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Kevin Brewer

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Orsett Psychological Services
PO Box 179
Grays
Essex
RM16 3EW
UK

orsettpsychologicalservices@phonecoop.coop

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Kevin Brewer BSocSc, MSc

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

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

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1. "NEW EMPIRICISM" FOR GLOBAL HEALTH TODAY

1.1. "NEW EMPIRICISM"

Kelly and McGoey (2018) stated that "today the authority of facts is both far-reaching and fragile" (p2). In many fields, including health, randomised controlled trials (RCTs) and "big data" have turned the subject areas into a "data management enterprise". Yet, "in the face of this muscular form of fact-making, faith in the technocrat is flagging" (Kelly and McGoey 2018 p2) as seen in "post-truth" politics, "fake news", and "alternative facts". "Unconstrained by the need to substantiate arguments with extensive research or reliable figures, political discourse, many fear, has become a race to the bottom" (Kelly and McGoey 2018 p2) [1].

Kelly and McGoey (2018) responded to the question of "what constitutes authoritative evidence in this political climate", and their answer talked of a "new empiricism". This is highlighted in that "'what works' cannot be disentangled from the question of 'who counts'" (p19). One example here is large-scale philanthropy (or "philanthrocapitalism" [2]) seen in private foundations, like the Gates Foundation and Bloomberg Philanthropies [3]. These "actors" "uphold themselves as 'partners' in the provision of public services, despite the fact that the

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[1] Kelly and McGoey (2018) argued that "post-truth" is a product of neoliberalism, where "rational policy does not arise from a deliberative consensus over how best to serve public interest, but rather from the seemingly objective need to enhance market efficiency to promote economic development... The cascade of policies undertaken in the name of value for money – from deregulation and tariff elimination to the privatisation of public domains previously considered exempt from market relations – have dismantled social safety nets intended to protect the most vulnerable in society and radically exacerbating social stratification and inequalities... The universalising logic of cost calculation evacuates the politics from these policies and discredits alternatives as failing to meet the principles of good management" (p6). Furthermore, the rise of populism can be seen as a reaction to this "rational logic" - ie: "truths" that draw "their rhetorical power not from the technical accuracy, but rather from their emotional salience" (Kelly and McGoey 2018 p2).

[2] Understanding the "moral values informing particular economic arrangements and institutions" is the moral economy approach (Hesmondhalgh 2017). Thus, "all economies are suffused with values and beliefs about what constitutes proper activity, regarding rights and responsibilities of individuals and institutions and qualities of goods, service and environment" (Hesmondhalgh 2017 p206). This is a challenge to the view that markets are neutral.

[3] Private foundations arose in part from the "incapacity of the nation-state to deal with the new health threats associated with globalisation", as well as the "state as incompetent and wasteful", according to neoliberal thinkers (Reubi 2018).

question of what legitimates and obligates them to serve the public remains unanswered. Until now, the 'charismatic authority' wielded by powerful philanthropists has largely been seen as sufficient to legitimate their growing influence over human affairs. This authority comes in part from the ability of private philanthropists to selectively publicise global health 'miracles' even while troubling questions over cost-effectiveness and corporate harm to the public are ignored. Indeed, the tangled vested interests of these actors with the pharmaceutical, tobacco, food and drink industries tend to inflate the value of market-based initiatives while obscuring the root causes of collective distress" (Kelly and McGoey 2018 p18).

"Tsing (2012) suggests that the modern world is characterised by 'the triumph of technical prowess over nature'..., a triumph that depends on forms of 'scalability'. Scalability does not connote an ability to use scale, but rather to expand without changing" (Ehrenstein and Neyland 2018 p60). Put simply, the assumption is that the results of a small clinical trial in one place can be scaled up to a whole country, as in the case of vaccines, say.

But there are "frictions of scaling up, beyond the expected logistical troubles of bringing vaccine doses to remote health-care centres" (Ehrenstein and Neyland 2018 p76) (eg: bacterial adaptation or the response to the price of the vaccine) [4]. The latter was observed by Ehrenstein and Neyland (2018) in their study of a pneumococcal vaccine in Burkina Faso.

1.2. PHILANTHROCAPITALISM

McGoey and Thiel (2018) talked about "the new philanthrocapitalists whose enormous personal fortunes have become legitimated partly by giving some of those fortunes away" (pp112-113). "Philanthrocapitalism" (Bishop and Green 2008) is a term which describes "a new way of doing philanthropy, which mirrors the way that business is done in the for-profit capitalist world", and that "capitalism itself can be philanthropic, working for the good of mankind" (quoted in McGoey and Thiel 2018) .

The point is that "extreme private wealth" is presented as a "public good". Barnett (2000) referred to "corporate populism", "whereby the equivalence of corporate interests with public welfare is upheld as obvious and unchallengeable, as natural to the new philanthrocapitalists as a religious theodicy – and

[4] Generally, clinical trials are often over-represented with adult Western males, or specifically, the HIV viral strain dominant in the USA is different to Uganda, say (Ehrenstein and Neyland 2018).

increasingly adhered to by less-affluent constituents who receive few obvious benefits from subscribing to the orthodoxy" (McGoey and Thiel 2018 p117).

"Defined crudely, theodicies are belief systems that seek to understand God's willingness to tolerate pain and worldly suffering" (McGoey and Thiel 2018 p117). Today, it is a "secular theodicy". Mega-giving cements this secular theodicy by providing a form of charismatic authority. "Philanthrocapitalist mega-gifts provoke awe not simply from those in receipt of the gift but also from most of those watching. The power of today's mega-giving is thus much broader than enrolling the direct receivers of gifts into a moral relationship... Mega-giving produces symbolic power – and symbolic costs – that affects recipients and non-recipients alike. One major aspect of its symbolic costs is the way that voluntary gift-giving dissipates obligatory and collective demands for wealth redistribution..." (McGoey and Thiel 2018 p121).

Reubi (2018) focused on the "perceived lack of transparency and accountability" of philanthropic private foundations [5]. Hesselman (2011) described them as "among the most unaccountable organisations in democratic societies" (quoted in Reubi 2018). Though there may have been a decline in "democratic accountability" or "public accountability" (Rushton and Williams 2011), Reubi (2018) argued that a new form of accountability has emerged - "epidemiological accountability" (a combination of audit and epidemiology). Auditing brings the practice of verification and performance indicators, while epidemiology is based in statistics. For example, the Bloomberg and Gates foundations have developed a "saved lives" metric to assess which of their projects are working or not working (Reubi 2018).

This focus on "value for money" includes the use of RCTs (advocated by "randomistas"; Ravallion 2009) to evaluate international aid. This idea comes from Bannerjee and Duflo (2011) as "a radical rethinking of the way to fight global poverty".

Donovan (2018) explored the growth of this approach within international development as "a shift in the politics of knowledge within the aid industry. Randomistas problematised settled practices and

[5] For example, critics have "expressed concerns about whose interests are being served by the select few who make the decisions for private foundations. Thus, sociologist Linsey McGoey (2015) has queried whether the strong presence of former drug industry executives among the decision-makers at Gates has contributed to the foundation's bias for pharmaceutical solutions, while political economist David Stuckler and his collaborators have suggested there could be a link between Gates's refusal to tackle non-communicable diseases and the foundation's substantial investment in Coca-Cola and other corporate giants of the agro-food sector (Stuckler and Siegel 2011)" (Reubi 2018 p87).

knowledge, turning 'matters of fact' into 'matters of concern' (Latour 2004) through their insistence on the pervasive lack of knowledge within international development circles. They offered experimentation as the authoritative and feasible means of achieving certainty and, eventually, the reduction of global poverty. In doing so, they translated epistemological and ethical values into practice. Proponents have depicted RCTs as the key to conclusive knowledge about 'what works' in development through their engagements with multiple publics, including academics, aid workers, policymakers and what Krause (2014) calls the 'donating public'. Yet in the wake of their success, an ongoing search for epistemic closure has, in turn, problematised RCTs [6], leading randomistas to search for ways to repair their favoured method. The result is not the achievement of certainty but rather an extended 'experimental system' (Rheinberger 2010) in which the randomistas became some of the most authoritative voices in international aid" (p28).

1.3. CASE STUDY OF EBOLA OUTBREAK

The 2013-2016 West African Ebola outbreak (appendix 1A) was unprecedented, and it was classified as a "Public Health Emergency of International Concern" (PHEIC) by the World Health Organisation (WHO) on the 8th August 2014 (Kelly 2018). A PHEIC is defined, by the WHO, as "a situation that is serious, unusual or unexpected; carries implications for public health beyond the affected State's national border; and may require immediate international action" (quoted in Kelly 2018). Such a situation "ushered in a new set of investigative priorities and protocols, guided by a 'moral obligation to learn as much as possible as quickly as possible' [WHO]" (Kelly 2018 p138). Kelly (2018) was interested in "the forms of fact-making that emerged under these conditions of acceleration".

Soon after the declaration of PHEIC, data on Ebola cases showed an exponential growth (described as a "hockey-stick" graph), and projections based on this information were alarming [7]. "The hockey-stick graph provided the necessary proof that this outbreak was, in fact, an extraordinary event and was thus able 'to stimulate action when decision is imperative but

[6] The findings of RCTs are not always applied in "real-life", despite the faith in them. For example, certain drugs are recommended for post-heart failure, but the doses are rarely to the level used in RCTs (Ouwerkerk et al 2018). Because of the side effects of these drugs, some patients do not benefit from the recommended dose. Ouwerkerk et al (2018) advocated a "personalised medicine approach" where biomarkers (eg: cholesterol level) are used to decide the level of dosage of drugs.

[7] 6553 actual cases in September 2014 versus 1.4 million predicted by January 2015 (Kelly 2018).

knowledge is incomplete' [Lakoff 2015]" (Kelly 2018 p142). The WHO were also concerned about "shadow-zones" (ie: under-reporting of cases by local communities or countries).

But Kelly (2018) observed, "as spurs for global health attention, the models were effective [8]; as guides for public health action, however, they were less so. Empty beds in newly built treatment units testified to the gross disparity between the modellers' predictions and the situation on the ground" (p142) [9].

Herrick (2017) has talked of "a charismatic gap" between the perceptions of the risk of a disease and its actual risk. Referring to Botswana (3000 miles away from the outbreak), there was greater concern about Ebola (little risk) than non-communicable diseases (NCDs), like alcoholism (high risk). "Global health attention, Herrick argues, is not a measure of the breadth of scientific evidence but rather of the intensity of 'collective distress [Herrick 2017]. Only diseases that convey an acute sense of threat or empathy can garner public concern and precipitate political action. Circumscribed to the tedium of incidence and prevalence, NCDs fail to engage popular imagination and persist as so-called 'neglected epidemics'" (p143).

Global health attention and predictions of the future exist in "the universe of the unverifiable" (Caduff 2014) [10] [11]. Representations of the data like the

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[8] "Any model implicitly or explicitly makes simplifications, ignores variables, and simplifies or ignores interactions among the variables in the models and among possibly relevant variables not included in the model" (Wimsatt 1987 quoted in Potochnik 2015).

Potochnik (2015) considered the role of idealised models in science in the context of the debate as to whether the aim of science is truth or understanding: "Idealised models, even though they are false in some regards, must get us somewhere that mystic revelation does not" (p72).

[9] Rodney (1973) argued that the most negative consequences of colonialism on Africa was that "Africa lost power": "Power is the ultimate determinant in human society, being basic to the relations within any group and between groups. It implies the ability to defend one's interests and if necessary to impose one's will by any means available. In relations between peoples, the question of power determines manoeuvrability in bargaining, the extent to which one people respect the interests of another, and eventually the extent to which a people survive as a physical and cultural entity. When one society finds itself forced to relinquish power entirely to another society that itself is a form of underdevelopment".

[10] The hockey-stick graph fits with "worst-case scenarios", or what Caduff (2015) called "pandemic prophesy". "Less data-driven that "scientifically inspired", the authority of a catastrophic forecast, Caduff argues, rests not in the accuracy of its model, but in the resonance of its prognosis... Proclamations of the coming plague capture the eschatological structures of feeling that predominate in times of radical uncertainty... The hockey-stick's dramatic and seemingly irreversible sweep keyed into popular notions of Ebola as the world-ending 'Andromeda strain'" (Kelly 2018 pp143-144). The use of epidemiological forecasts and the assessment of risk allows health professionals "to have trust in a particular kind of future, even if there is no evidence that this future is likely to materialise" (Caduff 2014 quoted in Kelly 2018) (appendix 1B).

[11] Caduff (2015) described the "pandemic prophesy" thus: "destruction without purification, death without resurrection — in short, dystopia without utopia. This means that pandemic prophecy is only seemingly apocalyptic; as a discursive practice, it invokes standard apocalyptic tropes, but it lacks the

hockey-stick graph have "evidential charisma" (Kelly 2018). "The hockey-stick validates and amplifies an understanding of the Ebola outbreak's existential significance as both a global health and a moral crisis, creating a symbolic anchor for the response. Its curve, the syntax for apocalyptic anxieties, provided a centre of gravity around which solidarity could form – a sense of purpose and collective duty to a moral cause" (Kelly 2018 p147). The point of focus here was an Ebola vaccine.

Traditionally, vaccines take time to produce and test, but in this situation the "pace at which vaccine candidates had moved from laboratory experiments on animals [12] to large-scale studies in the human population was breath-taking" (Kelly 2018 p149). Short-cuts were made, but it was felt justified. But, for Kelly 92018), time will tell, and she ended: "It remains to be seen, however, how these norms and standards will be legitimised, and what forms of institutional and collective action will materialise out of research conducted in times of emergency. As the global health enterprise becomes increasingly oriented towards anticipating uncertain futures, it is critical that we confront the mechanisms through which charismatic evidence emerges in contexts of crisis, and the processes by which it infuses with seemingly irresistible authority the designs and interventions of powerful actors and institutions" (p154).

1.4. APPENDIX 1A - INDIRECT CONSEQUENCES OF EBOLA

There are long-term psychosocial effects to the Ebola virus disease (EVD), including stress and stigma for survivors and households whose members had been ill (eg: Hansen et al 2016 - study of women's quality of life).

Green et al (2018) also reported that parents from households who experienced EVD became more "harsh" in their child-rearing practices. Around 200 parents in West Point, Monrovia, Liberia, were presented with twelve scenarios of bad behaviour by a child (eg: kicking a parent), and asked about their discipline response. A score was calculated between 0 (no endorsement of harsh

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hope and desire for another world" (p7).

[12] "Annually, more than 115 million animals are used worldwide in experimentation. While those experimental models provide valuable information, they do not efficiently extrapolate to human physiology, with an estimated 10% success rate. This provides a strong rationale to develop more predictive human models" (Hay and O'Farrelly 2018 p2). One possibility is the use of human pluripotent stem cells (PSCs) in human models "in a dish". PSCs include "human embryonic stem cells,derived from the inner cell mass of blastocysts unsuitable for human implantation; and induced PSCs, generated by the reprogramming of somatic cells" (Hay and O'Farrelly 2018 p1).

discipline) to 12 (high endorsement). Data were collected at the beginning of the Ebola outbreak in the city (summer 2014) and then one year later (post-outbreak).

Exposure to EVD was scored as "yes" or "no" based on self-reports for the household. Other measures were also taken, including household quarrels, parental anxiety, and child well-being using simple scales.

Overall, 7% of households in the sample experienced the disease, and this group showed an increase in preference for harsh punishment, while the rest of the sample showed a decrease between 2014 and 2015.

Parents from households exposed to the EVD reported significantly more conflict and anxiety, but less behavioural problems exhibited by their children.

Green et al (2018) summed up: "Results suggest that the experience of being closely affected by EVD through sickness or death could increase parents' preference for harsh verbal or physical discipline. If these preferences were to translate into behaviour, children in these households may be facing an elevated risk of maltreatment, potentially in addition to traumatic exposures associated with EVD. Exposed families also reported lower levels of overall family wellbeing, suggesting even broader patterns of negative interactions that can contribute to family violence and poor child outcomes". A simple explanation is that stressed parents become more harsh in their discipline.

The study gave a unique insight into child-rearing behaviour in an unusual situation, but full details of parenting and family variables were not included, and many measures were self-reported and brief (eg: one question about parental anxiety).

1.5. APPENDIX 1B - PERFORMING RISK

Stem cells have the potential to be used in regenerative medicine, but there are risks associated with their use. Wainwright et al (2018) considered the risks faced by clinicians in the development of stem cell therapy for liver disease. Risk was viewed as "performative" - ie: "not so much a matter of more or less technical assessments of costs and benefits, or a reflection of a particular cultural perspective, but rather a resource in dynamically accounting for multiple institutional, medical and social dilemmas" (Wainwright et al 2018 p149).

Wainwright et al (2018) reported interviews with five consultant clinicians involved in a leading cell transplant programme in the UK [13]. The shortage of organs

[13] In total there were over 60 in-depth interviews with scientists and clinicians in the USA and the UK.

for transplant has led to interest in stem cell therapies. Put crudely, stem cells would grow a new liver.

Risk was measured differently for these consultants as compared to organ transplantation. One interviewee said: "if you transplant a whole liver, it's very clear when the liver fails as the patient will die. With cell transplantation, the point at which the graft fails is less easily defined. Re-transplantation is a lesser thing. As a rule it's an infusion of more cells, and so it changes your concept of transplantation" ("Surgeon 32") (p155).

The work of the consultants was "pushing the boundaries", and they juggled the need to be bold with recklessness. This is seen in one extract: "If I'm not prepared to do something, someone else will do it. There's someone right behind me, who's going to clamber over my back, prepared to do that. There is great pressure on individuals and institutions to 'push ahead'" ("Surgeon 32") (p159).

However, the response of the public was perceived as negative towards "experimental treatments" like their's. One interviewee said: "The general population doesn't understand the difference between clinical and research. I don't think we explain it very well as scientists. And I think we're all too happy to allow people to think that research is something in a nasty dark laboratory with people doing scary things, where anything clinical is safe. And neither view is correct. It's somewhere in between the two" ("Physician 37") (p163).

There was also the regulatory framework to consider, which could be limiting of the researchers' progress: "In India and China, for example, where it's a lot easier to do the research, even though people might criticise them for being unethical and things like that, those were the things that were being done here and those were things that couldn't be done now, because of regulations more than anything else. And that’s not fair. That sort of thing is not good" ("Surgeon 46") (p165).

Overall, Wainwright et al (2018) felt that they had "begun to trace how clinicians tend to represent themselves as (and this is our heuristic phrase) caught between the 'rock of courage' and the 'hard place of caution'" (p166).

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2. ETHICS AND BIOMEDICAL RESEARCH

2.1. INFORMED CONSENT

Informed consent is the bedrock of research. Here are some ethical issues to consider.

Sharp (2004) found that the average length of consent forms in oncology clinical trials was 2700 words. This researcher argued that 1000 words is sufficient, and anything longer is not read properly. In fact, research shows that the longer the form, the less information the participants take in (Appelbaum 2015).

There is also the level of complexity of the information provided. Hochhausr (2008) remarked on a drug trial consent form containing over 10 000 words, and "was so complicated that the risk section for the three drugs [being studied] included 160 possible side effects... Is it possible for prospective subjects to remember and make informed decisions based on so many risks" (quoted in Appelbaum 2015).

Participants may also struggle to understand how a clinical trial differs from normal medical treatment. Appelbaum (2015), in reference to cancer trials, distinguished two dimensions of "therapeutic misconception": "Failure to understand the absence of individualisation of treatment in clinical trials, and mistaken beliefs about the likely benefits of participation based on a misunderstanding of the study's methods" (p219).

So , if individuals do not fully understand what they are consenting to, is it really informed consent? Miller and Wertheimer (2011) offered a "fair transaction model" of informed consent, "whereby investigators would disclose the information necessary for fair consideration of participation in a study, but without an expectation that subjects would necessary grasp the disclosure in its entirety. They, too, believe that it is unrealistic to expect informed consent to result in fully autonomous decision-making, but more explicitly rely on the vetting of research studies by research ethics committees to ensure that potential subjects are not being asked to participate unreasonably" (Appelbaum 2015 pp222-223).

2.2. GENETIC RESEARCH

The idea that genetic information "carries special potential for harm" and so needs special ethical rules is called "genetic exceptionalism" by Murray (1997). It is based on the "predictive quality for one's future health, a kind of 'probabilistic future diary' (Murray 1997); the relevance of genetic information for one's relatives as well as for oneself; the history of stigma and discrimination associated with claims about genetic traits, leading to everything from forced sterilisation to genocide and the Nazis' Final Solution. Other 'special' qualities include the way in which research on a small segment of an identified group can confer risk on all members of the group, without their prior knowledge or consent, and the ability to track population migration through genetic research" (Davis 2015 p229).

Murray (1997), in fact, disagreed with genetic exceptionalism because "there are very few traits that are entirely genetic (or entirely environmental), and that most of the factors associated with genetic information and genetic research have non-genetic analogues that deserve the same level of protection. Knowing about my cholesterol level and my sky-diving hobby, for example, provides as much of a 'future diary' as most genetic information" (Davis 2015 p229). Furthermore, the "more we treat genetic information as fundamentally different, the more support we provide for genetic determinism, that is, 'the notion that genetics exerts special power over our lives' (Murray 1997)" (Davis 2015 p229).

Davis (2015) pointed out that genetic research is in many ways different to other research because it can be carried out without the individual's knowledge (though similar to covert observation), or their presence (using stored biological samples). "Genetic research on stored tissue samples is unusual in that research use can persist long after the source of the tissue is dead. Thus, research on stored tissue has highlighted an old philosophical debate on whether deceased persons can have interests and whether those interests can be harmed" (Davis 2015 p232) (appendix 2A).

Tomlinson (2013), however, made this point: "once a donor to a research biobank has willingly parted with his tissue, and both it and any accompanying medical information have been de-identified, then the donor's welfare is no longer at risk – and she no longer needs any ethical protection. Subject to no risk, she's no longer a human 'subject'. As for her tissue? It's like her trash. Once left by the curb it's no longer 'hers'" (quoted in Davis 2015).

Mello and Wolf (2010) offered the concept of "tiered consent", where donors of biological samples have the

choice of consent for the current project only or to allow unspecified future use, say. "Thus, the relatively small percentage of people who want to limit the use of their tissue can do so" (Davis 2015 p233).

2.3. VULNERABLE POPULATIONS

Research involving "vulnerable populations" faces the question of what is meant by vulnerable. Definitions include: "Susceptibility to exploitation..., those at an increased likelihood to incur 'additional or greater wrong'..., and those facing 'a significant probability of incurring an identifiable harm while substantially lacking ability and/or means to protect oneself'" (Schonfeld 2015 p240).

Lange et al (2013) talked of a "typology of sources of vulnerability and attendant duties". So, vulnerabilities can be "inherent (those that are unavoidable features of the human condition), situational (those that pertain to the particular context of the participant), or pathogenic (related to dysfunctional social or personal relationships). Each of these vulnerabilities can be experienced either acutely (what they term 'occurrent') or chronically ('dispositional—latent or background')" (Schonfeld 2015 p240). Kipnis (2003) expanded the categories to seven - cognitive (eg: learning disabled), juridic (legal authority over the decisions of others), deferential, medical (eg: parents willing to do anything to improve the health of their child), allocational, structural, and social.

Though the idea of vulnerability is meant to protect certain individuals and groups, there can be a downside to the term, including (DuBois et al 2012):

- Reinforce stigmas.
- Discourage researchers from using those individuals.
- Create barriers to research and so harm to those individuals.
- Becomes an excuse for excluding certain individuals.
- "denying individuals the ability to choose to participate in research when they are capable of making such choices, even if they are members of a traditionally 'vulnerable' group, unjustifiably impedes the exercise of their autonomy" (Schonfeld 2015 p244).

2.4. INCENTIVES FOR RESEARCH

Biomedical researchers often provide financial or medical incentives for individuals to participate. Wertheimer (2015) considered the ethical issues with this.

He outlined four possibilities:

i) Use only volunteers (with no incentives) and accept that research will be limited.

ii) Educating people about the benefits to society of volunteering for research.

iii) Financial incentives to compensate the risk/costs of participation in the research.

iv) Take advantage of (sick) individuals whose interest it is to volunteer (eg: improved medical care during the trial for individuals who could not afford treatment - "coercion through lack of income"; Rosen 2012).

Concentrating on the third possibility, Wertheimer (2015) reflected on how much to give, and on the fourth possibility with poor individuals. The key concepts are coercion, undue influence, and exploitation.

