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Global Health, and
Inequality

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An independent academic psychologist, based in England, who has written extensively on different areas of psychology with an emphasis on the critical stance towards traditional ideas.

A complete listing of his writings at <http://psychologywritings.synthasite.com/>. See also material at <https://archive.org/details/orsett-psych>.

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1. GLOBAL HEALTH

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1.1. THEORETICAL FRAMEWORKS

Vaughan and Adjaye-Gbewongo (2021) observed that "patterns of disease are intimately connected with the social, economic and political conditions of life, but also with the biopolitics of disease categorisation and data collection and with epidemiological imaginaries" (p4).

The concept of "epidemiologic (or epidemiological) transition" (ET) (Omran 1971) (table 1.1) has been applied to explain the changes in disease patterns in sub-Saharan Africa (SSA). Omran (1971) proposed three "Ages" in human societies in relation to disease:

i) "Age of Pestilence" - epidemic disease and famine are the dominant causes of population mortality (eg: England up to the eighteenth century).

ii) "Age of Receding Pandemics" - the above problems are overcome and/or are less frequent (eg: England 18th to mid-20th century).

iii) "Age of Degenerative and Man-Made Disease" - "ageing populations, mortality and morbidity are both dominated by what we would now call chronic non-communicable diseases" [NCDs] (Vaughan and Adjaye-Gbewongo 2021 p6) (eg: England since mid-20th century).

The ET model assumed that economic development/growth is the driver of transitions. Szreter's (2021) analysis of British history in the 18th and 19th centuries "indicates that plague mortality fell, not because of factors that could be attributed to

- Atherosclerotic cardiovascular disease is an example of a disease of ET. Once a problem only in developed countries, it is now more common in developing ones (Libby 2021).
- The prevalence of ischaemic heart disease rose from 100 million globally in 1990 to 180 million cases in 2019 (Roth et al 2020), but this hides a declining prevalence in the USA and UK between 2014 and 2019, say (though risk factor controls - eg: smoking cessation) (Libby 2021).
- The traditional candidate for a heart attack was a middle-aged, cigarette smoking, White male with high blood pressure, but "coronary artery disease now affects an increased number of younger women, and - with the ageing of the populations in many countries - the very old now account for an increasing proportion of patients with cardiac conditions" (Libby 2021 p524).
- With increasing global obesity (and "its attendant dysmetabolism"; eg: diabetes), all ethnic groups are vulnerable (Libby 2021). Also, "environmental factors, such as air pollution, noise, disturbed sleep and other stressors have gained increasing recognition as contributors to the risk of atherosclerotic event in part through the activation of inflammatory pathways" (Libby 2021 p527).

Table 1.1 - Example of ET.

'economic development', but because of aggressive anti-plague state policies which actually inhibited the free movement of trade" (Vaughan and Adjaye-Gbewongo 2021 p20). Furthermore, famine is an example of an opposite pattern - supposedly eliminated before the 19th century, but returning in the "Great Irish Famine" (1845-1848) (Vaughan and Adjaye-Gbewongo 2021).

The ET model "complemented the post-war liberal social science orthodoxies of demographic transition and modernisation theory" (Szreter 2021 pp39-40).

Szreter (2021) criticised the failure to explore economic growth and urbanisation further: "It is simply invoked as a benign influence, via supposedly automatically generated 'rising standards of living'. There is nothing here about the causal role in this of worker protest, labour organisations, collective bargaining and the long, complex history of trade-union struggles for initial recognition and then for improved pay and conditions" (p43).

Additional "stages" and transitions have subsequently been added, and there are criticisms of this model, including that the transitions are linear (ie: reversibility is possible; Szreter 2021; appendix 1A). Variations like an "Accelerated Transition Model" (eg:

Japan), or a "Contemporary or Delayed Model" (eg: Chile) have been proposed (Szreter 2021).

Szreter (2021) observed that the "development policy world of discourse is full of 'transitions'. They come in many shapes and sizes and degrees of complexity, sometimes called models, sometimes called theories. The intellectual work that all 'transitions' do is to deal ahistorically with the problem of time. They are handy translation devices between past, present and future. They enable social scientists and policy practitioners, trained in all the multitude of important biomedical, engineering, planning and socio-economic disciplines involved in development and public policy work, to appear to acknowledge that they live and work in historical time. However, they do this without having to engage with the complexity of the history, which historians research and write, involving the contingencies of ideological, cultural and political conflict" (p71).

Mercer (2014) argued that the distinction between infectious and NCDs is unhelpful in the global south, particularly with the impact of the HIV/AIDS epidemic in eastern and southern Africa since the 1980s (Vaughan and Adjaye-Gbewongo 2021).

An alternative is "health transition" (eg: Frenk et al 1991), which includes wider factors beyond disease like health systems, and education (Vaughan and Adjaye-Gbewongo 2021).

Those who reject any form of transition idea for the global south, emphasise the "double burden of disease" (ie: infectious and NCDs together) (or a "triple burden of disease" including malnutrition) (Vaughan and Adjaye-Gbewongo 2021). Frenk and Gomez-Dantes (2011) proposed a different "triple burden", "consisting of, firstly, the 'backlog' of common infections, undernutrition and maternal mortality; secondly the 'emerging challenges' of NCDs and, thirdly, 'problems directly related to globalisation, like pandemics, and the health consequences of climate change'" (Vaughan and Adjaye-Gbewongo 2021 p8). A "quadruple burden" might include communicable diseases like HIV and TB, maternal and child mortality, NCDs, and injury and trauma (Vaughan and Adjaye-Gbewongo 2021).

Interactions, co-morbidities or multi-morbidities is yet another way of viewing disease in populations (eg: "syndemics"; Singer 2009; appendix 1B). Singer et al (2017) explained: "Specifically, a syndemics approach examines why certain diseases cluster (ie: multiple diseases affecting individuals and groups), the

pathways through which they interact biologically in the individual and within populations, and thereby multiply their overall disease burden and the ways in which social environments, especially conditions of social inequality and injustice, contribute to disease clustering and interaction, as well as to vulnerability" (quoted in Vaughan and Adjaye-Gbewongo 2021).

Meanwhile, the "developmental origins of health and disease" (DOHaD) approach focuses on the individual life course (Barker and Osmond 1986) (table 1.2) (appendix 1C). Adult diseases have origins in the foetal environment (or prior generations with epigenetics) (Vaughan and Adjaye-Gbewongo 2021).

- Based on the DOHaD (and the subsequent "thrifty phenotype hypothesis"; Hales and Barker 2001), "the 1000 days between conception and a child's second birthday has been presented in contemporary epidemiology as a critical period that will determine future health and potential" (Pentecost 2021 p252) ¹. In South Africa, for instance, this has been the basis of policy by the Department of Health since 2013 (Pentecost 2021).
- The DOHaD approach has, for instance, introduced the idea of "life-course epidemiology". "Unlike traditional epidemiological models for chronic disease, life-course models 'explicitly require the temporal ordering of exposures and their inter-relationships' [Kuh et al 2003], which occur across the life course and across generations. These new configurations of exposure and outcome alter the ways in which science and policy conceive of and articulate risk" (Pentecost 2021 p263).
- Accepting the strengths of the DoHaD approach, Pentecost (2021) also warned against "blithe universalism": "We cannot rely on a singular grand transition narrative to understand change in polities as diverse as South Africa, India, the Philippines, Brazil and Guatemala; nor is it useful to discard all models or comparisons... for transition theories to remain useful they need to better account for the effects of imperialist expansion, colonialism, early and late globalisation and socio-economic inequality" (p268).

Table 1.2 - The DOHaD approach.

