processes of adaptation to changing political and environmental circumstances. Indigeneity appears, once more, as a biocultural unity (with specific genetic and linguistic/cultural markers) but socially and historically decontextualised.

Questions remain about how these ethno-racial representations of morbidity and alterity are appropriated by dominant and non-dominant sectors of society, and how indigenous peoples themselves make sense of diabetes as the institutions of science scrutinise their bodies.

In her ethnographic experience with Oaxacans from Santa Maria Atzompa, Everett (2011) found that the genetic aetiological accounts circulating in Mexico had not made inroads at the household level and genetic susceptibility was not part of the explanatory models of people with diabetes. A similar finding comes from Laura's ethnographic research among an ethnic minority in southern Oaxaca. During her year of fieldwork, nobody ever mentioned genetic susceptibility as depending on their ethnic belonging. When they were asked why they thought they got diabetes, they usually referred to strong emotions related to stressful life circumstances. Diabetes narratives revealed stories of poverty, unemployment, classism and physical and emotional abuse, phenomena that thrive in contexts where structural violence silently permeates social relations.

Cristina, a woman in her fifties, had been diagnosed with diabetes 18 years earlier. One year before Laura met her, she had started experiencing diabetes complications and had had a toe amputated. When asked why she got diabetes, she said: 'I got diabetes from a *susto* [fright], a *coraje* [anger] I had when I was young. My father was a prominent political figure and they killed him. I was only 25, the oldest among my siblings and I had to take care of them. That's how I got diabetes.' Cristina explained that her father's killing hit her hard and that from that moment her life had been punctuated by several illness episodes. Moreover, diabetes affected her financially as she resorted to private medical doctors and expensive medications.

Pancho, a teacher living with diabetes for more than 15 years, was emaciated, unable to stand and on dialysis when Laura met him. He explained that his diabetes was due to a terrible *susto* he had in Mexico City when he took part in a street protest with his fellow teachers: 'I was part of the struggle of the teachers' union and during the protest we were attacked by riot policemen. They trampled on my *compañeros* and when I saw them falling I got terribly scared.' He reacted so strongly to the violence he witnessed at the hands of the Mexican police, he said, that his blood turned sweet.

When research participants were asked about the great numbers of diabetics in their community, they talked about environmental and dietary change, culture loss and social disruption (Montesi 2017). Of the 38 people in Laura's sample, only four, all males (between 39 and 52 years of age), literate and with a relatively high socio-economic position (two had been in the past high-ranking officials in the municipality, one was a teacher and one co-owned a pharmacy) mentioned heredity as a possible causative factor. In these cases, genetics was related to family history, not to ethnic belonging. When she purposefully inquired about genetic susceptibility to diabetes, people denied such a predisposition, as the words of Anita, 55 years old and diagnosed with diabetes 18 years earlier, demonstrate: 'I don't think it's a matter of race because at the time of my grandmother and of my great-grandparents nobody had diabetes. Today everyone has diabetes, including the young.' Most of the people with diabetes Laura worked with were first-generation diabetics, with vivid memories of healthy parents.

Aetiological accounts may change in the future as people with diabetes begin to have memories of disease in their own families and genetic explanations become more commonplace. Research into how younger generations understand diabetes aetiology and ethno-racial health outcomes is critical and urgent. As our opening anecdote with

the tourist guide shows, the Mexican susceptibility hypothesis is already being appropriated by urban people with greater access to media. Moreover, the genetic link of Mexicans (and 'Latinos' or 'Hispanos' more broadly) to diabetes has also found coverage in the US, strengthening racist attitudes towards Mexicans, as this comment in a racist website demonstrates:

I have commented several times here re. the high cost of diabetes to a society. Diabetics' healthcare costs 2½ times the amount of non-diabetic healthcare. Diabetes is the cause of most blindness, amputations, kidney dialysis, & have 4x the chance of heart attack and stroke. A few years ago the *New York Times* had a week-long series of articles re. *Latinos' high rate of the disease*. *NYT* claimed that 50% of them have it or will develop it! And they brought up the issue of their diets, and lack of exercise. I also heard top US health officials express their concern over the coming diabetes epidemic *as we become a more Hispanic nation – and where the \$\$\$\$\$\$\$ is going to come from?*

(SentryattheGate, comment on American Renaissance website, our emphasis)

In the current climate of white supremacy and rising numbers of hate crimes, it becomes imperative to look at the potentially stigmatising effects that racialising scientific narratives have on ethnic minorities.

