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Health and Stuff

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A complete listing of his writings at <http://psychologywritings.synthasite.com/>.

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# **1. BURDEN OF DISEASE**

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## **1.1. HEALTH AND DISEASE**

Defining health and disease is far harder than might appear at first glance as shown by this debate in the philosophy of science journals.

Boorse (1977) defined disease as "an adverse departure from the statistically typical contributions of sub-system to survival and reproduction in a reference class" (Kingma 2016 p392), and health is the absence of disease. So, for example, a healthy pregnant woman is "a woman who performs statistically typical functions for being at the stage of pregnancy that she is in" (Kingma 2016 p395). The "reference class" is other pregnant women. This approach is called the "biostatistical theory of health" (BST).

Kingma (2010) took the view that normal functioning is situation-specific. So, "there are situations – harmful situations – where the statistically typical causal contributions to survival and reproduction are pathological according to medical judgement. Examples include overdosing on paracetamol; excessive exposure to sun, heat, or cold; and exposure to carbon monoxide (CO) and certain infectious agents. The explicated BST must label the responses to these situations – liver failure, sunburn, frostbite, and so on – normal, therefore healthy, and is thus unable to account for a considerable sub-set of pathologies" (Kingma 2016 p393).

The reference class is important. If the whole population is the comparison group, as Hausman (2011) proposed, then there are anomalies. Kingma (2016) gave these two examples: "First, there is breastfeeding. Hormonal changes involved in lactation suppress most women's menstrual cycle and ability to conceive. It also diminishes a woman's ability to lubricate the vaginal wall in response to arousal... Both effects are or can be

considered pathological in non-breastfeeding women, but are considered normal and healthy for breast-feeding. Second, consider erect penises. Erections impair a man's dispositional ability to pass urine. Thus... erect penises are pathological" (pp395-396).

Kingma (2016) was reacting to the claim of the BST to be value-free. But the existence of a defined reference class is not value-free because "the BST can only start to use statistical abstractions to determine what is normal if it has defined actual or hypothetical reference populations. Those populations are stratified by age, sex, and perhaps race, but not by, say, having diabetes, Huntington's disease, or being congenitally deaf. This specification is both necessary and crucial; if those latter populations would also be admissible as reference populations, then the diseases that define them would be statistically normal and therefore healthy according to the BST" (Kingma 2016 p402).

## **1.2. MEASUREMENT**

Attempts have been made to measure the burden of disease (ie: the years lived with the disability), like "disability adjusted life years" (DALYs). Weye et al (2021) proposed a new measure called the "Health Loss Proportion (HeLP).

The burden of illness is hard to measure with co-morbidities (eg: two (or more) mental disorders - "concordant multi-morbidities") <sup>1</sup>, or "discordant multi-morbidities" (mental disorder(s) and physical health condition(s) together) (Das-Munshi and Prina 2021).

The DALYs include premature mortality (ie: years of life lost), and disability (ie: years lived with disability; YLDs). YLDs combine the duration of a disability, and a disability weight. The latter is scored from 0 (full health) to 1 (death). "The product of duration and disability weight provides the YLDs, a unit which rests on the assumption that mildly disabling disorders over longer periods can be the equivalent of severely disabling disorders over short periods (ie: the constant proportional trade-off assumption). The YLDs permits the combination of a range of disorders to calculate the non-fatal burden of disease. When added to the years of life lost, the composite measure is counted

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<sup>1</sup> Co-morbidities suggests two disorders together, but individuals may experience more than two simultaneously or overlapping in different ways. Thus the use of multi-morbidities. Psychology Miscellany No.151; August 2021; ISSN: 1754-2200; Kevin Brewer

as DALYs" (Weye et al 2021 pp310-311).

DALYs are unable to capture fully the burden of mental and substance use disorders, argued Weye et al (2021). These authors analysed Danish data for eighteen mental and substance use disorders using YLDs and HeLP. HeLP "can be interpreted as the average proportion of health loss that individuals diagnosed with a specific mental or substance use disorder experience because of this disorder and additional co-morbid mental and substance disorders. Technically, the average annual proportion can be converted into weeks and months (eg: living 1 year with a disorder with a HeLP of 0.5 would be equivalent to losing 6 months [or 26 weeks] of full health)" (Weye et al 2021 p315).

It was calculated that for the period 2000 to 2015, for the whole population of Denmark, mental and substance use disorders were associated with 758.6 YLDs per 100 000 person-years, but 27 586 YLDs per 100 000 for individuals with the disorders. "When quantified as a HeLP, on average, each person living with a mental and substance use disorder lost the equivalent of 27.6% of healthy life per year due to their disorder. When assessed for each disorder, the HeLP ranged from 4.4% in people with ADHD, to 65.9% in people with schizophrenia" (Weye et al 2021 p317).

Mental disorders have a wider impact than just the individual, and these are described as "inter-sectoral costs and benefits" (ICBs). Formally, Drost et al (2013) defined ICBs as "[T]he indirect spillover costs and benefits for all non-healthcare sectors of society, attributable to the implementation of a health-related prevention programme" (p179).

Drost et al (2013) provided a review of the literature up to the summer of 2012 on ICBs (n = 52 relevant studies). Four areas emerged from the analysis:

i) Education - eg: risk of dropping out due to mental health problems; teacher-student conflict.

ii) Labour and social security - eg: difficulties with co-workers; loss of income/employment of significant others who are carers.

iii) Household and leisure - eg: homelessness; reduced leisure opportunities for carers.

iv) Criminal justice system - eg: domestic violence;

consequences for victims.

### 1.3. EATING DISORDERS

Eating disorders are "physically, mentally, and socially disabling, and are associated with the highest rates of cause-specific mortality among mental disorders. Compared with people without eating disorders, those with these disorders have lower employment participation, greater absenteeism and presenteeism, higher health-care and informal care costs, and lost lifetime earnings for those who die prematurely" (Santomauro et al 2021 p320).

Santomauro et al (2021) attempted to calculate these levels of disability with eating disorders using data covering 1980 to early 2019 (n = 54 relevant studies). It was estimated that 55.5 million people worldwide in 2019 had an eating disorder (ie: 717.3 per 100 000 people) <sup>2</sup>. In total, this was manifest as 6.6 million DALYs, which included a higher rate for women than men, and particularly younger individuals. Binge eating disorder caused the greatest burden.

The Global Burden of Diseases, Injuries and Risk Factors Study (GBD) 2019 <sup>3</sup> includes only anorexia nervosa and bulimia nervosa, and found 2.9 million DALYs globally (Vos et al 2020).

So, "eating disorders are four times more common than previously thought and associated with double the disability burden" (Thomas and Becker 2021 p263), and maybe even more. Thomas and Becker (2021) noted the absence of certain eating disorders in Santomauro et al's (2021) analysis. For example, childhood-related eating disorders like avoidant/restrictive food intake disorder, which is reported in 3-4% of elementary school children (Thomas and Becker 2021). This disorder "carries risk for psychiatric (eg: suicidality) and medical (eg: low bone density) complications, suggesting that the burden in disability-adjusted life-years could be substantial" (Thomas and Becker 2021 p263).

Santomauro et al's (2021) analysis also excluded sub-threshold eating disorders (ie: close to the diagnostic threshold) (eg: atypical anorexia nervosa, where food intake is restricted, but the individual is not underweight). There are health risks associated with this behaviour (eg: lower bone mineral density and so increased risk of fractures). Thus, DALYs associated with

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<sup>2</sup> Thomas and Becker (2021) saw this estimated as "a stunning claim" because it was 42 million higher than the GBD 2019 figure.

<sup>3</sup> At <http://www.healthdata.org/gbd/2019>.

it (Thomas and Becker 2021).

#### **1.4. OBESITY AND LIFE-COURSE**

Overweight and obesity are "a persistent national public health concern" (p1), especially in the USA where 70% of adults are classed as so (ie: body mass index;  $BMI \geq 25.0 \text{ kg/m}^2$ ), and at least a quadrupling among children and adolescents since 1980 (Yang et al 2021).

Yang et al (2021) explained: "Because youth who are overweight or obese tend to become overweight and obese adults, these shifts forecast increasing future burden of disease" (p1). But the life-course path of BMI is understudied. The research that does exist describes an inverted U-shape pattern "with weight rising steadily until middle age and stabilising before an unintentional decline in later life linked to advanced age and treatments for co-morbidities" (Yang et al 2021 p1).

If the increasing youth obesity continues into later life, then the inverted U-shape pattern will be flatter - ie: a longer period of weight gain during the lifetime - followed by poorer health outcomes in older age linked to excess weight (eg: types II diabetes; hypertension) (Yang et al 2021).

There are also gender, ethnicity, and socio-economic differences in this pattern. In the latter case, for example, children with parents with lower educational qualifications are much more likely to be obese at six years old than where the parents had higher qualifications in the USA, and this difference continues into adulthood. Also non-Whites in the USA, and women, are disproportionately more likely to be obese (Yang et al 2021).

Yang et al (2021) investigated this question: "Do the BMI disparities in early life diminish, persist, or grow in middle age to late life?" (p2). This research question was assessed with three hypothetical positions:

1. "Inter-cohort change hypothesis" - Cohorts vary in their BMI over the life-course with recent cohorts having higher BMIs.

2. "Intra-cohort inequality hypothesis" - Ethnic and educational differences are more important in influencing BMI life-course trajectories than cohort.

3. "Inter-cohort difference in intra-cohort



inequality hypothesis" - Both cohort differences, and ethnic and educational differences explain BMI trajectories.

Data were used from four US long studies (covering individuals born from the 1890s to the early 1980s) that included measures of BMI.

Hypothesis 1 was supported when comparing the BMI for different cohorts - each more recent five-year cohort had a higher average BMI. Or put another way, younger cohorts were reaching the cut-off for obesity ( $BMI \geq 30$ ) earlier in life than older cohorts. For example, for individuals born in 1955-59, the mean BMI was 30.1 in their 60s, compared to a mean BMI of 30.0 in the 40s of the cohort born in 1965-69, and in the 30s of the 1980-84 cohort.

Hypothesis 2 was "largely supported". Black and Hispanic men and women had higher BMIs than Whites at all ages, as did all individuals with lower educational qualifications (compared to higher qualifications).

There was also evidence to support Hypothesis 3. In other words, both of the previous sets of differences combine. For example, the life-course BMI trajectory of a younger cohort Black individual was higher than an older cohort White individual. All Americans are getting fatter in younger cohorts, and some sub-groups (based on minority ethnicity and lower socio-economic status ) even more so.

### **1.5. WORK-RELATED BURDEN OF DISEASE**

The WHO and International Labour Organisation (ILO) calculate the work-related burden of disease and injury (ie: deaths and DALYs related to occupational risk factors).

Pachito et al (2021) concentrated on long working hours as the occupational risk factor for alcohol consumption, risky drinking (>14 drinks per week for women and >21 for men), and alcohol use disorder. The standard working week was defined as 35-40 hours, and compared to 41-48 hours, 49-54 hours, and  $\geq 55$  hours per week.

The assumption is that long working hours cause stress and alcohol consumption is a coping mechanism.