In the first case, Wertheimer (2015) stated: "If a doctor were to implicitly or explicitly threaten to abandon a patient if he does not agree to participate in research, then the patient's decision is coerced and involuntary. If a patient were to mistakenly fear that he would be abandoned if he did not agree, then we might say that his decision to participate is involuntary although he has not actually been coerced. But those sorts of situations aside, we should probably simply abandon the concern that offers of payment or medical care are coercive" (p253).

In relation to undue influence, financial incentives will appear larger to poorer individuals. Wertheimer (2015) quoted the example of a woman in India (Rambha), facing eviction and needing life-saving medical treatment for her son, who "signed up to be a human guinea pig in drug trials for foreign pharmaceutical companies. In explaining her decision, Rambha said 'I am helpless, I have to do this... They don't really force us, but I don’t have a choice'" (NBC News 2012 quoted in Wertheimer 2015). Wertheimer (2015) responded: "This is a sad story, but it seems that Rambha knew what she was doing. She was participating in research in order to provide for her family. I am reluctant to say that her judgment was distorted or that it would have been better to deny her that opportunity" (p255).

The use of participants in poorer countries for drug trials is increasing, but is this exploitation? On the one hand, these individuals are recruited because the study could not or would not be undertaken in a richer country. On the other hand, individuals who would not receive medical treatment at all normally, receive good quality treatment during the trial. Wertheimer (2015) made the distinction between "harmful exploitation" ("the exploiter gains by harming the exploitee") and "mutually advantageous exploitation" (both parties gain from the transaction), and between "non-consensual" and "consensual exploitation". The latter refers to the situation "in which the exploitee gives valid consent in the sense that she is competent, has adequate information, and is not coerced" (Wertheimer 2015 p256).

2.5. MISCELLANEOUS

Biometrics uses physical characteristics, like fingerprints or iris, to identify individuals. The United Nations High Commissioner for Refugees (UNHCR) use biometrics in relief situations as many people in refugee camps do not have traditional sources of identification like passports. It helps in the distribution of aid, it is argued (Rose 2018).

The International Committee of the Red Cross and Crescent (ICRC), however, "have been more circumspect" (Rose 2018).

Issues related to biometrics in humanitarian situations include (Rose 2018):

- Lower standards of security and data handling.
- Refugees may worry about who will see the information.
- Stigma.
- The motivation of the companies producing the technology.
- The technology not working (eg: fingerprint recognition and dirty hands).
- Establishing informed consent.

2.5.1. Polycystic Ovary Syndrome

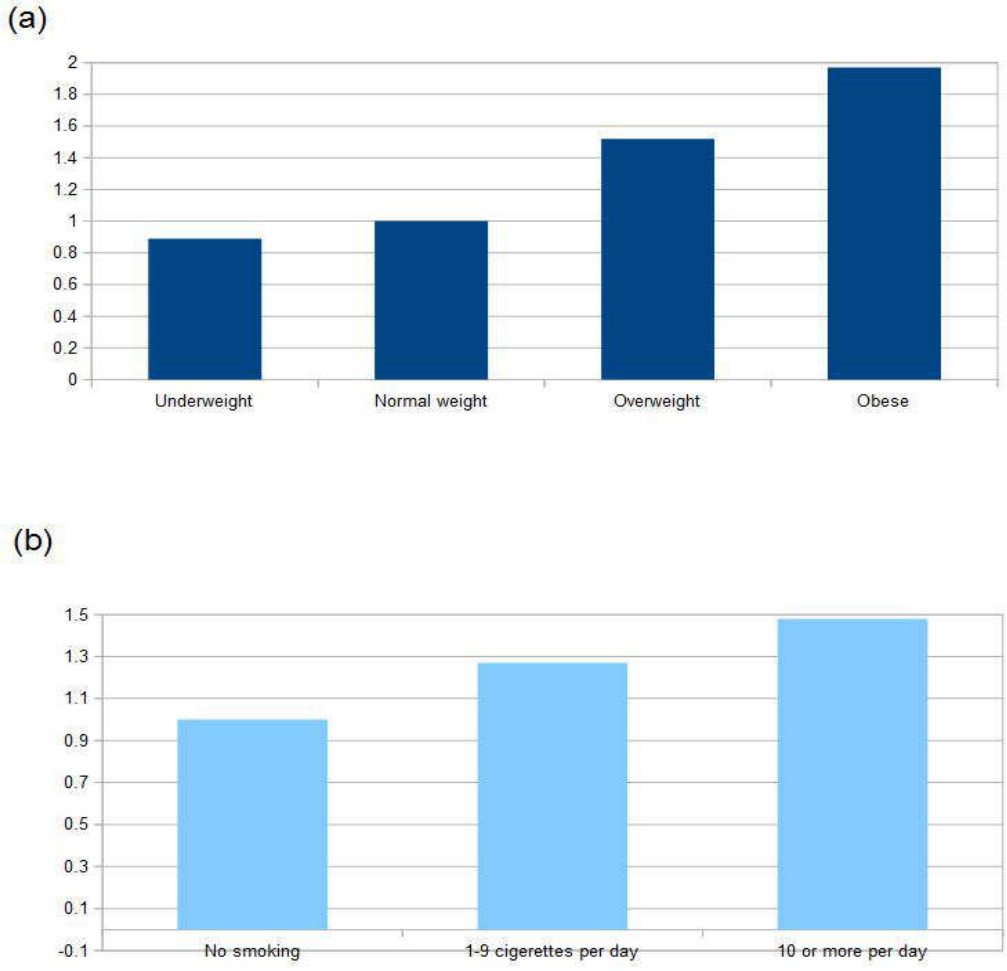
One cause of infertility is polycystic ovary syndrome (PCOS), which is also linked to obesity and type 2 diabetes risks. PCOS is an endocrine condition, which has both heritable and environmental causes

(Valgeirsdottir et al 2019).

One cause of PCOS is exposure in the womb to, for example, increased testosterone, which has been shown in experiments with rats, for instance (eg: Ramezani Tehrani et al 2014). Experiments with humans are not possible, so researchers have to look at population data for naturally occurring events.

This is what Valgeirsdottir et al (2019) did with Swedish data. The Swedish birth registry was begun in 1973, and includes information on all pregnant women in the country. Valgeirsdottir et al (2019) concentrated on female births between 1982 and 1995 (n = 681 123), of which 3738 individuals (0.54%) had been diagnosed with PCOS by age 15 years old.

Compared to the rest of the cohort, the PCOS group were more likely to have had an overweight or obese mother during pregnancy, and a smoker (figure 2.1), and were a small baby. Valgeirsdottir et al (2019) summed up:



(Data from Valgeirsdottir et al 2019 table 3)

Figure 2.1 - Adjusted odds ratios for daughter developing PCOS based on (a) maternal weight and (b) smoking.

"Our results indicate that a high maternal BMI [body mass index] is an independent risk factor for the later development of PCOS in the offspring. This may be a direct or indirect effect of maternal fat tissue synthesis and secretion of adipocytokines, or of raised or altered inflammatory factor profiles disturbed glucose metabolism, or hormonal effects on the foetus, but it could also be a consequence of genetic factors. An abundance of fat tissue may also have direct effects on the placenta" (p249).

Though this study was large, and used data collected at the time of pregnancy rather than depending on recall, it only included women who sought medical care in hospitals for PCOS, and between 15-28 years old (Valgeirsdottir et al 2019).

2.6. APPENDIX 2A - MORAL STANDING OF DEAD

Luper (2018) began: "In choosing to do certain things, we appear to presuppose that we can act in the interests the dead, and that we have a duty to do so. For example, some of us go to great lengths to carry out their final wishes. Given that the dead no longer exist, however, it seems that nothing can be good or bad for them: they lack prudential interests. In that case, it is hard to see how we could owe them anything. They seem to lack moral standing altogether" (p1).

Luper (2018) argued against this position, and in favour of the view that the dead "have interests that are advanced or hindered by those who are still alive" (p1) (ie: "post-humous harm (or benefit)"). Is post-humous possible?

Luper (2018) argued that such harm could occur if the dead are wronged. He used the example of an individual who is researching a cure for a disease, but dies before succeeding. However, the work gives us ideas, and a cure is discovered, which would not have happened without those ideas. "So maybe we are doing something for the dead when we bring about things that they wanted to happen. Perhaps we are obligated to do some such things, and wrong the dead when we fail" (Luper 2018 p5).

Luper (2018) summed up the arguments: "If it is good for us to fulfil some sorts of desires (and bad not to) and, as suggested here, the fulfilment of our desires can be brought about by post-humous events, then others may benefit (or harm) us after we are dead by fulfilling (or thwarting) these desires. On this view, it also makes good sense to say that we may wrong the dead, given the principle that, other things being equal, it is wrong to harm anyone. If, on the other hand, post-humous events cannot affect their prudential interests, it is best to conclude that wronging them is out of the question. If

beyond being harmed, they are beyond being wronged" (p6).

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3. MEDIA AND PUBLIC HEALTH

3.1. INTRODUCTION

The media play an important role in shaping public health debates by choosing which issues to report and how to report them. So, "media production needs to be considered in its broadest terms, not simply as 'discourse' manufactured in newsrooms, television studios and other media institutions, but as the outcome of specific networks, occupational practices, technologies and structural contexts with embedded ideological assumptions" (Henderson and Hilton 2018 p373) (appendix 3A). Put another way, how particular views become the accepted norms.

The role of the media is especially relevant with non-communicable diseases, particularly linked to "unhealthy commodity industries" (Freudenberg 2014) [14]. These industries market their products, like alcohol, tobacco, and ultra-processed food and beverages, with strategies like "making 'their' industry goals appear to be 'our' universal goals which are 'naturally' in everyone's interests. For example, promoting the idea that people should be free to choose what they eat, regardless of how healthy their choice..." (Henderson and Hilton 2018 p373).

Abroms and Maibach (2008) proposed that mass media can be used to influence public health at three levels:

[14] A meta-analysis of 48 studies of mass media health campaigns in the USA calculated, overall, around "9% more people performing the behaviour after the campaign than before" (Snyder and Hamilton 2002 quoted in Abroms and Maibach 2008).

i) Individual - eg: change health cognitions (eg: knowledge and beliefs; self-efficacy).

ii) Social network - campaigns aimed at friends, parents, siblings, and spouses in order to encourage the individual to change their health behaviour.

iii) Community - eg: changing social norms.

3.2. SOCIAL ISOLATION

Social isolation among older adults can be associated with poor health.

Breheny and Severinsen (2018) concentrated on the media representation of this issue in New Zealand in an analysis of a 2016 online article entitled, "One in 10 elderly Kiwis could be 'socially isolated', Age Concern says", and readers' comments.

The researchers were interested in how the issue was framed. "The frame can be identified through signature rhetorical devices relating to the author's position (how they describe the issue and what they emphasise), suggested causal roots (what is identified as the main cause and where blame is laid), solutions proposed (who is responsible, what is included and excluded) and expressed core values (what values are evident)... As such, the framing of an issue by the media is a form of political influence, which promotes a particular interpretation through the selection, emphasis or omission or certain views, and can overlay moral judgements" (Breheny and Severinsen 2018 p485).

The article included an embedded video of "Lorna" recounting spending Christmas Day alone, and saying "I might as well be dead". The article talked generally about the issue and made the claim about social isolation - "It's as dangerous to your health as smoking 15 cigarettes a day".

The readers' comments were categorised into four themes:

a) Social isolation as the individual's problem (39% of 379 comments) - "Socially isolated people were viewed as having the freedom to make individual choices to alleviate isolation" (Breheny and Severinsen 2018 p488).

There was also the suggestion that loneliness was the individual's own fault - eg: "I can't help but think 'you reap what you sow'" (p488).

b) Social isolation as the family's problem (30% of comments) - comments varied between "I'm sorry, but where the hell is her family?", to "Her kids have their own lives".

c) Social isolation as the community's problem (19% of comments) - eg: "If we all reach out and take time to be friends to those lonely people live close to us [sic], surely things can change" (p489).

d) Social isolation as a result of social change/globalisation/Western culture (4% of comments) - eg: "The curse of western civilisation, where the elderly are cast off by their families to live their lives out often in total isolation or nursing homes because they are to much trouble and yet in lands not far away the elder are treated respectfully and live within the family group" (p490).

The focus on the individual or their family often involved blaming and shaming comments. The framing of the "'crisis of loneliness' as a personal trouble looks to the character of the individual, their skills and efforts. It is the fault of the individual if they are lonely. This framing creates distance from wider social determinants, such as the challenges of an ageing population, socioeconomic factors, and social and community structures. Individual control over social isolation is emphasised, and this prompts moralising judgements of isolated older people. This aligns with neo-liberal principles of reducing government intervention, enhancing individual responsibility for outcomes and understanding inequality in outcomes as an inevitable consequence of poor individual choices" (Breheny and Severinsen 2018 pp490-491).

Breheny and Severinsen (2018) commented: "Those who post comments may not represent the range of views on the topic; people who largely disagree with the article framing may be more likely to respond. Online commenting provides space for voices of dissent, and so the prevalence of views may not reflect wider population views. What this analysis does provide is examination of the ways that within the highly social topic of social isolation, responsibility is mostly devolved to the individual and their family and neighbours. This demonstrates the difficulty that people have conceptualising issues as reflecting social and systemic causes" (p490).

3.3. ALCOHOL AND SMOKING AND PREGNANCY

Riesch (2018) began: "The nature of scientific and, in particular, biomedical research is that it is beset with uncertainties. When it comes to advising individuals, health advice is rarely clear-cut. Rather, it is often qualified with statistical statements. As a result a fair amount of attention has been paid to the

communication of risk and the effects and content of uncertainty... Furthermore, because the media plays a large role in disseminating scientific findings, a lot of research has concentrated on the way such uncertainties are represented" (p107).

The uncertainty of experts disagreeing and thus conflicted messages are communicated exacerbates this situation. Riesch (2018) used the example of the risks of drinking alcohol during pregnancy and two UK public health bodies. In May 2007 the Department of Health (DoH) advised abstinence, but the National Institute for Health and Clinical Excellence (NICE), in October 2007, stated that small amounts of alcohol were not a concern.

Taking risks through lifestyle choices is seen as a moral issue. Lupton (1993) stated: "If individuals chose to ignore health risks, they are placing themselves in danger of illness, disability and disease, which removes them from a useful role in society and incurs costs upon the public purse. Should individuals directly expose others to harm – for example by smoking in a public place, driving while drunk, or spreading an infectious disease – there is even greater potential for placing the community at risk" (quoted in Riesch 2018).

Pregnant women are the lenses of such moral analysis. Foetal Alcohol Syndrome (FAS) was first described in the 1970s (Jones and Smith 1973), and it referred to the physical, behavioural, and cognitive abnormalities of offspring of heavy drinking women. Subsequently, Foetal Alcohol Effect (FES) and Foetal Alcohol Spectrum Disorder (FASD) have been to used to cover less serious symptoms from less serious drinking during pregnancy. There is a "considerable amount of uncertainty" about all these conditions (Riesch 2018). "It seems reasonably certain that low and steady amounts of alcohol during pregnancy pose very low risks to the foetus. But this also means that there is no particular safe limit under which we can say with absolute certainty that it is safe to drink" (Riesch 2018 p111).

Golden (2005) described the history of the debate about FAS, and argued that "those who generally consider alcoholism to be an illness, as opposed to reflecting an individual's moral failings, directly impacts on whether FAS is perceived as an unfortunate event or as a form of child abuse" (Riesch 2018 p112).

Riesch (2018) added another layer to the debate in how British popular press presents women and alcohol generally (eg: "ladette culture"), and a social class element. "More often than not, alcohol is perceived to be a problem. Particular examples include teenage binge drinking, national embarrassment at the behaviour of British holidaymakers in foreign resorts, and for turning Friday night city centres into no-go areas for older

people. Such concerns have a distinct class association and alcohol is rarely seen as a middle class problem. When health agencies flag up concerns over middle class drinking, the press reaction is overwhelmingly negative..., adopting the stance that the state has no business telling us how to lead our lives" (Riesch 2018 pp112-113).

These are some of the wider issues in the background of advising pregnant women about drinking alcohol. Riesch (2018) analysed eight UK national newspapers for the period March 2007 to May 2008 (ie: covering the period of the conflicting advice by the DoH and NICE). The response to the abstinence advice was strong in the tabloids, as the case of this editorial in the "Daily Mail" (16th October 2007): "It still won't be illegal to drink during pregnancy, for sure, but I can't help wondering how long before this new initiative gives a licence to every tutting busybody to harass and humiliate pregnant women enjoying a night out. [...] I don't believe for a minute that alcohol is good for developing foetuses, but I reckon the jury's still out on the harm that a moderate amount can actually do" (p117).

Many newspapers asked for clarity of message from the public health bodies. But Cavanagh (2009) warned that "it is not reasonable to replace more accurate information with less accurate merely because it is simpler to communicate" (quoted in Riesch 2018).

Overall, Riesch (2018) argued for "the need to be aware of the various audiences and their interpretation of the issues – for example, the perception of risk will differ when considered from the perspective of an individual than when considered from the vantage point of a public health body" (p121).

McCallum and Holland (2018) investigated how newspapers, television and websites presented the public health messages on alcohol and pregnancy in Australia in 2013-14. One hundred and ten items were collected - 60 newspaper stories, 36 articles from parenting and pregnancy websites, and fourteen television news or current affairs stories.

There were a number of themes (frames) identified, but the two most prominent were "contested evidence and advice", and "women's rights".

The former were presented in three ways:

a) Juxtaposition of conflicting evidence - eg: "no harm in daily tipple for mum" vs "pregnant women who drink as little as two glasses of wine in a session could be setting their kids up to fail in school".

b) Highlighted women's "confusion" - eg: "women

still in dark about drinking while pregnant".

c) Actively promoting opposition to the official guidelines - eg: quoting non-experts.

"Stories drawing on the 'women's rights' frame tended to emphasise individual women's personal experience of pregnancy and to place responsibility for alcohol consumption with them. The flipside of privileging a woman's individual responsibility is that it could lead to the blaming of mothers for having a child with FASD, without regard for the availability of resources to manage the conception and pregnancy or the constraints of their social circumstances on their choices" (McCallum and Holland 2018 p420).

Hodgetts and Crabb (2018) concentrated on smoking in pregnancy in relation to the Australian media personality Chrissie Swan photographed by paparazzo smoking in her car while pregnant with her third child in 2013. Subsequently, she made a radio interview "confession", from which the researchers elicited a number of themes.

a) "I just failed and failed" - Emphasising that "giving up is so hard", Swan "draws upon, and naturalises, a foetal-centred account of the 'good mother'" (Hodgetts and Crabb 2018 p453).

b) "There's no 'right time to quit' when you're doing it all" - eg: "I'd win for a few days and then I would have a cigarette and I would feel terrible and wracked with guilt and then I'd be off the cigarettes for a week and then I'd get stressed out and I'd have one again. [...] When I realised I was having difficulty I went online and I looked for ways to quit and the first step, because you know I'm mad for Google" (p454).
This theme emphasised two issues - smoking as "being a condition beyond Swan's volition, and as an (externalised) compulsion she needed to 'fight'", and the context of "a mother trying to 'do it all'" (both work and family) (Hodgetts and Crabb 2018).

c) "Too hard to 'ask for help'" - Swan presented "an account of acute isolation in her efforts to quit smoking. Swan explains that those who might have been expected to serve as key social supports ('my mum, my best friend, my partner') remained unaware of her smoking because it was too shameful to confess ('the secret that is the most shameful is the hardest to ask for help about'). As was the case throughout the transcript, the shame around smoking depicted here arises from a construction of the behaviour as less 'unhealthy' than 'wrong'" (Hodgetts and Crabb 2018 p455).

Hodgetts and Crabb (2018) concluded that "tobacco-related public health interventions have been dominantly informed by addiction and lifestyle models, the result of which, as Poland et al (2006) argue, has been to underplay the 'social meaning of smoking in... people's everyday lives'" (p457). Consequently, there is an "identity paradox ('I know it's wrong... yet here I am having five cigarettes a week') is resolved through a construction of 'good intentions thwarted' by an irrational addiction (largely) beyond her control. In turn, while a positive identity is managed, the broader effect of such an account is once again to medicalise smoking in a manner that deflects attention from the social, cultural and economic factors that influence smoking behaviours" (Hodgetts and Crabb 2018 p458).

3.4. CONFLICT OVER IMMUNISATION

Stephenson et al (2018) examined the representations of parents' responses to childhood immunisation in Australian newspapers in 1997-8 and 2015-16. This covered a period of policy changes about immunisation [15], and the development of advocacy groups campaign against compulsory immunisation. One hundred and fifty-three articles from four newspapers were analysed.

"Australian newspaper coverage of parents often avoids over-simplistically representing parents as pro or anti-vaccination. Some of the more nuanced positions (eg: hesitancy, complacency) that have been identified by public health researchers as contributing to patterns in vaccination are evident in newspaper reporting, in both 1997–1998 and 2015–2016" (Stephenson et al 2018 p477).

Different responses to different "types" of parents were noted:

a) Hesitant and complacent parents - "Hesitant parents" are those who are unsure about immunisation, but usually agree for their children to be vaccinated. In 1997-8 these parents were presented in a negative way, but the newspapers were less negative in 2015-16. A similar pattern was found for "complacent parents" (who ignore, forget, or neglect immunisation).

b) Alternative parents (eg: "anti-vaxers") - These parents "deliberately choose to not vaccinate their children because of moral or religious beliefs, lifestyle choices, or concerns about vaccine safety or effectiveness" (Stephenson et al 2018 p476). Representations of this group had become more negative

[15] First National Immunisation Programme (NIP) in 1997 to lift vaccination rates; "No Jab No Pay" (introduced in 2015) linking benefit payments to childhood immunisation.

over time. An extreme example from 2016: "Anti-vaxers have a special seat reserved for them at hell's dinner table, right next to Holocaust deniers and those who think 9/11 was an inside job" (p479).

3.4.1. Vaccine Refusal

"Vaccine hesitancy" is where parents refuse some or all vaccines or propose an alternative schedule for their children's immunisation [16]. Preventable disease outbreaks are more likely in areas of higher vaccine refusal (Navin and Largent 2017a).

Medical authorities can respond to refusal with:

- Compulsory vaccination - vaccine refusal is a crime;
- Mandatory vaccination - withholding public goods or services from parents whose children are not vaccinated.

With such policies, there is also the possibility of vaccine exemption. For example, in Ontario, Canada, enrolling in school or daycare depends on prior vaccination, but parents can enrol their unvaccinated children if they produce "a notarised affidavit that the province's vaccination requirements 'conflict with my sincerely held convictions based on my religion or conscience'" (Navin and Largent 2017a p226). There is also medical exemption.

Navin and Largent (2017a) outlined three ways that medical authorities could limit the increasing number of non-medical vaccine exemptions (NMEs):

1. Eliminationism - No NMEs or only for selected vaccines (eg: non-serious diseases).

But, for instance, the "most passionate vaccine refusers will likely remove their children from schools and state-supervised daycare centres, rather than have them vaccinated" (Navin and Largent 2017a p227). Or if states or provinces vary in their policies, refusal parents may just move. "In an era of mass mobility, a country's herd immunity depends on the existence of high vaccination rates throughout the entirety of the country, such that geographical clusters of low vaccination rates can be harmful to the entire community (Navin and Largent 2017a p228).

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[16] Daley and Glanz (2017-18) noted three main themes among vaccine-refusing parents:
- Belief that their child was not at risk from diseases rarely seen in the West, like measles and polio;
- Belief that certain vaccine-preventable diseases are not that serious (eg: measles);
- Anxiety about immediate side effects of the vaccines.

Also there is a risk of political polarisation, and "a vaccine-sceptical political party could quickly undermine decades of work developing herd immunity and could expose the community to significant risks" (Navin and Largent 2017a p228).

2. Prioritising religion - NMEs only for religious reasons.

But this introduces unequal treatment between individuals who hold religious views and those that do not. "We might be able to justify prioritising religion if people who objected to vaccinating their children because of their religious convictions had weightier reasons for objecting than did people who objected for reasons of secular moral conscience or personal integrity. But there is no reason to think that the weightiest reasons for refusing vaccines are religious reasons" (Navin and Largent 2017a p229).

There is also the problem of legally defining "religious reasons" as well as the risk of dishonesty in claiming religious reasons when not "really" a believer.