Ethno-racial transplant medicine in the UK

Worldwide, increasing numbers of patients are affected by chronic kidney disease (CKD) and end-stage renal disease (ESRD), and are putting a substantial burden on global healthcare resources. This is due to the growing numbers of elderly people and the global pandemic of type 2 diabetes. In the UK, the annual incidence of ESRD has doubled over the past two decades to reach about 100 new patients per million of population (El Nahas and Bello 2005); this figure is expected to rise at an annual rate of 5–8 per cent (Lysaght 2002). 'Racial factors' have been described as playing a role in the susceptibility to CKD, as shown by the high prevalence of CKD related to hypertension, diabetes or both among BAME (black, Asian and minority ethnic) individuals in the UK (El Nahas and Bello 2005).

The National Institute for Health and Care Excellence (NICE) guidelines have identified higher-risk groups for diabetes, such as those aged 25–39 and of South Asian, Chinese, African-Caribbean or black

African descent (NICE 2017). In a research review from 2002, the UK's Department of Health and the Medical Research Council attempted to address the rise of diabetes cases in minority communities, suggesting the implementation of innovative lifestyle changes, such as, for instance, working with Indian restaurants to provide low-fat alternatives on their menus (Department of Health 2002). Embedded in this health strategy lay the assumption that there was something 'faulty' within the minorities' diets which required a fix, reinforcing simplistic notions of minority culture and/or identity. This has also been promoted through the work of national network organisations such as Diabetes UK (Keval 2016).

Minority communities have been represented over the years as being at higher risk of getting diabetes and hence of experiencing related complications, such as kidney failure. The NHS website on organ donations and ethnicity states that patients from BAME communities are more likely to need an organ transplant than the rest of the population as they are more susceptible to illnesses such as diabetes and hypertension, which may result in organ failure and the need for a transplant. ESRD or chronic renal failure is permanent kidney failure (Gordon 2001; Sehgal 1999) and is treated by one of three forms of renal replacement therapy: haemodialysis (mainly done in hospitals), peritoneal dialysis (done usually at home) and kidney transplantation (Gordon 2001). Dialysis is the clinical purification of blood and thus it is a substitute for the normal function of the kidney. Dialysis is generally considered more expensive than kidney transplantation (Laupacis et al. 1996; Yen et al. 2004). In the foreword to a report on the Transplant Summit of 2006, the All-Party Parliamentary Kidney Group in the UK states that: 'Transplantation is better for the patient. Furthermore, transplantation is cheaper than dialysis. Increasing transplantation rates would therefore be an all-round win' (All-Party Parliamentary Kidney Group 2006: 3).

This demonstrates how transplantation is depicted by modern biomedicine as the optimum treatment for end-of-stage kidney failure and as the cheapest option for healthcare systems. This solution to renal failure is represented as the best option not only for patients in terms of their quality of life but also for the rest of society in terms of expenditure on healthcare. However, despite this call for increasing the number of transplants, there is a shortage of organs, from living or cadaveric donors, across different countries. The 2006 Transplant Summit report also mentions that the UK currently has one of the lowest donation and transplantation rates amongst European countries. They continue by saying that this is considered to be partly because of differences in health service capacity and structure: for instance, the report cites Spain as an example, describing

it as having almost three times as many intensive care unit beds (from where donor organs are often retrieved) compared to the UK. In addition, the report lists ‘procedural and attitudinal short-comings’ as possible reasons for the low rate of donations. The text continues by adding that:

Innovative solutions must be found to maximise the opportunities for donation within the UK so that we can bridge the gap between accelerating demand and the declining supply of suitable organs available for transplantation. A national campaign should be launched to encourage potential donors to join the organ donor register. This should make clear to potential donors what the consequence of low donation rates are; not only for those individuals in need of an organ, but for the NHS as a whole.