NCDs were "framed initially as 'diseases of civilisation', linked to increased affluence and the lifestyles of highly industrialised regions..." (Vaughan and Adjaye-Gbewongo 2021 p11). They are also viewed as "lifestyle diseases", and modifiable risk factors, like smoking or poor diet, have been identified. But this "tends to direct attention away from political economy

¹ The first 1000 days concept can be linked to Bryce et al (2008).

and environment towards individual responsibility. Directing attention to 'modifiable risk factors' is, of course, important for public health, but it has limits and can lead to the invisibilisation of other conditions (and risk factors) that do not neatly fit this reductive definition of non-communicable disease" (eg: mental health; air pollution) (Vaughan and Adjaye-Gbewongo 2021 p12).

Furthermore, "the framing of the category of NCDs in Africa contains assumptions about the continent's social and economic development, and also ideas about 'race', ethnicity and difference which are inherited from colonial thinking and reconfigured in the post-colonial period. As we know, preconceptions that have no basis in scientific fact can directly influence the practice of data collection. Put simply, there are some so-called facts about the epidemiology of sub-Saharan African societies in the last hundred years which we will probably never know because it was assumed that Africans were immune to certain conditions owing to their 'stage of development' or inherent 'racial' characteristics" (Vaughan and Adjaye-Gbewongo 2021 p12). For example, detailed data were not collected on cancer or heart disease in SSA prior to the 1980s (with the exception of South Africa) (Vaughan and Adjaye-Gbewongo 2021).

A related issue is the measures used to collect data - eg: questionnaires developed in and for European and North American populations. The question is "whether these instruments "when applied to various African populations, are actually measuring what was intended to be measured and whether the constructs themselves translate accurately across cultures deserve further attention" (Vaughan and Adjaye-Gbewongo 2021 pp15-16) (appendix 1D). Vaughan and Adjaye-Gbewongo (2021) also lamented the lack of longitudinal health data in Africa.

A recent approach to understanding disease in populations in the global south is "radical contextualisation" (Chapman and Berggren 2005). "Employing a radical, historically informed ethnographic method allows researchers to better understand the multiple and multiplying effects of the changing environment, broadly conceived, and its complex interactions with individual and social bodies" (Vaughan and Adjaye-Gbewongo 2021 p17). For example, a "cultural preference" for large female bodies in Africa can be understood at a number of different levels, including body fat as a "reservoir" in an environment of food precarity, adult obesity as a reaction to undernutrition

in the early years, obesogenic environments (eg: limited "good" food choices; high insecurity that limits physical exercise), and/or as "an act of resistance against the imposition of yet another 'western' norm: in this case the (historically recent) 'cultural preference' for the slim female form" (Vaughan and Adjaye-Gbewongo 2021 p18).

1.2. PARA-COMMUNICABLE DISEASES

Diseases are traditionally viewed as "communicable" (ie: infectious and contagious), and "non-communicable", which are non-transmissible, "they are commonly analysed in biomedicine as a risk assumed to be linked to an individual's own inborn genetic constitution or framed as resulting from personal choices and 'lifestyle' behaviours" (Moran-Thomas 2021 p237). This dualism is "a relatively recent invention" (Moran-Thomas 2021 p237).

There is a "middle ground" - "para-communicable conditions" (ie: diseases overlap) (Moran-Thomas 2021). Diabetes is traditionally classed as a wholly NCD, but Moran-Thomas (2021) described cases of "contagious diabetes" (literally and metaphorically), or more precisely, say, diabetic ulcers. For example, bacteria in open wounds are able to transfer genes and become drug-resistant. "In cases where people live for months or years walking in sandals with open diabetic wounds on their feet, it is also possible that horizontal gene transfer occurred directly between the bacteria infecting lower limb ulcers and the bacteria living in local soils" (Moran-Thomas 2021 p245).

"Para-communicable" also refers to the interaction between bodies and environments (eg: individuals living in highly polluted environments). Here the contagion is not in the traditional biomedical sense, but the contagion of stressful situations, and "food apartheid" (Moran-Thomas 2021). Local diets around the world have become replaced by "industrial diets".

Commenting on her fieldwork in Ghana and Belize, and on diabetes, Moran-Thomas (2021) stated: "Not only did the infectious/non-communicable dualism often appear ill suited to capture a full picture of diabetes causation, but there seemed to be a looping effect of these attributions - certain diseases' 'geography of blame' can in turn shape institutional funding and access to medical technologies that already exist. I came to see para-communicability as the partially connected set of ways in which aetiology, treatment, morbidity and mortality are imagined and enacted" (p245).

Pentecost (2021) referred to a similar idea with the "nutrition transition paradox" in South Africa, where she observed poor pregnant women categorised as "food insecure" (through lack of money and poor diet), but also as "overweight" by the ante-natal clinics (based on body mass index).

1.3. POPULATION AGEING

Transitions approaches make assumptions about the global ageing of populations. For example, Cowgill (eg: 1974) was concerned that "a linear transition to modernisation implied and assumed a decline in the status of older persons due to the effects of urbanisation, migration and industrialisation" (Sivaramakrishnan 2021 p90).

Cowgill (1988) stated: "One of the dilemmas of modern societies is that, while sociological processes have fostered a devaluation of old people, demographic processes have led to increasing numbers and proportions of aged in their populations. Thus, such societies have larger proportions of older people than ever before, while at the same time older people have less value and utility to those societies. These countertrends give rise to the further anomaly that societies whose relative affluence permits them to provide the greatest comfort and security to their aged members instead deprive them of useful roles and consign high proportions of them to relative poverty" (quoted in Sivaramakrishnan 2021).

But ageing around the world is different to the "Western" experience. "Many elderly people were faced less by the social isolation characteristic of ageing in the 'west' and more by the double burden of caring both for themselves and for grandchildren" (Vaughan and Adjaye-Gbewongo 2021 p22).

In India, for example, "many elderly people experienced extreme economic precarity: dying of 'old age' was, in fact, frequently a euphemism for dying of starvation" (Vaughan and Adjaye-Gbewongo 2021 p22).

1.4. "PATHOLOGIES OF MODERNISATION"

Despite the population health improvements of economic development in a country, this process creates "new forms of disease and death... pathologies of modernisation", like those related to tobacco smoking

(Reubi 2021).

Twentieth century data, however, on the "African smoker", for instance, have tended to rely on small-scale surveys with easily accessible, but not necessarily representative, samples (eg: medical students; patients at large urban hospitals), or modelling studies. "The picture of smoking in Africa that physicians and epidemiologists painted through their surveys and estimates seemed alarming. It showed that, as some had feared, the continent was in the grip of a serious and mounting epidemic" (Reubi 2021 p136).

Not everyone agreed with this picture for a number of reasons, including (Reubi 2021):

a) The wide variation in prevalence rates - For example, in Nigeria, smoking urban adult males ranged from 7% to 53% depending on the study (Reubi 2021).

b) The general lack of data on African populations.

The "African smoker" in the late 20th century was perceived as male, young, and urban. This linked the "smoking epidemic" to industrialisation/modernisation. Lopez et al (1994) outlined a four stage model of smoking prevalence, smoking-attributable deaths, and attitudes to smoking with economic development:

I - Smoking becoming widely accepted, but still mostly males (eg: SSA in 1990s).

II - Smoking among a large majority of males, and now increasing for females. The appearance of smoking-attributable deaths in larger numbers (eg: China in late 20th century).

III - Male prevalence declines with public awareness of the dangers of smoking (eg: Western countries in recent years).

IV - Tobacco control measures and declining prevalence (eg: Western countries today).

So, "the belief that smoking prevalence and smoking-attributable diseases would soon be increasing markedly in the region [Africa] led many epidemiologists and physicians to think that Africa presented them with the opportunity to prevent the tobacco epidemic from happening altogether for the first time in history" (Reubi 2021 p146).