3. Inconvenience - Make the application process for NMEs burdensome. For example, in Michigan state in 2015 it became a requirement to use an official application form, and to attend immunisation education sessions before receiving an exemption. The number of NMEs subsequently fell by one-third (Navin and Largent 2017a).

Navin and Largent (2017a) preferred this option.

Giubilini et al (2017) proposed a variation of inconvenience called "the contribution model". Because vaccine refusers risk reducing herd immunity, or benefiting from herd immunity without contributing to it, there is an unfairness. Giubilini et al (2017) proposed that, similar to conscientious objectors to war who work on the "home front", parents who receive a vaccine exemption for their child "make an alternative contribution to public health that is commensurate to child vaccination, ie: that entails a roughly equal public benefit" (p237) (eg: giving money or time). Clarke et al (2017), for example, proposed the idea of a tax for vaccine refusers that "should be proportionate to the risk of infecting others posed by the non-vaccinated and to the magnitude of the harm entailed by the infectious diseases for which parents decide not to vaccinate their children" (Giubilini et al 2017 p238) [17].

[17] Daley and Glanz (2017-18) reported their work in Colorado, which determined that unvaccinated children were over twenty times more likely to develop whooping cough than vaccinated children, and

Navin and Largent (2017b) challenged the idea of contributionism: "We reject this transactional account of parental rights to NMEs. Parents do not need to earn their right to make medical decisions for their children through acts of good citizenship" (p242).

3.5. FRAMING RESPONSIBILITY

Douglas et al (2018) considered framing [18] in relation to the Public Health Responsibility Deal (RD) launched in the UK in 2011. This was voluntary agreements between the government and the food, beverage and alcohol industries to undertake public health activity.

Douglas et al (2018) studied public statements by these industries in relation to RD in national daily newspapers and online news websites in Britain between October 2010 and February 2015. The researchers found and analysed 247 relevant articles.

Industry spokespersons accepted the RD as positive for public health, but used four types of arguments (framing) to:

a) Downplay the responsibility of industry for public health problems - eg: "Over the last 10 years, the consumption of soft drinks containing added sugar has fallen by 9% while the incidence of obesity has been increasing, and 61% of soft drinks now contain no added sugar" (British Soft Drinks Association) (p381).

b) Present the industry as already playing its part - eg: "Through the Responsibility Deal, UK food and drink manufacturers are working in partnership with government, non-governmental organisations and other stakeholders to tackle the causes of obesity and poor public health. It is an important part of the UK food manufacturing industry's commitment to achieving responsible and sustainable economic growth" (Food and Drink Federation) (p381).

c) To emphasise individual consumer choice - eg: "I don't believe the public want the way they eat, drink and exercise in their own homes legislated by government. Helping people make better choices has to be a better long-term approach" (Wine and Spirit Trade Association) (p381).

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over six times more likely to be hospitalised with pneumonia.

[18] Koon et al (2016) stated that "research on framing looks at how actors create meaning in the policy process and how they package these meanings for instrumental and expressive purposes. In this way, a frame emerges, interacts with others and helps shape the terrain of the debate" (quoted in Douglas et al 2018).

d) To accept the RD as preferable to legislation - eg: "The intended introduction of [minimum unit] pricing intervention is misguided and appears to run counter to the Responsibility Deal set out by this government" (A food, beverage and alcohol company) (p382).

Douglas et al (2018) commented: "Despite a small minority of dissenting views founded on concerns about 'nanny-statism, the RD was portrayed as wholeheartedly welcomed by industry and reportedly played an explicit part in CSR [corporate social responsibility] agendas" (p384).

Hawkins and Holden (2013) distinguished three types of framing:

- Diagnostic - defining a problem.
- Prognostic - offering solutions.
- Motivational - encouraging change.

Applying these to the industries' comments:

i) Diagnostic framing - public health problems were framed as "ones of personal responsibility of individual consumers... or an irresponsible minority, thus deflecting attention from the potential contribution of industry" (Douglas et al 2018 p384).

ii) Prognostic framing - the industries presented themselves as taking "sufficient voluntary action".

iii) Motivational framing - "the policy-making arena needed to be made more accessible to industry because of its reported expertise and ability to reach the public. The promotion of partnership working appeared to be designed to extend influence and claims for legitimacy of industrial interests" (Douglas et al 2018 p384).

Douglas et al (2018) concluded: "Industry is not a disinterested partner in public health. It has been argued that its primary goal is to maximise profit and its ultimate responsibility is to shareholders, creating inherent tensions and potential conflicts and potential conflicts of interest... One criticism expressed from the outset of the RD by some commentators was that public–private partnership would allow and provide a platform for industry to appropriate public health initiatives to advance or protect its own interests" (p385).

Whelan (2018) examined Canadian newspapers' coverage of hand hygiene from 1986 to 2015, and found that "responsibility for hand hygiene shifted over time, from a focus on public handwashing to curb the spread of disease in the community, to the responsibility of healthcare providers to clean their hands to prevent

healthcare- associated infection (HAI). However, the last few years of coverage show a growing tendency to responsibilise patients for ensuring healthcare providers' good hand hygiene" (p425) [19].

The period of the study included the Severe Acute Respiratory Syndrome (SARS) epidemic of 2003 affecting Canada (particularly Toronto), and growing concern over HAI.

Whelan (2018) studied 518 articles from fifty newspapers. The articles overall advocated handwashing to stop epidemics and HAI, despite the scientific evidence not being clear-cut (Whelan 2018).

Whelan (2018) pointed out three problems with the focus on individual handwashing:

i) It ignored contradictory evidence.

ii) It fostered stigmatisation of non-compliant individuals, who may actively continue to resist the health messages.

iii) The focus on the individual ignores wider and more complex issues. Wilkins (1993) argued that "news media present coverage of scientific issues 'stripped of social, economic and political context' and discuss risks 'in terms of specific people, governments or corporations to ''blame'', rather than more deeply examining the political and economic system which makes decisions about risk'" (Whelan 2018 p433).

3.6. COMMUNICATING NUMBERS

Kristensen et al (2018) explored how the numbers used in public health campaigns are perceived by individuals. They focused on a Danish health campaign launched in 1998 - "6 a day - eat more fruit and vegetables".

"When a phenomenon moves from one sphere (it may be the sphere in which it originated) to another, a translation process takes place during which the phenomenon, in this case the message, is endowed with a

[19] "Responsibilisation 'captures the duality of responsibility for the self and for others by drawing attention to the active components of many discourses that assign responsibility to specific categories of agents as is exemplified in the slogan: "Only you can stop drinking and driving", which individualises the responsible driver"' (Hunt 1999 quoted in Whelan 2018). This is applying the idea of moral regulation: "The position that you should wash your hands (a moral argument) becomes subsumed in the goal of reducing infection; hand-washing is now routinely presented as the obvious, easy way to meet this goal. This mixing of the moral and the utilitarian creates, Hunt argues, a hybrid form of discourse, ‘an apparently benign form of moralization in which the boundary between objective hazards and normative judgments becomes blurred’ [Hunt 2003]" (Whelan 2018 p427). Put simply, public health becomes an individual's responsibility.

different meaning which may simplify the original version, while at the same time creating uncertainties and ambiguities" (Kristensen et al 2018 p461). The "6 a day" message "may best be understood as a work of constructing a mould, and then offering the hollow form to the public" (Kristensen et al 2018 p461).

Kristensen et al (2018) performed a number of semi-structured interviews with experts from the public health authorities, food companies, and members of the public.

"Despite the in-depth discussions and data-based research by the partners involved in designing the campaign, the scientific evidence behind the campaign was never communicated to the public" (Kristensen et al 2018 p466). So, members of the public were not sure about the health benefits of the message.

But the number carried weight. For example, "Bente, a 35-year-old mother, related to '6 a day' as a moral rule, using it to discipline herself in her choices of food. Even though she did not adhere to the exact number of fruit and vegetables, she perceived the message as an objective truth – a recommendation that should be followed. Bente commented that she trusted the message and did not question how the policy-makers arrived at their conclusions, believing that those responsible 'did a good job', and adding that 'as long as rules are realistic, no one poses any questions'" (Kristensen et al (2018 p467).

Kristensen et al (2018) concluded: "Although people apparently did not pay much attention to the fixed number as such, they were nevertheless influenced by the implicit numerical logic with its connotations of absolutism and legitimacy. They assimilated the moral message 'to eat more fruit and vegetables' in their daily lives and perceived '6 a day as a rule of thumb" (p470).

3.7. ADVERTISING

3.7.1. Direct-To-Consumer Advertising

Adams and Harder (2018) examined direct-to-consumer advertising (DCTA) in the USA for prescription drugs aimed at overweight and obese individuals. One hundred and twenty advertisements aired on television between 1997 and 2015 were analysed for messages about the "healthy lifestyle".

The authors found two forms of healthy lifestyle presented through:

i) "Drug compliance ads" - The use of the advertised drug is key to health management. "In terms of disease aetiology, these advertisements focus on the non-

preventable origins of the condition and on how the efforts on the part of the patients to manage the condition without the use of drugs are partially to wholly ineffective. Frequently, advertisements explicitly or implicitly convey the message that genetic factors are the underlying cause of the focal health problem. This enables drug compliance advertisements to either ignore or downplay the role of healthy behaviours not involving drug use, such as diet and exercise, in prevention or disease management" (Adams and Harder 2018 p443).

For example, an advertisement for a cholesterol-reducing drug showed sport-playing older adults with the caption: "High cholesterol is a tougher opponent than you think... for millions of adults with high cholesterol, diet and exercise aren't always enough" (p443).

ii) "Complementary drug use ads" - A healthy lifestyle is the combination of diet and exercise, and the advertised drug.

For example, a weight-loss drug advertisement showed unhealthy foods, and included the voiceover saying: "Eat right, stay active. But if that's not enough, ask your doctor about adding [drug name]" (p444).

Adams and Harder (2018) concluded that both forms of DTCA "regard drug use as a type of healthy behaviour" (p446). They continued: "By presenting drug use as a type of behavioural solution, DTCA draws on the dominant public health discourse concerning the importance of adopting and maintaining healthy behaviours. By defining drug use as a healthy behaviour, DTCA appears less like profiteering through corporate-based interests and more like a legitimate, non-biased source of health information. In other words, it somewhat resembles public health promotion, the goal of which is to prevent and manage disease" (Adams and Harder 2018 p446).

3.7.2. Social Media

Gupta et al (2018) considered the use of social networking sites by alcohol marketers. Two months of Facebook data were collected in December 2015 and January 2016 for India and Australia. The Facebook pages of 256 alcohol brands in India and 287 in Australia were found, and the ten most "liked" brands in each country were analysed.

The brands used general and specific strategies to encourage engagement with users.

a) General approaches - eg: sponsorship of events; competitions and giveaways.

b) Specific to India:

eg: inspirational talks - "Statements such as 'Progress comes when you step outside your comfort zone' (Haywards 5000) and 'Every little thing contributes to great success. #Pause and let's raise a toast to all your victories' (Black Dog) indirectly relate success and hard work to alcohol consumption" (Gupta et al 2018 pp406-407).

eg: camaraderie - "This leap day, take a giant leap towards friendship and catch up with that long lost friend of yours over a #DaaaaamnColdDaaaaamnCo#Stayrefreshed (Foster's)" (p407).

c) Specific to Australia - eg: creating stories related to the brand's tradition, or cultural heritage. "For example, Jägermeister uploaded photos and videos prompting users to celebrate Australia Day by drinking alcohol, and Johnnie Walker and Stella Artois uploaded images of the brands' founding fathers narrating stories about the history of their distilleries/breweries in a specific region" (Gupta et al 2018 p406).

3.8. NEWS MEDIA AND PHARMACOVIGILANCE

Adverse drug reactions (ADRs) are a public health risk, particularly post-marketing (ie: when a drug is available to the public). Fatal ADRs "may be as high as the fourth leading cause of death" as the under-reporting of ADRs generally is high (Dew et al 2018).

"Suspected ADRs are a frequent reason for doctor–patient contact...; however, practitioners appear to start from the normative position that drugs released to the market are safe, and that adverse reactions reported to them can be dismissed as unreliable or a symptom of patient hypervigilance" (Dew et al 2018 p389). Backstrom et al (2000), for example, found that doctors in northern Sweden were reluctant to officially report ADRs for various reasons, including lack of time, perception of lower importance, and limited knowledge about the reporting rules. "Physicians then underestimate ADRs and patients under-recognise them" (Dew et al 2018 p389).

Pharmacovigilance is the surveillance of medications once they are in general use. Dew et al (2018) explored the role of the news media here with the case of "Eltroxin" (a prescription-only drug for hypothyroidism) in New Zealand. It was introduced in July 2007, and reports of ADRs started to appear in local newspapers around one year later. In response to a growing number of reports, the medical authorities made statements discrediting the claims of ADRs. "The high number of ADRs could therefore be explained away as an over-reporting of adverse reactions by irrational patients" (Dew et al 2018

p396).

Dew et al (2018) argued that the media opened a new avenue of pharmacovigilance that was missing in New Zealand at the time. The usual source of reporting ADRs is via doctors and health care professionals. "However, there are several barriers to reporting with this mechanism. First, the patient has to consider his or her symptom to be a result of the prescribed medication. This could be particularly difficult, especially with people with co-morbidities or chronic illness that has some fluctuation in symptoms. Second, the patient has to confront the health professional, usually the one who prescribed the medication in the case of the general practitioner, with the bad news that a prescribed medication is causing problems. This is a face-threatening act in that it threatens the face of the health professional because something they have done with good intentions has caused harm... Patients may be reluctant to engage in such face-threatening acts... Third, research suggests that health professionals consistently dismiss patient claims that a prescribed drug is the cause of symptoms" (Dew et al 2018 p396). The media helped in overcoming these barriers.

Dew et al (2018) concluded that the media provided "another channel for promoting enhanced ADR reporting. However, we do not seek to promote media-centricism, where the media are positioned as producing the primary causal effect... Rather, we consider news media to be part of existing ADR reporting processes at both formal and informal levels" (p399).

3.9. CHOLESTEROL AND STATINS

Boseley (2018) described a battle for hearts and minds in the media over the cause of heart attacks. The traditional focus on cholesterol is being challenged by "a small group of dissident scientists" who point to sugar instead. This latter group even advocate high fat diets contrary to official advice. They have been called "cholesterol sceptics" and "statins critics" (Boseley 2018).

The issues disputed include:

- The link between total cholesterol and cardiovascular disease.
- The link between low-density lipoprotein (LDL) cholesterol and cardiovascular disease.
- The benefits of cholesterol-lowering treatment (statins).
- The level of side effects of statins.

Malhotra et al (2017) stated their position clearly

in the title of their article: "Saturated fat does not clog the arteries: Coronary heart disease is a chronic inflammatory condition, the risk of which can be effectively reduced from healthy lifestyle interventions". Their evidence came from a meta-analysis of observational epidemiological studies that found no association between saturated fat consumption and specific (heart-related) or general mortality (de Souza et al 2015).

Malhotra et al (2017) advocated "an energy-unrestricted Mediterranean diet (41% fat) supplemented with at least four tablespoons of extra virgin olive oil or a handful of nuts".

They argued that the drive towards "low fat" foods and medications "has been misguided", and advocated increased physical activity (Malhotra et al 2017).

Malhotra (2013) outlined his concern: "when you take the fat out, the food tastes worse. The food industry compensated by replacing saturated fat with added sugar" (p2).

Nunan et al (2018) offered a rebuttal of Malhotra et al's (2017) "opinion editorial".

Firstly, de Souza et al's (2015) meta-analysis was based on studies viewed as low-quality in terms of methodology (table 3.1), and any associations were "very low" (de Souza et al 2015 quoted in Nunan et al 2018).

- Observational studies do not intervene, whereas RCTs allow manipulation of variables. Thus, data from RCTs are viewed as "better".

- Collins et al (2016) outlined 4 strengths of RCTs:

i) Like-with-like outcome comparisons.
ii) Like-with-like outcome comparisons.
iii) Robustness for detecting effects.
iv) Generalisability of evidence.

- Observational studies are better for detecting long-term effects, and rare outcomes (Collins et al 2016).

Table 3.1 - Observational epidemiological studies vs randomised controlled trials (experiments) (RCTs).

A meta-analysis of better quality studies (Hooper et al 2015) found that long-term reduction of saturated fat intake reduced cardiovascular risk.

Secondly, Nunan et al (2018) challenged the extra olive oil with the Mediterranean diet. Studies of this diet show that replacing saturated fat with unsaturated fat is beneficial.

Overall, Nunan et al (2018) said that Malhotra et al (2017) "choose a binary and simplistic approach that gives little regard to the complex narrative regarding

saturated fats, as this is not a biologically homogeneous group of compounds. The triglyceride composition, fatty acid chain length, food source and nutrients and non-nutritive compounds in the foods all determine the effects of saturated fat on health" (p2).

Arguing against statins, Malhotra (2013) stated: "The fact that no other cholesterol lowering drug has shown a benefit in terms of mortality supports the hypothesis that the benefits of statins are independent of their effects on cholesterol" (p2). He continued: "Adopting a Mediterranean diet after a heart attack is almost three times as powerful in reducing mortality as taking a statin" (Malhotra 2013 p2).

Collins et al (2016) review of the evidence emphasised the benefits of statins in reducing cardiovascular events. For example, daily statin use reduces LDL cholesterol by more than 50%, and consequently, over five years, 10% of high risk patients would be prevented from heart attacks and strokes.

There is evidence of some side effects of statins, but limited in the studies (eg: 1-2% of patients over five years) [20]. Collins et al (2016) were pragmatic: "The harmful effects of statin therapy can usually be reversed without any residual effects by stopping it, whereas the harmful effects of heart attacks or strokes that occur because statin therapy has not been used can be devastating" (p2546).

These researchers made this point: "There is a serious cost to public health of making misleading claims... adverse media coverage was linked to increased reticence among the doctors to discuss and prescribe statins, and reduced compliance by the patients (including those with pre-existing cardiovascular disease) due to raised awareness of perceived side-effects" (Collins et al 2016 p2554).

Ravnskov et al (2018) sought to show the causality between cholesterol and cardiovascular disease, and between statins and lowere cholesterol are difficult to establish.

Demasi (2018) was concerned with the move to recommend statins to individuals with low risk of heart disease, and the financial interests/conflicts of groups, like the US National Cholesterol Education Programme, that encourage the increased use [21]. She talked of "diagnosis creep" "whereby simply changing the definition

[20] Demasi (2018) criticised Collins for admitting in the media that he had not seen "the full data set on statin side effects". Furthermore, Collins' employer had received research funding from the pharmaceutical industry, she pointed out.

[21] Pro-statins experts are accused of being paid by drug companies. But statins are out of patent and so do not make money for the companies that originally marketed them (Boseley 2018).

of a disease or lowering the threshold of a surrogate marker turns healthy people into patients and leads to overdiagnosis and unnecessary treatments" (Demasi 2018 p906) [22].

3.10. CYBERCHONDRIA

The Internet is being used more often for health-related searches. Starcevic and Berle (2013) explained: "People seek medical information on the Internet because it is easy, results are obtained quickly and the process is anonymous and bypasses administrative hurdles. One can make almost any inquiry without feeling embarrassed. It is also cheap or does not cost anything. Perhaps, the most important positive aspect of obtaining health information online is a sense that one is empowered by that information. This can help break barriers in communication with physicians and allow a more active participation in any discussions about diagnosis, care and treatment" (p205).

On the negative side, "cyberchondria" [23] has emerged. This is "excessive or repeated health-related searches on the Internet that are distressing or anxiety-provoking" (Starcevic and Berle 2013 p205). The term, however, has been used to describe anyone seeking health information on the Internet, at one end, as a "21st century counterpart of hypochondriasis, or a "new disorder" (or "the new frontier in illness anxiety"; Harding et al 2008) (Starcevic and Berle 2013).

Starcevic and Berle (2013) distilled the key elements from many definitions - "excessive" active Internet health-related searches, and this behaviour is not pleasurable or entertaining, leading to increased anxiety. These authors did not see it as a separate disorder, but as part of health anxiety and hypochondriasis. Importantly, it is not Internet searches that are occasional, or regular that are entertaining, or searches that make individuals feel reassured.

Starcevic and Berle (2013) outlined the characteristics of the Internet that maintain cyberchondria:

a) "Spurious possibilities" - Search results are ranked according to popularity, and less common illnesses can become top ranked because of curious individuals who have clicked on the unusual answers. Thus, the anxious individual is faced with multiple sclerosis, for example,

[22] Demasi (2018) described the criticisms she had received for making a documentary in Australia which questioned the use of statins by low risk patients.

[23] The term was probably first used in 1999 in the "Wall Street Journal" (Starcevic and Berle 2013).

at the top of the list for numbness rather than more common causes. "This will only increase anxiety, which may then lead to further online searches in an effort to find both a more likely and more reassuring symptom explanation. This may then become akin to a never-ending journey because individuals who are particularly concerned about the probability of having a serious illness (eg: those with high levels of health anxiety) will have difficulty distinguishing the real risk from an artificially created one" (Starcevic and Berle 2013 p208).

b) Too much information - The anxious individual is looking for the "perfect" diagnosis, and the wealth of health information allows a never-ending search. "Thus, cyberchondria may be reinforced, with the ultimate reward (full or perfect explanation) being expected only at the end of the searching process. This possibility accords well with the observation and findings that many people with hypochondriasis have perfectionist traits and other features of obsessive–compulsive personality disorder" (Starcevic and Berle 2013 p209).

c) Ambiguity and uncertainty of information - Online searches lead to ambiguous medical terms, for instance, which prompts further searching, and, in fact, more information does not reduce uncertainty, only increases it.

d) Trustworthiness of information - "Unfortunately, much of the health-related online information has been found to be inaccurate, misleading, incomplete or oversimplified. Furthermore, websites of some patient support groups or organisations established to raise awareness of certain illnesses and raise funds for medical research may provide selective or misleading information (eg: on the prevalence rates and tendency for some illnesses to be underdiagnosed) as an unintended consequence of their mission to 'promote' particular diseases and draw attention to the plight of their sufferers" (Starcevic and Berle 2013 p209).

Furthermore, some individuals do not trust "official" medical websites, and deliberately seek less trustworthy sources (Starcevic and Berle 2013).

3.10.1. Perseverative Cognition

The perseverative cognition (PC) hypothesis (Brosschot et al 2006) proposed that "worry and/or repetitive thinking may lead to disease by prolonging stress-related physiological activation by amplifying short-term responses, delaying recovery, or reactivating responses after a stressor has been experienced" (Clancy

et al 2016 p1).

PC includes worry and rumination about past and future events (and related thought processes) [24], which directly alter physiology (eg: higher heart rate and blood pressure) (and subsequently health) (eg: meta-analysis by Ottaviani et al 2015).

Clancy et al (2016) added that PC also influences health and disease indirectly via unhealthy behaviours and increased health risks. In a meta-analysis, these researchers found that "increases in PC are associated with increases in health risk behaviours (substance use, alcohol consumption, unhealthy eating, and smoking) that are driven primarily through rumination. In contrast, measures of worry and reflection were not associated with health behaviours" (p9).

3.11. APPENDIX 3A - SOCIAL BOTS

Social media platforms are occupied by "social bots" (ie: "software programmes that automatically produce content and emulate human behaviour"; Kitzie et al 2018 p1). Social bots on Twitter, for example, write original tweets, and follow and retweet other users. They can engage in malicious activities, including (Kitzie et al 2018):

- Identity attacks (eg: impersonating a user's friend to extract personal information).

- Astroturfing (ie: "making it appear as if the vast majority of people are in favour of a particular position"; Kitzie et al 2018 p2).

- Smoke screening (ie: using other hashtags to distract users from the issues of a debate).

Kitzie et al (2018) performed a case study of the activity of these bots on Twitter after a mass shooting at Stoneman Douglas High School in Parkland, Florida (24th February 2018).

The data collected included a random sample of 120 000 Twitter users and 5000 social bot accounts in the month following the event, and related to "popular" hashtags.

Six key strategies were found to be employed by retweeted bot accounts:

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[24] Rumination is "thinking perseveratively about one's feelings and problems" (Nolen-Hoeksema et al 2008), and it involves brooding and reflection. "Brooding is described as a passive and judgmental form of rumination, whereas reflection is more contemplative with a focus on problem-solving" (Clancy et al 2016 p3).

i) "Baiting" - eliciting an angry or emotional response (eg: "planned parenthood has killed more babies last year than all school shootings combined").

ii) "Instilling doubt" - posting dubious information that instils doubt about democratic institutions (eg: "anyone else hacked about the FBI wasting resources on a phony witch hunt while letting 17 people get slaughtered").

iii) Sharing factual information.

iv) Spreading conspiracy theories - eg: survivors were "crisis actors".

v) Organising political action.

vi) Using shooting for commercial gain.