The data came from fourteen cohort studies in six countries. Longer working hours was associated with increased alcohol consumption, but the greatest increase was associated with 49-54 hours per week (approximately

18 g of alcohol per week more, where 1 "drink" is 10-12 g). "It is conceivable that exposure to working  $\geq 55$  hours/week may be associated with less available time for social activities and hence alcohol consumption" (Pachito et al 2021 p20).

There was no significant association between working hours and risky drinking, and there were no data on alcohol use disorder.

Age was an important variable. "Alcohol consumption seems to be increased as an effect of the exposure of long working hours for the age group of 45-59 years old, and risky drinking for the age group of 30-34 years old" (Pachito et al 2021 p23). Socio-economic status was not important.

Pachito et al (2021) rated the methodological quality of the studies included as low.

Pega et al (2021) produced a systematic analysis for long working hours and heart disease, and stroke. It was assumed that long working hours led to heart disease and stroke in two ways - directly, via physiological responses (eg: increased blood pressure), and indirectly, via behaviours (eg: smoking, unhealthy diet).

The data for 2000 to 2016 were taken from 2324 cross-sectional surveys and 1742 secondary datasets (eg: official statistics). It was calculated that in 2016 9% of the global working population worked  $\geq 55$  hours per week, and that heart disease and stroke produced 23.3 million DALYs. Put another way, 3.7% of deaths from ischaemic heart disease and 6.9% from stroke were attributable to long working hours. "The disease burdens were disproportionately higher in the South-East Asian and Western Pacific regions, men, and people of middle to older working age" (Pega et al 2021 p10). The risks had increased between 2000 and 2016.

The data were not able to distinguish the quality of the work. Overall, the studies were rated as "moderate quality". But the quality of the data varied. "Most data regarding long working hours were obtained from national statistics offices with established, official data collection protocols (eg: statistical standards), but variation can still be expected. All surveys used self-reported data on working hours. Several studies showed both reliability and validity of self-reported hours, compared with administrative records...; however, this may vary. This could lead to under- or over-estimations of the burden, depending on the direction of the error" (Pega et al 2021 p11).

### 1.5.1. Employment Protection Legislation and Health

Since the 1990s, employment protection legislation (EPL) has been reduced in the West, thereby allowing employers to hire and fire workers more easily. But, at the same time, employment rights are stronger for permanent workers. This has led to the "segmentation of the labour market, whereby outsiders tend to move from one temporary contract to another while insiders enjoy high protection and stability" (Schuring et al 2020 p851).

Paid employment is associated with better health than no employment, while exit from employment is detrimental to health. There is the concern that "EPL flexibilisation that reduces employment protection may also increase the risk that vulnerable workers, particularly those in poor health or with less education, exit paid employment, perpetuating the employment gap of workers by education and health status" (Schuring et al 2020 p851).

Schuring et al (2020) investigated this concern with longitudinal data from 2003 to 2014 from the "European Union Statistics on Income and Living Conditions" (EU-SILC) panel. A sample of over 330 000 individuals aged 30-59 from 23 EU countries was analysed.

Employment status was self-reported as employment, disability (ie: unable to work), unemployment, retirement, economic inactive (eg: caring for children), or other (eg: student). Health was self-rated on a five-point scale from "very good" to "very bad". Three groups of educational attainment were distinguished, and countries were scored for EPL.

Over a four-year period, lower-educated workers were more likely to exit paid employment than higher-educated individuals, as were self-rated poorer health respondents (compared to good health respondents). Reduction in EPL in a country exacerbated these differences.

Reduced EPL led permanent workers to early retirement, especially for those in poor health, while for temporary workers health status did not matter, but unemployment was greater among lower-educated workers. It was concluded that "in most countries, employment protection laws benefit workers in poor health more than it benefits workers in good health" (Schuring et al 2020 p855).

The EU-SILC had "the variation in mode of data collection, translations and cultural interpretation" (Schuring et al 2020 p856) between countries.

The study did not investigate entering paid

employment which may be easier in countries with reduced EPL.

This study was able to analyse the effects of changes in EPL within countries, whereas earlier studies had compared between countries (eg: Reeves et al 2014). These had found that "higher employment protection is associated with a smaller employment gap between healthy and unhealthy persons" (Schuring et al 2020 p851).

## **1.6. PREVALENCE OF AUTISM SPECTRUM DISORDER**

Calculating the prevalence of disorders depends on the data available with the larger the sample the better. A full population data set would be best, as in the National Pupil Database (NPD) in England, which each term counts all pupils aged 2-21 years old in State education provision <sup>4</sup>.

Roman-Urrestarazu et al (2021) used the spring 2017 census of the NPD to investigate the prevalence of autism spectrum disorder (ASD). In the census, ASD is recorded as pupils needing ASD-specific support <sup>5</sup>.

In total, the NPD included over seven million pupils, of which 1.76% were identified with ASD (ie: 2.81% of males and 0.65% of females) <sup>6</sup>. This group was more likely to have socio-economic disadvantage than the total population, and the standardised prevalence was highest among Black pupils. The higher rate in this ethnic group was mediated by their socio-economic disadvantage. It is not clear, however, if "(1) children from socially disadvantaged families may be at higher odds of developing ASD, or (2) having a child with ASD can increase the risk of a family experiencing poverty" (Roman-Urrestarazu et al 2021 ppE7;E9).

There are mixed previous findings about this. For example, Becerra et al (2014) found higher ASD rates in the US immigrant children, while Durkin et al (2010) found lower rates among Black and lower socio-economic status groups (Roman-Urrestarazu et al 2021).

Roman-Urrestarazu et al (2021) found great regional diversity with prevalence varying from 3.3% to 0.63% at the extremes. This may be due to differences in education

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<sup>4</sup> The NPD does not include pupils in independent schools or home-schooled (estimated at 7% of 3-18 year-olds) (Roman-Urrestarazu et al 2021).

<sup>5</sup> The NPD "does not account for pupils with sub-clinical ASD or those who do not meet service thresholds to receive support" (Roman-Urrestarazu et al 2021 pE9).

<sup>6</sup> Compared to previous studies in England, Baron-Cohen et al 2009) found a prevalence of 1.57% in a school-based population study in 2009.

support provision across England and Wales, the authors suggested.

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## **2. DRUGS AND SUBSTANCES**

- 2.1. Alcohol use disorder and homelessness
- 2.2. E-cigarettes
- 2.3. Opioid agonist treatment
- 2.4. Micro-dosing and self-blinding
- 2.5. References

### **2.1. ALCOHOL USE DISORDER AND HOMELESSNESS**

Alcohol and drug use are high among individuals experiencing homelessness in the West (eg: up to 58% prevalence for alcohol and up to 54% for other drugs, but means of 38% and 24% respectively from 29 studies; Fazel et al 2008) <sup>7</sup>.

The risk of an overdose event is also an issue. For example, 3.7% of 5000 US veterans who had experienced homelessness in the previous thirty months had an alcohol overdose requiring hospital treatment (Riggs et al 2020).

A common method of treatment is the "therapeutic community model" where homeless addicts live in shared spaces while practicing abstinence (Kertesz 2021) <sup>8</sup>.

Collins et al (2021) proposed an alternative approach of harm reduction for alcohol use disorder (AUD) with a randomised clinical trial in Seattle, USA with three community-based services <sup>9</sup>. It involved 308 adults who were homeless randomised to behavioural harm-reduction treatment for AUD (HaRT-A) and extended-release naltrexone (XR-NTX) <sup>10 11</sup>, HaRT-A and placebo, HaRT-A or usual community-based supportive services (figure 2.1) for twelve weeks of treatment and 24 weeks of follow-up. Outcome measures were taken at 12, 24 and 36 weeks, and included alcohol use quantity (not abstinence), and alcohol-related harms (table 2.1).

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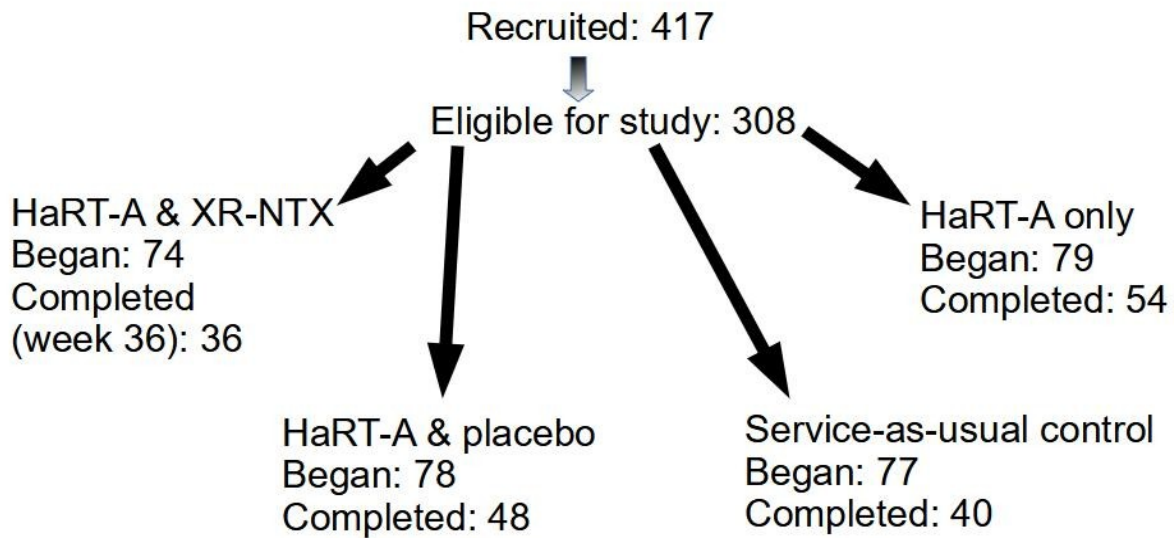
<sup>7</sup> "Alcohol use disorder is ten times more prevalent in people experiencing homelessness than in the general population, and people experiencing homelessness are six to ten times more likely to die of alcohol-attributable causes than the general population" (Collins et al 2021 p288).

<sup>8</sup> Abstinence is not necessarily the goal of individuals themselves (eg: less than 10% aspired to it) (Collins et al 2021).

<sup>9</sup> Previously, Collins et al (2019) had reported benefits over three months for HaRT-A as compared to services-as-usual controls.

<sup>10</sup> Naltrexone is a medication that combats the positive effects of alcohol and other drugs. Technically, it is an opioid receptor antagonist.

<sup>11</sup> In earlier research, Collins et al (2015) reported benefits among 31 individuals with AUD and homelessness of HaRT-A and XR-NTX.



(Based on figure 1 p292 Collins et al 2021)

Figure 2.1 - Number of participants in each condition.

- Self-reported peak alcohol quantity - Number of standard alcohol drinks on "peak drinking day in past month".
- Alcohol frequency - In past thirty days.
- Alcohol-related harm - Short Inventory of Problems-2R (Miller et al 1995): 15 items (eg: "My family or friends have worried or complained about my drinking"; "I have been sick and vomited after drinking"; "My physical health has been harmed by my drinking").
- Physical- and mental-related quality of life - Short Form-12 Survey (Ware et al 1996) (eg: "how much bodily pain have you had over the last four weeks?").