Reubi (2021) was critical of the 20th century picture of the "African smoker", and of Lopez et al's (1994) stages/model. Twenty-first century data did not confirm the predicted pattern of increasing smoking prevalence with economic development. One reason is the poor quality of 20th century data mentioned earlier, while another is "the fact that, because of the global economic recession of the 1970s and the structural adjustment programmes imposed by international lenders, most African countries experienced economic decline throughout the 1980s and 1990s" (Reubi 2021 p152).

Reubi (2021) ended by challenging the narrative that modernisation will inevitably lead to increasing smoking in the population in Africa as in the West. That is not to say that it may, but Reubi (2021) wanted epidemiologists and others to consider alternatives.

1.5. APPENDIX 1A - "RETURN OF THE GERMS"

A survey of germs and infectious diseases in 1970 would have seen them as defeated by humans with successful vaccines and medicines. But the subsequent half-century has challenged such a view - eg: with the appearance of Ebola in the 1970s, HIV/AIDS in the 1980s, and anti-biotic resistant "superbugs". These "represent only a few of the infectious disease eruptions that now occur among humans every year, and efforts to stem them have taken on a renewed and urgent role in modern medicine. Some of these contagions are new to our species; others are resurgent old enemies" (McKenna 2020 p50). Covid-19 has shown this written large.

"The planet that slid down the far side of the 20th century's wave of confidence is the planet that enabled the spread of covid-19" (McKenna 2020 p53). It was unprepared (despite warnings), and ignored its own behaviour that contributed (eg: rapid global travel; proximity to wild species). "Social determinants of health" (eg: poverty) are also part of the "return of the germs" (McKenna 2020).

The reality of health inequalities is described by Prince's (2021) study of cancer patients in Kenya: "Cancer diagnosis and treatment are slowly becoming available in some government hospitals and clinics across the country but, where it is available, it is costly and often offered by doctors without oncological expertise. The expansion of health insurance schemes has increased access, but this has been realised only very partially

(for some people, and for some forms of treatment). Thus, many people cannot afford treatment, and diagnosis is often made only very late in the cancer's process. Accordingly, forms of 'living with' cancer vary immensely" (p325).

As well as that, the variety of infections and NCDs faced by individuals means that boundaries between conditions are "extremely porous, and do not clearly crystallise as separate conditions" (Prince 2021 p326).

1.4.1. Travel Time to Healthcare

Access to healthcare is impacted by geographical factors, like time and cost of travel to appropriate facilities, and, in turn by, transportation infrastructure, for instance. Lower-income populations are disproportionately affected by these factors, and "people facing long travel times to healthcare facilities are less likely to seek care when it is needed, and the consequences of failing to seek care include increased mortality and morbidity from treatable conditions" (Weiss et al 2020 p1835).

Maps of travel time to healthcare facilities help policymakers allocate resources, including new facilities, outreach programmes (with mobile healthcare staff), subsidised transportation, or telemedicine.

Using data from open sources like "Google Maps" (as of August 2019), Weiss et al (2020) calculated the global distance to hospitals and clinics for both motorised and non-motorised travel. It was estimated that 91% of the world's population (6.6 billion people) could reach a hospital or clinic within one hour using motorised transportation (travelling at optimal speed), but only 57% (4.1 billion) by walking (ie: at 5 km per hour). There was great variety in travel time, particularly for rural populations, and environments (eg: at 1 km per hour for non-motorised water travel).

With motorised transportation, 60% of the global population live within 10 minutes of a hospital or clinic (ie: 4.4 billion people) and 6 billion people (83%) within thirty minutes. "These results suggest that the spatial coverage of healthcare facilities is very good in most regions for individuals with access to the fastest means of transportation" (Weiss et al 2020 p1836). By walking alone, the figures were 14% and 40% respectively. "The disparity between motorised and non-motorised travel times illuminates a potential causal association between individuals' decisions on whether to seek healthcare and

their available modes of transportation" (Weiss et al 2020 p1836).

There are limitations to these figures, including:

i) "Walking time" is a theoretical concept as sick individuals may have mobility restrictions.

ii) Travel times do not include waiting times for public transportation, or daily and seasonal variations.

iii) Healthcare facilities vary in their availability (eg: opening times).

iv) The cost of healthcare - ie: the individual cannot afford care even if it was provided nearby.

v) The type and quality of healthcare provided by the nearest facility.

vi) The estimates are "potential rather than actual travel times to healthcare, because although individuals have a propensity for choosing the closest facility, they could choose to seek healthcare from facilities farther from home" (Weiss et al 2020 p1837).

1.5. APPENDIX 1B - SYNDEMICS

In Botswana, for example, "chronic but 'communicable' HIV epidemic collides with that of a chronic 'non-communicable' one and an ageing population" (Vaughan and Adjaye-Gbewonyo 2021 p28). The former is paediatric HIV, and the latter is hypertension among the older women (sometimes grandmothers) who have to care for these children. This could be taken as an example of syndemics ², as "uncontrolled adult hypertension threatened to amplify or exacerbate paediatric HIV infections" (Brada 2021 p300). Put simply, if the older women become ill or disabled, the highly-dependent HIV-positive children will suffer. "So, while many children in Botswana depended on members of their extended families, and particularly older women, for elements of daily care, such as feeding, bathing and clothing, caring for these HIV-positive children also entailed the demands of their infections, including adherence to their anti-

² Syndemics can be seen in three features: "1) the clustering of two or more diseases within a population; 2) the interaction of these diseases on biological, social and psychological levels; and 3) the social forces that give rise to clustering. A key aspect of the term is that the two diseases are not simply co-present, but that they amplify or enhance one another synergistically" (Brada 2021 p306). Psychology Miscellany No. 160; 10th January 2022; ISSN: 1754-2200; Kevin Brewer

retroviral medications and attendance at regular clinic appointments" (Brada 2021 p303).

Data have shown that older women face a greater burden of NCDs than men (eg: obesity; hypertension) (eg: Keetile et al 2015).

1.7. APPENDIX 1C - BREASTFEEDING

"Since the 1930s, breastfeeding discussions have been a conduit for anxiety about women's autonomy, malnutrition, child psychological development, and chronic non-communicable diseases (NCDs) in newborns and children... Over the last two decades, a body of published work in leading journals has traced links between NCDs and various forms of inadequate breastfeeding, including research into cancers, diabetes, cardiovascular diseases and respiratory diseases - all of which contribute to a high burden of morbidity and mortality in low- and middle-income countries" (Burns 2021 p276). Kelishadi and Farajian (2014), for example, have been strong advocates of the benefits of breastfeeding (Burns 2021). This fits with the DOHaD approach.

In Southern Africa, for instance, the positives of breastfeeding have been met with fears that HIV could be transmitted via this body fluid in the late 1980s and early 1990s. Coutsooudis et al (2001), for example, established the risk as very low, and anyway, breastfeeding was "a potentially better public health choice than the already established riskier choice of infant formula for women unable to keep up the costs and the correct proportions of mixed formula, and unable to provide 100 per cent sterile water and bottles to prevent other life-threatening infections" (Burns 2021 p289).

1.8. APPENDIX 1D - METHODOLOGICAL ISSUES

1.8.1. Measurement Equivalence

Collecting accurate health data in lower- and middle-income countries can be problematic for a number of reasons including that many survey instruments were developed in the West. "Thus, they may not be as valid in other cultural settings. In addition, even for measures that were developed and tested for global use, one must still consider the extent to which they capture the phenomena they intend to measure" (Adjaye-Gbewonyo 2021

p181). This is the issue of validity which is a universal challenge.

But in terms of cross-cultural research, "measurement equivalence" is important, and Sweetland et al (2014) distinguished five types of equivalence (Adjaye-Gbewonyo 2021):

i) Linguistic - Translations of questions retain their meaning.

ii) Content - Scale items correspond to experiences across cultures.

For example, the Center for Epidemiological Studies of Depression (CES-D) Scale includes the item, "I felt like everything was an effort", which Lacasse et al (2014) found was interpreted differently in a Rwandan sample than in the West.

iii) Conceptual - The same construct is being measured across cultures.