The majority of retweets of bot accounts were by humans. "This finding supports the conclusions of prior work that while bots amplify conversation surrounding significant issues (eg: political elections, crisis situations), people are primarily responsible for the dissemination of bot-generated content... Another significant finding was that a subset of bot-generated content is not malicious. This content could be produced by 'benign' bots, employed within journalism contexts to share news related to the Parkland shooting and its aftermath" (Kitzie et al 2018 p8).

Kitzie et al (2018) explained the retweeting by humans as linked to ingroup/outgroup behaviour. "People develop risk perceptions based on their commitment to a particular way of life and worldview. Therefore, people may share content that criticizes institutions like the mainstream media if they view this institution as presenting a risk to their way of life. Content that bolsters a specific ideology, such as a pro-gun control agenda, may appeal because it affirms their sense of self. This sense is derived, in part, by the groups to which people belong. Therefore, supporting specific in-group ideologies and members by sharing content may help reinforce an individual's perception that they belong to the 'correct' group with desirable ideologies" (Kitzie et al 2018 p8).

More widely there is concern about misinformation, disinformation, and "fake news". Chadwick et al (2018), for example, investigated the sharing of tabloid news stories on Twitter during the 2017 UK general election campaign.

Among 1313 Twitter users, two-thirds admitted to having shared news stories in the past month that were

"problematic in some way" [25]. Tabloid news stories were more likely to be shared than other types of news. In terms of reasons for sharing, "those who are motivated to entertain/troll and debate with others are more likely to engage in misinformation and disinformation when they share news. Those who seek to persuade/inform others are less likely to do so" (Chadwick et al 2018 p4268).

Chadwick et al (2018) commented that "UK tabloid newspapers negatively affect the quality of civic life on social media because they provide a fertile context for misinformation and resources for disinformation", and that "the more users engage with politically like-minded others online, the less likely it is that they will be challenged for dysfunctional behaviour. Over the longer term, these people are less likely to encounter the kind of opposition that might make a difference to the quality of the news they share" (p4270).

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4. ALLERGY AND IMMUNITY

4.1. ALLERGY

Allergic rhinitis ("hay fever" - ie: sneezing, runny nose, blocked nose, or red itchy eyes) is where the immune system overacts to allergens in the air, and it has been increasing in the industrialised world in recent years (Klein 2018).

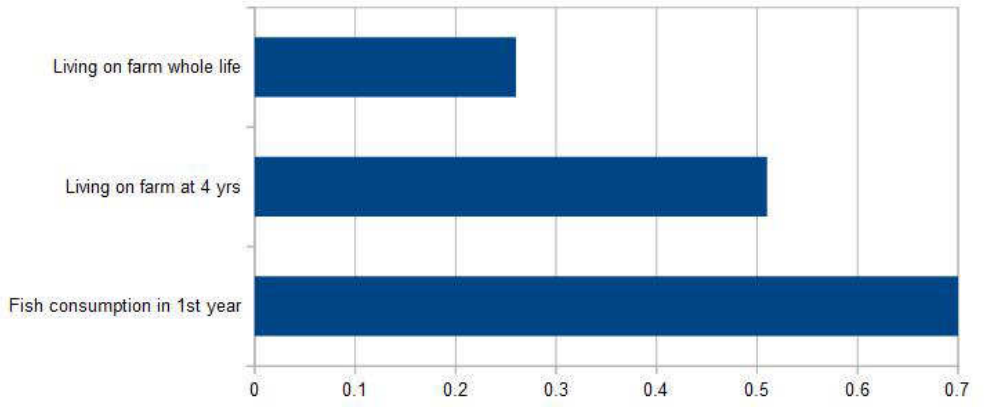
Studies have found that early experiences influence the development of this condition - including eating fish or living on a farm (versus urban life) reduced the risk, while anti-biotics in the first week of life increased the risk (Vasileiadou et al 2018) [26].

Vasileiadou et al (2018) investigated two of these factors in a longitudinal study of children born in western Sweden in 2003. Over 3500 parents completed questionnaires when the children were twelve years old. The outcome measure was allergic rhinitis at 12 years old (ie: in the last twelve months), while information on diet in the first year, and place of habitation were collected at the time.

Around one-fifth of the children had allergic rhinitis. Living on a farm, or fish consumption (at least once a month) in the first year of life significantly reduced the risk of this condition at twelve years old (figure 4.1) [27].

Vasileiadou et al (2018) speculated on the findings: "It has been suggested that the immunological effects of omega-3 fatty acids, which are found in oily fish, explain how fish consumption can reduce the risk of allergic diseases. However, studies that provided infants

[26] The "paradoxes of progress" (Greaves 2018) has been applied to other diseases (appendix 4A).
[27] The combination of both factors did not lower the risk further.



(Data from Vasileiadou et al 2018 tables 2 and 3)

Figure 4.1 - Adjusted odds ratio for allergic rhinitis at 12 years old (where 1 = none of the factors).

and children with omega-3 fatty acid supplements have reported inconsistent results. Few epidemiological studies have successfully distinguished oily and lean fish consumption in childhood, and the results have been inconclusive. Another hypothesis is that other compounds than fatty acids in fish, including certain vitamins or proteins, might have an impact on allergic disease. For example, vitamin D is found in fish and has been associated with reduced allergy levels. Moreover, regular fish consumption might reflect living in a more positive socio-economic environment and a more healthy lifestyle in general" (p287).

Other studies with the same cohort in western Sweden have found that eating fish in early life reduces the risk of asthma at eight years old (eg: Goksor et al 2013). This was also found in another Swedish longitudinal study (Magnusson et al 2013).

Bjerg et al (2011) made use of Swedish data from the European Community Respiratory Health Survey (ECRHS) (Bjornsson et al 1994), which included 10 800 adults in three areas of Sweden in 1990, and the Global Allergy and Asthma European Network Survey (GA2LEN) covering 45 000 adults in 2008 [28]. Both surveys asked about asthma (including wheezing), and rhinitis (and smoking) (table 4.1).

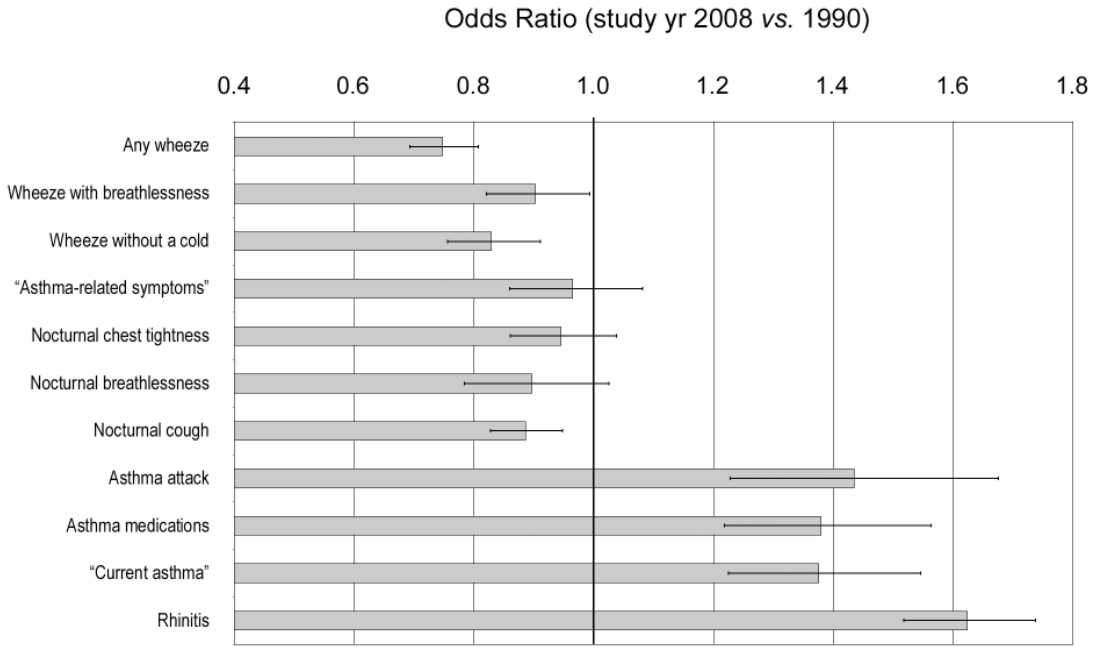
[28] For analysis purposes, the samples were 8982 and 9156 respectively.

- Any wheeze: "Have you had wheezing or whistling in your chest at any time in the last 12 months?"
- Wheeze with breathlessness: "Have you been at all breathless when the wheezing noise was present?"
- Wheeze without a cold: "Have you had this wheezing or whistling when you did not have a cold?"
- Asthma attacks: "Have you had an attack of asthma in the last 12 months?"
- Rhinitis: "Do you have any nasal allergies including hay fever?"
- "Asthma-related symptoms": Any wheeze and wheeze with breathlessness and wheeze without a cold.
- "Current asthma": "Do you have asthma?" and either or both of asthma attacks and use of asthma medications.

(Source: Bjerg et al 2011 p2)

Table 4.1 - Key questions on wheezing and asthma in surveys.

Comparing the two studies, wheezing had declined between 1990 and 2008, but asthma and rhinitis had increased (figure 4.2).



(Source: Bjerg et al 2011 figure 1)

Figure 4.2 - Odds ratio of symptoms in 2008 (where 1 = symptoms in 1990).

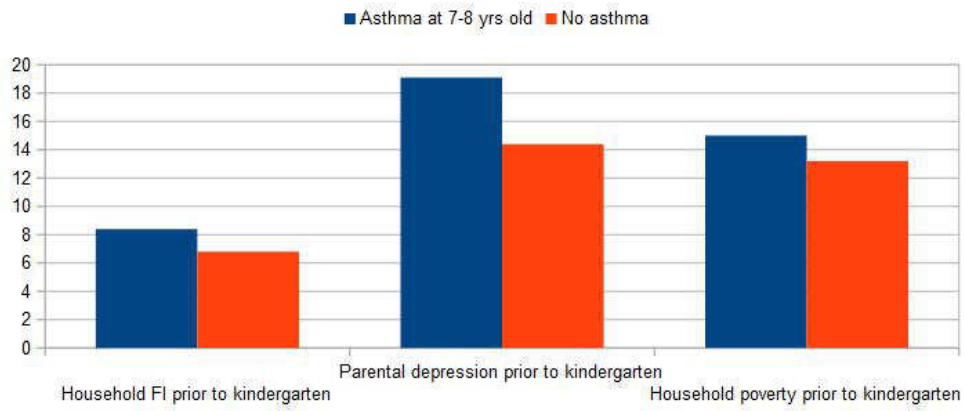
4.2. ASTHMA AND FOOD INSECURITY

Asthma has been associated with food insecurity (FI). FI is "limited or uncertain availability of nutritionally adequate food or an inability to reliably acquire it" (Mangini et al 2018 p1). It is associated with health problems. FI is predicted by maternal depression, minority ethnicity, and obesity. All of these factors interact to produce an asthma-FI association (Mangini et al 2018).

Mangini et al (2018) investigated this in relation to US children with data from the Early Childhood Longitudinal Study-Kindergarten (ECLS-K) cohort. The ECLS-K began in 1998 with over 20 000 kindergartners and followed them to 2007 (ie: 3-5 years old to 11-13 years old). Mangini et al (2018) had complete data on 6731 children.

FI was measured by eighteen standardised questions to parents via telephone interview for the previous year (Household Food Security Survey Module; HFSSM). Asthma was coded as present or absent from parents' information to medical professionals. Other variables were also scored like household poverty, and body mass index.

Overall, 11% of the sample had a diagnosis of asthma at 7-8 years old, and 8% at the end of the study (excluding those reporting asthma earlier). Compared to the rest of the sample, these individuals had significantly higher levels of household FI prior to kindergarten, poverty, and maternal depression (figure 4.3), and were more likely to be ethnic minority.



(Data from Mangini et al 2018 table 1)

Figure 4.3 - Percentage of respondents having selected significant associations.

Mangini et al (2018) offered an explanation for the relationship between FI and asthma thus: "exposure to

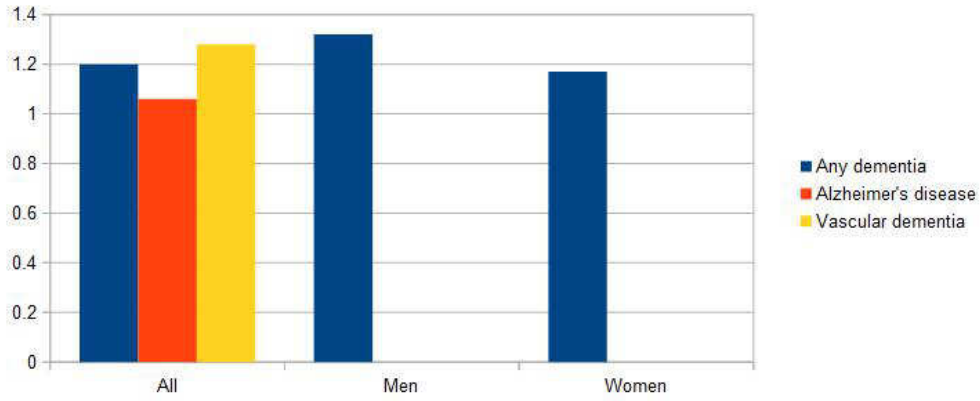
food insecurity could be one link in a chain of risk, exerting deleterious effects on household routine or structure or exacerbating sub-optimal living conditions, overwhelming a family's coping mechanisms in the short term. This destabilising stress, insofar as it contributes to chaotic home environments, could in turn affect children's risk of chronic disease, with or without an increase in parental emotional distress or parenting difficulties. Food insecurity may work across multiple domains via stress and/or associated inflammatory processes to negatively impact health and development. Although the aetiology of asthma is unknown, inflammation involved in triggering asthma is hypothesised to arise from diet-mediated increases in inflammation or metabolic changes related to pathological weight gain; poor diet with energy-dense foods may enhance that diet-mediated increase in inflammation and asthma onset" (p7).

Interestingly, maternal (or parental) depression had a stronger effect on the child's risk of asthma than FI. Mangini et al (2018) explained: "The association is likely mediated by both sociobiological and behavioural pathways. Parental depression may influence development of asthma via dysregulation of the hypothalamic-pituitary-adrenal axis. Behavioural pathways connecting parental depression to child asthma may include parenting behaviours such as parental sensitivity and growth-fostering behaviours, and the child's perceived level of family/home stress. Parental depression could negatively affect parenting behaviours and increase a child's perceived stress level, contributing to negative health outcomes in the child" (p5).

Though this study involved a large sample and so a good selection of data, no details were available on family history of asthma, maternal (parental) smoking, and exposure to air pollutants, which all have relevance to the development of asthma.

4.3. AUTOIMMUNE DISEASES

Wotton and Goldacre (2017) investigated the link between autoimmune diseases, like multiple sclerosis, and Alzheimer's disease (AD) using English hospital data. Around 1.8 million individuals were admitted to hospital between April 1998 and March 2012 with an autoimmune condition. These individuals were 20% more likely to have a subsequent admission to hospital for dementia than the general population. The risk was greater for vascular dementia than AD, and for men than women (figure 4.4).



(Data from Wotton and Goldacre 2017 table 2 p579 and table 3 p580)

Figure 4.4 - Odds ratios for later dementia-hospitalisation after autoimmune disease-hospitalisation (where 1.00 = general population risk).

An interesting finding was that admission for rheumatoid arthritis "seemed to protect against AD, but elevated the risk of vascular dementia" (Wotton and Goldacre 2018 p578). The authors speculated that non-steroidal anti-inflammatory drugs taken by rheumatoid arthritis sufferers was the reason.

The data used in this study were based on hospital admissions for twenty-five autoimmune diseases (ie: individuals at the severe end of the conditions).

4.4. MICROBIOTA

The human gut contains trillions of micro-organisms (known as the microbiota [29]) which interact with the host, and evidence is emerging of their modulation of health and disease (Kahrstrom et al 2016). This has led to the view of humans as "holobionts" (Gordon et al 2013) - a "super-organism" of human and microbial cells [30].

4.4.1. Diet-Microbiota Interactions

"The human gut is a bioreactor that typically encompasses hundreds or thousands of bacterial taxa, which predominately belong to two phyla: Firmicutes and

[29] Microbiota is the "body habitat-associated microbial communities", while the microbiome is their genes and gene products (Charbonneau et al 2016).

[30] It has been estimated that there are more than 100 microbial genes to every human gene in the body (Gilbert et al 2016).

Bacteroidetes" (Sonnenburg and Backhed 2016 p56).

The microbiota may play a role in relation to obesity and the Western-style diet. In germ-free mice (ie: no microbiota), for instance, the Western-style diet does not lead to obesity and related problems, and the microbiota of obese mice transplanted into lean mice leads to weight gain (Sonnenburg and Backhed 2016).

The type of diet influences the composition and function of microbiota, and recent research has highlighted three main themes (Sonnenburg and Backhed 2016):

i) The microbiota respond rapidly to large changes in diet (eg: a major change in fibre and fat content in the diet is seen in microbiota changes in 1-2 days).

ii) Long-term dietary habits are the dominant force in determining the gut microbiota composition.

iii) Changes in diet have a varied effect on different people because of the individuality of gut microbiota (eg: increased fibre increases microbiota diversity only for individuals with low microbiota diversity already).

4.4.2. Immune System

Germ-free mice have an altered innate immune system (that part of the immune system that is not learned from contact with pathogens). For example, the development of aspects of bone marrow is reduced and thus bacterial infection takes longer to remove from the body. It appears that the microbiota has a role in the development of the immune system (Thaiss et al 2016).

There are "multiple levels of interaction between the microbiota and the cells of the innate immune system..., which range from molecular events at the level of individual cells to the physiology of entire organs" (Thaiss et al 2016 p72).

The microbiota can confer resistance to pathogenic bacteria. Germ-free mice, for example, are more susceptible to certain bacteria (eg: Listeria monocytogenes) (Baumler and Sperandio 2016). Changes in the microbiota can promote infection by such bacteria (eg: anti-biotics decrease microbiota diversity and Clostridium difficile can colonise the gut leading to diarrhoea) (Baumler and Sperandio 2016).

Imbalances in the gut microbiota (known as dysbiosis) can trigger certain immune disorders, and T cells of the immune system are the means (Honda and Littman 2016).

A group of children with a high risk of developing asthma were found to have microbial dysbiosis of four specific bacteria. Mice with an experimentally produced reduction of these bacteria showed symptoms of asthma (Honda and Littman 2016).

4.4.3. Mother-Child Relationship

The maternal microbial ecology [31] (before, during and after pregnancy) has a relationship with pregnancy outcomes. Hypotheses about the "maternal-foetal microbial landscape" (Charbonneau et al 2016) included:

- Some activities of the maternal microbiota are beneficial to foetal development.
- Changes in the maternal microbiota influence gestational outcomes, like premature birth.
- Microbes transferred to the offspring before or during birth reflect the maternal environment (eg: diet).

"The initial microbiota of nursing infants is an assemblage of microbes derived from mother's faecal, vaginal and skin microbiota. Within weeks, pro-microbial and anti-microbial agents in breast milk help to guide development of a milk-oriented microbiota" (Charbonneau et al 2016 p52).

Subramanian et al (2014) collected monthly faecal samples in the first 2-3 years of a Bangladeshi birth cohort, and from analysis of the bacterial composition were able to define the "age" (state of development) of the child's microbiota. Deviations from the normal pattern can be expressed as a microbiota-for-age Z score (MAZ), and malnutrition has been shown to impair normal microbial development (Charbonneau et al 2016).

4.4.4. Probiotics

Dietary live bacteria supplementation (ie: probiotics) is increasingly popular. The reasons given for use include alleviation of gastro-intestinal (GI) symptoms to "fortification" of the immune system (Zmora et al 2018).

There are questions about the efficacy of the claims of probiotics, particularly in relation to the gut. Zmora et al (2018) focused on the GI tract with a study of eleven inbred mice and fifteen human volunteers. In the

[31] This includes vaginal, gut and oral microbiota.

latter group, changes in gut microbiome varied between individuals. In other words, a "one size fits all" probiotics approach benefited some individuals but not others.

The same researchers in Suez et al (2018) reported that probiotics "perturb rather than aid in microbiota recovery back to baseline after anti-biotic treatment in humans". This conclusion was based on a study of 21 healthy volunteers who took a standard dosage of a broad-spectrum anti-biotic for seven days, followed by 28 days of probiotics. Differences in microbiota were found five months later. Put simply, the anti-biotics killed the individual's own microbiota, which the probiotics replaced and inhibited the return of the original gut microbes.

4.5. MISCELLANEOUS

4.5.1. Diabetes

Traditionally, diabetes is categorised as type 1 and type 2, with the latter acquired in adulthood and linked to weight and unhealthy eating. Ahlqvist et al (2018) provided a more refined classification of type 2 diabetes based on 8990 newly diagnosed diabetes cases in the Swedish All New Diabetes in Scania (ANDIS) cohort. Glucose plasma after overnight fasting was analysed in blood samples.

Five clusters were distinguished:

1 - severe autoimmune diabetes (SAID) - early onset in adulthood and low body mass index (BMI); overlap with traditional type 1 diabetes.

2 - severe insulin-deficient diabetes (SIDD) - as cluster 1, but difference in glutamic acid decarboxylase anti-bodies (GADA).

3 - severe insulin-resistant diabetes (SIRD) - high BMI; highest risk of chronic kidney disease.

4 - mild obesity-related diabetes (MOD) - high BMI, but not insulin resistant.

5 - mild age-related diabetes (MARD) - similar to cluster 4, but older.

These clusters were replicated in three other Swedish cohorts.

4.5.2. Air Pollution

Air pollution has negative consequences for health, and for cognitive abilities. In a large-scale Chinese study, Zhang et al (2018) found that "air pollution impairs verbal tests, and the effect becomes stronger as people age, especially for less educated men" (p9193).

The data on cognitive ability came from national surveys in China in 2010 and 2014, which used the same 24 standardised mathematics questions and 34 word-recognition questions. The data on air pollution were obtained from the Chinese Ministry of Environmental Pollution, and an air pollution index was calculated combining sulphur dioxide (SO2), nitrogen dioxide (NO2), and particulate matter (PM10). At least eighty major cities were covered. Details of weather patterns were used to determine the impact of air pollution.

The key findings were:

a) Air pollution reduced cognitive test scores (ie: negative relationship between pollution and score).

b) Larger exposure to air pollution had a greater impact on cognitive performance (ie: dose response relationship).

c) Air pollution exposure appeared "to exert a more negative effect on verbal test performance than math test performance" (p9194).

d) "Men are more vulnerable to air pollution than women" (p9194).

Zhang et al (2018) speculated on these last two findings: "Air pollution has a stronger effect on white matter (required more by verbal tests) than on grey matter (required more by math tests). Since men have a much smaller amount of white matter activated during intelligence tests, their cognitive performance, especially in the verbal domain, tends to be more affected by exposure to air pollution" (p9195).

e) "Compared with younger age cohorts, the negative effect on the verbal test performance is more pronounced for the older cohorts, especially among males. As a result, the gender gap in the decline of verbal skills widens as people age. Such pattern, however, is less noticeable for the math tests" (Zhang et al 2018 pp9195-9196).

4.6. APPENDIX 4A - CHILDHOOD LEUKAEMIA

The most common form of childhood leukaemia is acute lymphoblastic leukaemia (ALL), which Greaves (2018)

argued is caused by "a multi-factorial mix of infectious exposure, inherited or constitutive genetics and chance, with patterns or timing of common infection in early life identified as the critical component and a potential route for preventive intervention" (p471) [32].

Greaves (1988) proposed the "delayed infection" hypothesis to explain how the immune system had evolved "to both anticipate and require microbial infectious exposure perinatally or in infancy" (Greaves 2018 p472). But in the "clean" modern world, there is an under-exposure to common infections, and the immune system becomes dysregulated. So, subsequently, an abnormal immune response to infections is involved indirectly in the development of ALL.

A case-control study by Gilham et al (2005) showed support for this idea. Comparing 1300 individuals with ALL and 6000 matched controls, the latter were more likely to have experienced day care in their first year of life (and exposure to common infections).