Table 2.1 - Primary outcome measures used by Collins et al (2021).

The HaRT-A and XR-NTX group did better against usual care (eg: mean alcohol quantity). HaRT-A plus placebo showed some benefits as did HaRT-A alone (figure 2.2).

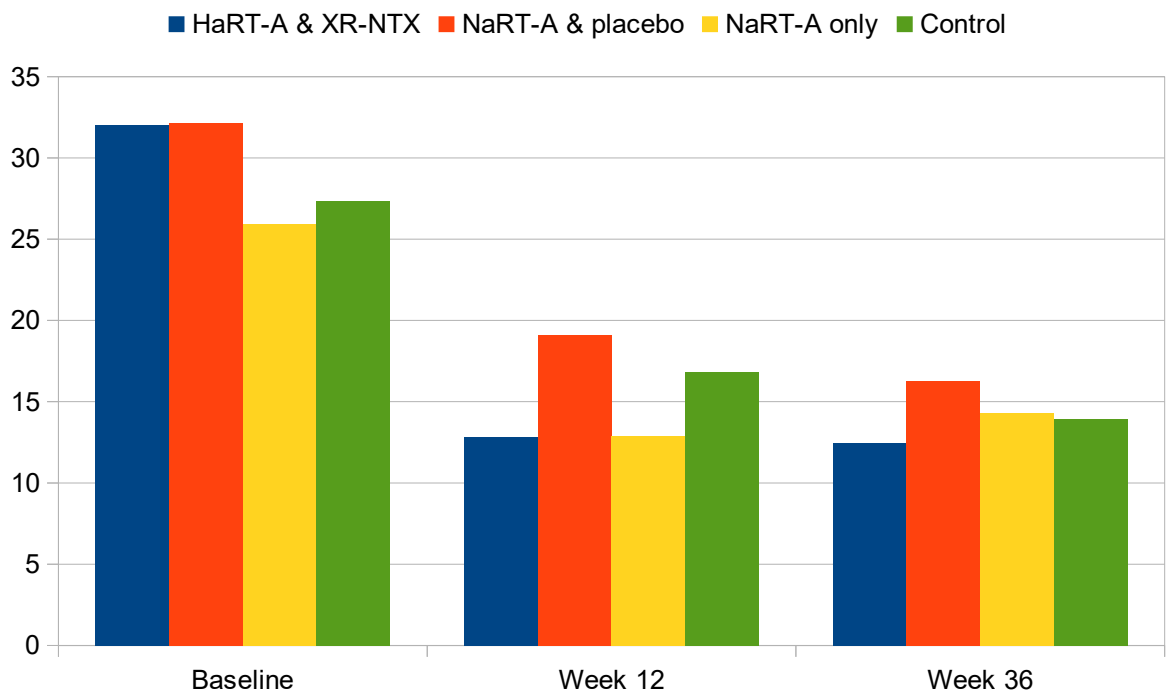
Compared to services-as-usual control group at week 12:

- HaRT-A and XR-NTX significantly improved on the primary outcome measures except mental health-related quality of life.



- HaRT-A and placebo significantly improved on the primary outcome measures, except alcohol-related harm, and mental health-related quality of life.
- HaRT-A alone had significant improvements on alcohol-related harm, and physical-related quality of life.

"After treatment discontinuation at 12 weeks, the active treatment groups plateaued, whereas the services-as-usual group showed improvements" (Collins et al 2021 p294). The researchers tried to explain this finding based on the drop-out of the control group, which was highest. They stated: "As study staff noted anecdotally, it is possible that participants in the services-as-usual control group who were able to return for follow-up assessments were simply those who were on a higher-functioning trajectory" (Collins et al 2021 p296).



(Data from table 2 p295 Collins et al 2021)

Figure 2.2 - Mean peak alcohol quantity at baseline, and at Weeks 12 and 36.

The treatment was relatively brief (12 weeks), as with the follow-up. The generalisability of the sample

had both positives and negatives. On the latter side, it was representative of the US homeless population in age, and ethnicity, though there were fewer young, and Latino individuals. The sample was also representative of the local Seattle homeless and AUD population, but the study took place in a "large, resource-rich city", and included polysubstance users. The findings would not be generalisable to housed individuals (Collins et al 2021).

Collins et al (2021) noted: "Even though the two groups in which participants received XR-NTX or placebo injections were double-blinded, there was no feasible way to mask study staff to the behavioural interventions because our aim was to keep staffing across the groups consistent to minimise differences between treatment groups. We therefore cannot preclude experimenter bias or expectancy effects for the unmasked treatment groups" (p297).

Kertesz (2021) observed: "For clinicians eager to strengthen the role of still under-used medications for addiction, this study delivers a measure of support. However, the data also suggest that the key ingredient might have been the offer of a structured, behavioural harm-reduction-focused therapy, based on client-centred, collaborative feedback, that draws on motivational interviewing and humanistic psychotherapy" (p261).

This study also challenges the necessity of abstinence as an outcome for homeless individuals with alcohol use disorder. Kertesz (2021) added: "This trial, to its enormous credit, models a structured form of treatment that can be offered to people with alcohol use disorder both when they experience homelessness and after they return to housing" (p261).

## **2.2. E-CIGARETTES**

Two key questions are attached to e-cigarettes and vaping:

i) The effectiveness in reducing tobacco smoking, particularly in comparison to other methods of smoking cessation.

ii) The harm - eg: solvents in e-cigarette liquids found to kill cells in the nose (Sven-Eric Jordt in Hamzelou 2020). Jacob George observed: "No one should claim e-cigarettes are completely safe. However... they

contain far fewer harmful chemicals than the 8000 chemicals in traditional tobacco cigarettes, the chemical interactions between which we have not even been able to fully comprehend" (quoted in Hamzelou 2020).

Concerning the effectiveness of e-cigarettes and smoking cessation, a recent study of US adults found no difference in methods of abstinence used.

The Population Assessment of Tobacco and Health (PATH) Study is a longitudinal US study with a nationally representative sample. Wave 1 (baseline) of data collection took place in 2013-14, Wave 2 in 2014-15, Wave 3 in 2015-16, and Wave 4 in 2017-18. Over 32 000 adults were interviewed at baseline.

Using data from Waves 1 and 2, Benmarhnia et al (2018), for example, found that e-cigarette use was associated with higher tobacco smoking abstinence (ie: short-term abstinence of thirty days), while Watkins et al (2020) found that e-cigarette use among older smokers was associated with smoking abstinence reported at wave 2, but not at wave 3 (ie: relapse) (Chen et al 2020). In the former case, however, the sample was self-selecting in that those who used e-cigarettes to help quit were younger than the rest of the sample, more nicotine dependent, White, and higher in income and education (Chen et al 2020).

Pierce et al (2020) analysed data from Waves 1 to 3, and included only daily cigarette smokers at Wave 1 (which Benmarhnia et al 2018 did not do), who attempted to quit by wave 2 and whose smoking was assessed at wave 3. Smoking frequency, e-cigarette use, and quitting were self-reported in retrospect for the past year.

At Wave 1, there were 9021 daily cigarette smokers, of which 2770 had attempted to quit by Wave 2. Around one-quarter of the latter had used e-cigarettes as a method to quit smoking, another quarter used other pharmaceutical aids (eg: nicotine replacement therapy), and the remainder no products. Thus, three groups for comparison.

At wave 3 there was no significant difference between the three groups in abstinence from tobacco smoking for thirty days or twelve months.

Frequency of e-cigarette use was not measured. But it was found that "over half those who used e-cigarettes in their quit attempt still used e-cigarettes a year later" (Pierce et al 2020 p12).

In conclusion: "Among US daily smokers who quit cigarettes in 2014-15, use of e-cigarettes in that attempt compared to approved cessation aids or no

products showed similar abstinence rates 1-2 years later" (Pierce et al 2020 p2).

Chen et al (2020) included data from Wave 4. They found that "e-cigarette users did not have higher rates of long-term abstinence from cigarette smoking but did have lower rates of abstinence from nicotine than their matched peers. This difference appeared to be largely due to high rates of continuing use of e-cigarettes among those who quit smoking cigarettes" (Chen et al 2020 p1534).

### **2.3. OPIOID AGONIST TREATMENT**

"Injecting drug use causes multiple health harms including overdose death and blood-borne virus transmission. Due to the criminalisation of illicit opioid use, many people who inject drugs experience incarceration, which causes further detrimental health effects" (Stone et al 2021 p301).

Opioids are the most common injected drug category, and opioid agonist treatment (OAT) (eg: methadone) "reduces injecting risk behaviour, the risk of HIV and hepatitis C virus (HCV) transmission, all-cause and overdose mortality in the community, in prison, and following release from prison, and increases engagement in the HIV and HCV cascades of care. Other causes of mortality might also be reduced during OAT, including injuries and suicide, and OAT might reduce reincarceration" (Stone et al 2021 p301).

Using existing data, Stone et al (2021) modelled the health benefits of OAT in three geographical areas of the world - Kyiv (Ukraine), Tehran (Iran), and Perry County (Kentucky, USA). Scaling up OAT (to 40% of community dwelling individuals who inject drugs) was estimated to reduce preventable drug-related deaths by between 12-24% over the next twenty years (compared to the status quo). "This is largely driven by reductions in overdose deaths in Perry County and reductions in HIV-related deaths in Kyiv and Tehran" (Stone et al 2021 p305).

If OAT was made available to prisoners equitable to community-dwellers, 27-51% of preventable drug-related deaths could be averted. Overall benefits would increase further with better availability of anti-retroviral therapy for HIV.

In real-life, such successes are limited by barriers to OAT including availability and access, and retention of participants on programmes.

## 2.4. MICRO-DOSING AND SELF-BLINDING

Anecdotal-based claims have been made about micro-doses of psychedelic drugs (eg: LSD (lysergic acid diethylamide)) and improved creativity. The micro-dose may be 10% of a normal dose (Wilson 2021). "Due to its underground origin, micro-dosing does not have a universally agreed upon definition, and inconsistencies exist in substance, dose, frequency, and duration of use" (Szigeti et al 2021 p1).

But is the benefits anything more than expectation (ie: placebo effect)? Because of the illegal position of these drugs, official clinical trials would be difficult to gain permission to undertake and fund.

Szigeti et al (2021) overcame this problem with an unusual trial design (including self-blinding). Firstly, the researchers found individuals online who already micro-dosed such drugs and asked them to participate <sup>12</sup>. One hundred and ninety-one participants <sup>13</sup> were sent empty medical capsules in which small pieces of drug-laced paper could be placed. Keeping some capsules empty (as the placebo), QR codes were recorded from each capsule, before mixing up the empty and full ones. So, the participants did not know which type of capsule was which (ie: self-blinding). They were instructed by the researchers to take certain capsules based on QR codes, which the experimenters knew, such that one-third of the participants took micro-dosed capsules for four weeks, one-third placebo capsules, and the remainder a mixture. Participants were regularly asked about their moods and creativity, and took objective cognitive tests.