(All-Party Parliamentary Kidney Group 2006: 7)

As a consequence, a public campaign to increase donations in the UK has been developed in the last decade. In the case of kidney transplantation, the campaign aims particularly to raise the number of living donations. It is common to find news aimed at increasing donations in the media. For instance, on 20 December 2016, the London *Evening Standard* published an article titled ‘Metropolitan police officer gives Christmas gift of life to sister by donating a kidney’. Interestingly, this is the story of two white siblings. The transplantation happened in a hospital in affluent Hampstead (north London). The article ends with a comment by one of the consultants, saying, ‘If you know someone who needs an organ I would urge you to think about being a donor’. Readers then are redirected to the NHS website for further information.

Similarly, the charity Give a Kidney promotes non-directed (also known as altruistic) donation in the UK. More than 100 people donated in this way in the UK in both 2013/14 and 2014/15, and the numbers are expected to keep on track at more than 100 per year. Research on non-directed living kidney donations has shown that the anonymity of the donor and recipient appears to be seen as a benefit, freeing recipients from the obligations of the gift (Bailey et al. 2016).

However, medical anthropology research in Spain (Sánchez Hövel 2014) has shown that public campaigns describe living donations as ‘altruistic’ and ‘supportive/caring’, not taking into consideration the long-term holistic wellbeing of living donors and the regret of having donated a kidney on the part of living donors when their health deteriorates later in life. Further research is therefore needed to establish the long-term consequences of living donations for living donors.

Undoubtedly, linking donation with gift-giving, altruism and self-sacrifice creates a 'medical duty obligating both individuals and collectivities' (Kierans and Cooper 2013: 222) to act as donors. Research has shown that possible organ donors have different degrees of duty according to the racial and/or ethnic categories they are thought to belong to (Avera 2009; Gordon 2002; Kierans and Cooper 2011). This classificatory system is based on the assumption that some genetically inherited human leukocyte antigen (HLA) types as well as blood groups appear in certain 'ethnic' populations more commonly than others, meaning that patients may be more likely to find a transplant match with someone in the same 'ethnic' group (Avera 2009). Therefore, individuals and collectivities thought to belong to certain ethnic or racial categories receive greater attention in terms of health campaigns aimed at increasing organ donation. This is the case of ethnic minorities in the UK, which are often urged to discuss organ donation (Siddique and Morris 2016).

For instance, in September 2017 the NHS had a specific website on organ donations and ethnicity that described BAME groups as 'more likely to develop medical conditions that need blood, organs or tissue donations'. The website also mentioned that 'people needing bone marrow are more likely to find a match with someone with a similar ethnic background', crudely implying that genetics equates to 'ethnicity' and 'race'. This has slightly changed today, with 'More donors from black, Asian and minority ethnic groups are urgently needed to address an increase in patients from the same communities dying whilst waiting for an organ transplant'.

As highlighted by previous medical anthropological research (Gordon 2002; Kierans and Cooper 2011), biological differences have been combined with race and ethnicity in this context, emphasising the largely arbitrary character of racial categorisations based on shared characteristics, such as, for example, skin colour ('black', 'white') or geographic location ('Asian'). Moreover, 'white' HLA types are constructed as the standard against 'rare' 'black' HLA types, failing to account for racial mixing and mixed heritage (Kierans and Cooper 2011).

There is also the failure to acknowledge that developments in immunosuppressants make HLA (mis)matches increasingly irrelevant (Gordon 2002: 136). Cohen (2001) writes about how transplantation rapidly went global with the development, production and marketing of the immunosuppressant drug cyclosporine by the Swiss pharmaceutical corporation Sandoz. This made transplants possible from a far larger group of potential organ donors than before, profoundly affecting the harvesting of organs and transforming the productivity of transplant

clinics and their organ-donation targets. Research on pharmaceuticals shows how the macro level of the pharmaceutical industry and health-care systems and the micro level of doctor–patient relations are interconnected (Britten 2008), affecting the expansion of pharmaceutical markets (Busfield 2010) and providing a quick and easy solution to the complex issues emerging when facing inequalities in access to transplantation and transplant listing. Kierans and Cooper write that:

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.