Caesarean delivery is associated with an increased risk of ALL (ie: reduced microbial exposure compared to vaginal delivery), while breastfeeding for the first six months at least reduces the risk (eg: maternal anti-bodies in the milk) (Greaves 2018).

To emphasise, Greaves (2018) is proposing a multi-factorial model involving genetics (ie: the "potential" for ALL) and environmental factors that trigger the disease. In the latter category, she included diet or calorie intake, and also random events or chance, which "get short shrift in cancer epidemiology". "Chance is likely to be an ingredient in each and every cancer, including childhood ALL. This is because inheritance of risk alleles is a lottery at conception, because exposures including infections, at particular times, may or may not happen and because mutational mechanisms alter genes independently of their function" (Greaves 2018 p481).

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5. FOOD AND HEALTH BEHAVIOURS

5.1. FOOD LOSS

"Food loss" is where available food is lost before consumption (eg: due to spoilage and food waste, "leaky supply chains"), and globally this is one-third of all production (Shepon et al 2018). "Opportunity food loss" is food losses due to dietary choices. "Favouring resource-intensive food items like beef and pork over plant alternatives thus carries a substantial opportunity cost" (Shepon et al 2018 p3804).

Shepon et al (2018) calculated for the USA that replacing all animal-based foods (eg: beef, poultry) with plant-based ones would produce more benefits than eliminating all supply chain food loss.

5.1.1. Climate Change

Increase carbon dioxide (CO2) in the atmosphere via anthropogenic (human-induced) climate change threatens human nutrition via two pathways (Smith and Myers 2018):

i) Changes in climate impact food production (eg: increase or decrease in rainfall).

ii) Changing the nutritional profile of staple crops - ie: reduced concentrations of protein, iron, and zinc.

Using data from 151 countries, Smith and Myers (2018) estimated deficiencies in populations from staple crops grown in higher atmospheric CO2 - 175 million people with zinc deficiency (2% of global population), 122 million with protein deficiency, and 1.4 billion

women of child-bearing age and children under five years old with iron deficiency. These figures are in addition to the 662 million people currently deficient in protein, 1.5 billion in zinc, and 2 billion in iron. These existing deficiencies will be exacerbated. "Being nutritionally deficient or sufficient is not a binary biological state, and the health burden of a mild deficiency becoming worse may be more severe than moving from sufficiency to mild deficiency. This is most clearly demonstrated by anaemia, where the moderately and severely anaemic make up a disproportionate proportion of the health burden; although only constituting 39% of the global anaemia prevalence, they together account for 92% of anaemia-related years lived with disability (a measure of morbidity attributable to a disease)" (Smith and Myers 2018 p838).

The changes predicted by Smith and Myer's (2018) model will impact the world unevenly. "Nutritionally vulnerable poor populations tend to have a larger share of their diet composed of vegetal foods, which would expose them to a greater likelihood of combined deficiency across all three nutrients" (Smith and Myers 2018 p836).

Smith and Myer (2018) proposed the solution of cultivating different crops with different sensitivity to CO2, encouraging dietary diversity, and natural fortification and supplementation programmes for nutritional deficiencies.

5.2. DIETING AND RISKY HEALTH BEHAVIOUR

Dieting among adolescent females has been linked to risky health behaviours, like smoking and binge drinking.

Raffoul et al (2018) analysed data from the COMPASS System, which involves a convenience sample of teenagers in Ontario and Alberta, Canada. Baseline data were collected in 2012, and follow-up in 2014. Raffoul et al (2018) focused on data from 3386 females in Ontario.

Dieting was established by the response to the question, "which of the following are you trying to do about your weight?" - lose, gain, maintain weight, or not trying to do anything about it.

"Current smoker" was defined as ever smoked 100 cigarettes in their lives and at least one cigarette in the past month, while "current binge drinker" was categorised as five or more alcoholic drinks on one occasion in the last month.

Overall, 58% of the respondents self-reported as dieting at baseline. Compared to non-dieters, this group were more likely to smoke (odds ratio 1.48) and binge drink (odds ratio 1.87). Put another way, of those who both smoked and binge drank, 71% were dieters.

Of the dieters at baseline, 70% were still dieting

at follow-up, and dieting at baseline predicted smoking and binge drinking two years later (odds ratios 1.76 and 1.48 respectively; 1.55 together).

5.3. FAT HATRED

Morgan (2011) explored the issue of weight-loss surgery in the USA today with the analogy of the "ugly duckling" (obese individual) and the "technoswan" (thinner post-surgery individual, who may have had other cosmetic surgery as well).

Morgan (2011) referred to Focucault's (1980) idea of an "apparatus", which he described as "a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measure, scientific statements, philosophical, moral, and philanthropic propositions" (quoted in Morgan 2011).

In relation to the "fat apparatus in America", Morgan (2011) distinguished three central elements:

i) Systemic fat hatred, fatphobia and fat oppression - There is a "fear and revulsion of the potentially 'fat-person-presently-dormant within-but-just waiting-as-fat-laden-flesh-ready-to-emerge-expand-and-visibly-engulf-self-and-identity with each potato chip or serving of a sensuous non-low-fat salad dressing' (Shildrick 1997)" (Morgan 2011 p198).

The key "oppression ideology" is seeing "fat persons as loathsome, animalistic, slothful, weak of will, ugly, asexual, gluttonous, lazy, and not only enveloped by excess, soft undisciplined flesh but totally defined by this stigmatized corporeality as the visible, undeniable mark of undisciplined desires out of control. When intersecting with other oppressive systemic mechanisms of power such as systemic racism, class bias, ableism, ageism, and American xenophobia and imperialism, being classified as fat is an even more virulent and toxic carnal site" (Morgan 2011 p198).

The mechanisms involved include "pathologising difference in size embodiment", stereotyping, economic discrimination, social exclusion, and public shaming (Morgan 2011).

ii) The "biomedicalised techno-aesthetic subjectivity" (Morgan 2009) - Individuals choose weight-loss surgery, but the individual that does so is a product of "technoscientific biomedicine", which "places greater emphasis on customisation, on 'shifting, on reshaping, reconstituting, and ultimately transforming bodies for varying purposes, including new identities' (Clarke et al 2003)" (Morgan 2011 p201).

This is an "extreme" version of Foucault's idea of

"disciplining the self" as a woman who undergoes this surgery has "set the stage for a radical rejection of her 'morbidly obese' identity as a high-risk carnal setting, exchanging it for the exemplar of the ideal neo-liberal, socially responsible, low-risk health subject" (Morgan 2011 p202).

iii) The increasing normalisation of weight-loss surgery - The experience of many individuals (mostly women) with "gastric surgical metamorphosis" is for Morgan (2011) a "coerced voluntarism". She applied Beck-Gernsheim's (1995) four stages of technological change to describe the normalising of this surgery:

a) "Gradual, non-controversial shifts from low tech to high tech - Beginning with "diet aids" and moving towards bariatric surgery over the 20th century in the USA.

b) "Politically unregulated implementation" - The end of the 20th century onwards is characterised by "the thunderous symphony of 'obesity discourses' in government, public health, the insurance industry, the pharmaceutical industry, and the media" (Morgan 2011 p204), without data on the risks of such surgery, for instance.

c) "Normalisation and market creation- technology as personal liberation" - To normalise a certain behaviour, there are "pathways of normalisation and constructions of acceptance" (Beck-Gernsheim 1995). Here, these include the "ascendancy of the definitive status of the BMI [body mass index]", the medical labelling of obesity as a "chronic disease", and weight-loss surgery becoming part of the "normalised cosmetic surgery culture".

d) "Forced implementation, coercion and regulation and surveillance" - The normalising of a practice is such that "to make 'choices' is increasingly obligatory and, sometimes, forced" (Morgan 2011 pp209-210).

Morgan (2011) admitted that weight-loss surgery had not yet arrived here, but referred to pre-natal testing, genetic screening, and the technologies of birth control as an example.

5.4. SUGAR PRICING

One strategy to deal with increasing obesity is for the authorities to tax sugar-sweetened beverages (SSBs), as in a few countries (eg: Mexican, Chile, Finland). "Research to date suggests that increasing the price of SSBs generates a small, but significant, reduction in their purchase (broadly, a 10% price rise reduces

purchases by 6%–8%), with a more pronounced effect in poorer households and that substitution towards other soft drink categories only minimally offsets the energy reductions achieved through decreases in SSBs" (Smith et al 2018 pp1-2).

Smith et al (2018) considered the application of a "sugar tax" to all sweet foods. The researchers analysed data on the expenditures of over 30 000 British households in 2012-13. There was a clear income gradient with lower-income households purchasing more sugar per person per day. For all households, more sugar was purchased in sweet snacks (mean 17.1 g) than in beverages (13.9 g) (and 6.9 g for SSBs).

It was calculated that increases in price would reduce purchases of sugar, but the different products were related. So, "price increases in SSBs are associated with an increase in purchase of other soft drinks and chocolate and confectionery, whereas an increase in the price of chocolate is associated with a reduction in purchase of SSBs, as well as a range of other snacks" (Smith et al 2018 pp7-8). This showed the complexity of estimating the impact of a sugar tax on a specific product or type of food. However, the researchers did see a general sugar tax as beneficial, particularly low- and middle-income groups, in reducing sugar purchases.

5.5. GASTROINTESTINAL DISORDERS

Irritable bowel syndrome (IBS) is a gastrointestinal disorder that affects around 10% of people, but more often women and people under fifty years old (Whelan et al 2018).

One strategy for management of IBS is the dietary restriction of fermentable oligosaccharides [33], disaccharides [34], monosaccharides [35], and polyols [36] (known as the low FODMAP diet) (eg: Straudacher and Whelan 2017).

However, the small number of studies (eg: ten randomised controlled trials; Whelan et al 2018) comparing low FODMAP diet and controls have weaknesses, including blinding of participants, outcome measures used, and selection of controls (Whelan et al 2018).

Whelan et al (2018) discussed some other problems with the low FODMAP diet and IBS, including:

i) Diagnosis of IBS - "There is currently no

[33] Eg: in wheat, rye, pulses.
[34] Eg: in milk and milk products.
[35] Fructose (eg: honey, jam).
[36] Eg: in stoned fruit, apples.

diagnostic biomarker for IBS and symptoms overlap with other organic gastrointestinal and gynaecological conditions and, as a result, IBS is often a diagnosis of exclusion of organic disease" (Whelan et al 2018 pp240-241).

ii) Measures of food intolerance - "For example, commercially available food intolerance tests are not valid markers of food intolerance but are often used by patients to inappropriately guide dietary exclusion" (Whelan et al 2018 p241).

iii) Self-report measures of gastrointestinal symptoms - eg: dichotomous questions; standardised questionnaires; stool descriptors.

iv) Enhancing dietary adherence - Barriers to adherence to low FODMAP diet include cost of alternative foods (eg: wheat-free bread), perception of low palatability of some alternative foods, and limited availability of alternatives outside the home.

v) Nutritional adequacy of low FODMAP diet (eg: micro-nutrients) - Staudacher et al (2018) summed up the risks: "The low FODMAP diet requires alteration of intake of a number of food groups, including grains, fruits and vegetables, and dairy products. There is, therefore, a potential risk of reduced intake of certain nutrients if suitable replacements are not included. Specifically, restricted foods such as wheat products are an important source of carbohydrate, fibre, B vitamins, and iron (from fortified breakfast cereals); pulses provide protein and fibre; milk provides calcium and fat-soluble vitamins; and fruit and vegetables provide a wide range of vitamins, minerals, and fibre. A reduction in overall food intake could also lead to decreased energy intake" (p107).

Energy intake may be reduced because of the restrictive intake of food generally rather than the low FODMAP diet specifically (Staudacher et al 2018).

Another dietary restriction is the gluten-free diet (GFD) [37]. Staudacher et al (2018) observed: "Although evidence consistently supports the role of a GFD in improving health in celiac disease, dermatitis herpetiformis, and gluten ataxia, the advantages of strict GFD adherence in other conditions or for lifestyle choices remains uncertain and in some cases untested"

[37] Gluten-free food consumption has increased generally in recent years. For example, 0.5% of US adults surveyed in 2009 reported eating a gluten-free diet compared to 1.7% in 2013 (Lambert 2018). This trend has been described as a "marketeer's dream and the perfect worried-well scenario" as individual's believe it will help in weight lose or improve overall health (Lambert 2018).

(p106). Issues for users include the access to and labelling of gluten-free foods, and risks like sub-optimal dietary habits (eg: high sugar and low fibre), and coronary heart disease (Staudacher et al 2018).

Other dietary interventions for gastrointestinal disorders include (Staudacher et al 2018):

a) High-fibre diet (increased cereals and fruit and vegetables) - some benefits in constipation (eg: Christodoulides et al 2016).

b) Lactose restriction (no dairy products) - concerns over sufficient protein, calcium, and vitamin D intake.

c) Specific-carbohydrate diet (no grains, sugars, processed foods, and milk) - potentially beneficial in inflammatory bowel disease.

5.5.1. Miscellaneous

Humans have consumed bread, for instance, for many years - from early agricultural communities (around 9000 years ago), or earlier. Arranz-Otaegui et al (2018) reported evidence of bread-like products among hunter-gatherers around 14000 years ago in north-eastern Jordan. The individuals were collecting wild grasses (wheat and barley) to produce flour as opposed to growing it themselves. This observation was based on the archaeological analysis of fireplaces (ie: microscopic charred food remains).

5.6. PHYSICAL ACTIVITY

Physical activity (PA) (eg: 30 minutes moderate intensity daily) is highly recommended for health. But PA can be occupational, leisure time, and transport-related (eg: walking to work). It has been assumed that the different PA domains were the same, but recent research has challenged this idea. There is a "PA paradox" (Holtermann et al 2018), in some studies, "while beneficial health outcomes have been associated with high level leisure time PA (LTPA), detrimental health consequences have been documented for high level occupational PA (OPA), regarding cardiovascular disorders, sickness absence and mortality" (Coenan et al 2018 p1320).

Holtermann et al (2018) proposed six hypotheses to explain the "PA paradox":

1. OPA is too low intensity or too long duration for cardiovascular benefits.

2. OPA elevates 24-hour heart rate, which is a risk factor for hearts problems.

3. OPA elevates 24-hour blood pressure, which is another risk factor.

4. OPA often involves insufficient recovery time.

5. OPA often involves low worker control, which is a risk factor for stress, and consequent health problems.

6. OPA increases inflammation levels.

Coenen et al (2018) performed a meta-analysis in relation to OPA. They found 33 relevant articles (26 studies) published up to September 2017. Only prospective studies covering OPA, and all-cause mortality were included.

Overall, male workers with high OPA had a significantly higher risk of death than in low PA occupations (ie: one-fifth greater risk, even after controlling for leisure-time PA). A non-significant relationship in the opposite direction was found for women.

Coenen et al (2018) explained their findings and the "PA paradox" in terms of the difference between OPA and LTPA: "High levels of occupational PA, commonly reached by tasks involving manual handling, repetitive work and prolonged static postures, elevate heart rate and blood pressure and are performed over long periods of time (often =40 hours/week), with insufficient time for recovery [38]. Leisure time PA, on the other hand, typically takes place in short moderate or high intensity bouts of predominantly aerobic activities, accompanied by much longer recovery periods" (p1324).

However, the researchers accepted a potential confounder - "high intensity occupational PA is typically prevalent among blue collar workers from lower socio-economic positions and low socio-economic status is associated with higher mortality" (Coenen et al 2018 p1324).

As with many meta-analyses, there was heterogeneity in the studies included. Methodological differences included:

- Length of study (4-50 years).

[38] Examples of OPA include construction, cleaning, refuse collection, elderly care, farming, and manufacture (Holtermann et al 2018).

- Measurement of OPA (usually self-reported).

- Samples.

- Categories of OPA - eg: "sedentary work", "standing or occasionally walking", "mild increase in heart rate", and "significant elevation in heart rate" (Etemadi et al 2014) vs "not active-light" and "moderate-hard" (Harari et al 2015).

- Control for confounding variables.

Suwabe et al (2018) showed that ten minutes of very light-intensity exercise (ie: 30% maximum) (comparable to walking at slow pace) led to increased connectivity between the hippocampus and cortical regions of the brain (ie: improved memory).

The participants were 36 healthy US students who performed the physical activity on an exercise bicycle before a memory test (Experiment 1) or a brain scan (Experiment 2). The experiments were repeated measures design, so the participants were also controls (sitting on the exercise bicycle without peddling for ten minutes). The memory task involved viewing 196 colour photographs of everyday objects on a computer screen (encoding phase), and then 256 colour photographs to identify objects seen before (retrieval phase). Of these photographs, one-quarter were the same, one-quarter new, and the remainder similar objects.

5.6.1. Pedometer-Based Intervention

Interventions to increase PA are often short-term (eg: six months), but what about long-term change? Harris et al (2018) reported the long-term follow-up of two trials in the UK:

a) Pedometer and Consultant Evaluation-UP (PACE-UP) (Harris et al 2017) - 12-week walking programme using pedometers with 1023 predominantly inactive 45-75 year-olds. Follow-up three years later.

b) Pedometer Accelerometer Consultation Evaluation-Lift (PACE-Lift) (Harris et al 2015) - 298 60-75 year-olds on a twelve-week walking programme using pedometers. Follow-up four years later.

Harris et al (2018) found 681 of the original participants from PACE-UP and 225 from PACE-Lift. All these individuals wore an accelerometer on a belt over one hip for seven consecutive days to measure PA. The intervention participants showed significantly more PA

than controls, and at a level similar to the original 12 months follow-up. It appeared to individuals had changed their behaviour on a more permanent basis after participation in the trial.

What factors led to the increase in PA? "Both PACE-UP and PACE-Lift included a pedometer, step-count diary, and patient handbook, including BCTs [behaviour change techniques] and practice nurse PA consultations" (Harris et al 2018 p11). Other research has confirmed the importance of the step-count diary and personalised goals, which were present in these interventions.

5.7. PATERNALISM

5.7.1. Sunbeds and Other Things

The use of tanning (or sun) beds is associated with skin cancer. This is confirmed by two recent meta-analyses. Boniol et al (2012) found that first use before age 35 years was associated with a relative risk of 1.87 for skin cancer, while Gandini et al (2011) reported that exposure to indoor tanning before 30 years old led to a 75% increased risk of melanoma (Andersen and Midtgaard 2017)

On the positive side, tanning beds are a source of vitamin D, and may prepare the skin for sun exposure ("pre-vacation tan") (Andersen and Midtgaard 2017).

A number of countries have imposed restrictions on the use of sunbeds (eg: Brazil total ban; USA no under 18s) (Andersen and Midtgaard 2017).

Andersen and Midtgaard (2017) explored the arguments for government intervention here (ie: paternalism). "Hard paternalism" infringes the right of autonomy with a total ban, say, whereas "soft paternalism" protects the individual when they would harm themselves (eg: a limit on the time on a sunbed). "Soft paternalism" also involves "nudges" to change behaviour (eg: health messages or incentives to not do the behaviour).

Andersen and Midtgaard (2017) offered the following arguments for paternalism:

i) The "weakness of the will" phenomenon - "Roughly, a person with a weak will believes that he has good reasons for taking a certain course of action, for example the prudent one of fastening his seat belt, but fails, for various reasons, to act in accordance with his own consideration of the relevant reasons in play" (Andersen and Midtgaard 2017 p278).

ii) "Evaluative delusions" (Dworkin 1971) - This is where individuals "assign an arguably irrational or

faulty weight to some of their competing values (for example, to the value of avoiding the inconvenience of driving with their seat belt fastened) in circumstances in which their 'normal capacities for deliberation and choice' cannot plausibly be held to be 'substantially impaired'" (Andersen and Midtgaard 2017 p278).

For example, a car driver insists that "'the inconvenience attached to fastening the belt every time he gets in and out of the car outweighs for him the possible risks to himself' (Dworkin 1971). Were this person now to be involved in an accident unprotected by a fastened seat belt and be severely injured, Dworkin points out, 'he would look back and admit that the inconvenience wasn’t as bad as all that' (Dworkin 1971). That is, he would reassess or weigh differently the inconvenience in comparison with the risk to himself" (Andersen and Midtgaard 2017 p282).

iii) The magnitude of the harm.

iv) The "oppressive patterns of socialisation" (Benson 1991) - Individuals' autonomy is limited by the internalisation of social norms (eg: women and physical appearance; Benson 1991).

What are the choices for the government?

- Publicity - informing people about the dangers of sunbed use.
- Taxation - increase the price of indoor tanning.
- Regulations - eg: frequency of use; protective glasses compulsory.
- Prohibition - eg: minimum age.
- Criminal sanction - eg: make indoor tanning equipment illegal and penalise those who use or sell it.

Andersen and Midtgaard (2017) concluded: "Given that the harm in question is significant and is moreover often either involuntarily incurred or incurred on the basis of considerations that fail to attach appropriate weights to the values involved, it is justifiable — perhaps even mandatory — for the state to attempt to prevent the harm in question. Doing so is most plausibly done by the use of criminal sanctions, which tend not to eradicate the values involved in artificial tanning to an intolerable degree" (p286).

Regulatory controls have a directive function (ie: "requiring people to behave in a certain way in pursuit

of desired outcomes"), and "symbolic and expressive functions, in that they communicate a moral message about the desirability and acceptability of certain forms of conduct" (Almond 2009). However, regulatory controls are "doubled-edged" in that "ill-judged enforcement" can undermine what it is trying to achieve (Almond 2009).

In relation to the latter, Almond (2009) discussed the case of the Health and Safety Executive (HSE) in the UK, and the perception of "health and safety gone mad" (or "frivolous" regulatory cases) in the media. One story that appears intermittently is the "banning" of floral display hanging baskets in town centres because of the risk of injury to passersby. "Outraged" members of the public are often quoted in the face of "over-officious" regulators (though actual facts can be omitted from the stories). "The media have an interest in reporting these studies because of their surface entertainment value and links to wider societal concerns, but they are not merely items of 'info-tainment'. Rather, they reflect wider political agendas and vested interests relating to issues of business responsibility and accountability, feeding into media-perpetuated social discourses about the desirability of limiting the 'drain on the economy' constituted by systems of regulation and legal control" (Almond 2009).

These issues link to the perception of a "compensation culture", with increasing personal injury claims, for instance. Though such an increase is "heavily overstated" by the media (Almond 2009). Haltom and McCann (2004) found that, in the USA, creating the myth of "undeserving plaintiffs and outrageous damage awards" helped business lobby campaigners who wanted to limit corporate liability (Almond 2009).

The "frivolous" stories of "regulatory myths" often relate to "traditional" ways of life (eg: children playing "conkers" needing safety goggles), more accurately, "a rather idealised one" (Almond 2009). This can be seen, like "urban legends", as symptomatic of anxieties about a "clash between modern conditions and some aspect of traditional lifestyle" (Brunvard 1981 quoted in Almond 2009).

Applying soft paternalism to alcohol consumption, one option is "minimum unit pricing" (MUP) (ie: price regulations based on alcohol content). One argument is that such a policy has an effect on "responsible drinkers". This is contrary to "prudentialism" - "All else being equal, public policy aimed at changing individual behaviour may disadvantage those who engage in that behaviour in an 'irresponsible' manner, but should not disadvantage those who engage in that behaviour in a 'responsible' manner" (John 2018 p35).

Prudentialism is based on the concept of the "responsible" and "irresponsible" individual or

behaviour. For example, an individual who drinks than drives home would be seen as irresponsible, but what about a heavy drinker who walks home (John 2018)? John (2018) preferred the term "imprudent" - ie: "a risk of material harm to others or a significant, foreseeable risk to the individual's own future health" (p36).

In a situation of policies to benefit the population as a whole, Rose (2008) referred to the "fundamental axiom" of preventive medicine - "a large number of people exposed to a small risk may generate many more cases [of disease] than a small number exposed to a large risk" (quoted in John 2018). In other words, there will be a greater effect on the overall population to target a large number of people with a moderate risk ("responsible drinkers") than a small number of individuals with a high risk ("irresponsible drinkers").

Another issue is the "absolute prevention paradox" (John 2014), where a health policy "can seem to burden each individual agent more then they benefit him/her, even if their expected impact on overall population health is positive" (John 2018 p39). So, reducing alcohol consumption for everybody is a burden for each individual, but the overall population health will benefit.

But "luck egalitarianism" is the idea that "it is unfair to treat the prudent and the imprudent the same way" (John 2018 p40). On the other hand, a policy that separates the responsible and irresponsible could undermine "solidarity", which is a concept "central to the functioning of nationalised healthcare systems" (John 2018 p39).