All three groups showed similar improvements in the subjective measures. Participants who guessed which capsules they were taking showed the best improvements, suggesting the benefits were due to the placebo effect.

Objective measures of creativity would have been better (Bernhard Hommel in Wilson 2021).

Commenting on their methodology overall, Szigeti et al (2021) stated: "It is our view that the present part-controlled, part-observational design yields data superior to conventional observational data (inclusion of placebo control), but inferior to controlled clinical trial data (incomplete control over recruitment, screening, assessment, drug administration etc). This study does, however, have greater ecological validity

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<sup>12</sup> LSD was the most common drug used.

<sup>13</sup> Initially, 1630 individuals signed up to participate, but only 240 started the study and of them, 191 completed it.

than would a fully controlled lab study" (p14).

The key limitation was the lack of verification of the drug used (ie: its purity and dose size). Szigeti et al (2021) countered that "our results should not be understood as clinical evidence, rather they are representative of 'real life micro-dosing'" (p14). Likewise, there was no independent confirmation that the participants followed the procedure, particularly the self-blinding aspect.

The researchers have created "a novel, cost-effective, self-blinding, citizen-science methodology" (Szigeti et al 2021 p15).

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### **3. INTERNET AND HEALTH INFORMATION**

The colloquial phrase "Dr Google" sums up the use of the Internet to search for answers to health questions. The Internet is used "before seeking care to understand why they are ill, whether they should get care, and where they should get care. The value of performing an internet search for health purposes is controversial, with concerns that it leads to inaccurate diagnosis, inappropriate triage (ie: choosing the right location to seek care), and increased anxiety (cyberchondria [Loos 2013])" (Levine et al 2021 p2). At the two extremes, individuals may not seek help when they should or become terrified about their symptoms when medical help is not needed.

It is estimated that two-thirds of US adults do health-related Internet searches, and half of these self-diagnosis (Levine et al 2021).

Levine et al (2021) investigated Internet searching and diagnosis, triage, and anxiety with 5000 US adults in April 2019. The online participants were presented with case vignettes (of about fifty words) (table 3.1), and asked their opinion before searching on the Internet and updating their opinion. The appropriate diagnosis and triage of each case were determined beforehand by twenty-one physicians. The cases varied in severity (eg: viral illness; heart attack), and four triage categories were

- "18-year-old male; Has fever 102; Neck stiff; Light bothers him" (Correct diagnosis - meningitis; correct triage - emergency).
- "7-year-old female; White stuff in back of throat; Painful front of the neck; No cough, no congestion; Temperature 102" (Correct diagnosis - strep throat; correct triage - same-day).
- 65-year-old female; Triggered by tilting her head back to look up; Each attack lasts about 30 seconds; No hearing problems or weakness (Correct diagnosis - vertigo; correct triage - one-week).
- "34-year-old female; No fever; Had also had a sore throat and cough; No other medical problems" (Correct diagnosis - common cold; correct triage - self-care).

(Source: eTable 1 Levine et al 2021)

Table 3.1 - Three examples of case vignettes used by Levine et al (2021).

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used - emergency (immediate emergency attention required), same-day (urgent, not emergency, seek help on the day), one week (not an emergency, but will not get better by itself, see a doctor within one week), and self-care (let get better on its own).

Before the Internet search, diagnosis of emergency cases was correct by 40% of the participants and self-care cases by 67%. Correct triage for emergency cases was 87% and 69% for self-care cases. Anxiety increased with the seriousness of the case.

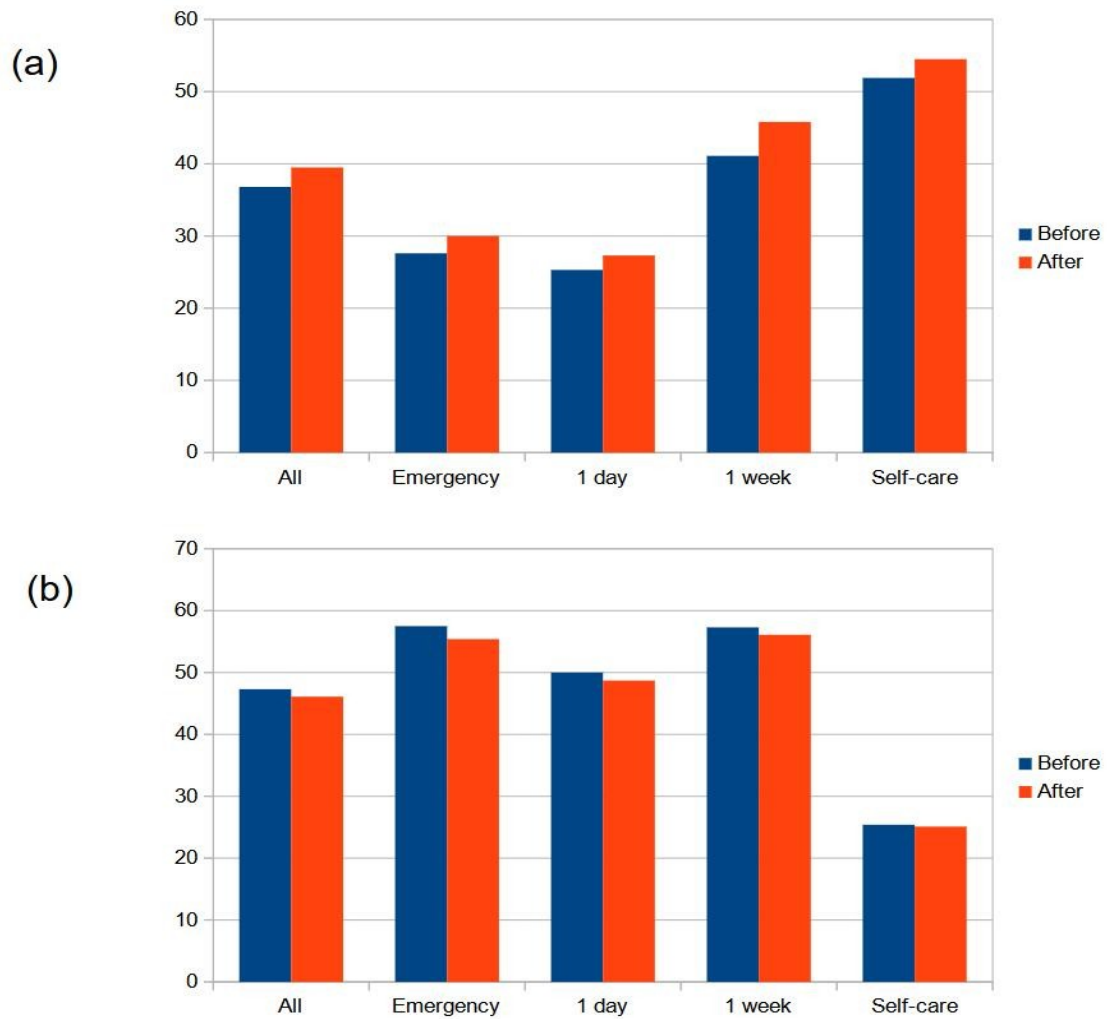
The participants spent an average of twelve minutes on Internet searching. Accuracy of diagnosis increased in all types of cases, with 10% moving from incorrect to correct diagnosis while 5% went the other way. But triage accuracy did not change (with 6% moving in either direction with correct and incorrect triage), nor did self-reported anxiety (figure 3.1).

Martin et al (2019) had found that patients in an emergency department waiting room did not report increased anxiety after an Internet search. Though observational studies have mixed findings here (Levine et al 2021).

Levine et al (2021) found that correct diagnosis and triage was more likely with increasing age, education, and income, and with living with chronic disease.

Levine et al (2021) suggested that the improvement in diagnosis in their study after Internet searching was due to "that over time, search engines have tried to direct people to higher-quality health information. For example, several search engines have their own built-in health information curated by major medical centres..." (p9). Few of the participants used social media (1.5%), where the quality of health information may be lower (Levine et al 2021).

The authors noted that their "results could be framed quite differently. Although it was associated with no harm, any benefit of an internet search was small" (Levine et al 2021 p9). It was possible that anchoring occurred (ie: "internet searchers may simply look for information to justify their initial decision rather than being open to all recommendations"; Levine et al 2021 p10).



(Data from eTable 2 Levine et al 2021)

Figure 3.1 - Mean % correct before and after Internet search: (a) diagnosis; (b) triage.

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## **4. PRE-PUBERTAL BIPOLAR DISORDER**

Pre-pubertal bipolar disorder (PPBD) (or very early onset sub-type of bipolar disorder) is a diagnosis with controversy. One view is that it is a forerunner of adult bipolar disorder. A Canadian longitudinal study (eg: Duffy et al 2018), for example, has found a developmental trajectory of bipolar disorder "shifting from sleep and anxiety symptoms and disorders in childhood to minor depressive and adjustment disorders (internalising symptoms related to stressors) in early adolescence (around or after puberty) to major depressive disorder and hypomanic symptoms in mid-adolescence and to bipolar disorder in late adolescence and early adulthood" (Duffy et al 2020 p4).

But certain criteria of bipolar disorder are not evident in childhood. "For example, it is clear that many of the symptoms of mania cannot be experienced by children in the same way as they are in adults, and therefore their expression is very different or lacking altogether. For example, heightened libido, grandiosity and diminished insight don't have meaningful equivalents in children. Furthermore, many of the symptoms, thought to be distinctive of mania in adults, are less remarkable when they occur in children, and may even be regarded age-appropriate. For example, believing you are a superhero with special powers is of some concern in an 18-year-old but is perfectly normal in an 8-year-old" (Malba and Bell 2020 p1).

There is also the issue around the criteria of adult bipolar disorder, particularly the "bi-polar" part. In other words, the condition has two poles - mania and depression - as opposed to "mixed states". If the latter, "it further complicates the transposition of clinical phenotype from adults to children and makes the prospect of identifying definable antecedents exceptionally challenging. This is especially so, given that mixed states are extremely poorly defined in adult bipolar presentations" (Malba and Bell 2020 pp1-2).

In terms of the history of PPBD, in the 1990s a pre-pubertal sub-type of bipolar disorder was proposed, which was characterised by "chronic irritability and explosive temper (taken as a manic equivalent) in the context of neurodevelopmental and externalising behaviour problems" (Duffy et al 2020 p2). This was linked to reports in the USA that as many as 40% of children with attention-deficit hyperactivity disorder (ADHD) also showed "mania" (eg: Wozniak et al 1995). "These reports caused

significant debate as findings were not replicated in several centres outside the US" (Duffy et al 2020 p5).

Dubicka et al (2008) presented five vignettes of children and adolescents with various symptoms to clinicians in the UK and the USA. The latter were more likely to diagnose mania, while the UK clinicians diagnosed pervasive developmental and adjustment disorders (Duffy et al 2020).

Paediatric bipolar disorder has rapidly increased in diagnosis in the USA (eg: 40-fold between 1994 and 2003), but not in other countries (Duffy et al 2020). "Whereas some US centres have maintained that pre-pubertal bipolar disorder is characterised by non-episodic, chronic, ultra-rapid cycling, mixed/irritable states, in the UK, and perhaps elsewhere, such cases are more likely to be conceptualised as oppositional defiant disorder (ODD), conduct disorder and/or ADHD with emotional dysregulation" (Duffy et al 2020 p6).