For example, a "pseudo-etic syndrome" - ie: "one which is culture-bound but is assumed to be universal and is consequently imposed on other cultures through measurement and treatment" (Adjaye-Gbewonyo 2021 p185).

iv) Technical - The methods are comparable across cultures.

"Familiarity with using Likert scales and self-assessments, for instance, can be affected by the literacy levels, formal educational attainment, socio-economic status and cultural values of those to whom the instruments are being administered" (Adjaye-Gbewonyo 2021 p186).

v) Cultural - The results of the questionnaires can be interpreted across cultures.

Adjaye-Gbewonyo (2021) noted a dilemma that "lies in the conflict between generating measures that can be compared across time and place - which is often desired when studying the epidemiology of disease and health transitions - versus generating results that are context specific and therefore potentially more applicable and meaningful in certain settings but not necessarily comparable across populations" (p203).

However, Hill and de Menil (2015) stated that "health researchers should not dismiss inquiries into mental health for fear that symptoms will differ too much across cultures. It is possible to meaningfully translate

these concepts into the local idiom and thereby shed light onto emotional questions that would otherwise remain in the dark" (quoted in Adjaye-Gbewonyo 2021).

1.8.2. Epidemiological Surveillance

"Epidemiological surveillance" is the "ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation and evaluation of public health practice closely integrated with the timely dissemination of these data to those who need to know" (Centers for Disease Control and Prevention (CDC) 2012 quoted in Sanuade 2021).

It is important to understand the disease patterns of a country or region, but this is weak in SSA. The "2016 Global Burden of Disease" (GBD), which is "regarded as the most comprehensive worldwide observational epidemiological study to date" (p213), takes its data for SSA almost exclusively from South Africa (Sanuade 2021).

The GBD is part of health metrics, which include the disability-adjusted life year (DALY). The purpose is "to attach numerical values to various health conditions and disabilities to create a health metric that will combine both morbidity (that is, years of life lived with disability) and mortality (that is, years of life lost) into a single value. The DALY therefore creates a standard way of quantifying the impact of diseases and risk factors on human health in order to help inform how resources should be spent" (Sanuade 2021 p214).

However, DALYs have proved not to be comparable between high- and low-income countries in reality because they ignore different access to resources, for instance (Sanuade 2021). Generally, DALYs view the burden of disease on older adults as less important than younger individuals, which critics view as an ethical concern (Sanuade 2021).

"Based on current evidence, the DALY has not "satisfactorily served as an appropriate universal standard; however, it has persisted because of 'the new, economically justified biomedical sovereignty that it helped to usher in, as the major source of power changed from politics to economics' [Parks 2014]" (Sanuade 2021 pp215-216).

Three sources of data are needed to improve on current metrics particularly in SSA (Sanuade 2021):

- i) Hospital records - Depend upon the accuracy of

record-keeping.

Sanuade (2021) noted the case in 1970s Ghana in an economic crisis: "This economic crisis created a situation where some hospital staff started using the same medical folders for different patients. That is, once a patient did not visit the hospital for a while, the medical folder of that patient was given to a new patient. This created a situation where the medical records of some of the existing patients were completely lost and it was difficult to monitor the medical histories of these patients. When doctors became aware of this, some of them told their patients to go home with their folders to avoid this confusion" (p217).

Accurate records only cover those who access healthcare services, and the ability of hospitals to detect and diagnose disease correctly.

ii) Community surveys - Representative surveys of the population. Leaving aside issues of sampling, there is the "honesty" of the respondents (eg: forgetting; stigma of certain illnesses).

Large-scale and long-term studies are expensive.

iii) Census data - Though a census is meant to cover the whole population of a country, there are many reasons why completeness is a problem, varying from logistics (eg: not enough census forms) to citizens not wanting to be counted by the government (Sanuade 2021).

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2. PATIENT-PHYSICIAN CONCORDANCE

Patient-physician concordance describes a similarity in social characteristics between doctor and their patient (eg: same ethnicity). Such concordance may improve clinical outcomes compared to discordant interactions.

Greenwood et al (2020) investigated this idea in relation to ethnicity in the USA, and infant mortality. "Black newborns are more than twice as likely to die in their first year as White newborns [1090 vs 490 deaths per 100,000 births, respectively]. The reasons behind these disparities range from increased rates of eclampsia and pre-eclampsia during pregnancy, to pre-term delivery, to social determinants like socio-economic inequality and racial bias" (Greenwood et al 2020 p21194).

The researchers analysed hospital birth records for 1.8 million children in the state of Florida between 1992 and 2015, and found four key patterns:

i) Black infants experienced inferior health outcomes (eg: mortality) than White infants, but this difference is reduced (halved) if the physician is Black compared to White.

ii) This difference is reduced further in medically complicated births.

iii) (i) and (ii) are more evident in hospitals that deliver more Black babies.

iv) Racial concordance does not impact the health outcomes of the birthing mothers (eg: mortality).

Concordance effects were not found among Latino newborns, but they were evident based on socio-economic status. Greenwood et al (2020) commented: "While this may be a function of the context, viz Florida, it is worth exploring whether concordance exists across other ethnic minorities" (p21198).

This was a study that analysed large amounts of population data, and the researchers were "unable to observe the mechanism that is driving the observed result" (Greenwood et al 2020 p21197). It could be that the selection process - ie: the allocation of newborns to physicians. Greenwood et al (2020) explained that "most accounts, as well as our discussions with practicing paediatricians, suggest that newborns are assigned

in a quasi-random format to the on-call paediatrician (the birth process itself being quasi-random due to timing)..." (pp21197-21198). But patients can choose physicians to the extent that they have a choice. So, the analysis is quasi-experimental (ie: no true randomisation of patients).

The analysis ignored births outside of hospitals (estimated at 1.5% in the USA; Greenwood et al 2020).

The ethnicity of the physicians was established from publicly available photographs, and, of 9992 physicians, pictures were not found for 1947 (who were excluded from the analysis).

Greenwood et al (2020) ended that "it is important to note that physician performance varies widely among physicians of both races, suggesting that exclusively selecting on physician race is not an effective solution to mortality concerns" (p21198). Finally, key questions emerged from the findings: "1) whether physician race proxies for differences in physician practice behaviour, 2) if so, which practices, and 3) what actions can be taken by policymakers, administrators, and physicians to ensure that all newborns receive optimal care" (pp21198-21199).

Greenwood et al (2018) produced an analysis of Florida data for patient-physician gender concordance and heart attack (acute myocardial infarctions; AMI) survival rates. Emergency department admittances between 1991 and 2010, survival rates, and gender of patient and attending physician were collated. Four conditions were distinguished - patient female/physician male; patient female/physician female; patient male/physician female; patient male/physician male.

There was an asymmetry for survival rates "particularly notable" for female patients who were less likely to survive when treated by a male physician as compared to a female one.

After controlling for hospital and physician variables, the researchers found that "male physicians are more effective at treating female AMI patients when they work with more female colleagues and when they have treated more female patients in the past" (Greenwood et al 2018 p8573).

Greenwood et al (2021) admitted that they could not explain the reason for their findings.

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3. INEQUALITY AND INEQUITY

- 3.1. Cancer
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3.1. CANCER

Health inequalities (eg: in mortality, incidence, and survival across groups) can be distinguished from health inequity (ie: "those disparities that can be traced to unequal, systemic, economic, and social conditions"; McNeill Ransom et al 2011 quoted in Wailoo 2017).

Inequalities have their roots in many causes including social and biological, whereas "the focus on inequities seeks to call attention to differences that are created by malleable social circumstances" (Wailoo 2017 p790). So, creating health equity will create health equality.

Cancer is one medical relevant here, particularly in relation to ethnicity in the USA. For example, Black women have a lower incidence of breast cancer than White women, but a higher mortality from it (Wailoo 2017).