5.7.2. Food Reformulation

Diet-related non-communicable diseases (eg: type 2 diabetes, stroke) are seen as partly the product of unhealthy diets with high fat, sugar, salt, and overall calorie intake. One policy response to this problem is mandatory nutrient limits (MNLs), where government regulations specify the amount of salt, fat or sugar, for instance, in certain foods (known as "food reformulation").

"When a food is reformulated, 'the consumer does not have to modify drastically his or her habitual dietary food pattern' (van Raaij et al 2009), but nevertheless benefits from an improved diet. In this sense, it is an upstream intervention, modifying an environmental determinant of ill health... — or, more colourfully, 'stealth health' (Schwartz and Brownell, 2007). Reformulation may be industry-led (voluntary reformulation) or may be government-led (mandatory nutrient limits)" (Kaldor et al 2018 p55).

MNLs are used in over twenty countries (eg: salt in

flour and bread - Netherlands; tans fatty acids in food - Denmark) (Kaldor et al 2018).

The main objections to MNLs are the paternalistic limiting of an individual's choice (ie: free dietary choice) and interference in the free market/food industry. Resnik (2010) argued against trans fat limits, in particular, because it could "open the door to excessive government control over food choices". Alternative (or "softer") options are available, like labelling and education, it is argued.

Voluntary food reformulation by food manufacturers is also offered as an alternative to MNLs, but Kaldor et al (2018) pointed out that individual food choices are still compromised. Kaldor et al (2018) stated that "if the choice is between a voluntary and a mandatory scheme for improving the composition of food, the impact on freedom of choice can be considered moot. This paves the way for other, more decisive considerations — effectiveness, cost-effectiveness, cost to each stakeholder, potential for conflict of interest and ways to manage that conflict — to be taken into account" (pp63-64).

5.7.3. Reducing Sugar in New York

Reducing the consumption of sugar-sweetened beverages by government intervention (eg: price based on sugar content; size restrictions) is supported by medical groups, but opposed by the food and beverage industry. In 2012 the mayor of New York City proposed a cap on the size of such beverages to sixteen ounces, but this was defected by legal action two years later (Bateman-House et al 2018).

The American Beverage Association, for example, campaigned against the "soda cap" as "unjustifiable intrusion on consumer choice" and used civil rights-type images. It was also argued that the working class would suffer more, including the loss of employment as businesses presented themselves as at risk (Bateman-House et al 2018).

The New York Board of Health, which proposed the "soda cap", presented the policy as a "nudge" (rather than paternalism) (eg: "making healthy choices easier"), and highlighted the unfair burden of obesity on the poorer members of society (Bateman-House et al 2018).

Bateman-House et al (2018) argued that the public health officials failed to "reshape the policy narrative". For instance, "interventions not intended for 'your own good', but for the common good, are perhaps not properly considered paternalistic" (Bateman-House et al 2018 p51). In other words, presenting a counter-narrative to the dominate one of consumer rights in the USA. This

was seen in Berkeley, California, in 2014, where over three-quarters of voters agreed to a sugary drink tax in their city. The tax was presented as empowering consumers with a public health campaign of "Berkeley vs Big Soda", "which subtly captured themes of community solidarity against corporate interests and influence. This may become an easier argument to make in light of revelations about Coca-Cola's efforts to shift attention away from calories by funding researchers willing to prioritise the importance of exercise in maintaining a healthy weight (Bateman-House et al 2018 p50).

5.8. HEALTH PROMOTION SIDE EFFECTS

Health promotion (HP) interventions are "meant to promote the health of individuals, communities, organisations etc, to empower, to build capacities, to be sustainable, so simply put: to help and do good" (Gugglberger 2018 p557). But what if some HP interventions unintentionally cause harm? "Unintended effects of health promotion interventions are usually not foreseen, can be difficult to observe, but occur none the less" (Gugglberger 2018 p557) [39].

Unintended consequences of HP interventions can be (Gugglberger 2018):

- "Good" - eg: increased social interactions for individuals on lifestyle behaviour change programmes.
- "Bad" - eg: stigmatisation of individuals on weight loss programmes; increased anxiety after increased awareness of health risks.
- "Ugly" - eg: conflict and division between individuals receiving and not receiving HIV/AIDS-related humanitarian aid.

Allen-Scott et al (2014) listed the factors that lead to unintended harm in public health interventions:

i) Limited evidence of efficacy of the programme.

ii) Boomerang effect - "the prevention of one extreme lead to another extreme" (Gugglberger 2018).

iii) Lack of community engagement.

iv) Ignoring the root causes of health problems,

[39] Other terms include "side effects" (Gugglberger et al 2017), "non-health outcomes and spill-over effects" (Goebbels et al 2012), and "spin-off effects" (Agarwal and Brydges 2018).

like social conditions.

v) A programme used in a high-income country implemented in lower-income ones.

Cho and Salmon (2007) outlined the negative unintended effects of health communication campaigns, including desensitisation (where the repeated message desensitises the individual to the risk), and "obfuscation" (confusion and misunderstanding) (Gugglberger 2018).

5.8.1. Active Transportation

Active transportation (AT) (ie: "the practical use of walking, cycling, and public transit") is promising for HP, both in terms of increased physical activity among individuals, and in reducing air pollution with less car use (Saidla 2018).

Promotion of AT by governments includes the investment in infrastructure (eg: bike lanes), social marketing to encourage AT, and policies to discourage car use (eg: increased petrol duty). Such promotion is called "health in all policies" or "healthy public policies", which "aim to address the social determinants of health through the explicit consideration of the health effects of policies that are outside the traditional health sector" (Saidla 2018 p601).

Saidla (2018) outlined the example of Helsinki in Finland, where over three-quarters of daily trips were by AT in 2013 (eg: 2600 kms of bicycle lanes in metropolitan area). The policy changes since the 1960s leading to this situation was "most strongly motivated by a desire to protect a high degree of livability" (Saidla 2018 p600), rather than HP. A former member of the council said about AT: "It is a question of aesthetics and pleasure living in a city. It makes the city nice, beautiful, and easy to move around in" (p606).

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6. CANCER ISSUES

6.1. PATIENT ADVOCATES

Cancer patient advocates (CPAs) represent "those affected by cancer" to medical authorities and other relevant groups (eg: government committees). "While many patient advocates continue to focus on patient care, others have set up their own advocacy organisations, hosted fundraising events, pressured politicians to increase cancer research funding or helped to solve systemic problems like insurance denials, or become involved with the cancer research system" (Collyer 2005 p73).

Advocacy began in 1950s America, and those involved come from varied backgrounds, but "most have embarked on this path because of an experience with cancer, either personally or through a loved one" (Collyer 2005 p73). In the USA, this is facilitated through the National Cancer Institute's (NCI) Specialised Programs of Research Excellence (SPOREs), "with their emphasis on the translation of basic research findings to the clinic" (Collyer 2005).

Collyer (2005), herself a CPA in the USA, commented that the "role is not a career for most cancer patient advocates, and their time and commitment to research efforts should be respected" (p77). It is also important for CPAs to maintain objectivity, she argued, and to "stand ready to say unpopular things in potentially intimidating situations, and even be willing to walk away from finances and personal associations with the research community if it would compromise the ability to act on behalf of the patient community" (Collyer 2005 p78).

Patient advocacy organisations (PAOs) generally have been successful in raising public awareness about their diseases, risk factors, and treatment options. "One reason is that because many PAOs were started and are run by patients or former patients with serious diseases, they have credibility with the public, legislators, and government agencies... and are therefore frequently consulted" (Rose 2013 p680).

But there are concerns about the independence of some PAOs, particularly in relation to conflict of interests. "Institutional conflicts of interest arise

when an institution's own [secondary] interests or those of its senior officials pose risks of undue influence on decisions involving the institution's primary interests" (Lo and Field 2009 quoted in Rose 2013).

In order to achieve their primary aim of advocacy, PAOs need to raise funds usually, and who the money is accepted from can become a concern (eg: pharmaceutical companies). For example, pharmaceutical company, Eli Lilley donated over $3 million to US PAOs in the first half of 2007 (Rothman et al 2011), while the "Colorectal Cancer Coalition" (US PAO) received four-fifths of its income from pharmaceutical companies (Marshall and Aldous 2006).

A conflict of interests may lead PAOs to advocate for drugs that have limited benefits, to promote their use without full testing, or even encourage the use of drugs despite known risks (Rose 2013).

PAOs have traditionally been trusted, which is the belief that the PAO will live up to its commitment and not harm those depending on it, while trustworthiness includes the competency to perform those actions (Rose 2013). Trust can be increased by the PAO's commitment to its primary aim, and by signalling that behaviour (ie: its trustworthiness). Rose (2013) called "trust in trustworthy organisations 'appropriately placed trust'". There is also "misplaced trust" (ie: trusting an untrustworthy organisation), and public relations and marketing can promote this (Rose 2013).

Rose (2013) argued that PAOs should develop conflict of interests policies that separate the PAO's fundraisers from policymakers, have independent scrutiny of funding relationships, and full disclosure of financial relationships. Some PAOs may find it appropriate to have no funding from pharmaceutical companies, or at least only a small portion (Rose 2013).

6.2. MEASURING TREATMENT SUCCESS

As new treatments for cancer are developed, it is important to establish their effectiveness. "Overall survival" (OS) is the most important criteria in cancer (Saad and Katz 2009).

"Progression-free survival" (PFS) is also used. It is defined as "the time elapsed between treatment initiation and tumour progression or death from any cause, with censoring of patients who are lost to follow-up" (Saad and Katz 2009 p460). "Time to tumour progression" (TTP) is similar, but focuses only on disease progression (Saad and Katz 2009). "Both PFS and TTP have traditionally been considered as surrogate end points for OS, as far as the drug approval process is

concerned" (Saad and Katz 2009 p460) [40].

Saad and Katz (2009) surveyed the use of OS, PFS, and TTP in clinical trials with advanced breast cancer. Fifty-eight studies published between 2000 and 2007 were found. TTP was used most often, followed by PFS (together around two-thirds of studies).

"Time to treatment failure" (TTF) was also used in one study, and this was defined as "the time from the date of randomisation until the date of disease progression, relapse, or death from any cause without documented progression or relapse" (Saad and Katz 2009 p463). This definition is "typically used for PFS" (Saad and Katz 2009). A better definition of TTF is "the time elapsed between treatment initiation and tumour progression, treatment discontinuation due to toxicity, patient preference, or death" (Saad and Katz 2009 p463).

Saad and Katz (2009) concluded that "PFS and TTP seem to be the primary end points most frequently used in contemporary randomised trials in advanced breast cancer. However, PFS and TTP have often been used interchangeably. The lack of uniformity regarding the definition of end points may lead to miscommunication and to confusion when results of different trials are compared, and uniform adoption of the definitions seems therefore in order" (p463).

When a new cancer drug, say, is approved on the basis of surrogate end points, like PFS, in the USA, subsequent studies are required to clarify the OS. "Bevacizumab", for example, was given official approval by the Food and Drug Administration (FDA) for breast cancer based on PFS, but later studies found no improvement in OS, and the drug was subsequently no longer approved (Kim and Prasad 2015).

How common is this situation? Kim and Prasad (2015) examined all FDA cancer drug approvals between 2008 and 2012, and identified 54, of which two-thirds (n = 36) were approved based on a surrogate end point. Subsequently, five drugs were shown to improve OS, eighteen failed to show this, and thirteen were untested. Kim and Prasad (2015) concluded that "most cancer drug approvals have not been shown to, or do not, improve clinically relevant end points" (p1993).

Booth and Eisenhauer (2012) commented on the use of PFS as "a growing belief in the oncology community that delaying progression in metastatic disease is a worthy goal, even if OS is not improved. But is a new treatment

[40] Using OS as the primary trial end point requires large samples and longer trial follow-up. Thus, the use of surrogate end points in trials of drugs before they are officially approved (eg: phase III randomised clinical trials) (Booth and Eisenhauer 2012).

that improves PFS really an advance for patients?" (p1030).

The proportion of clinical trials of drugs for breast, colorectal and some forms of lung cancer published in the "Journal of Clinical Oncology" using PFS rose from none in 1975 to one-quarter by 2009 (Kay et al 2011).

Why is PFS not a good indicator of OS? Booth and Eisenhauer (2012) offered five reasons, with particular reference to solid tumours:

- Changes in tumour size may affect PFS but not OS.
- Statistically significant improvements in PFS may not translate into actual OS improvements.
- Date of death in OS is exact, but the measurement of PFS can vary between studies.
- Biological changes in the tumour that produce better PFS, but not OS.
- The crossover design of trials involves each participant having a period of time with the drug and with a placebo (or another treatment). Booth and Eisenhauer (2012) noted that "it can be argued that such trials do not really evaluate the impact of a new treatment but rather evaluate the sequence of administration of two treatments" (p1031).

6.3. FLIGHT ATTENDANTS

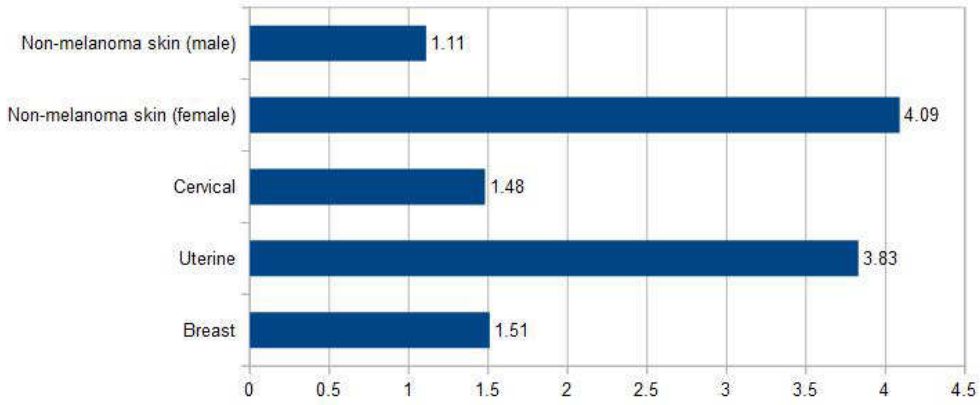
Flight attendants (FAs) are exposed to "several known and probable carcinogens in the cabin environment", including cosmic ionising radiation at altitude, circadian rhythm disruption, and poor air quality (including second-hand tobacco smoke) (McNeeley et al 2018). Not surprisingly, FAs have higher rates of specific cancers than the general population.

The Harvard Flight Attendant Health Study (FAHS) (McNeeley et al 2014) began in 2007, and McNeeley et al (2018) analysed data collected in 2014-15 from 1642 current or former US FAs [41] [42] [43]. The data were compared to the US National Health and Nutrition Examination Survey

[41] This was a 40% response rate from the original sample.
[42] Over 90% were current FAs.
[43] The mean age was 52 years, with net job tenure of 20 years, and 15% "ever diagnosed with any cancer".

(NHANES) in 2013-14 for the general population [44].

There was a higher prevalence of each cancer among cabin crew compared to the general population. This included one and half times more breast or cervical cancer, and four times more non-melanoma skin cancer (figure 6.1). The length of job tenure was also associated with an increasing risk for this latter cancer. These findings confirmed the greater prevalence of breast and skin cancer found in previous studies (eg: Finnish cabin crew studied between 1967 and 1992; Pukkala et al 1995).



(Data from McNeeley et al 2018 table 1)

Figure 6.1 - Greater prevalence of selected specific cancers for FAs (where 1.00 = general population).

Limitations of this study include:

a) Cross-sectional design, "which precludes inferences about causality, as an observed association may reflect the effect of flight attendant work on a given condition, or the effect of an outcome on a factor related to employment as a flight attendant" (McNeeley et al 2018 p6). It is possible that some individuals had a cancer diagnosis before employment as a flight attendant because date of diagnosis information not collected. So, incidence (ie: new cases) may have been a better measure than prevalence (ie: number of cases).

b) The two groups compared were not entirely similar (eg: age; gender) (table 6.1). There were differences between the FAHS and NHANES cohorts particularly in

[44] The researchers only included employed adults with at least a high school education, and similar socio-economic status to the FAHS cohort.

ethnicity profile, smoking status [45], and weight (McNeeley et al 2018).

	FAHS	NHANES
Age (years): 18-39 40-59 ≥ 60	 15 54 32	 31 50 20
Female	>80	54

Table 6.1 - Age and gender profiles of two cohorts (%).

c) Health information, including cancer diagnosis, was self-reported with no independent verification from medical records.

d) The FAHS cohort is a volunteer sample recruited via airport and online means. Such individuals "may differ from those recruited using a more randomised approach in terms of various factors, including their socio-economic status, attitude toward health research, and factors related to time and ability to complete online surveys" (McNeeley et al 2018 p6).

The authors continued: "Our study may have attracted a disproportionate number of flight attendants with cancer, leading to detection bias, as flight attendants with worse health are likely to be more motivated to participate in an epidemiological study of flight attendant health, are likely to attend regular medical check-ups (this is true for flight attendants in general), and the question of cancer risk in relation to flight exposures is well known within the aviation community" (McNeeley et al 2018 p7).

e) Insufficient information on some potential confounding factors, like leisure-time UV exposure (ie: sun-bathing habits), which is a risk for skin cancer.

f) No details of actual exposures to carcinogens, only the use of length of job tenure as a surrogate measure.

On the positive side, this study involved a large sample of FAs, who are rarely studied [46], with data on a range of cancers, work experiences, and potential

[45] Current smokers: 8% (FAHS) vs 15%.

[46] McNeeley et al (2018) noted two previous meta-analyses with included eight and seven studies retrospectively. These may have included the same studies.

confounders (eg: smoking status). The survey was completed online, which is convenient to the participants (and common among epidemiological studies today) (McNeeley et al 2018).

Other strengths of this study include:

- Most of the FAs were current employees.
- Any US FAs eligible for study (ie: working on domestic and international flights).
- Use of validated questionnaires.
- The findings were presented as a standardised prevalence ratio (SPR), which is "an indirect method of standardisation which compares observed and expected prevalence given rates in the reference study population, which in our case was the NHANES. The SPR was weighted by age category (18–39, 40–59, and 60+ years) and analysed separately by gender" (McNeeley et al 2018 p2).

Disruption of the circadian rhythms generally may increase the risk of breast cancer. For example, a meta-analysis of mostly case-control studies found an increased risk (He et al 2015), but the Nurses' Health Study, a large cohort study, did not (Ramin et al 2013). Sleep duration is usually self-reported (Richmond et al 2018).

Richmond et al (2018) analysed data from the UK Biobank, which included questionnaire data and genetic information. The sample involved over 180 000 women. Generally, those with a breast cancer diagnosis were more likely to be:

- Older
- Higher body mass index
- Less physically active
- Earlier age of menarche
- Post-menopausal.

However, they were less likely to:

- Never smoked
- Do night shift work
- Have used oral contraceptives.

An inverse association between "morningness" ("larks") and risk of breast cancer was found.

6.4. LUNG CANCER

Hypertension can be effectively treated with drugs like angiotensin converting enzyme inhibitors (ACEIs). Concern has emerged about the long-term use of these drugs, and in particular, the increased risk of lung cancer (Hicks et al 2018) [47].

Observation studies have found mixed evidence, and RCTs that find an association are often small scale and short-term. Hicks et al (2018) reported a large population-based study from the UK. Data from 700 general practices (over fifteen million patients) for the period 1988 to 2015 were analysed.

There were over 200 000 individuals taking ACEIs, and they had a 14% increased risk of lung cancer compared to individuals taking other drugs for hypertension. This was an incidence rate of 1.6 per 1000 person-years compared to 1.2. In other words, a very small risk was increased slightly [48].

Methodological issues include:

1. Large-scale study.

2. Only new prescriptions of drugs and subsequent cases of cancer included. But no information on adherence of taking medication.

3. Controlled for potential confounders in statistical analysis (eg: age; body mass index; smoking status). Though no information about duration and intensity of smoking. Some confounders not controlled - no information on, for example, diet, family history of lung cancer, exposure to asbestos, and socio-economic status.

4. Persistent cough is a side effect of ACEIs, which may lead to more lung examinations and consequently chance of diagnosis of lung cancer.

6.5. MISCELLANEOUS

(1) Relative risk of a disease is increased by the presence of many genes, for instance. A recent meta-analysis of genotype data identified sixty-three gene

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[47] ACEIs can lead to an accumulation of bradykinin, or substance P (peptides) in the lungs, both of which could stimulate cancer growth (Hicks et al 2018).

[48] There was a lot of media coverage of this increase, and the NHS felt the need to comment (https://www.nhs.uk/news/medication/blood-pressure-drug-linked-possible-small-increased-risk-lung-cancer/; accessed 9th November 2018).

locations associated with prostate cancer. Individuals with all genes had a much greater risk of the disease than the general population (Schumacher et al 2018).

A risk assessment for breast cancer is based on three sets of information (Cuzick et al 2017):

i) Interview data - eg: age, family history, use of hormonal replacement therapy.

ii) Mammography data.

iii) Genetic data - over 100 single nucleotide polymorphisms (SNPs) have been identified as relevant. "The occurrence of different SNPs is largely independent, but much less is known as to whether their effects are independent or whether interactions between the risks for different SNPs exist, and more work is needed to determine this. Linking specific SNPs to different types of breast cancer... is also an important goal" (Cuzick et al 2017 p99211).

(2) In the 1980s a technique to reduce the pain of inoperable pancreatic cancer that involved injecting alcohol into the nerves surrounding the pancreatic tumour also prolonged life. It was initially assumed that these individuals survived longer because the pain reduction had improved their mood and helped withstand additional chemotherapy and radiation (Dolgin 2017).

But subsequent research has suggested that blocking nerves with pain treatment could stop cancer (ie: nerve-blocking therapy). For example, individuals who take beta-blockers, which impede part of the nervous system, have lower rates of cancer. It seems that nerves can stimulate tumour growth (Dolgin 2017).

(3) The incidence of cervical cancer and its associated mortality has been declining in Australia since the introduction of the National Cervical Screening Programme (NCSP) in 1991. The NCSP involves screening every two years between the ages of 18 and 69 years old, and coverage was over 80% (Hall et al 2018).

In 2017, primary human papillomavirus (HPV) screening every five years was added to the NCSP. Hall et al (2018) calculated that if "high-coverage vaccination and screening is maintained, at an elimination threshold of four new cases per 100 000 women annually, cervical cancer could be considered to be eliminated as a public health problem in Australia within the next 20 years. However, screening and vaccination initiatives would need to be maintained thereafter to maintain very low cervical cancer incidence and mortality rates" (p1).

However, these calculations are "not generalisable to specific population sub-groups, such as Aboriginal and Torres Strait Islander women, migrants, or disadvantaged sub-populations" (Hall et al 2018 p8). This is partly because of lower uptake of screening in these groups. Indigenous Australian women are over twice as likely to be diagnosed with cervical cancer and nearly four times more likely to die from it than non-Indigenous Australian women (Hall et al 2018).

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7. DRUGS, SMOKING AND OTHER UNHEALTHY BEHAVIOURS

7.1. DRUGS

7.1.1. Stroke and Methamphetamine

Methamphetamine use is high in some countries (eg: USA), with an estimated 35 million stimulant users (predominately of methamphetamine) worldwide (Lappin et al 2017). The form of use has moved from amphetamine to crystallised methamphetamine in recent years (Lappin et al 2017).

There are health issues related to methamphetamine use, one of them being stroke, particularly among younger adults (ie: under 45s). Lappin et al (2017) reviewed the evidence. Seventy-seven relevant articles were found, of which the majority were case reports. Amphetamine as a cause of stroke was identified in up to 13% of cases generally.

In terms of younger adults, Westover et al (2007), for example, in a large epidemiological study of 18-44 year-old hospitalised stroke sufferers, calculated that amphetamine increased risk of stroke fivefold (compared to twofold for tobacco or cocaine use) versus no substance use. Amphetamine use increased the risk of death after stroke.

7.1.2. Cannabis for Crack

The United Nations has estimated worldwide cocaine use at between 14 to 21 million people, of which many use the form crack cocaine (Socias et al 2017).

Treatment for crack cocaine use is limited, but

there is evidence that some cannabinoids may reduce craving (eg: rats; Parker et al 2004). In other words, the use of cannabis to reduce crack use. Socias et al (2017) explored this possibility among a community-recruited sample of people who use illicit drugs in Vancouver, Canada. Participants were recruited via snowball sampling between June 2012 and May 2015.