Duffy et al (2020) offered this possible explanation: "Unique aspects of the US health system may have been important in the greater acceptance of pre-pubertal mania (bipolar disorder) as a valid diagnosis. It has been argued that the US health system often drives clinicians to engage in 'diagnostic upcoding' and managed care has been anecdotally reported as providing more funding for a diagnosis like bipolar disorder, than for difficulties such as parent-child relational problems... It has been argued that the expansion of bipolar disorder has been created in order to market new drugs into the more profitable realm of everyday emotional problems, rather than limiting them to classical forms of bipolar disorder, and in so doing, medicalising personal and social difficulties" (p7).

Duffy et al (2020) summarised two problems with PPBD:

a) Bipolar disorder has high heritability, and "children of affected parents would be the most likely group expected to manifest an early-onset pre-pubertal form of bipolar disorder – if it existed" (Duffy et al 2020 p7). But this has not been found in longitudinal studies of high-risk individuals (eg: children with parent(s) with bipolar disorder).

b) A lack of "reliable and objective biomarkers" (p7) for PPBD. Kendler (2016) observed that "since DSM III, our field has moved toward a reification of the DSM that implicitly assumes that psychiatric disorders are

just the DSM criteria. That is, we have taken the index of something for the thing itself" (quoted in Duffy et al 2020).

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## **5. HEALTH AND VARIOUS**

- 5.1. Leisure activities
- 5.2. Environment
  - 5.2.1. Climate change
  - 5.2.2. Air pollution
- 5.3. References

### **5.1. LEISURE ACTIVITIES**

"Leisure activities" (LAs) can be defined as "voluntary non-work activities that are engaged in for enjoyment, and encompass actions such as: taking part in hobbies; participating in arts; taking educational classes; reading; watching television; socialising; shopping; listening to music; volunteering; joining religious activities; participating in political parties, trade unions, or environmental groups; engaging in libraries, archives, culture, and heritage activities; taking part in sports or exercise groups; cooperating in community, neighbourhood, or tenants' groups; and participating in social clubs" (Fancourt et al 2021 p329).

LAs are important for physical and mental health (both subjective and objective), and have been described as "the principal driving force underpinning the human desire to render life meaningful... or to give it a sense of passion, pleasure and purpose" (Blackshaw 2016 quoted in Fancourt et al 2021).

Fancourt et al (2021) lamented that there is "no unifying theoretical framework explaining how leisure activities affect health" (p329), despite "thousands of studies". These researchers identified over 600 "potential mechanisms of action" in their literature review.

Fancourt et al (2021) proposed the "Multi-Level Leisure Mechanisms Framework" which integrates five categories and three levels (micro (individual), meso (group), macro (society)):

i) Psychological processes - eg: affective state impacted by LAs (micro-level); development of group identity (meso- and macro-level).

ii) Biological processes - eg: improving physical functioning where physical activity part of LAs (micro-level); affecting disease patterns across society (macro-level).

iii) Social processes - eg: increased social contact (micro-level); supporting group cohesion (meso- and macro-level).

iv) Behavioural processes - eg: influencing individual choice (micro-level); spending on leisure assets (macro-level).

v) Health behaviours - eg: disengagement with unhealthy behaviours (micro-level); health-care policy (macro-level).

In the model, LAs "involve multiple components and simultaneously causal strands", and "the mechanisms involved in complex interventions are non-linear and can involve positive and negative feedback loops, recursive causality (whereby mechanisms can reinforce one another via feedback loops, leading to outputs functioning as inputs), self-reinforcement (whereby the successful activation of one mechanism might lead to adaptation of an individual's engagement with a leisure activity so that this mechanism is further enhanced), disproportionate relationships (whereby small changes in individual's leisure patterns can lead to big differences in mechanisms and outcomes), and emergent outcomes (whereby mechanisms and outcomes develop during the implementation of a leisure intervention)" (Fancourt et al 2021 p333). The relationships are not static, and have to be seen in the context of the individual's life.

## **5.2. ENVIRONMENT**

### **5.2.1. Climate Change**

High outdoor temperatures (heat) are a health risk, particularly as the world warms in the 21<sup>st</sup> century. Predicting the burden of future morbidity and mortality can be helped by quantifying the effect in recent years. Vicedo-Cabrera et al (2021) covered the period 1991 to 2018, and included data from 723 locations in forty-three countries (collected through the Multi-County Multi-City Collaborative Research Network).

Firstly, the relationship between daily mean temperature and all-cause mortality was calculated for the four warmest consecutive months in each location. A range of 15 - >25 °C depending on the country, and in total, nearly 30 million deaths. The actual data were compared to simulations of temperature without human-

induced climate change. Overall, over one-third (37%) of warm-season heat-related deaths could be attributed to human-induced climate change, but the figures varied between countries. This depended on factors like "the level of warming, the built environment and the age structure and underlying health status of the population" (Vicedo-Cabrera et al 2021 p498).

The study did not include large parts of Africa and South Asia due to lack of data (Vicedo-Cabrera et al 2021).

Lomotey (2021) asked, "Is climate change a racist crisis?", and answered, "Yes, simply because those who have done the least to cause the problems are the ones who are suffering the most" (p18).

Consequently, Verges (eg: 2019) preferred to use the term "capitalocene" to describe the current age because capitalism is behind the climate changes, whereas "anthropocene" "implies all humans are responsible for the state of the environment when some are very much more responsible than others" (Lomotey 2021 p11).

The term "climate anxiety" has been coined to explain feelings of shock, disorientation, and a sense of powerlessness when thinking about the future climate changes (Randall 2021). Randall herself, however, preferred "climate distress", "partly because it doesn't have the overtones of a diagnosis, and partly because people are usually describing a whole range of painful feelings, many of which are not anxiety" (p23).

A study in Finland found that around one quarter of respondents reported anxiety related to future climate (Randall 2021).

The response to grief and loss can be applied here (Randall 2021):

- Accept the reality of the crisis.
- Work through the painful emotions (eg: feelings of loss).
- Adjust to the "new world".
- Choose a path of action.

### **5.2.2. Air Pollution**

Outdoor air pollution is known to have a negative  
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effect on cardiovascular and respiratory health, but what about the brain? "Emerging evidence suggests that air pollution can also directly (eg: via translocation of ultra-fine-pollutant particles across the nasal olfactory nerve) or indirectly (eg: via inflammatory signalling from other organ systems, particularly the lungs) harm the central nervous system" (Reuben et al 2021 p2). Could psychiatric disorders be a consequence?

Reuben et al (2021) reported longitudinal data on air pollution exposure in childhood and psychiatric problems in adolescence and early adulthood. The sample from England and Wales involved twins born in 1994-5 ("Environmental-Risk (E-Risk) Longitudinal Twin Study). The 2232 twins were studied regularly up to 18 years old (the latest data collection).

Exposure to air pollution was calculated at 10 and 18 years old based on official data for the participants' residential area. Psychiatric disorders at age 18 were based on self-reports of symptoms in the past year during an interview. Statistical analysis included controlling for co-variables like socio-economic status, family psychiatric history, and "neighbourhood disadvantage" (eg: level of crime).

Overall, exposure to more air pollution was associated with psychopathology. But this general pattern included variations in the detail. After controlling for co-variables, the relationship was strong for nitric oxides exposure. There was significantly greater psychopathology in the top quartile of exposure compared to the rest of the sample. This was found to be "independent of urbanicity; individual and family risks, such as family psychiatric history; and disadvantageous neighbourhood characteristics correlated with air pollution, including deprivation, dilapidation, disconnection, and dangerousness" (Reuben et al 2021 p8).

Particulate matter (PM<sup>2.5</sup>) exposure was not generally associated with psychopathology, but the highest quartile of exposure had non-significantly higher psychopathology than the rest of the sample.

In terms of symptoms, externalising-spectrum disorders (eg: alcohol dependence; conduct disorders), and thought disorders (eg: hallucinations) were more common with higher air pollution exposure.

The impact of air pollution on psychiatric illness was small, in total, so it is "unlikely be a major aetiologic factor" (Reuben et al 2021 p8), but it is similar in magnitude to other neurotoxins like lead. A non-modifiable risk factor like family history of mental

illness has over twice the impact on the individual's likelihood to develop a mental disorder (Reuben et al 2021).

The strengths of this study included longitudinal data, the measurement of general psychopathology rather than specific mental disorders, a large sample, and control for many co-variates. In terms of limitations, these included (Reuben et al 2021):

- Estimates of air pollution exposure only.
- Pre-natal air pollution exposure not measured.
- Only two types of air pollution measured, but not carbon monoxide or lead, for example.
- Traffic noise was a co-variate not controlled for.
- The data were observational and so causation cannot be established.

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## **6. FAIRNESS, JUSTICE AND DIVERSITY**

- 6.1. Medical neo-colonialism
  - 6.1.1. Universalism
  - 6.1.2. Lack of diversity
  - 6.1.3. Football and mental health
  - 6.1.4. Gender
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- 6.8. Kashmir
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- 6.10. References

### **6.1. MEDICAL NEO-COLONIALISM**

Medical treatment and care vary greatly between the rich and poor countries of the world, as does the administration of clinical trials. Both situations raise their own ethical issues.

The increase in clinical trials performed in developing countries in recent years (ie: the global movement of research) is "very much comparable to economic globalisation models of cost-benefit with the Global South nations offering lower salaries for human labour and shortened timelines for clinical testing. Moreover, a fundamental incentive for the geographical shift in research derives from more tolerant regulatory and ethical barriers than in Western Europe, North America and Japan" (Kim et al 2017 p401). The "ethical laxity" is a concern.

"Clinical trials that have been designed by the Global North, for the Global South, however, have too often shown sub-standard oversight in comparison to the degree of fidelity implemented in their own countries, for their own subjects" (Kim et al 2017 p403). This double standard has been described as part of "medical neo-colonialism". Simply, neo-colonialism generally is where former colonies (ie: independent countries) are treated as if they were still colonies of the mother

state (Nkrumah 1996) <sup>14</sup>.

Luria and Wolfe (1997) explained, for example: "Researchers might inject live malaria parasites into HIV-positive subjects in China in order to study the effect on the progression of HIV infection, even though the study protocol had been rejected in the United States and Mexico" (p855). This study was actually done by Heimlich et al (1996 quoted in Luria and Wolfe 1997). Angell (1988) stated: "Human subjects in any part of the world should be protected by an irreducible set of ethical standards" (quoted in Luria and Wolfe 1997).

Kim et al (2017) proposed an institutional review for randomised controlled trials (RCTs), say under the auspices of the World Health Organisation (WHO), that would assess the ethics of studies in the same way throughout the world.

The RCT, which compares a drug to a placebo, say, is the "gold standard" for assessing treatments. The control or placebo group receiving saline solution, for example, at least have "standard care" to compensate. But in poorer countries where standard care is low quality, the placebo group are highly disadvantaged, and so there is a question of the ethics of such groups in such countries.