(Kierans and Cooper 2011: 13)

Therefore, ‘ethnicity’ and ‘race’ become biopolitical constructions in transplant medicine in the UK; these are often used to contrast the behaviour of ethnic minorities when it comes to donations in comparison to that of the ‘white population’, implying a higher moral stance for the latter. During an interview⁴ in a renal unit in the UK, an Asian patient – we will call him Sadiq – in his forties told Melania:

They [healthcare professionals] said to me that a lot of Asian people don’t donate organs. My mum went through it and one of her kidneys was only 30 per cent efficient so they said no because she obviously was living on one; and my wife was not compatible and then after that I told the rest of the family not to go for it because I didn’t want that responsibility. If it can happen to me it can happen to anybody in the family so I’ve just said I’d rather wait the time and wait for a donated dead one. [...] Obviously, I got my brother and my sister, both of them went and had the tests done. I told them to go and have the tests done to make sure they don’t have any possibility of kidney problems so that they are clear. I didn’t want to take a kidney from any of those just in case. [...] We spoke to a few people and again a few of my cousins came forward and said they would donate, but then again, the mental state I was in at the time. I refused to take it. [...] I mean my cousin was only 20 at the time he offered as well; he was very fit, but I just said no. I’d rather wait it out and take it from someone that has already died rather than taking it from someone that is living; and if they get any complication it’s just mentally you wouldn’t ... you would feel responsible for that.

The words of Sadiq mirror the attitudes and feelings of other renal patients Melania interviewed. Despite the difficulties of living on dialysis and their daily suffering and pain – which Yannis, a Greek man in his fifties, described as a form of disability – patients find it extremely difficult to follow healthcare professionals' advice to ask family members if they can act as living donors. This was also common among those who identified themselves as 'white'; of the 53 people in the sample, many noted that they would feel 'guilty' and 'to blame' if the donor became sick later in life, following the donation. 'I wouldn't want anyone to carry that burden, you know', commented Scott, a 69-year-old white British man.

Another important point is the fact that patients like Sadiq internalise what healthcare professionals communicate to them regarding ethnic minorities and donations; this certainly has important repercussions in terms of self-identity as well as in terms of perceptions of their own communities. As Nazroo et al. (2007) have shown, treating categories – such as Caribbean, black and South Asian – as universal needs to be problematised. This challenges the ideology of transplant medicine in the UK, which identifies people from different continents as the same only because they are defined as ethnic minorities in the UK. Moreover, within the same ethnic groups there are many differences, and mixed heritage in an increasingly globalised world is not considered. For instance, in terms of vulnerability to cardiovascular disease, there are similarities between white British and South Asian British people when talking about their health experiences (Lambert and Sevak 1996). This leads to the conclusion that using 'race' or 'ethnicity' to explain disease in a specific group is not robust enough.

Minority groups are constructed as dangerous to themselves and in opposition to the white majority; the 'problematisation' of minority health generates binary states of normal/pathological trajectories, with the latter associated with minority groups in the NHS in Britain (Keval 2016). As the UK government has, decade after decade, attempted to 'manage race relations' (Craig et al. 2012), there has been a corresponding effect on concepts of health and health services, with the notion of taking responsibility for one's own health becoming a prime focus for governments (Keval 2016) – for instance, through encouraging lifestyle changes.⁵

Therefore, in this context, minority communities are not only represented as being at higher risk of becoming diabetic, showing an evident ethno-racialisation of the disease, but solutions to diabetes' further complications, such as kidney transplantation, are also constructed as ethno-racial issues, as minority individuals are represented as unwilling to act as donors.