One hundred and twenty-two individuals reported intentional use of cannabis to reduce crack use at least once. Crack use was reduced, but cannabis use increased in such situations. All the data were self-reported, and no information was available on the concentration of the cannabis.

These findings fit with a small-scale study in Brazil, where two-thirds of 25 treatment-seeking crack users stopped its use over nine months using cannabis (Labigalini et al 1999).

But "other studies have revealed that long-term cannabis dependence might increase cocaine craving and risk of relapse among individuals with poly-drug substance use disorders (...eg: Viola et al 2014), suggesting that patterns of cannabis use and dependence, and the timing of self-medication with cannabis might play a role in explaining the different outcomes across studies" (Socias et al 2017 p140).

7.1.3. Addiction and Opioids

The medical approach to addiction sees it as a compulsion, but a philosophical approach presents the addict as a willing participant (the willingness model; Brody 2012). Based on the ideas of Socrates, individuals are faced with choices and temptation alters the understanding of what is the good option. "For Socrates, 'yielding to temptation' is not being unwillingly overpowered, but it is the experience of being a willing participant choosing what is at that moment wrongly thought to be best" (Brody 2012 p15).

Vowles et al's (2015) review calculated that addiction occurred in 8-12% of individuals taking prescription opioids, but most the data include were from the USA (Stannard 2018).

One suggestion to deal with opioid abuse is "abuse-deterrent formulations", which are difficult to crush, chew or dissolve, for instance. "However, the active agents still retain euphoric or respiratory depressant properties. Indeed, the dissemination of such formulations has spawned sophisticated ways of defeating them and has led to increasing heroin use and death rates. This has reinforced the notion that complete prevention of abuse will not be achieved by pharmaceutical strategies alone, but must include

psychosocial and other (eg: regulatory, educational) approaches" (Stein 2018 p770).

Stannard (2018) noted that "opioid prescribing continues to increase despite clinical evidence that this is unlikely to be a helpful strategy. The problem does not seem to be awareness of the evidence, but rather hopelessness about what to do instead" (p118).

Many clinical trials of opioids are short-term, and so evidence on their long-term effectiveness is lacking. "There is no evidence that any opioid is more effective than others and little evidence that opioids differ in their propensity to cause harm" (Stannard 2018) [49].

7.2. SMOKING

Ma et al (2015) observed that cigarette smoking is the most common preventable cause of many diseases that lead to six million deaths per year globally.

Smoking behaviours, including cessation, may have a heritability of 50% (eg: Hardie et al 2006), and the relevant genes are involved in the dopaminergic reward system (ie: dopamine receptors, dopamine transporters, and enzymes). So, variants in the genes linked to the level of the neurotransmitter dopamine in the brain "appear to be more likely to be involved in smoking cessation" (Ma et al 2015 p1).

One gene in particular has received attention (DRD2 on chromosome 11). Noble et al (1994) first reported that the A1 version of this gene (as opposed to the A2 version) was significantly higher among current and former smokers than among non-smokers in the Caucasian population.

Ma et al's (2015) meta-analysis of twenty-two studies found that smokers with the A2 version of the gene (in the Caucasian population) were more likely to stop than with the A1 version.

As cigarette use declines, other tobacco products are growing in the West. For example, among US adolescents, around 10% use smokeless tobacco (eg: snuff, chewing tobacco), and the same number smoke cigars (Hawkins et al 2018).

Hawkins et al (2018) examined tobacco control policies, and the use of smokeless tobacco and cigars with data from the Youth Risk Behaviour Survey (YRBS). In particular, over half a million 14-17 years-olds from eight waves of the YRBS between 1999 and 2013.

Three questions were used as the outcome measures:

[49] Opioids are grouped into weak (eg: codeine) and strong (eg: morphine) (Stannard 2018).

- "During the past 30 days, on how many days did you use chewing tobacco, snuff, or dip, such as [6 brands]?".

- "During the past 30 days, on how many days did you smoke cigars, cigarillos, or little cigars?".

- "During the past 30 days, on how many days did you smoke cigarettes?".

The response options were 0, 1 or 2, 3 to 5, 6 to 9, 10 to 19, 20 to 29, 30. Analyses were performed on 0 (no) vs 1-30 (yes), and categories of 0, 1-5, 6-29, 30.

Tobacco control policies were operationalised as state excise taxes (eg: percentage of retail sales price). The mean tax was 43% of price for smokeless tobacco, 33% for cigars, and 40% for cigarettes.

Smokeless tobacco use varied between states from 2.8% to 14.8% of the samples, and cigar use from 4.5% to 15.2%. More males than females used these products, and the average use was 1-5 days per month.

Smokeless tobacco taxes had no effect on smokeless tobacco use, but cigarette taxes did. A 10% increase in cigarette taxes, for example, was associated with a 1% increase in smokeless tobacco use among males only. Cigar taxes had no effect on cigar use, but a 10% increase in cigarette taxes was associated with a 1.5% increase in cigar use among males and 0.7% increase among females. Hawkins et al (2018) concluded that "the higher price of cigarettes may be encouraging adolescents to substitute smokeless tobacco and cigars" (p8).

In terms of studies with adults, Delnevo et al (2004) found an increase in cigar use in New Jersey after cigarette tax was increased, while, in Spain, roll-your-own cigarette-use increased with more tax on manufactured cigarettes (Sureda et al 2017).

Smoke-free legislation (eg: a smoking ban in public places) to reduce second-hand or passive smoking can have benefits for respiratory disease. For example, less admissions to US emergency departments for asthma after the introduction of smoke-free legislation (eg: Herman and Walsh 2011).

Such studies, however, lack a control group, as well as not accounting for other tobacco control policies, or distinguishing between state and local policies (Hawkins et al 2016).

Hawkins et al (2016) attempted to overcome these weaknesses. They investigated the effects of state and local smoke-free legislation on emergency department visits for childhood asthma, ear infections, and respiratory infections in three north-eastern US states, while controlling for cigarette taxes.

For the period 2001 to 2010, emergency department visit data for children (up to 18 years old) were amassed

from seventy-four hospitals in Massachusetts, twenty-six hospitals in New Hampshire, and fourteen hospitals in Vermont. Details of smoke-free legislation and cigarette taxes for each state and city were collected. Monthly emergency department visits were calculated before and after the legislation was introduced.

Overall, there was no changes in asthma cases after smoke-free legislation or cigarette taxes increases, but there was a reduction for 10-17 year-olds. The same pattern was found for ear infections, and upper respiratory infections, but there was an overall reduction (up to 10%) in emergency department visits for lower respiratory infections after state smoke-free legislation was implemented, and after cigarette taxes increases.

Hawkins et al (2014a) used data from 29 US states to examine birth weight based on cigarette taxes and smoke-free legislation. For over 16 million births between 2000 and 2010, mothers reported tobacco smoking during pregnancy with a yes or no response. Cigarette tax increases for the nine months prior to delivery were calculated along with the presence of smoke-free legislation at workplaces and restaurants. Birth weight was the outcome variable (categorised as low or normal at 2500 g).

Rates of low birth weight varied from 3.8% to 8.4% in different states, cigarette tax increases varied between $0 and $2.75, and nineteen states had smoke-free restaurant legislation.

The data were analysed in two main areas:

i) The association between cigarette taxes and smoke-free legislation, and the likelihood of smoking during pregnancy - Smoke-free legislation had no relationship to maternal smoking, but "cigarette tax increases were associated with a reduced number of White mothers with a high school degree or less who smoked and a reduced number of black mothers across all educational levels who smoked" (Hawkins et al 2014a p4) (ie: negative correlation) [50]. Every $1.00 increase in cigarette taxes was associated with around a 2% reduction in maternal smoking [51].

ii) The association between smoke-free legislation and cigarette taxes, and birth weight - Again, no relationship for smoke-free legislation. Increases in

[50] Generally, White mothers with less education were more likely to smoke (40% vs 2% of more educated White mothers) (Hawkins and Baum 2014).

[51] Every $1 increase in cigarette taxes led to ten fewer cigarettes smoked per month overall, but this was 22 less for lower educated White women, and fourteen less for lower educated Black women (Hawkins and Baum 2014).

cigarette taxes were associated with increased birth weight (ie: positive correlation) in a statistical relationship of every $1.00 increase in tax and up to 5 g gain of birth weight. There were variations based on ethnicity and education level.

Altogether, increases in cigarette taxes were associated with improved birth outcomes.

Hawkins et al (2014b) used data from the Massachusetts Registry of Vital Records and Statistics for 1996 to 2009 to examine maternal smoking, and breastfeeding. The Parent Worksheet for Birth Certificates includes information on average number of cigarettes smoked per day during pregnancy (which the researchers dichotomised as yes or no). Also country or state of birth, and language preference for health-related materials was self-reported by the mothers.

The Hospital Worksheet for Birth Certificates (completed by, for example, a nurse) included information about the birth, hospital stay, and discharge (including whether breastfeeding had been initiated).

Foreign-born mothers were less likely to smoke during pregnancy than US-born mothers, and more likely to initiate breastfeeding. The least likely to smoke were Portuguese-speaking ethnic groups. The exception to breastfeeding initiation were Chinese- and Vietnamese-born mothers. The authors noted: "Although foreign-born mothers had more disadvantaged socio-economic profiles than US-born mothers, as measured by educational attainment and insurance status, they engaged in more positive health behaviours" (Hawkins et al 2014b).

7.2.1. E-Cigarettes

Tamimi (2018) considered the "moral quandary" associated with the growth of e-cigarettes. On the one hand, they are less harmful than tobacco smoking and can aid in quitting smoking, but there is "the similarity in the way e-cigarettes are consumed compared to smoking cigarettes; the use of promotional images and messages, to advertise for e-cigarettes, similar to those used in the past to promote traditional cigarettes as well as the growing involvement of the tobacco industry in manufacturing and marketing e-cigarettes" (p128).

Tamimi (2018) referred to her semi-structured interviews with fifteen e-cigarette users and thirteen Stop Smoking Advisors in southern England. She noted that the "long-term use of nicotine products was a controversial issue. Although for some advisors, quitting smoking was the main aim, for others, it is not only the smoking cessation that they were aiming to achieve, it is

the elimination of nicotine addiction. E-cigarettes are used by many smokers to stop smoking cigarettes; however, the pattern of their usage differs. In my study, some used e-cigarettes with a view to quitting their use at some point in the future, others used them as a substitute to tobacco smoking without the intention to quit them. However, the Stop Smoking Advisors brought e-cigarettes into the world of medicinal nicotine, they fitted e- cigarettes within the Nicotine Replacement Therapy framework" (Tamimi 2018 pp135-136).

One advisor commented about nicotine: "It's a chemical that they don't need, it's not going to benefit them so that's that the danger it may open up a door for an addiction they did not have, to begin with... It's a double edge sword" (p136).

Marcotte (2014 quoted in Tamimi 2018) suggested that e-cigarettes have created a "new moral panic", while Saletan (2009 quoted in Tamimi 2018) commented that "the war on smoking became cultural, with disapproval and ostracism of anyone who lit up; and that, although e-cigarettes have removed the war's scientific basis, our cultural revulsion persists. Therefore, so does our prohibition and condemnation".

One e-cigarette user interviewed seemed aware of this concern: "I think generally there is less of a stigma around electronic cigarettes, and that certainly wasn't in the beginning anyway, when it was still seen as a novelty and people... started using them as a way of quitting and it was supposed to be a healthy thing, and I think there was no stigma. Now that it's become kind of lifestyle thing in itself, I think the stigma has returned a bit. And this kind of links up to... just generally a stigma and the people judging other people's lifestyle choices. In the end... it is a lifestyle choice and I think the stigma that smokers had has kind of carried on to the e-cigarette users in the sense that the stigma surrounding the addiction itself. People see you as weak because you give in to the addiction" (pp136-137).

So, whether to ban e-cigarettes? Beauchamp and Childress (eg: 2009) proposed four moral principles for assessing an issue or policy - autonomy, beneficence, non-maleficence, and justice.

Autonomy refers to respect for the individual to make their choices (ie: free from coercion) (table 7.1). Hall et al (2015 quoted in Tamimi 2018) noted that "prohibiting e-cig[arette] infringes on smokers' autonomy to use a less harmful nicotine product while inconsistently allowing individuals to begin and continue smoking cigarettes".

MacKenzie (2011) discussed four conceptions of autonomy:

- i) Decisional - "the capacity to make informed, voluntary decisions about health care choices, such as whether to accept or refuse a specific treatment or to participate in a clinical trial" (p277). Thus, the importance of understanding (the choices), and voluntariness.

- ii) Conscientious - "fidelity to the goals, standards, norms, or principles to which a person is committed and by which she guides her conduct" (p278) (ie: responsibility to themselves and others).

So, in "exercising conscientious autonomy, patients will often defer to and trust in the authority and judgment of health care professionals, but this is quite different from merely complying with doctors' orders. Conscientious autonomy requires capacities to critically reflect on and articulate the reasons for one's commitments; take responsibility for one's ongoing health care practices; and exercise judgment about when deference and trust in medical authority is appropriate and when it is not" (p282).

- iii) Libertarian - the right to individual choices in one's personal life (eg: to choose contested surgical interventions or physical enhancements).

- iv) Relational - the relational, social and political dimensions of autonomy (eg: social justice).

Table 7.1 - Different conceptions of autonomy.

Beneficence relates to benefiting all, and "smokers who substitute tobacco with e-cigarettes, take positive steps to contribute to the welfare of others by eliminating the harms from second-hand smoke" (Tamimi 2018 p138).

With non-maleficence, a policy should not do harm, but an e-cigarette ban "perpetuates harm by preventing addicted smokers from using a less harmful nicotine product" (Hall et al 2015 quoted in Tamimi 2018).

The final principle of justice refers to equal opportunity here, and a e-cigarette ban deprives individuals who want to quit smoking from using this method.

Tamimi (2018) observed that e-cigarettes have "established a new entity encompassing 'clean' and 'dirty' nicotine. E-cigarettes may result in a social structural transformation of addiction; where a culture of nicotine use in this new form becomes socially acceptable in the West" (p141). In terms of the four principles outlined above, she stated that "e-cigarettes can be permitted to be sold in ways that respect the autonomy of smokers by allowing them to reduce the harms of smoking. At the same time, in line with the non-maleficence principle and to maximise utility in the society, regulations such as restricting e-cigarettes advertisement and age restriction are put in place to

protect younger generations from developing a new addiction" (Tamimi 2018 p141).

7.3. UNHEALTHY BEHAVIOURS

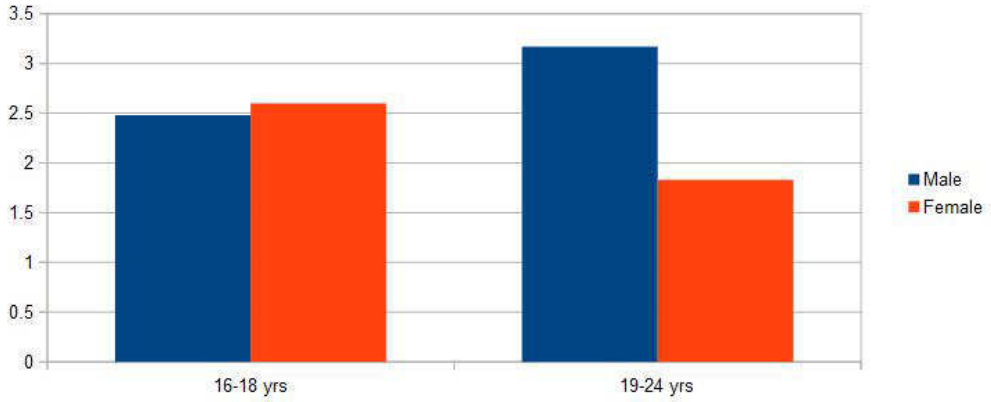
7.3.1. Self-Poisoning

Self-poisoning may represent a suicide attempt, non-lethal self-harm, or an accident. Data on the number of cases are usually based on emergency department attendance.

Tyrrell et al (2018) included another method - data from 674 UK general practices as well as hospital records - and concentrated on 10-24 year-olds between April 1998 and March 2014. This produced a cohort of 1.7 million individuals. In total, over 40 000 poisoning events from around 31 500 individuals were recorded in general practice records (prevalence of below 2%).

The most common substance of self-poisoning was paracetamol, followed by alcohol, and medications (eg: anti-depressants). Female cases peaked at 16-18 years old, while males were 19-24 years old (figure 7.1). Individuals from the more deprived areas were approximately twice as many as those from less deprived areas.

Nearly half of the cases (42%) of poisoning did not include information on the substance involved.



(Data from Tyrrell et al 2018 table 3)

Figure 7.1 - Adjusted incidence rate ratios based on age group and gender (where 1.00 = 10-15 years old).

7.3.2. Violence

Excluding war, interpersonal violence is estimated to kill over 400 000 individuals per year globally

(making it the 19th most common cause of death), and fifth most common for life-reducing injuries (Fazel et al 2018).

Treating interpersonal violence as a public health issue requires identification of individual-level modifiable risk factors. Fazel et al (2018) sought these in their umbrella review of twenty-two meta-analyses (published prior to 2018). Risk factors were grouped into neuropsychiatric (eg: mental disorders; substance abuse), historic (eg: child maltreatment), or other (eg: low empathy).

Overall, neuropsychiatric factors were strongest for interpersonal violence, and within that category, substance abuse was ranked highest (over seven times greater risk of violence).

Specifically for intimate partner violence, substance misuse, and exposure to violence as a child were the most important risk factors, along with specifics to the relationship like marital dissatisfaction, and previous abuse by one partner.

But, the researchers noted, "the overall quality of the underlying evidence was not strong, with the majority of reviews demonstrating small study effects and large heterogeneity" (Fazel et al 2018 p612).

7.3.3. Gambling

Parke and Griffiths (2002) outlined some of the challenges when studying slot machine gamblers:

i) Player-specific factors - eg: dishonesty and social desirability in interviews; infringement of player anonymity; lack of self-understanding.

ii) Researcher-specific factors - eg: "blending in" in participant and non-participant observations; sampling issues.

iii) External factors - eg: gaming establishments not designed for covert research; "gatekeeper" issues.

From their experience, Parke and Griffiths (2002) made some recommendations for researchers, including building relationships with the gaming industry, introducing incentives for gamblers to participant in research, and developing idiographic methods (like working in a gambling establishment or becoming a gambler).

7.3.4. Adolescent Self-Harm

The Children's Society (2018) analysed data from the

Millennium Cohort Study in the UK, and reported that 22% of 14 year-old females and 9% of males self-harm.

But the question used was "hurt themselves on purpose in any way", which could mean anything (Wilson 2018).

But Max Davie argued that self-harm is a more acceptable way to express anguish today (quoted in Wilson 2018).

But the longitudinal study, "Understanding Society" (https://www.understandingsociety.ac.uk/) has reported no change in happiness among 11-15 year-olds between 1995 and 2016 (Wilson 2018).

7.4. BARRIERS TO TREATMENT

7.4.1. HIV

Anti-retroviral therapy (ART) can be beneficial for persons living with HIV infection (PLHIV), but it requires such individuals to use the treatment. There are reasons for not receiving treatment, including lack of awareness of HIV-positive serostatus, dropping out of treatment, misconceptions about HIV treatment, and individual characteristics, as well as structural barriers like poverty, and availability of treatment.

Kuznetsova et al (2016) explored the barriers and facilitators to ART with interviews of eighty PLHIV in St Petersburg, Russia, in 2013-14. Two groups of barriers and facilitators were distinguished from the interviews - related to the HIV medical service, and individual-level ones:

i) HIV-medical service:

a) Barriers

- Difficulties accessing care providers - eg: long waiting time or journey to the service.

- Dissatisfaction with quality of service - eg: the doctor "asked me just a single question, that's it. Here is your referral. 'See you in half a year', that's it" (female respondent).

- Negative attitudes held by staff - eg: "There were some nurses in the hospital. They discussed me like 'rubbish came'" (female respondent).

b) Facilitator - positive experience with medical staff - eg: "Thanks to my doctor in the local clinic, she called me all the time to find out my news. She convinced me to do [HIV] lab analysis" (male respondent).

ii) Individual-level factors:

a) Barriers

- Perceived good health and no symptoms of HIV.
- Current life problems.
- Low value placed on own health.
- Stigma and worry about HIV status becoming known - eg: "what if I meet somebody from my [group of] acquaintances" (female respondent).
- Fears related to learning about illness.
- Substance abuse.

b) Facilitators

- Importance placed on health.
- Support from HIV community.
- Decline in health.
- Cessation of substance abuse.

Kuznetsova et al (2016) described their study as the first interview-based on with PLHIV in Russia on their perceptions of medical care. There were common factors with previous studies, like substance abuse and social support, but also specific issues to Russia. For example, "HIV care is highly centralised, leaving very few choices about where persons can get medical treatment. Thus, dissatisfaction with services may lead persons to completely drop out of the care system rather than seek an alternative provider" (Kuznetsova et al 2016).

7.4.2. Meningitis Belt

Deaths from meningitis are highest in the "meningitis belt" (sub-Saharan Africa from Senegal to Ethiopia), as is the death of newborns from the disease (Sejvar 2018).

GBD 2016 Meningitis Collaborators (2018) showed that vaccination had been relatively successful throughout the world between 1990 and 2016, particularly for Haemophilus influenzae type b meningitis [52], but the reduction in deaths from vaccine-preventable measles and tetanus "dwarf the progress made in preventing deaths from meningitis" (Sejvar 2018 p1029).

Widespread vaccination programmes have been difficult to implement in the "meningitis belt" [53], as

[52] The other main types are Neisseria meningitidis (meningococcal) and Streptococcus pneumoniae (pneumococcal) (Sejvar 2018).

[53] Similarly, vaccinating individuals exposed to Ebola in the Democratic Republic of Congo was limited by armed groups fighting in the region of the outbreak, and the problem of storing the vaccine at

well as "limited capacity for CSF [cerebrospinal fluid] analysis, the challenge of making a clinical diagnosis of meningitis in neonates and young children, and limitations in laboratory diagnostics that can be done on site" (Sejvar 2018 p1029).

7.4.3. Attitudes of Staff

Stigma is often experienced by individuals with mental health problems, but those with alcohol and other drug (AOD) problems as well are "highly stigmatised" (McCann et al 2018). Schomerus et al's (2011) review found that the latter group were blamed more for their situation, and were more likely to experience rejection and discrimination than individuals with mental health problems without AOD problems.

Stigma can act as a barrier to help-seeking, particularly if negative attitudes are held or believed to be held by medical professionals. For example, Boyce et al (2010) found that undergraduates in the health sciences had negative attitudes towards clients with AOD problems compared to those with mental problems, and learning disabilities.

McCann et al (2018) investigated whether such attitudes persisted with an online survey of paramedics (ie: ambulance services) in six states in Australia. The questionnaire included four vignettes of patients - an individual with depression and suicidal thoughts; depression and AOD problems; psychosis; psychosis and AOD problems. Twenty attitude items were completed for each vignette.

A total of 1152 paramedics completed the survey (around 7% of the workforce). There were stronger stigmatising attitudes towards the two vignettes with AOD problems than without (figure 7.2).

McCann et al (2018) concluded: "While it does not necessarily follow that negative attitudes and desire for social distance lead to discriminatory care and treatment, in many instances these attitudes may have adverse implications for paramedics' professional behaviour, clinical decision-making and quality of care for, and subsequent treatment access by, patients with mental health and/or AOD problems and for paramedic peers" (p10).

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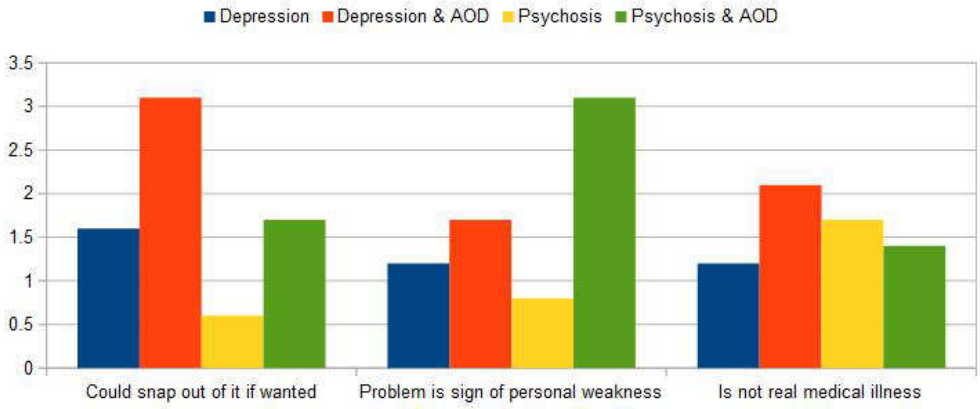
very low temperatures (MacKenzie 2018).