Luria and Wolfe (1997) argued that the rich sponsoring country's level of standard care should be part of the agreement to perform a clinical trial in poorer countries.

"Informed consent is central to human research. A thorough consenting procedure acts as a barrier to harmful bioethics and empowers participants with choice of and within the trial. The neo-colonial world undermines informed consent in two main ways - by misguided information or by limiting participation freedom" (Kim et al 2017 p405). The latter is seen in individuals agreeing to participate in trials because it is the only way to receive treatment. For example, one participant in a HIV trial in the Ivory Coast enrolled because of the offer of "free health care and a hope to shield [them from disease]" (Annas and Grodin 1998 quoted in Kim et al 2017). "The hope that being involved in a trial, and any trial at that, may then cure all the

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<sup>14</sup> Sivanandan (1979) observed: "One epoch does not lead tidily into another. Each epoch carries with it a burden of the past - an idea perhaps, a set of values, even bits and pieces of an outmoded economic and political system. And the longer and more durable the previous epoch the more halting is the emergence of the new" (p111). This author applied this observation to Britain at the end of the Second World War as traditional imperialism ended, and the "continued exploitation of colonial labour" occurred via immigration (Sivanandan 1979).

ailments of the participant, creates a pool of willing volunteers who, despite attempts at acquiring an 'informed consent', will enrol on the basis of misguided hope. It creates an extremely simple study population for the multi-national drug companies to use" (Kim et al 2017 p406).

Annas and Grodin (1998) argued that informed consent cannot be seen as valid if an individual has only the choice of no treatment normally or treatment as part of the trial.

Informed consent also requires the individual understands what they are agreeing to (literacy), and it makes sense to them (cultural sensitivity) (Kim et al 2017). On the other hand, cultural sensitivity that allows the head of the village to consent for all members opens the possibility of corrupt individuals taking advantage of this tradition. "When this simple picture of a village head is amplified to that of a corrupt national governing body, no doubt with the persuasive help of multi-national companies and powerful corporations, the potential for harm becomes stark. This, therefore, highlights the importance of maintaining absolute ethics, thereby giving power to the individuals rather than paying homage to cultural diversity in these instances" (Kim et al 2017 p405).

Medical neo-colonialism is also seen in the focus of clinical trials in the Global South - ie: for treatments relevant to the rich countries, like "allergic rhinitis and overactive bladder, rather than imminent health issues such as malaria, tuberculosis and neglected tropical diseases. While it can be argued that these studies bring about global medical benefit, it is difficult to justify the true social value of conditions that are not imminent health concerns of the Global South. Moreover, drugs and pharmaceuticals to be used primarily in the Global South may never be tested in the Global North" (Kim et al 2017 p406).

Furthermore, how generalisable are clinical trial results from the poorer to the richer countries? Individuals in the trials may experience malnutrition, say, and its effects on the body and interaction with the treatment.

Kim et al (2017) ended: "The issues that form the divide between the Global North and South are deeply rooted in historical socio-political factors and encompass neo-colonial and post-colonial <sup>15</sup> aspects of

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<sup>15</sup> "Post-colonialism" "describes the socio-political, economic, cultural and intellectual hybridity of Psychology Miscellany No.151; August 2021; ISSN: 1754-2200; Kevin Brewer

dependency and exploitation. These concepts suggest that medical globalisation of clinical trials may be placing greater importance in scientific advancement than the welfare of the individuals involved, particularly in the developing world setting" (p407).

### **6.1.1. Universalism**

Wu (2021) began: "The dispute over the universality of diseases dates from the time of imperial expansion in the second half of the nineteenth century. Along with the question of universality, the pursuit of universal standards of measurement for disease also has a long history" (p1). Such universality allows for scientific rigour, and the promotion of public health, for example, but it can also be restrictive. For example: "The fundamental assumption of universalism is that mental illness is universal and that our job in looking cross-culturally is to find evidence for these universals. Two things may obscure the true nature of universal illnesses: first, the way we label conditions in different settings, and second, how conditions are expressed in different cultures" (Leff 1988 quoted in Wu 2021).

The criticisms of Western psychiatry's approach include the medicalisation of daily life to increase its power, being hi-jacked by capitalism (and in particular, pharmaceutical companies), and "reductionism that insults a sense of self" (Wu 2021 p11).

Wu (2021) explained the context: "These critiques, though emerging in different times, sketch a picture in which psychiatry is a hegemonic and inhumane science in service to state authorities or global big pharma. They, however, ignore that a 'globalised psyche' was in high demand in the precarious post-war era. From the late 1940s to the early 1970s, psychiatrists, like many medical and social scientists, shared a vision of the universality of mental disorders that differed greatly from present-day critiques of the globalisation of mental illness and the role of big pharma" (pp11-12).

### **6.1.2. Lack of Diversity**

Many gene locations (loci) have been identified in

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the people residing in decolonised states. The post-colonial theory accounts for the development of a new identity of the colonised person, as determined by the racism and subjugation that fundamentally arise from the construct of a colonial society" (Kim et al 2017 p403).

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relations to type 2 diabetes. But the studies on which such observation are based have "insufficient representation of individuals of non-European ancestry" (Chen et al 2021 p840).

Chen et al (2021) aggregated data from genome-wide association studies that included around one-third of individuals of non-European ancestry. In total 242 loci related to type 2 diabetes were found, but focusing only on individuals with European ancestry would have led to 24 fewer new loci. Thus the importance of diverse populations in genetic studies.

### **6.1.3. Football and Mental Health**

Professional football is male dominated with "masculine codes of deflection" (eg: hiding of weakness) (Bennett 2021). Mental health problems would be an example of a "hidden weakness", yet Carmody et al (2020) found that 16% of 1034 English male players reported symptoms of depression in 2020.

Bennett (2021) criticised such research for ignoring racism as causal factor of mental health problems. He stated: "The lack of analysis of racism is primarily because these studies are mostly quantitative, and are profoundly incurious about the diversity and lived experiences of professional footballers. As a consequence, players are falling victim to a biological, symptom-based approach that is largely ignorant of the crucial structural factors underpinning players' mental health issues, particularly for Black players, who make up 30% of professional footballers in England and Wales" (Bennett 2021 p265) <sup>16</sup>.

The biological approach suppresses the Black players' experience. "The danger is that the lived world of Black professional footballers is made captive to medical forms of diagnostic categorisations and is hidden behind what could be called, adapting Fanon's [1967] metaphor, a sports medicalised mask" (Bennett 2021 p265).

### **6.1.4. Gender**

Many mental health projects in poorer countries depend on volunteers because salaried counsellors, say, is unsustainable. Chase et al (2021) noted: "The past decade has seen a proliferation of psycho-social

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<sup>16</sup> Brownrigg et al (2017) tried to get at the lived experience of professional footballers using an interpretative phenomenological analytical approach.

interventions delivered by lay community workers, a predominantly female workforce. Under the right conditions, task shifting in this way can address geographical and socio-economic inequities in access to care and support women's empowerment. Yet, such interventions also carry the risk of further entrenching gender inequalities when female community workers are viewed instrumentally as a source of more affordable clinical labour" (p267).

Concentrating on Nepal, volunteer counsellors were recruited in 2016 by the Government from women's co-operatives. "Initially, there was enthusiasm and even competition within women's co-operatives for the opportunity to receive counselling training. After beginning to practise, however, counsellors started to voice concerns over inadequate remuneration. Most were young married women who bore the heaviest burden of domestic labour in their families while occupying the lowest rungs of the social hierarchy. The cash incentive offered was insufficient for them to be recognised as fully fledged professionals or get reprieve from domestic responsibilities, resulting, in many cases, in women bearing a double workload. Ultimately, remuneration issues led many counsellors to resign within the first 2 years of the programme" (Chase et al 2021 p268).

Simply, Chase et al (2021) argued, there is a need for women to be paid the appropriate salary for their community psycho-social work.

#### **6.1.5. International Bureaucracies**

Littoz-Monnet (2021) described an expansion of activities of the World Health Organisation (WHO) and United Nations Educational, Scientific and Cultural Organisation (UNESCO) in relation to bioethics (eg: governance of human genetic data). "International bureaucracies expand their activities in new domains, which can be related, or not, to their formal mandates. Mission creep does not necessarily involve a formal mandate change; rather it takes place when international secretariats engage in a significant amount of activities into new areas (such as standard-setting activities, support programmes, and dissemination activities)" (Littoz-Monnet 2021 p858).

Littoz-Monnet (2021) argued that this expansion is "through subtle mechanisms, in a way which is informal, mundane, technical, and depoliticised" (p859) <sup>17</sup>.

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<sup>17</sup> Hay (2014) defined depoliticisation as "the set of processes (including varied tactics, strategies, and Psychology Miscellany No.151; August 2021; ISSN: 1754-2200; Kevin Brewer



Consequently, there is often little reaction from states.

Littoz-Monnet (2021) outlined five tactics of the expansion:

1. An issue is framed as "global", and thus requiring an international response.
2. The new issue is linked to the bureaucracy's mandate and existing issues.
3. The international bureaucracies refer to their "in-house" expertise on the subject.
4. The pressure they exert is presented as "apolitical, neutral and universal" (p860) (ie: "issue technicalisation") (Littoz-Monnet 2021).
5. The organisations present themselves as a "neutral broker" on disputes.

Applying these tactics to the area of bioethics, Littoz-Monnet (2021) described UNESCO's framework on bioethics from the late 1980s as a good example of tactic 1 above. The organisation "presents its intervention in the field as a response to 'globalisation', stressing that 'the development and diffusion of science and technology are increasingly global in nature' and that 'there is also an urgent need to establish and promote common norms and values, promote ethical principles and standards to guide scientific progress and technological development' [UNESCO 2008]" (Littoz-Monnet 2021 pp866-867). Bioethics were linked to UNESCO's mandate (eg: human rights) (tactic 2), and the organisation claimed expertise with the establishing of the International Bioethics Committee (tactic 3), for instance.

The WHO "moved" into bioethics in the 2000s, and "they framed bioethics as connected to public health, which falls directly within the mandate of WHO, thus shifting away from the UNESCO's discourse which linked bioethics to human rights concerns" (Littoz-Monnet 2021 p870) (tactic 5 above). Littoz-Monnet (2021) showed tactic 4 in action also: "In line with its self-proclaimed role of neutral broker, WHO approached bioethics in a very technical manner. It has, essentially, published what it calls 'recommendations' or 'technical guidelines' in specific issue domains. These

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tools) that remove or displace the potential for choice, collective agency, and deliberation around a particular political issue" (quoted in Littoz-Monnet 2021).

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instruments are presented as apolitical, neutral, professional responses to specific problems" (p873).

All of this is not to say that the involvement of these two organisations in bioethics is a bad thing.

## **6.2. AFRICAN-CENTERED PSYCHOLOGY**

Referring to "transpersonal psychology", but relevant to many areas of knowledge, Hartelius et al (2007) made the point that "if transpersonal psychology aspires to be a fully integrative human psychology, a psychology that is not only East-West but also North-South, it will need to invite voices from the rest of the world" (quoted in Ebede-Ndi 2016).