"One hundred years ago, most health experts believed that health disparities were natural – part of a normal fabric of the social and biological order. Few experts would have championed a cause or call to reduce cancer disparities because any disparities were seen as defined by different bodies and different biological risks" (Wailoo 2017 p791). As was the case so often at this time, there was a racial element (appendix 3A).

"Experts of this era framed cancer as a disease of civilization, and saw 'primitive' societies as relatively protected from its ravages. So too did class differences frame the cancer question. In an era where infectious diseases (tuberculosis, pneumonia, and others) were the leading cause of mortality, poor people lived in worlds where infectious disease, childhood mortality, and early

death dominated. By contrast, better-off people who enjoyed longer life spans survived these threats in greater numbers. The consequence of their survival was that they lived long enough to reach the so-called 'cancer age' – a dominant view that linked cancer to privilege, ageing, and higher social status" (Wailoo 2017 p792).

The mid-20th century in the USA (based on the "New Deal") saw changes in understanding, aided by better health statistics. Cancer as "a white disease" was replaced by awareness of the high incidence among African Americans in the 1970s (Wailoo 2017).

"Today, some fifty years later, the ideal of achieving health equality across all groups seems unreasonable – especially as we acknowledge just how many complex social, behavioural, biological, and economic factors shape disparate outcomes across groups, and as the drive to achieve health equality has been frustrated by political and biological scepticism" (Wailoo 2017 p799). The striving for equity, argued Wailoo (2017), is a way to overcome these problems, and it "injects the language of social justice into the health debate. The pursuit of equity, however, has this limitation – it focuses on a goal that is extremely difficult to measure" (p799).

3.2. ADOLESCENT HEALTH

Socio-economic status (SES) impacts health as well as lifespan, and these inequalities are "typically established early in life" (Elgar et al 2015). Concentrating on adolescence, the Health Behaviour in School-aged Children (HBSC), which covers North America and Europe, has shown these differences.

Elgar et al (2015) analysed the 2002, 2006, and 2010 HBSC data collected covering nationally representative samples of 11, 13 and fifteen year-olds from thirty-two European countries, and Canada and the USA.

SES was categorised based on responses to four questions ("does your family own a car, van or truck?"; "doing the past 12 months, how many times did you travel away on holiday with your family?"; "how many computers does your family own?"; "do you have your own bedroom for yourself?").

The measures of health included physical activity (at least sixty minutes per day), body mass index, psychological symptoms (eg: feeling nervous), physical symptoms (eg: headaches), and life satisfaction.

Data on national income for each country came from the World Bank Databank.

The total sample was over 492 000 respondents.

Between 2002 and 2010, there were small increases in physical activity, body mass index, number of physical symptoms, and life satisfaction. All health measures, except life satisfaction, showed increases in health inequality (ie: a widening of the gap between the most and least affluent).

At a national level, higher income inequality (ie: more unequal countries) was associated with less physical activity, larger body mass index, and more psychological and physical symptoms.

3.3. FLINT

"Flint in Michigan is infamous for its water crisis. From 2014, the state government decided to divert the city's water supply through ageing pipes that contained lead, a neurotoxin, making many people unwell and leading to some deaths" (Lewis and Sadler 2021 p326) (appendix 3B).

The subsequent community reaction and collaborations with researchers also found that Flint was "an asthma hotspot" (correlated with the sites of former car factories and lead contamination in the soil) (Lewis and Sadler 2021).

3.4. HEAT

In mid-2021, the western USA and Canada experienced a record-breaking heatwave (eg: 50 °C) (Editorial 2021). Such heat causes death. The WHO estimated that 166 000 people died in heatwaves between 1998 and 2017 (Witze 2021).

The risk is even greater in cities. Thus, the need for strategies to cool them (eg: "cool roofs" - roofs painted white or covered with an energy-reflecting material), and better planning (eg: early warning systems) (Editorial 2021).

Inequalities within urban areas is also an issue. Wealthier neighbourhoods, for instance, have green areas which can reduce the heat effect (Witze 2021). Hoffman et al (2020) calculated a difference of 2.6 °C within US urban areas between the richest and poorest neighbourhoods. For the poorer communities, it is "a result of the impervious surfaces and lack of tree

canopy, but it is probably also linked to racist urban planning policies, such as decisions to build large highways and industrial buildings (with their heat-absorbing concrete) in communities of colour" (Witze 2021 p350).

3.5. APPENDIX 3A - RACE AND BIOMEDICINE

Pollock et al (2021) considered "race" and biomedicine - how to study the topic without legitimising race as a scientific category. M'charek (2013) described "[t]he challenge in studying race is to denaturalise without dematerialising it, and to simultaneously attend to materiality without fixing race" (quoted in Pollock et al 2021).

There is a conflict between scientific positivism that underlies biomedicine, where scientific knowledge is presented as objective, value-free, and true, and critical approaches that highlight the socially constructed nature of all knowledge. In relation to the latter, and race, ideas like "the Racial Contract" (Mills 1999), and "racial projects" (Omi and Winant 1986) have represented the argument that "certain racial knowledges and discourses... become embedded within social practices and structures" (Pollock et al 2021 p436).

This fits with Karkazis and Jordan-Young's (2020) second trajectory of scholarship on race and biomedicine - "what race is made to do: that is, how race functions and how it is operationalised in the context of the biosciences, biomedicine, and contemporary biotechnologies... In this area of work, race is viewed as concept or indeed a political technology that has been deployed or called on in ways that actualise certain outcomes -whether that be to reinscribe notions of 'biological difference', structurally created health inequalities, and skewed life-chances, or to problematise the very notion of race and its effects" (Pollock et al 2021 p436). The first trajectory of scholarship has focused on the history of race and racial classification in the biosciences and biomedicine (Pollock et al 2021).

Focusing on genetics, Pollock et al (2021) noted that "geneticists seem to be convinced of the non-existence of race yet need social categories of difference to order their data and to interpret the results. Some geneticists go further and have recently claimed to have evidence that the results of genetics seem to map onto social clustering and therewith provide evidence for the existence of biological race" (p439).

This has been called the "molecularisation of race" (Duster 2006), or the "reinscription of race at the molecular level" (Abu El-Haj 2007).

van Oorschot and M'charek (2021) observed: "The relationship between genetics and race is complex and fraught. While the Human Genome project of the 1990s was explicitly introduced as a way to attend to our common humanity – that which makes us the same – genomics as a discipline has tended to concern itself largely with genomic differences between populations" (p557).

3.5.1. Forensic Genetics

Genetics play an important role in modern forensics. One example is the identification of bodies in countries where individuals "disappeared" (eg: during the "dirty wars" in Central and South America in the second half of the twentieth century). This has been called "human rights forensics" (Smith 2017), and it is a response to "clandestine burial" by violent actors (eg: paramilitaries; repressive government forces). Indigenous groups have often been the focus of such violence (eg: Mayan population in Guatemala) (Smith and Garcia-Deister 2021).

Smith and Garcia-Deister (2021) described three groups working in "human rights forensics" in Central and South America - the "Fundacion de Antropologia Forense de Guatemala" (FAFG) in Guatemala, the "Equipo Argentino de Antropologia Forense" (EAAF) in Argentina, and the "Equipo Mexicano de Antropologia Forense" (EMAF) in Mexico.

The researchers explained that the "rise of human rights forensics in Argentina and Latin America coincided with a contemporaneous global shift in organising around the category of Indigenous peoples. The 1990s were pivotal in the emergence of global Indigeneity as something separate from race or ethnicity, subject to different rights and modes of redress" (Smith and Garcia-Deister 2021 p454). They coined the term "genetic syncretism" to describe "where Indigenous practices, beliefs, and interests are brought into genetic practices but not subsumed by it" (Smith and Garcia-Deister 2021 p462). Put simply, "partners in documenting and mourning genocide" (Smith and Garcia-Deister 2021 p462).