Hence, it is difficult to consider transplant medicine as a neutral biomedical technology (Ohnuki-Tierney et al. 1994), as it deeply affects and is also affected by cultural definitions of personhood and the dynamics of social relations within families, communities and countries. It tests different boundaries (Kierans 2011: 1469) as bodies become artefacts for social and political control, through increasing fragmentation and commodification within the context of biomedicine and economics (Scheper-Hughes and Lock 1987). Through these medical and governmental ethno-racial discourses, we can engage with constructions of sameness and alterity as transplant medicine provides a space to discuss what it means to be human, shedding light on the cultural and social constructions of the self and the other (Sharp 1995; Douglas 2003, 2004).

Conclusions

The re-enchantment of scientists and lay people with genetic aetiologies and solutions to health problems is a social phenomenon that deserves full attention. It is important to recognise, though, that this is often an ambivalent re-enchantment (Bliss 2012). The cases of Mexico and the UK demonstrate the vitality of race and ethnicity as categories that shape biomedical and popular understandings of health and illness and, therefore, have an impact on how public health interventions are imagined. Transplant medicine and genetic modification (although not currently available) stand out as techno-fixes that operate at the individual level and simultaneously suit private interests. This has the inevitable consequence of shifting responsibilities for illnesses and conditions from the structural to the individual, yet they are marked by race and ethnicity. In Mexico, which is one of the largest consumers of sodas, the Coca-Cola Foundation has developed an interest in the genetic causes of diabetes: it is financially contributing to the Genoteca Indígena (Facultad de Química 2007). The suspicion is that the biggest producer of sugary drinks in the world has an interest in blaming faulty genes for the obesity and diabetes epidemic.

Epidemiology maps diseases along lines of race/ethnicity, gender or social class, providing a picture of a population's state of health. Its results can be used either to reinforce existing social hierarchies through racialised discourses of genetic predisposition compounded by unhealthy lifestyles or to explore social inequalities. CE offers theoretical tools to read ethnic and racial differences in this latter light, as the result of social histories marked by oppressive relationships that have an enduring, intergenerational impact on local biologies.

Breilh (2010) contends that the biological is always endowed with historicity; this means that physical, chemical and biological phenomena, as well as phenotypes and genotypes, are historically conditioned and cannot be isolated, fractioned or studied separately from their structuring social processes. Moreover, he adds, the connection between the biological and the social is not an extrinsic one but exists by virtue of subsumption (*subsunción*) (2010: 16). What are the implications of this theoretical standpoint?

A CE approach does not deny ethno-racial differences in disease patterns but sees them as incarnate results of pathways of power. This leads to novel conceptualisations of 'race'. For example, Guthman has explored non-genomic ways of thinking about 'race' and biology, suggesting that social constructions of race not only have material effects on social lives but can somatise 'race' (2014: 1156). Likewise, the concept of local biologies (Lock and Nguyen 2010) stresses the continuous, multi-level interactions among bodies within their life webs (Kuzawa and Sweet 2009).

Another relevant point of CE is the shift of gaze from 'health' to 'life'. Its object of inquiry is life itself, conceptualised as the sustaining web where everything happens or ceases to happen. This means that no aspect of our biology can be understood without taking into consideration its embeddedness in a complex ecology of mutually constitutive inter-relationships. Breilh criticises monocausal and multicausal explanations of disease because they favour proximate determinants of health over society-level ones. This critical posture has a practical, applied and political implication: if health has an intrinsic 'collective' nature, solutions to health crises have to be collective, too. Under this light, genes cannot be faulty, lifestyles cannot be bad and solutions can be technical only as a temporal relief. CE offers cues on how to overcome 'the epidemiological notion of the social as an inductive construction from the individual' (Breilh 2010: 17). A CE approach, therefore, does not analyse patterns of health and disease as the sum of individual risky behaviours or genetic make-ups but as the outcome of structures of power at work. It is social relations that empower or constrain people in and beyond their biologies. So what can a CE approach tell us about the appalling prevalence and incidence rates at which indigenous peoples and ethnic minorities worldwide experience diabetes or renal failure?