In response, Ebede-Ndi (2016) reflected on the field of "African-centered psychology". This author stated that there are "opposing views about the existence of an African identity and the nature of an African-centered psychology. Africa is a continent of 54 countries, and each country has its own tribes and cultures; it is then not possible to describe an African-centered psychology that represents all Africans" (Ebede-Ndi 2016 p65). But for those who want to talk of such a psychology, "Afrocentrism" is important. This includes "[A]n intense interest in psychological location as determined by symbols, motifs, rituals, and signs...[and] a commitment to lexical refinement that eliminates pejoratives about Africans or other people" (Ebede-Ndi 2016 p66).

"Pan-Africanism" is another important idea, which can be described as "the common lived experience, felt emotion, and shared memory of African people on the continent and in the diaspora" (Ebede-Ndi 2016 p67). These concepts are not without difficulties (Ebede-Ndi 2016).

An African-centered psychology involves "the liberation of the African mind, empowerment of the African character, and enlivenment and illumination of the African spirit" (Ebede-Ndi 2016 p72). Karenga (1992) identified three theoretical approaches to achieving this in psychology (Ebede-Ndi 2016):

i) "The traditional" - Using the "Eurocentric psychology models" but with "African" criticisms.

ii) "The reformist" - More wholesale criticisms of Eurocentric psychology because of the racist assumptions implicit in the models.

iii) "The radical" - A need for an entirely new African-centered psychology because Eurocentric psychology cannot be changed for the good.

Likewise, in relation to psychological methodology, Banks (1982) outlined three critical approaches (Ebede-Ndi 2016):

a) Deconstructive - "denounce and expose the biases and weaknesses in the scientific literature about Black people" (Ebede-Ndi 2016 p72).

b) Reconstructive - Attempting to correct the biases.

c) Constructive - The desire to create "new paradigms and methodologies that stem from an organic, authentically African epistemological and ontological base" (Harrell 1999 quoted in Ebede-Ndi 2016).

For example, "the construction of an African version of the Western Diagnostic and Statistical Manual of Mental Disorders (DMS) that can describe the nosology and nosography of African illnesses that are both visible and invisible: 'The development of an African-centered classification of disease, that is, nosology, should at a minimum (a) use African languages and logic and (b) explore the application and relevance of these ideas and notions in illuminating...''the suffering of the spirit'' [Nobles 2013]" (Ebede-Ndi 2016 p73).

Myers (1988) described an "optimal African worldview" as consisting of "(a) viewing the spiritual and material as one, (b) knowing the self through symbolic imagery and rhythm, (c) valuing positive interpersonal relationships among people, (d) emphasising the union of opposites, (e) processing the inter-relatedness of human and spiritual networks, (f) identifying the extended self and the multi-dimensionality of self, (g) assuming self-worth is intrinsic in being, (h) valuing spiritualism, oneness with nature and communalism, (i) being positively consistent despite appearances due to relationship with the source, and (j) having a life space that is infinite and unlimited" (Ebede-Ndi 2016 p74).

## **6.3. MENTAL HEALTH AND RACISM**

### **6.3.1. Racial Violence**

The publicising of anti-Black violence in the USA helps gain support for campaigns against such behaviour, but it is stressful for watching Black Americans (Curtis et al 2021).

Curtis et al (2021) sought to establish the link between such violence and mental health (known as the "spillover effect") using Google search data, and survey responses from the Behavioural Risk Factor Surveillance System (BRFSS). The hypothesis was that "national psychological distress would be higher in weeks when racial violence incidents occurred and with higher national interest in racial incidents" (Curtis et al 2021 p2).

Data for the period 2012-2017 were used. Google searches for information about 38 police killings of Black individuals were collected from Google Trends, and the BRFSS recorded the average number of poor mental health days in the past month self-reported by Black respondents. The BRFSS is a nationally representative survey of 400 000 individuals about health-related behaviours.

Self-reported poor mental health days among Black BRFSS respondents was higher in weeks when there had been two or more high publicity racial incidents compared to no such incident. The Google search data gave information about public interest. Anti-Black violence and high national interest predicted poor mental health days for Black, but not White, respondents, which Curtis et al (2021) took as "consistent with causal effects" (p4).

An example of the relationship is the case of two separate killings in one week in November 2014 (Akai Gurley and Tamir Rice), and in the subsequent week Black respondents to the BRFSS had 0.13 more poor mental health days compared to no-incident weeks.

Poor mental health days were self-reported, and no information was available on the underlying link between racial incidents and poor mental health, nor on individual differences and moderating or mediating factors (eg: age; prior mental health problems; exposure to media).

Curtis et al (2021) felt that when racial violence is publicised, "any adverse spillover effects must be weighed against the potential for heightened public awareness, reduced anti-Black bias, and the spawning of socio-political movements that lead to reform actions and

preventive measures" (p5).

### **6.3.2. Black Women's Experiences**

Bryan et al (2018) reflected on the experiences of Black women in post-World War II Britain and their health, noting that they have "for years tolerated the lowest-paid jobs and the least satisfactory working conditions". Add to this, the "double day" of working and family demands. Bryan et al (2018) stated: "This means high levels of stress and anxiety in our working and our domestic lives; we are constantly under pressure. In health terms, the result is that we are more likely to suffer from heart attacks, strokes and hypertension than any other group in this society". Poor housing, poverty, and the ever-present "possibility of racist attack" are further compounders.

### **6.3.3. Environmental Racism**

Health disparities are linked to poverty, but, on top of that, Washington (2020) argued, racial disparities are added because of differences in exposure to environmental pollutants. She noted that "solidly middle class" African Americans are exposed to higher levels of industrial chemicals, air pollution, and poisonous heavy metals in both urban and rural USA than poor Whites. This is an example of "environmental racism" (defined as "systems that produce and perpetuate inequalities in exposure to environmental pollutants"; Washington 2020 p241).

Further add to this, availability of good quality food. Washington (2020) commented: "The term food deserts is often used for neighbourhoods that lack grocery stores and other vendors of fresh produce. I prefer 'food swamp' because such neighbourhoods are often teeming with places selling junk food, alcohol and tobacco" (p241).

## **6.4. EPISTEMIC INJUSTICE**

Large-scale healthcare systems can feel impersonal and bureaucratic, and patients are not listened to. This situation can be explored, as Carel and Kidd 2014 did, using the notion of "epistemic injustice" (Fricker 2007). Simply, this is "downgrading certain persons' testimonies and interpretations" (Carel and Kidd 2014 p531).

Fricker (2007) distinguished two types of epistemic injustice:

a) Testimonial injustice - Patients' views are downgraded because "they are often regarded as cognitively unreliable, emotionally compromised, or existentially unstable..." (Carel and Kidd 2014 p530).

For example, a disputed diagnosis, like Chronic Fatigue Syndrome. When the medical position is that a condition is psychological (or even imagined), sufferers' experiences of physical illness are disbelieved, rejected, or accorded no credibility (Carel and Kidd 2014).

b) Hermeneutical injustice - The difficulty of communicating the experience of illness can mean that the sufferer's views are devalued.

Carel and Kidd (2014) quoted this example from a patient collected in their research: "I asked a professor whether being exposed to reduced oxygen levels long-term, the way I am, would have any detrimental effects on cognitive function eg: would that explain why my memory had rapidly become much worse? He just laughed off my genuine and serious concern by saying he had the same problem and sometimes couldn't even remember his wife's name. I never did get a proper reply to that question" (p533).

At the same time, health professionals are "epistemically privileged" which means that they can decide what comments of the patients to act upon. However, Carel and Kidd (2014) did not argue that "the patient-clinician relationship is necessarily and inevitably an epistemically unjust one, but rather that certain of the forms it can take are prone to generate epistemic injustice" (p531). Patients' views can be given both too low and too much credibility (Carel and Kidd 2014).

There are three aspects to being epistemically privileged (Carel and Kidd 2014):

i) Authority - "A person or social type ('doctor', 'consultant') may be epistemically privileged because they have the authority to establish, and where necessary to enforce, the standards and norms for epistemic exchange in a given community. For instance, the medical community is epistemically privileged because it can define and characterise medical concepts (like 'health' and 'disease') and so sets the terms for authoritative

debates about health and healing" (Carel and Kidd 2014 pp535-536).

ii) Role - eg: "gatekeepers" who have the power to allow or refuse certain people.

iii) Decision - The power to make decide between different views, and to settle an issue.

Davis (2016) developed the idea of epistemic injustice by suggesting that certain groups may be "afforded epistemic privilege in a particular domain. For instance, a gay man may be wrongly attributed with credibility excess in the realm of fashion, or an Asian student may be wrongly attributed with a credibility excess in the domain of mathematics" (Spencer and Carel 2021 p6). "Credibility excess" is where some individuals are "judged comparatively more worthy of epistemic trust than other subjects, all things being equal" (Medina 2011 quoted in Spencer and Carel 2021).

#### **6.4.1. Wrongful Depathologisation**

Spencer and Carel (2021) introduced the idea of "wrongful depathologisation", where "a psychiatric disorder is simultaneously stigmatised (because of sanist attitudes towards mental illness<sup>18</sup>) and trivialised (as it is not considered a 'proper' illness)" (p1)<sup>19</sup>. This can be linked to epistemic injustice, as "when ill persons are belittled, silenced, or have their testimonies ignored because of prejudices that depict them as irrational, unreliable, or epistemically defective" (Spencer and Carel 2021 p2), and includes the de-prioritisation of psychiatric services in favour of "patients who are really ill" (Thornicroft 2006 quoted in Spencer and Carel 2021). Yet, at the same time, the mental disorder is trivialised as "a merely eccentric personality traits" (Spencer and Carel 2021 p2), for example.

Spencer and Carel (2021) used the example of Obsessive Compulsive Disorder (OCD). It is not just negative stereotypes that are the concern, but also positive stereotypes. Spencer and Carel (2021) stated: "On the surface, positive stereotypes may appear to right the wrongs of negative stereotypes: 'Women aren't less

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<sup>18</sup> "Sanist" or "sanism" (Perlin 1992) is similar to racism and sexism, but discrimination based on "madness" or "sanity" (Spencer and Carel 2021).

<sup>19</sup> Kidd (2019) talked of "pathophobia".

capable than men; they are more empathetic and nurturing', or 'Black people aren't less accomplished than white people; all the best athletes are Black' are some examples of this (appendix 6A). We suggest that in some cases, positive stereotypes may be more insidious than their negative counterparts because their putatively complimentary appearance makes them harder to detect: 'In contemporary contexts the relative ease with which positive stereotypes can 'fly under the radar' and evade red flags may, ironically, make them more damaging to general egalitarian social beliefs than not only the absence of any stereotypic information but negative stereotypes, too' (Kay et al 2013)" (p5).

Spencer and Carel (2021) outlined four ways in which positive stereotypes are detrimental:

i) Individuals in the stereotyped group feel that they must live up to the positive expectations.

ii) Individuals who do not live up to these stereotypes are harshly criticised.

iii) Positive stereotypes emphasise and perpetuate group differences.

iv) The positive stereotypes juxtapose the negative ones.