Pollack et al (2021) commented on such projects: "While recognising that forensic genetics reinforces racial ideologies that are inextricable from colonial and post-colonial violence, they are also attuned to the

simultaneous elements of resistance that can emerge in and through these technologies as they open up pathways for local and global Indigenous (self)recognition and demands for justice" (p440).

Ultimately, the issue is how to support individuals and their ethnic, racial, and/or Indigenous identities without essentialising such concepts.

Talking about forensic genetics, but relevant to genome projects generally, van Oorschot and M'charek (2021) stated: "Biogeographic ancestry searching, for instance, can be understood to reify associations between bodies and spaces and, hence, enact race... while familial DNA searching may run the risk of further stigmatising and racialising specific families and communities" (p558). Biogeographic ancestry searching is the desire to know the geographical origins of one's DNA based on general patterns known from the past, while familial DNA searching has been used to find suspects via their genetic relatives (ie: the similarity in DNA).

Whether meaning to do so or not, familial DNA typing as a means to find perpetrators of crime raises the "possibility of ethnic and racial stereotyping" - for example, in the generation of facial sketches of unknown suspects from the DNA results (van Oorschot and M'charek 2021).

van Oorschot and M'charek (2021) examined two murder cases in the Netherlands where familial DNA searching was used to find the perpetrator. One case (Marianne Vaatstra ³) was "mired in controversy about the ethnic identity of the unknown perpetrator from the very start and involving incendiary racist claims about the perpetrator" (van Oorschot and M'charek 2021 p555). The other case (Milica van Doorn ⁴) was different in that the legal authorities "kept race at bay" (van Oorschot and M'charek 2021).

3.5.2. Stem Cell Donation

Bone marrow or haematopoietic stem cell (SC) transplantation is used with conditions like blood cancer. "The treatment relies on the recipient receiving genetically-matched SCs, often taken from a donor from within the patient's family, or via a global network of registries. In cases where clinicians resort to the registries, white patients are understood to be more

³ Details at https://en.wikipedia.org/wiki/Murder_of_Marianne_Vaatstra.

⁴ More information at <https://irenevanoorschot.com/2020/10/30/example-post/>.

likely to find a matching donor than racially minoritised patients, a situation framed in policy in different global north countries as a health injustice or 'unmet need'" (Williams 2021 p471).

Williams (2021) explored attempts to increase non-White donors in the UK. The idea of duty was often used (what Williams (2021) called an "ethico-racial imperative").

SC donor/recipient compatibility is related to human leukocyte antigen (HLA) types. Biologically related individuals have a high chance of compatibility. With unrelated individuals, similar HLA types are grouped as "populations". Individuals from the same ethnic group have a higher likelihood of being in the same HLA population. So, the social categories of race and ethnicity become subsumed and redefined within HLA populations. Simpson (2000) noted that "'when ideas of DNA, genomes, gene pools and populations cross over into popular ideas about culture and ethnicity', ethnic identities might well become 'imagined genetic communities'" (Williams 2021 p475).

As part of such a community, which may also be confirmed via genetic ancestry testing, individuals can feel an obligation and duty to their group. Meanwhile, drives for volunteers for biomedical projects like tissue donation confirm such ideas.

Returning to SC donation, Williams (2021) reviewed UK documents on the subject, interviewed seventeen actors in the field, and undertook participant observation at "donor drives" (eg: "Race Against Blood Cancer").

Williams (2021) emphasised that a "sense of racialised obligation infuses much of the work of recruitment... this work is highly affective – trying to draw an audience into a narrative on highly personal and emotive terms often through creative practices. We see this in the recruitment co-ordinator's exasperation with the woman who declined, insufficiently influenced by the 'semantic complex' of guilt/duty (Lemke 2013) in the co-ordinator's words ⁵. Importantly though, much of this work is animated by more than mutual racial identity. It is, crucially, personal biography (often through bereavement or concern for a loved one currently seeking an SC donor) that often underwrites these appeals" (p482).

The words of one of the speakers at a drive sum up this idea: "'Be a positive role model to your community', he said, looking out across the church hall, speaking

⁵ Williams (2021) observed an occasion when a woman was not persuaded to sign up to donation, though she admitted feeling guilty. Afterwards the co-ordinator said: "she felt guilty, but not guilty enough to register" (p481).

slowly as if to ensure the message sank in. 'Be a positive role model to your race'. He pointed out that[...] from today, who knew what might happen - one of the people who sign up later to be a stem cell donor could be a lifesaver[...] Beginning to draw the presentation to a close, he very soberly stated: 'Time is running out for people, especially our people'" (fieldnotes December 2019; Williams 2021 p485).

Williams (2021) saw such drives, though important, as the state outsourcing their responsibility as "minoritised citizens who are now faced with the task of leading the charge against a racialised inequity in healthcare provision. [...] What does it tell us that so much of the ongoing and difficult work to ameliorate health inequalities is actively placed in the hands of racialised communities themselves, rather than framed as a collective onus borne by us all, regardless of how we identify or are read, to address the historical striations of inequity that our health systems so urgently need addressed?" (p484).

3.5.3. Sickle Cell Disease

Sickle Cell Disease (SCD) is an example of a condition that almost exclusively afflicts one particular group - namely, Black individuals. Concentrating on sufferers in Brazil, Creary (2021) noted "two different modes of suffering authenticate the lived experience - one is based on the disease state, the other is based on the ways in which racial inequalities and disadvantage contribute to its own suffering while also entangled with disease-based suffering" (p492). Royal et al (2011) quoted a sufferer saying: "Being Black and knowing that most people that suffer from SCD are Black also makes it a little easier to deal with because I can associate with more people suffering with the disease" (quoted in Creary 2021).

Creary (2021) explored a patient activist group for SCD focused around social identity that struggled with the case of "Mira", "a petite, fair complected woman of means who has sickle cell trait (SCT) and is the mother of two sons who have passed away from complications with SCD" (p494).

Creary (2021) reported an argument, for example, at a meeting where it was suggested that "the suffering of a mother is not equitable with the suffering of those living with SCD" (p502). The speaker said: "I don't doubt

that Mira has a good cause and that she fights with the suffering of losing her children, but feeling it here, knowing it here [hits her chest again], only we can know" (pp501-502). This is an example of a "hierarchy of suffering" for Creary (2021). The "pain" (physical) of some individuals is greater than the "pain" (emotional) of others. "Mira" responded to the above comments with an "open letter" that ended: "Shut up those mouths that open to say that a mother does not feel the same pain as their child" (p502).

"Mira" with SCT status was a carrier of a gene for this rare genetic condition, but not a sufferer of SCD, and this put her "in between notions of normal and pathological... The carrier status... transmits a biosocial suffering" (Creary 2021 p503).

"Mira" was leading a SCD patient activist group, and Creary (2021) described the difficulties that this created. Self-identifying as "mulata" (mixed ethnicity), she was from a higher social class than most of the members of the organisation. Creary (2021) described the situation: "In the case of the SCD movement, a movement that constitutes individuals who decry their neglect and attribute that neglect to racism, discrimination, and lack of access to social capital, Mira's presence (wanted or not) may offset some of the group's low level of social capital. In her study on the issues and strategies of advocacy groups who serve racial minorities, low socio-economic populations, and women, Strolovitch (2008) notes that advocacy groups can be disenfranchised along several axes: 'they might lack financial resources; they might now be or have been in the past the objects of de jure facto discrimination; they might lack electoral power and therefore have no or few elected representatives; or they might lack 'cultural capital' because they are socially stigmatised by the broader society or dominant culture'. Mira likely capitalises on the cultural markers of whiteness (high education, high-skilled employment, high income) that allow for learned savvy in institutional spaces. Simultaneously, these same markers negate any suffering that are mapped onto the typical lived experience of those with SCD" (pp506-507).