Ethnographic work on indigenous peoples with diabetes shows that diabetes sufferers link their illness to wider circumstances involving family and community disruption as well as social and environmental violence. The study of the narratives of people with diabetes reveals

what a strong contribution ethnography can bring to health studies and why a mere account of lifestyles cannot be regarded as sufficient to stem diabetes. For instance, the seriousness with which anthropologists have approached and listened to life histories has led them to acknowledge the emotional dimension of experiences of vulnerability (see Jacobo and Orr, this volume), and the synergistic interactions between violence, suffering and diabetes (see Weaver and Mendenhall 2014, for instance). Biomedical studies have proved that 'chronic stressor exposure (such as living in poverty) has a health impact that goes beyond the supposedly bad behaviour of some people' (Kelly and Ismail 2015: 457).

Similarly, research on renal failure and transplantation can illuminate how ethno-racial difference and sameness are constructed, represented and internalised by different social actors. The communicative process is highly dependent on and structured by inequalities of power and resources; the organ shortage implies an assumption that organs go to waste if not donated, so every citizen should contribute to the transplant enterprise (Lock and Nguyen 2010). Normative theorists, clinicians and policy makers likely expect that patients make treatment decisions that enhance their health (Gordon 2001). Patients, however, make decisions according to non-normative factors, including their emotional and social notions about the repercussions of organ donation on a donor and on the patient's relationship with the donor. There is therefore a need for a renewed focus on patients' self-identity to explore how their treatment choices are embedded in the many relationships within which they are implicated.

The moral economy of transplantation has largely been boosted because of the global epidemic of chronic diseases such as renal failure, hypertension and diabetes. However, substantive research indicates that chronic diseases are themselves 'pathologies of power' (Farmer 2004) and symptoms of gender, class and ethno-racial inequalities that become embodied and are passed down from generation to generation. In order to break with this intergenerational cycle of violence, radical societal transformations are needed. CE recognises the practical and ultimately political nature of the scientific enterprise since 'there is an interdependence between how we *look* to reality, how we *think* it and how we *act* in it' (Breilh 2010: 8). CE offers 'collective health' as a theoretical, methodological and applied tool that focuses on group processes as they generate specific ways of living and dying. The 'social' is not an external variable useful to understand patterns of disease in individuals and groups, but the very condition that enables 'patterns' to occur (Breilh 2013: 20). Under this paradigm, biogenetic reductionism has no *raison d'être* and its

exclusion from epidemiology clears the way for alternative explorations of race and ethnicity, which include the biological down to the genes but address them through a *longue durée* approach that links embodiment with social history.

Notes

1. See for instance the case of legal and spatial exclusion of Chinese immigrants suffering from leprosy in the province of British Columbia, Canada, where racialised governance came into practice through health strategies of segregation and isolation (Mawani 2003:3–21).
2. In 2012 the Mexican Ministry of Health started to include data on ethnicity in its administrative and epidemiological records, based on linguistic criteria (the patient speaks or does not speak an indigenous language). However, no data are available based on ethnic self-adscription.
3. In 1962, Neel proposed that the diabetic genotype was a 'thrifty' genotype, 'in the sense of being exceptionally efficient in the intake and/or utilization of food' (1962: 354). The spread and increase of diabetes worldwide was explained by Neel as an effect of 'civilisation'. Stripped down to its essentials, he suggested that 'genes and combinations of genes which were at one time an asset', especially in the feast-or-famine days of hunting and gathering cultures, had become a liability 'in the face of environmental change' (1962: 359).
4. This research was part of the ATTOM study, which was funded by a grant from the Programme Grants for Applied Research (PGfAR) funding stream, from the National Institute of Health Research (NIHR), United Kingdom (ref: RP-PG-0109-10116). This publication presents independent research. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.
5. See Menéndez (1998) for further details on where the concept of lifestyle comes from and the disciplinary differences (between medical anthropology and biomedicine/public health) when analysing it.

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'*Critical Medical Anthropology* offers thought-provoking interventions to understandings of health, illness and healthcare. It extends a legacy of critical anthropological research, inviting and stimulating south-north dialogue, while generating inspiring new thinking at the intersections of health, social justice, human rights and political economy.' - **Ciara Kierans**, *University of Liverpool*

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