Spencer and Carel (2021) argued that "positive stereotypes can dilute a psychiatric diagnosis such as OCD by emphasising the usefulness of traits such as being tidy, making lists, and being organised" (p7). For example, a television personality who was self-diagnosed as OCD said in an interview: "I love having OCD. It makes me really organised. And I've always believed that if your drawers are really organised and tidy, then your life will be organised" (Michelle Mone in 2015 quoted in Spencer and Carel 2021).

Spencer and Carel (2021) gave this example (from Drummond 2018) to show the reality of OCD as a psychiatric diagnosis: "Amy is a 25-year-old woman who fears that she might cause a catastrophic fire if she does not ensure she has turned off all electrical appliances and the gas cooker. After using appliances, she repeatedly checks that they are switched off, returning up to 50 times. In the past two years, she has tried to avoid using all electrical or gas appliances and asks her mother, with whom she lives, to use these for her. If she does have to use an appliance, she will



repeatedly ask her mother for reassurance that she has not caused a fire" (p8).

"The term 'OCD' in public discourse rarely refers to the mental disorder but, rather, has become a shorthand description of someone who dislikes mess" (Spencer and Carel 2021 p12). This is seen in the use of "slightly OCD" in everyday language. For example, one Twitter post said: "Toilets bleached regularly and sinks thoroughly cleaned. I've become slightly OCD" (Lainey Robinson in 2020 quoted in Spencer and Carel 2021).

This can also be described as "wilful hermeneutical ignorance", where "marginally situated knowers are wilfully misunderstood by the dominantly situated knowers" (Spencer and Carel 2021 p12). Those in power ignore or make use of terms that describe the experiences of marginalised groups in order to maintain their power. "By misrepresenting the meaning of the term 'OCD', the dominantly positioned (in this case, people without psychiatric illness) rob people with OCD of an essential hermeneutical tool to convey the nature of their condition" (Spencer and Carel 2021 p13).

So, in summary: "Wrongful depathologisation can lower the credibility awarded to accounts of suffering (testimonial injustice) and obscure the more disabling aspects of OCD (wilful hermeneutical ignorance)" (Spencer and Carel 2021 p15).

## **6.5. CHIRAL EQUIPOISE**

Clinical research has often involved male participants only, and consequently, there is "a particular convention in scientific knowledge production: that of the 'male-as-default,' where the relevance of sex differences or female-specific considerations in clinical research has historically been ignored or downplayed" (Dahlen 2021 pp1-2). Criado Perez (2019) was critical of this approach: "Female bodies (both the human and animal variety) are, it is argued, too complex, too variable, too costly to be tested on. Integrating sex and gender into research is seen as 'burdensome'" (quoted in Dahlen 2021).

Dahlen (2021) argued that "any tendency to reductively consider the human participants of clinical research as a group of imagined 'sex-neutral persons' (most often male), rather than fully seeking to understand the variable of the unique needs of females, is an ethical error" (p2).

Clinical research is based on the concept of

equipose (ie: "the condition of uncertainty or not having a rational preference for one treatment option or another"; Dahlen 2021 p2). Very simply, it is not known which of two drugs, say, is better for a particular disease and only research can answer that question. Freedman (1987) advocated that "genuine uncertainty explains why we are morally required to investigate a question in a trial involving humans..." (quoted in Dahlen 2021).

But the lack of sex-specific data has created a paradox (Dahlen 2021). On the one hand, the lack of knowledge about sex differences produces the uncertainty that encourages research, but, on the other hand, the "male-as-default" position assumes that knowledge is already available.

Dahlen (2021) asked the question: "How do we build a theoretical comprehension of a human population that requires knowledge generated through trials, which sees all persons as possessing equal value and moral worth, while also including sex specific considerations?" (p6). She answered using the idea of "chirality" (handedness) from chemistry. Bodies contain pairs of organs which are similar but not exactly the same, like hands. "Both of your hands are equally important. But they are not exactly the same. No matter how you rotate them, you cannot superimpose them or call them precisely equivalent. You cannot turn one into another" (Dahlen 2021 p7).

Applying this analogue to clinical research, human sexes are similar but not exactly the same. "It is scientifically and philosophically wrong to assume that the sexes are exactly equivalent or that one is essentially inter-convertible with the other when it comes to research", stated Dahlen (2021 p8). The motivation for research should, thus, be "chiral equipose", "suggesting that in ethical deliberations around clinical research we consider not only the uncertainty between therapeutic options, but also ask: for which sex?" (Dahlen 2021 p1).

Bias can also be within a gender group and based on ethnicity or nationality, say. For example, prostate cancer is common among men, and genomics has helped in understanding. But the data are derived from Western populations. Li et al (2020) produced the Chinese Prostate Cancer Genome and Epigenome Atlas (CPGEA) based on 208 Chinese men, which was compared to 2544 patients in thirteen Western cohorts. There were "markedly distinct" differences in the genomics of the tumours

between the Western and Chinese men.

## **6.6. ORGANOIDS AND NEURODIVERSITY**

Brain organoids ("mini-brains" about 4 mm in diameter) are of growing interest to neurobiology researchers (eg: Alzheimer's disease and Parkinson's disease) (Barnhart and Dierickx 2021).

But the use of organoid models to study neurodevelopmental conditions like Autism Spectrum Disorder (ASD) has the potential for tension between scientists and the "disability community". The former rely on a medical model and seek a cure, while the latter favour a "social model" of disability that encourages diversity in society (Barnhart and Dierickx 2021).

Nesse and Stein (2012) criticised the medical model for "a temptation to conceptualise disorders in an essentialist way that oversimplifies reality" (quoted in Barnhart and Dierickx 2021), including that it "often ignores the daily social and environmental contexts which influence the experiences of disabled people" (Barnhart and Dierickx 2021 p3).

The other view is quite different: "For many disability advocates, autism is not a pathology, disorder, or deficit. Autism is a difference and a form of human diversity that is worthy of value. Neurodiversity is a concept and disability movement which invites us to conceive autistic neurology and other neurodevelopmental differences as something that contributes to overall human neurological and cultural diversity. Its adherents oppose the pathologisation of autism and incorporate the social model of disability into the conceptual framework. The underlying idea of the social model is that disability arises from social, attitudinal, and environmental barriers rather than from the impairments themselves. Because of this, the neurodiversity movement also contains political and cultural contexts, as those within the movement are often responding to social oppression faced by neurodiverse people" (Barnhart and Dierickx 2021 p3).

However, many neurodiversity advocates are classed as "high-functioning" ASD, which is quite different to the "low-functioning" "version" (Barnhart and Dierickx 2021).

## 6.7. SURGICAL SELECTION

It is estimated that five billion people in the world do not have access to safe, affordable, and timely surgical care (White et al 2017).

Barriers to access to such care are varied, including the cost of the surgery, travel costs, available facilities and staff, and health literacy (eg: to know that surgery is required or possible) (White et al 2017).

The provision of free surgical care helps, which in some countries (particularly poorer ones) is done by non-governmental organisations (NGOs). One such NGO is "Mercy Ships", which includes a hospital ship that docks in Sub-Saharan African countries at the invitation of the authorities. The aim is to provide surgical care primarily to underserved patients.

White et al (2017) analysed the data from two visits to Madagascar by Mercy Ships in 2014-15 and 2015-16. The patient selection programme is a collaboration between government personnel, the local representatives of World Health Organisation and local NGOs, local medical staff, and community leaders, as well as respondents to adverts. The programme can be centralised (patients come to the ship for treatment) or decentralised (where remote sites are set up inland from the ship).

The decentralised strategy was found to include more poorer patients because it removed the travel cost barrier. Richer patients were between 2-4 times more likely to receive surgery with the centralised strategy.

## 6.8. KASHMIR

In Indian-administered/occupied Kashmir, the police set up in 2008 an in-patient clinic for treating drug and alcohol users. The aim was to help users move from addiction to abstinence. This included "group therapy sessions in which substance users performed narratives of their recovery – a practice that made visible their gratitude to the police, which oversaw the clinic and which, as an arm of the Indian military, many view as an illegal occupying force" (Varma 2018 p50).

Varma (2018) also showed the conflicting discourses at work with patients <sup>20</sup>. "While patients publicly pledged to remain sober and technically complied with the clinic's demands, they privately demonstrated ongoing commitments to nasha (intoxication), which places

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<sup>20</sup> Varma (2018) spent twenty months in Kashmir in 2009 to 2013.

substance use, romantic love, and the search for divine unity in Sufism on the same phenomenological register" (Varma 2018 p50).

There was an intersection of biomedical discourses (of the clinic), politics (over the status of Kashmir), and the religious experiences of Sufis (with nasha).

The clinic (Drug De-addiction Centre; DDC) was in the compound of the police headquarters, and this associated it with the Indian security forces. Varma (2018) explained: "While clinicians told me they wanted to carve out an independent, neutral biomedical space, they were undercut by the DDC's dependence on the police for its daily functioning and by everyday clinical practices that reinforced the clinic's links to the structures of military rule <sup>21</sup>. As many patients quietly reminded me, somewhere in the control room, young protesters were being interrogated and tortured" (p52). The DDC was a "medical-penitentiary" (Varma 2018).

The police were also perceived as corrupt. Varma (2018) stated: "During interviews, many patients questioned the police's efforts to combat substance abuse, since they felt the police's own corruption and lax enforcement of existing drug laws were at least partly responsible for the region's drug epidemic. They said this out of the clinicians' earshot. If the clinicians heard these comments, they would likely be read as a form of resistance to treatment and result in the patients' being either punished or forced to stay longer" (p53).

The ethnographic study is able to take the perspective of the "addicts"/"patients", and see how they make sense of their lives in situations of conflicting and intersecting narratives/discourses.

## **6.9. APPENDIX 6A - BLACK ATHLETES**

Burfoot (1999 quoted in St Louis 2003) controversially asserted the "incontrovertible fact: black-skinned athletes are winning most races". This view can be described as "naturalised racial athletic aptitudes": "The suggestion is that physical specificities of body size and proportion, namely skeletal structure and musculature, and the physiological facts of sub-cutaneous differences in the muscles, enzymes and cell structures, form the basis for black

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<sup>21</sup> Varma (2018) reported witnessing clinicians asking security guards to beat patients who had broken the clinic's rules.

athletic advantage. However, it is crucial to note that these typologies are seen to emerge from a more fundamental genetic basis..." (St Louis 2003).

Rather than investigating the social, cultural, economic, and historical factors to explain "racial sporting performance", inherent, fundamental differences are used. "It has long been argued that the participatory over-representation of certain racial groups within particular sports is the result of a socially constructed tradition whereby individuals gravitate towards certain sports and athletic events because of a desire to emulate role models within their ethnic group" (St Louis 2003).

St Louis (2003) stated that "the correlation between race and athletic ability is not observed by a value-free scientific eye, but that pre-existing ideas about racial physical and moral capacities frame the very question and investigation of innate athleticism and athletic propensity". Such bias in science has been called "racial science" to describe how science was used to justify racist ideas in the 19th and 20th centuries (St Louis 2003).

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