In summary, Creary (2021) showed that "biosocial suffering" has both the physiological/disease elements and the social ones. Individuals with the same disease can vary on the social elements, and this produces a "hierarchy of suffering". In simple terms, being Black with SCD in Brazil is worse than being "White" with SCT (like "Mira").

There are individuals who want the greater level (status) of suffering and try to delegitimise others. This fits for me with a status attributed to the victim. Drawing on Parson's (eg: 1975) idea of the "sick role", there is a "victim role" which allows individuals certain "rights" and exemptions from everyday social demands.

Talking more generally, I note the difference between "real victims", who often do not want to publicise their suffering/position, and those whose suffering is "lesser" but gain from the status of "victim role". This latter group also suggests to me that the worse thing is "ordinariness". With the pressure to be a "winner", if you cannot be that, you can be a victim, and, at least, you are special for that reason.

3.5.4. Assisted Reproductive Technology

Ehlers (2021) reflected on the "racial politics" of assisted reproductive technology (ART) with the case in the USA in 2014 of "Cramblett v Midwest Sperm Bank". This was where a White woman gave birth to a Black child after a "mix-up" during donor insemination, and she filed for "loss of perceived genetic similarity" (Ehlers 2021 p514).

ART can both challenge "the notion that kinship is based on biology", and reaffirm it "by choosing a donor who resembles the legal parent(s)" (Ehlers 2021 p516). Mamo (2005) referred to an "affinity-tie" - ie: "a kinship device co-constructed between... [clients] imagining shared social and cultural characteristics and sperm banks' investment of the biomaterial, sperm, with an ability to create relatedness" (quoted in Ehlers 2021). In relation to donor insemination, the affinity-tie is the choice of sperm from a donor "similar" to the recipient.

"Importantly, race is often used as a proxy for affinity in ART: affinity is racialised, with genes often positioned as that which transfers racial identity. The significance of the idea of inheritability via genes as intimately tied to identity is evident when IVF donors are chosen based on racial categorisation in order to facilitate biogenetic relation (or best approximation). Such efforts represent a paradox given that genetics has resolutely shown that there is no genetic basis for race and that commonly defined racial groups are genetically heterogeneous and thus lack clear-cut boundaries" (Ehlers 2021 p516).

Ehlers (2021) pointed out that "repro-tech" (as she

called it) is "inextricable from political economy and broader property relations that rely on disparity: it is conditioned by market forces and logics, and it enables the reproduction of relations of capital accumulation" (p517). This fits with the idea from critical race studies (eg: Harris 1993) that "race is imagined as an inheritable (genetic) property" (Ehlers 2021 p517).

In an interview, Jennifer Cramblett stated that she and her partner (Amanda) chose a "blond-haired, blue-eyed individual" as the sperm donor in order to have a child that resembled them (genetically). "While not explicitly stated, Cramblett and her partner were seeking to reproduce a racially homogenous family through the commercial object of 'white sperm' – the biomaterial they presumed they had bought and now possessed as property" (Ehlers 2021 p517).

Legal complaints against sperm banks are based in "wrongful birth". "Ordinarily, wrongful birth is a malpractice claim brought against medical personnel who fail to notify parents of congenital diseases, disabilities, or birth defects so they can avoid or terminate the pregnancy. It is a claim of a civil 'wrong' on the basis of the denial of the right to avoid the birth of a child with a (said) defect" (Ehlers 2021 p519). But in the Cramblett case, the child had no such medical issues, and so the child's "blackness ostensibly stands in for the supposed disability on which the wrongful birth claim relies" (Ehlers 2021 p519).

Cramblett can be seen as having a "loss of investment in genetic capital" (Ehlers 2021 p522). Ehlers (2021) elucidated: "Here I mean that Cramblett's desire for biogenetic affinity can be interpreted as what George Lipsitz (1998) has called a 'possessive investment in whiteness' – that is, the effort to maintain the structured advantages linked to white racial identity, both for herself and her future child through the continuation of white lineage. Viewed through this lens, it can be tempting to see race-matching in IVF (by whites) as a form of neo-eugenics, a kind of 'better breeding' to maintain systems of individual and collective white structural advantage" (pp522-523). Rose (2007), for example, has observed generally that ART allows the individual neoliberal choice akin to "eugenics".

Ehlers (2021) ended: "Biomedicine facilitates family formation via technological means, but it specifically enables individuals to pursue family formation along lines of race: ART donor services are organised by (and reproduce) racial hierarchies and associated value, and

within ARTs race is positioned as proxy for affinity. As such, biomedicine is complicit in and can be used/deployed to affirm structural racism. Likewise, law is implicated in maintaining racial logics and ontologies of relative racial value" (pp525-526).

3.5.5. Population Genomic Projects

Referring to two population genomic projects in Vietnam and Singapore, Ha and Bin Khidzer (2021) described how the results were linked to "varying notions of 'Chinese-ness'" in the context of "an increasingly dominant Chinese geopolitical power" (p530). The Vietnamese project, funded by a private conglomerate, emphasised the ancient origins of the Vietnamese population as "genetically independent" of China⁶, while the government-funded project in Singapore found "self-identified Peranakans" to be a mixture of Chinese and Malay heritage. "The Peranakans view themselves as culturally distinct from the other major ethnic groups in Singapore—Chinese, Malay and Indian. However, members of the Peranakan community have lamented at being labelled Chinese. This newly legible facet of genomic admixture therefore raises questions on how Peranakan identity can be situated within the overarching multi-cultural frame, given how Peranakans have often been subsumed under the Chinese ethnic category in Singapore" (Ha and Bin Khidzer 2021 pp531-532).

The interaction of population genomics and current geopolitics, Ha and Bin Khidzer (2021) described as a "biological geo-body" (or "bio geo-body"). "Geo-body" (Winichakul 1997) is a term describing "how modern cartography produces nations and nationhood spatially. Siam, or Thailand as we know it today, may have existed long before the invention of the modern map. Yet, Winichakul (1997) argues that it was the mapping of Siam coupled with the use of military forces to enforce borders that gave rise to a new geo-body that contributed to the discourse of Siam. As such, modern cartography is an 'inscriptive device', to use Latour's terminology (1987), which concretised the culture, identity and the land of Siam into a natural entity. This mapping of Siam allowed the Siam regime to claim its sovereign power and identify its nationhood and geo-body" (Ha and Bin Khidzer 2021 p534).

The two genomic projects are "mainly concerned with

⁶ "The historical relationship between Vietnam and China has been long contested" (Ha and Bin Khidzer 2021 p536).

studying disease variations for pharmaceutical research, they also elucidate ancestral origins and history of population migration through comparing genome variants within their populations as well as across Asia. The implication is that extant notions of race, ethnicity and nationality become troubled as groups come to terms with new facets of their identity brought forth by population genomics" (Ha and Bin Khidzer 2021 p533). Similar issues have been noted in Taiwan (Liu 2020) with "the making of Taiwanese stem cells through the idea of genetic hybridity to construct Taiwanese national identity that is genetically distinct from the Chinese" (Ha and Bin Khidzer 2021 p533). While projects on "Chinese Han DNA (Sung 2010) are "co-opted into bio-nation-building projects of China" (Ha and Bin Khidzer 2021 p533).

Ha and Bin Khidzer (2021) scientists, researchers, and stakeholders of the two projects. The Vietnamese project began as a study of autism among children with whole genome sequencing of parents. It ended up as a description of the genetic relationship between Vietnamese, Thai and Chinese (Le et al 2019). A key finding was that "Vietnamese along with other South East Asian populations originated from Africa about 44,000 years ago and travelled from South to North route. This contradicts the common belief that Vietnamese population, or South-east Asian population, was a result of a North-to-South migration flow. In other words, the paper [Le et al 2019] asserted that South-east Asian populations did not come from East Asia (China)" (Ha and Bin Khidzer 2021 p539).

Ha and Bin Khidzer (2021) emphasised: "We are not interested in evaluating the truth value of this claim. Rather, we want to highlight the conflation between cultural perceptions, nationalistic values, and political complexity embedded in the knowledge claims produced by Vietnamese scientists. The mapping of a biological geobody of the Vietnamese reflects a form of 'genomic sovereignty' (Benjamin 2009) in which the less powerful nations, such as Vietnam, attempt to protect and market their property rights of their own biomaterials, while simultaneously identify the Vietnamese ethnic identity against the Chinese against the background of the military threats of China against Vietnam over their long-standing island disputes in the Eastern Sea (or South China Sea)" (Ha and Bin Khidzer 2021 540).

In an interview with Ha and Bin Khidzer (2021), part of the Le et al (2019) team said: "Based on the genomic data, we can infer that the Vietnamese do not originate

from the Chinese. Despite the 1000-year Chinese domination, Vietnam still managed to protect our own culture, language and genetic code" (p539).

In Singapore, "ethno-racial" categories inherited from British colonial times are part of the social hierarchy, but Peranakans "inhabit the space in-between the official race categories" (Ha and Bin Khidzer 2021 p541). The "Peranakan Genome Project" set out to explore the genetic admixture of these individuals. Referring to an interview with "Dawn" from the Peranakan Association, Ha and Bin Khidzer (2021) stated: "For Dawn and a few other Peranakan participants of the project who willingly contributed their DNA samples, the genetic ancestry component is important to the understanding of their selves and identities. Dawn was looking to confirm her family history which includes a narrative of origin from parts of South-east Asia. The Peranakan genome project was thus regarded as a technological platform through which she would be able to strengthen her claim to Peranakan heritage" (p544). The genomic information becomes part of a construction of a cultural identity within a framework of ethno-racial categories. "Genomic identity here is, therefore, packaged in a way that renders it flexible and accommodative to multiple levels of Chineseness, in contrast to the oppositional stance described in the Vietnam genome project. Ironically, while Peranakan identity depends on the idea of genetic and/or cultural hybridity distinct from the Chinese, its survival too is contingent on the unsettling of this 'hard' basis of identification" (Ha and Bin Khidzer 2021 p545).

Ha and Bin Khidzer's (2021) study shows how genomic information, particularly related to origins/history, is far from neutral, and in contested social historical cultural contexts (if there is anything else) become "ammunition" for one group or another.

3.6. APPENDIX 3B - LEAD IN WATER

Drinking water that contains level of lead that are below regulatory thresholds could still be a problem for individuals with kidney disease (Liverpool 2021). Danziger et al (2021) analysed data on over half a million US adults on dialysis between 2005 and 2017, and on lead concentrations in the drinking water of their cities. Higher lead concentration was associated with lower concentration of haemoglobin, which transports oxygen in the blood. This increases the risk of anaemia.

Individuals with kidney disease are more susceptible.

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4. DEMENTIA

- 4.1. Early signs
- 4.2. Cataracts
- 4.3. References

4.1. EARLY SIGNS

In the United States, racial and ethnic minorities are officially defined as individuals other than "non-Hispanic, single race Whites", and they constitute a diverse group totalling around one-third of the total population (Gupta 2021).

"As the population ages and becomes more diverse, the burden of age-related chronic conditions, such as Alzheimer's disease and related dementias (ADRD) are projected to disproportionately impact minorities, both in terms of prevalence and severity" (Gupta 2021 p2). For example, older Black and Hispanic individuals are up to twice as likely to have ADRD as White individuals (eg: Matthews et al 2019). They are also presenting with greater cognitive impairment, and spending more years living with dementia after age 50 (Gupta 2021).

An early sign of ADRD is "subjective cognitive decline" (SCD) (Reisberg et al 1982), which is characterised by "self-experience of deterioration in cognitive performance not detected objectively through formal neuropsychological testing" (Gupta 2021). There is some evidence of a fifteen-year period from SCD to ADRD (Gupta 2021).

But the formal diagnosis of SCD is problematic, particularly among minority groups (Gupta 2021).

Gupta (2021) analysed data from the Behavioural Risk Factor Surveillance System (BRFSS), which is a random telephone survey of US adults. It includes six questions about SCD asked to individuals aged 45 years and above (known as the "BRFSS Cognitive Decline" module). Data from 2015 to 2018 provided 19 276 individuals with SCD and 160 576 without.

SCD was defined by this question: "During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?" (p3). Four questions asked how often this had impacted day-to-day activities, and a final question was about seeking help. Gupta (2021) focused on three self-identified groups - White Non-Hispanic, Black Non-Hispanic, and Hispanic.

Overall, the prevalence of SCD for 2015-18 was

10.8%, but with the variations of 10.7% among Whites, 12.3% among Blacks, and 9.9% Hispanics.

Blacks and Hispanics with SCD were more likely to be younger (45-54 years age group), less educated, have low income, have no access to health care, to be living alone, and have functional limitations compared to Whites. For example, with functional limitations, around 57% of Hispanics and 54% of Blacks with SCD reported having to give up household activities due to SCD (always, usually, or sometimes responses) compared to 37% of Whites.

"Regardless of race/ethnicity, SCD prevalence was associated with differences in co-morbid chronic conditions and social determinants. Adults with SCD not only had two or three times the prevalence of some chronic conditions but were also disproportionately affected by social determinants compared to those without SCD. Study findings demonstrated several adverse determinants such as poverty, low education, access to health care and isolation compounded by a higher prevalence of chronic conditions across racial/ethnic sub-groups with SCD compared to without SCD" (Gupta 2021 p10).

Gupta (2021) accepted the following limitations to the data:

i) The BRFSS included non-institutionalised adults. "People living in nursing homes and long-term care facilities without cell phones assigned by a phone company may not be included. It is likely that both SCD and chronic conditions are more common among older adults living in these institutions" (Gupta 2021 p11).

ii) SCD was self-reported with no objective verification. For example, Blazer et al 1997) found individuals with objective cognitive decline who did not complain of subjective memory deterioration.

iii) Individuals with severe cognitive impairment would be excluded from participation in the survey due to the demands of answering questions over the phone.

iv) The SCD questions related to memory decline, "which may not capture the full domain of cognitive dysfunction" (Gupta 2021 p11).

4.2. CATARACTS

Longitudinal studies can help in establishing precipitating factors for future health problems. For example, the Adult Changes in Thought (ACT) study is an ongoing, population-based cohort of over 65s in the USA begun in 1994-6, which investigates associations with the development of dementia.

Sensory impairment is strongly associated with dementia, for instance. Concentrating on vision, Lee et al (2021) hypothesised that "older adults with cataract who undergo cataract extraction may have a lower risk of developing dementia compared with participants who do not undergo cataract surgery or participants who undergo other eye procedures that do not restore vision, such as glaucoma surgery" (pE2). Data were available from the ACT study for 3038 individuals diagnosed with cataract before dementia onset, of which 1382 had cataract surgery (46% in total). The surgery group had a significantly lower risk of developing dementia (hazard ratio 0.71).

A "social" explanation of the findings is that sensory impairment leads to social isolation and reduced cognitive stimulation, and this increases the risk of dementia. While a "physiological" explanation is that "[C]ataract-related visual impairment may decrease neuronal input, potentially accelerating neurodegeneration or magnifying the effect of neurodegeneration through cortical atrophy" (Lee et al 2021 pE6). Related to this, visual deficit may increase the cognitive load and exacerbate cognitive decline this way.

The researchers tried to control for confounders like the surgery group being more healthy or health-conscious. But this was an observational study, and only a clinical trial could establish causation. Lee et al (2021) defended their work in that "the present study may be the highest-quality evidence we will have to address the underlying question because there could be ethical and practical concerns regarding a trial that delays cataract surgery" (pE6).

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