(Data from McCann et al 2018 table 3)

Figure 7.2 - Percentage agreeing or strongly agreeing with selected statements.

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8. TREATMENTS

8.1. DAILY ASPIRIN

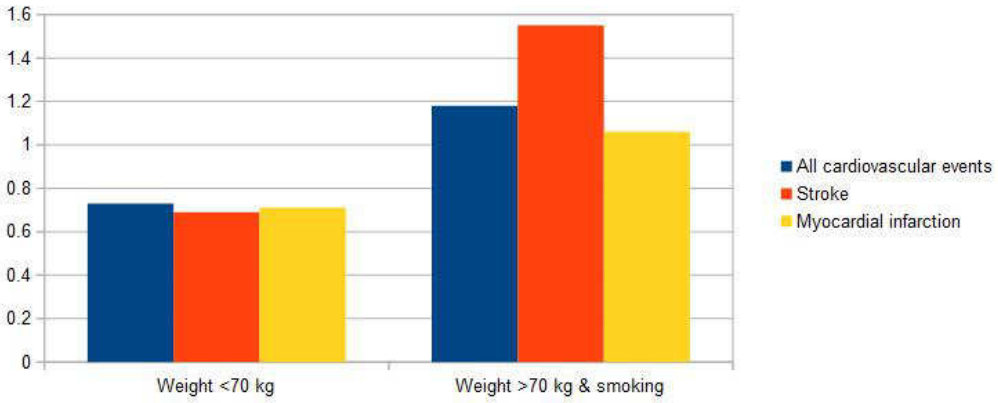
A "one-dose-fits-all approach" is the idea that the same dose of a drug will benefit everybody in the same way. Studies usually compare one dose level with a control, as in the case of daily aspirin to prevent cardiovascular problems. But this strategy has yielded only "modest long-term reductions" (Rothwell et al 2018).

Rothwell et al (2018) argued that body weight/size (or body mass index; BMI) was key, and different levels of dosage are required. They stated: "If the effectiveness of lower doses decreases, and the effectiveness of higher doses increases, with increasing body size, then weight–dose interactions could explain why low-dose aspirin appears to prevent stroke only in women, and high doses only in men, despite them having similar BMIs" (Rothwell et al 2018 p388).

Rothwell et al (2018) analysed data for different doses from different trials of aspirin to prevent cardiovascular events. The researchers focused on individual patient data, which allowed adjustment for weight and height (ie: weight-stratified analysis).

From the ten randomised clinical trials analysed, it was found that low doses of aspirin daily (75-100 mg) were beneficial in reducing future cardiovascular events in individuals weighing less than 70 kg (particularly 50-69 kg), while higher doses (≥300 mg) were better for individuals weighing more than 70 kg. Smoking and larger body size had an increased risk of cardiovascular events with the low-dose aspirin (figure 8.1).

The lessened effect of low-dose aspirin at larger body size was "driven more by weight and height than by BMI" (Rothwell et al 2018 p394), and suggested that less aspirin made it through the stomach and into the bloodstream (ie: "insufficient systemic bioavailability").



(Data from Rothwell et al 2018 table 2 p392)

Figure 8.1 - Hazard ratios of cardiovascular events with daily low-dose aspirin (where controls = 1.00).

8.2. CONTINUITY OF CARE

With the growth of medical technologies and health care as a consumer experience, Duffy and Lee (2018) suggested that non-personal care could become the "default option".

Pereira Gray et al (2018) challenged this idea, and showed the benefits of continuity of care by doctors in a systematic review. Twenty-two relevant studies up to 2017 were included. There were fifteen retrospective cohort studies, 4 prospective cohort studies, and three cross-sectional studies. Continuity of care was significantly associated with lower mortality rates.

Pereira Gray et al (2018) offered a possible explanation for this finding: "Continuity of care is associated with patients perceiving that the doctor has become more responsive. Patients then disclose more and medical management is more likely to be tailored to the needs of the patient as a person. The increased patient satisfaction may also be associated with an 'optimism' boost to health" (p11).

There were four key methodological issues with the studies included in the review:

i) The measurement of continuity of care - eg: Usual Provider of Care (UPC) index (the proportion of contact with health care services with the same doctor(s)). This does not take into account the total number of visits, their frequency, or sequence (Pereira Gray et al 2018).

ii) Length of time of study - from one weekend in

hospital to seventeen years.

iii) Outcome measure - eg: all-cause or specific cause mortality.

iv) Control of confounding factors - eg: healthcare usage; social variables.

8.3. NARRATIVE MEDICINE

Charon (2006) observed that despite the significant developments in medicine, patients often "lament that their doctors don't listen to them or that they seem indifferent to their suffering. Fidelity and constancy seem to have become casualties of the cost-conscious bureaucratic marketplace. Instead of being accompanied through the uncertainties and indignities of illness by a trusted guide who knows them, patients find that they are referred from one specialist and one procedure to another, perhaps receiving technically adequate care but being abandoned with the consequences and the dread of illness" (p3). Thus, there is a gap for, what Charon (2006) called, "narrative medicine" (ie: the individual's "story" of their illness).

Charon (2006) stated: "Narrative medicine has come to understand that patients and caregivers enter whole — with their bodies, lives, families, beliefs, values, histories, hopes for the future — into sickness and healing, and their efforts to get better or to help others get better cannot be fragmented away from the deepest parts of their lives" (pp12-13).

Charon (2006) noted four divisions between patients and doctors:

a) The relation to mortality - "Doctors may look upon death as a technical defeat, whereas patients may see death as both unthinkable and inevitable" (p22).

b) The contexts of illness - Doctors focus on the disease, while patients see the sickness in the context of their whole lives.

c) Beliefs about disease causality - Differences in views (even contradictions) about the causes of illness.

d) The emotions of shame, blame, and fear - These emotions can worsen the sickness experience for patients.

8.4. DISCORDANT TREATMENT

Tonsillectomy (ie: removal of the tonsils) is

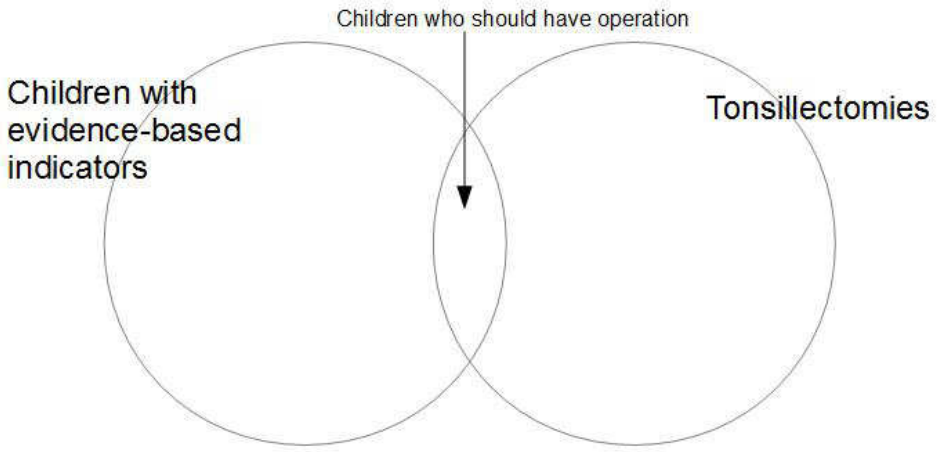
recommended for children with frequent sore throats (eg: seven or more in one year), but there can be long-term effects like increased respiratory infections and allergies (Sumilo et al 2018).

Sumilo et al (2018) investigated the appropriate use of this operation in the UK. Data from 739 general practices between 2005 and 2016 were analysed (n = 1.6 million 0-15 year-olds).

Those children meeting appropriate criteria for a tonsillectomy were an average incidence of 4.2 per 1000 person-years, of which 14% had the operation.

So, the majority of operations were performed on children not meeting evidence-based criteria (figure 8.2). This calculated at 32 500 unnecessary tonsillectomies annually, at a cost of £37 million to the NHS.

The authors noted a "guideline discordant clinical management of recurrent sore throat". This involved undertreatment of many individuals who had the evidence-based criteria for an operation, and the overtreatment of children not meeting the criteria.



(Based on figure 3 Sumilo et al 2018)

Figure 8.2 - The number of children receiving tonsillectomy based on evidence-based criteria.

8.5. THERAPY

Some studies show that cognitive-behavioural therapy (CBT) is beneficial for individuals with bipolar disorder (eg: Lam et al 2004), but others not (eg: Scott et al 2006).

Lam (2006) offered some reasons for the difference in findings, including:

- Outcome measures used (eg: relief of symptoms; duration of survival).

- Patient populations (eg: co-morbid or not; how diagnosed).

- Number of sessions and content of the therapy.

- Mixing of patients in remission and in acute episodes (ie: mixed sample) or not.

- Use of medication as well as therapy or not.

Leader (2008) criticised CBT as it promises change: "Today it is plasticity and change that govern self-image. Personality itself is represented as a set of skills that we can learn modify. Just as we can alter our bodies through cosmetic surgery, so we can change our behaviour through 'work' on ourselves" (p7).

He continued: "The market has triumphed here, as our inner worlds become a space for buying and selling. We pay experts such as life coaches to teach us how to change in the desire way. Aspects of ourselves, such as shyness or confidence, become commodities that we can pay to lose or amplify. Depression or anxiety are seen as isolated problems that can be locally targeted without calling into question the rest of one's existence" (Leader 2008 pp7-8).

Leader (2008) saw the problem more widely in "a modern self for which depth has become surface. In soaps and reality shows characters share their innermost feelings and emotions, as if there were a perfect continuum between interior and exterior life. If there's any ambiguity, a panel of experts is there, as on Big Brother, to explain people's motivations. The self is no longer a dark cave; everything is laid bare. In effect, we have been robbed of our interior lives" (p8).

Leader (2008) was criticising CBT's lack of interest in the underlying reasons for a behaviour. "The self had once been understood as a place of conflict: between reason and passion, between will and understanding, between repressed desires and their inhibition" (Leader 2008 p8). So, for CBT, "if a disorder is defined by symptoms, get rid of the symptoms and you've got rid of the disorder" (Ian Parker in Leader 2008).

8.6. ANTI-PSYCHOTIC ADHERENCE

Cramer and Rosenheck (1998) calculated that the mean rate of adherence to anti-psychotic medication was 58% [54]. In other words, just over half of individuals with

[54] Delayed onset of symptom reduction may reduce adherence (appendix 8A).

psychosis taking these drugs do so as advised. Non-adherence is key in relapse [55].

Rittmannsberger et al (2004) showed this in a study in Linz, Austria. Adherence to the drug regimen in the last month was assessed by interview for every patient admitted to one psychiatric hospital between December 1998 and June 1999 [56]. Additional information was collected from medical professionals and relatives, and follow-up of one year was implemented.

There were 95 patients in the study (most with a diagnosis of schizophrenia). Overall adherence was 43% ("took as prescribed"), with 28% admitting "took less than prescribed", and the remainder "did not take at all". Adherence was significantly higher among patients in regular contact with their psychiatrists, and younger patients.

Non-adherence (compared to full adherence) led to more hospitalisation (mean 45 vs 21 days). However, level of insight into illness was the best predictor of future hospitalisation (appendix 8B).

The key methodological issue was the means of assessment of adherence, which was self-reported in the main. Rittmannsberger et al (2004) stated: "In general, we found that most patients were frank about their non-adherence. If the patient reported having been adherent, we contacted the patients' relatives and treating physicians to get additional information. We are aware that all these data are subjective and may be biased for various reasons, and we regard our results as representing the minimum level of non-adherence. That is, we are quite sure that the patients we rated as non-adherent were indeed non-adherent and that we might have missed some cases of non-adherence by rating some patients as adherent when they were not" (p178).

The more accurate methods of assessing adherence are quantity accounting (eg: number of pills left of those prescribed for a set period) [57], drug monitoring (eg: blood test for level of the drug in the body), devices for recording use (electronic monitoring) (eg: every time a pill bottle is opened is recorded) [58], or direct observation. The latter, in particular, requires the individual to be in a controlled environment (ie: hospitalised). These methods are not foolproof, however,

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[55] Side effects have a role to play here (appendix 8C).

[56] How the individual is asked about their adherence can influence recall and response - eg: "do you ever forget to take your medication?"; "are you careless at times about taking your medication?" (Ley and Llewelyn 1995).

[57] Pharmacy refill records tell the time between repeated prescriptions, and this can give a general picture of adherence similar to pill counts.

[58] Individuals who know about the recording device can open the bottle at the correct time, say, but not necessarily take the medication (Sarafino 1994).

and are expensive (table 8.1).

Other methods used include outcome measures (ie: changes in behaviour or the condition that suggest non-adherence), and clinicians' judgments (Ley and Llewelyn 1995).

In terms of all medications, mean correlations between patients' reports and pill counts of +0.47 have been found, +0.80 with recording devices, but +0.15 with clinicians' estimates (Ley and Llewelyn 1995).

Pill Counts	Drug Monitoring
• Individuals may throw pills away (or share them) to hide non-adherence ("pill dumping"; Raymond et al 2017). • Cannot distinguish between deliberate non-adherence and forgetting or loss (passive adherence). • Requires researcher to count pills on a regular basis. • Change individual's behaviour because they know being watched.	• Stress of giving blood (or urine) sample, and risk of drop-out. • Accuracy of testing method (eg: good at showing that the drug is present in system, but not whether the correct amount taken at correct time). • Expense of regular testing (eg: laboratory analysis costs; nursing staff). • Change individual's behaviour because they know being watched.

Table 8.1 - Key disadvantages of pill counts and drug monitoring of medication adherence.

Most pill counts occur at appointments with medical staff, and so the individual knows when their adherence will be checked. But unannounced pill counts, where a research assistant, say, unexpectedly appears at the individual's home, can be better (though costly in terms of staff). Alternatively, unannounced telephone-based pill counts, but they do depend on the honesty of reports.

Raymond et al (2017) evaluated this method with adolescents and young adults in New York City and HIV medication. Telephone calls were made approximately monthly. Some participants were difficult to reach (eg: cell/mobile phone out of service), and some individuals reported taking more pills than prescribed ("overadherence"). "Although giving participants dedicated study cell phones... might increase retention rates, this may be cost-prohibitive. In addition, other non-phone-related factors such as unpredictable schedules and lack of privacy made it difficult to complete these unscheduled calls" (Raymond et al 2017 p1012).

The researchers also found "the importance of establishing a non-judgmental context for the pill-count

calls" (Raymond et al 2017 p1012).

Improving adherence for anti-psychotic medications led to the barriers, facilitators, and motivators (BFM) checklist (Pyne et al 2014), which identifies the BFM of individual patients for taking anti-psychotics.

Pyne et al (2018) compared 36 patients completing the 76-item BFM checklist [59] (table 8.2) and 39 not in the southern USA, and their adherence to anti-psychotic medication at six and twelve months follow-up. Adherence was measured on a self-reported five-point scale, ranging from "I never missed taking my medication" to "I stopped taking the medication altogether".

Adherence was better in the BFM checklist group than the other group at six months, but not twelve months.

Barriers:
- I am feeling really good
- My meds remind me that I am sick
- My friends tell me that my meds don't work

Facilitators:
- I take my meds with my meals
- My doctor or mental health provider listens to me
- My doctor or mental health provider gives me frequent pep talks about the importance of taking my meds

Motivators:
- I think something good is going to come out of taking my meds
- If I take my meds, I will do a good job at work

(Source: Pyne et al 2014)

Table 8.2 - Items from BFM checklist.

8.7. ORTHOKERATOLOGY

Shortsightedness (myopia) is increasing around the world (Hiraoka et al 2018). One attempt to reverse the condition is orthokeratology (OK), which involves wearing particular contact lens during the night.

Hiraoka et al (2018) reported data over ten years for 53 patients using OK lens (and 39 wearing ordinary sight correction lens) beginning in adolescence in Japan. Myopia was reduced in the OK group, but worsened in the other group. The success was such that the OK group did not need to wear any vision-correction aids during the day.

The study did not match the two groups for age, and the normal contact lens-wearers used a variety of lens types. Also "the present study is limited by its

[59] 28 barriers, 30 facilitators, and 18 motivators.

retrospective design, which might have lead to inter- and intra-observer bias as well as selection bias" (Hiraoka et al 2018 p287). On the positive side, for this type of study, the sample was relatively large, as well as the length of the study period (Hiraoka et al 2018).

8.8. APPENDIX 8A - DELAYED ONSET

Anti-psychotic medication was traditionally seen as taking 2-3 weeks from starting it to reducing psychotic symptoms (Kapur 2004). But a meta-analysis by Agid et al (2003) showed that psychosis improved within the first week of treatment. "This early improvement in psychosis was not just due to a change in aggression and excitement but was a specific and distinct improvement in core psychotic symptoms (ie: conceptual disorganisation, hallucinatory behaviour, grandiosity and unusual thought content). In fact, the improvement in psychosis during the first two weeks of treatment was much greater than the improvement observed during any subsequent two-week period during treatment" (Kapur 2004 p402).

8.9. APPENDIX 8B - RELAPSE

Relapse of schizophrenia has been linked to the following factors, as well as poor medication adherence, and less insight to illness: being male, younger age at onset of disorder, longer duration of untreated psychosis, substance abuse, and low pre-disorder level of functioning (Porcelli et al 2016).

These factors are based mostly on early development of schizophrenia and first relapse. Other factors may be involved in subsequent relapses, like metabolic syndrome (MetS) (Godin et al 2018) [60].

MetS is "a collection of clinical and biological abnormalities resulting in a predisposition to diabetes, cardiovascular disease, and stroke" (Godin et al 2018 ppe1-2). It is often associated with obesity.

Godin et al (2018) studied a sample of patients from ten areas of France in the FACE-SZ (FondaMental Academic Centres of Expertise for Schizophrenia) cohort. Between November 2013 and December 2015, 185 individuals diagnosed with schizophrenia were followed for one year.

MetS was diagnosed with three or more of the following five criteria:

- High waist circumference (males >94 cm; females >80

[60] For example, Pelayo-Teran et al (2017) found that low adherence to medication was associated with the first relapse, but not subsequent relapses.

cm).
- Hypertriglyceridemia (high levels of fatty molecules called triglycerides in blood).
- Low HDL cholesterol level.
- High blood pressure.
- High fasting glucose concentration.

One-third of the sample had a relapse in the one-year follow-up, and MetS, and the severity of schizophrenia were the key risk factors, but not non-adherence to medication, and lower insight into illness.

Godin et al (2018) summed up: "Combined with previous results, the present study suggests that risk factors for relapse may vary throughout the evolution of schizophrenia. Most previous studies focused on early relapses and their association with poor adherence, poor insight into the illness, male sex, and cannabis consumption. Our study suggests that these risk factors disappear in a stabilised community-dwelling population with schizophrenia with mean illness duration of 11 years. Only the severity of the illness and MetS were found to predict relapse at the 1-year follow-up" (pe6).

8.10. APPENDIX 8C - SIDE EFFECTS

The side effects of anti-psychotics are due to which part of the molecule (Nettle 2004):

- Binds to acetylcholine receptor - drowsiness, dry mouth, blurred vision, constipation.

- Binds to adrenaline receptor - reduced blood pressure, dizziness.

- Binds to histamine receptor - weight gain, drowsiness.

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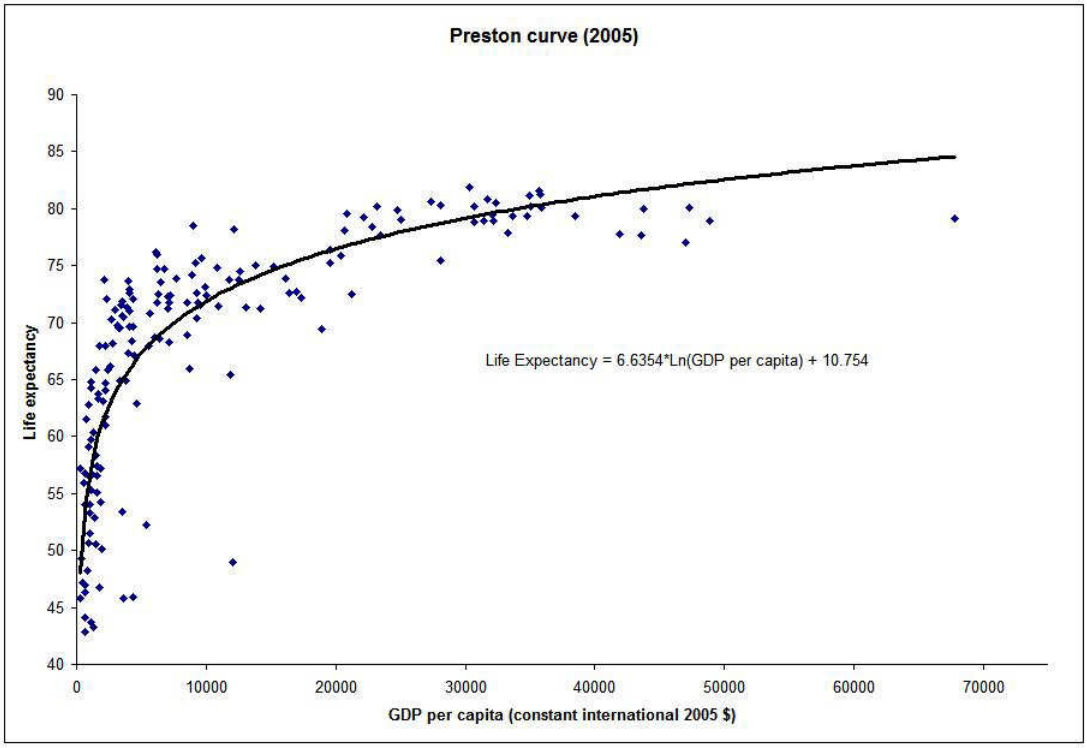
9. GLOBAL ISSUES

9.1. EDUCATION AND LIFE EXPECTANCY

Life expectancy has increased dramatically in the 20th century, particularly in rich countries, and improvements in health generally go with that. Preston (1975) produced a graph showing increases in national income per head and life expectancy together. He explained the relationship as "the effect of medical progress and health care over and above the effect of income" (Lutz and Kebede 2018 p343). This is known as the "Preston curve" (figure 9.1).



(Source: Radeksz based on http://www.ganfyd.org/index.php?title=File:PrestonCurves.png; in public domain)

Figure 9.1 - A Preston curve for 2005 data.

Alternatively, Caldwell (1986), concentrating on poorer countries, focused on "female autonomy" as a way to reduce mortality - ie: female education, along with good health services. Less educated groups in a society have higher mortality, while children of better-educated mothers have lower mortality, for example. But better-educated people tend to live in rich households (Lutz and Kebede 2018).

So, is income or education the more important determinant of improved health and life expectancy? Bloom and Canning (2007) took this position: "Although there is a strong case for the direct effect of income on health due to nutrition and health interventions becoming more affordable, it may be that income is also acting as a proxy for a wider measure of socio-economic status and development and that the causal effect is due to other mechanisms, for example, education" (quoted in Lutz and Kebede 2018).

The problem is establishing causality. There are significant statistical associations or correlations, but that is not the same as causation. Lutz and Skirbekk (2014) introduced the idea of "functional causality" (where traditional scientific causality cannot be established), which has three criteria - "(i) there must be strong empirically observed associations between the two factors studied; (ii) there must be a plausible narrative about the mechanisms through which one force influences the other; and (iii) other obvious competing explanations of the observed association should be ruled out" (Lutz and Kebede 2018 p348). Lutz and Skirbekk (2014) felt that the global-level relationship between educational attainment and health and mortality met these criteria for the last century or so.

Lutz and Kebede (2018) analysed data for 174 countries for the period 1970 to 2010. Income was operationalised as gross domestic product (GDP) per person, and education as mean years of schooling of the adult population aged fifteen years and above. Statistical modelling showed that improvements in education produced life expectancy increases around three times greater than improvements in income.

Lutz and Kebede (2018) concluded that data suggested a "plausible hypothesis" that "the apparent positive association between health and income can largely be attributed to increasing educational attainment, which at the same time leads to rising incomes... and better health outcomes" (p358).

In terms of educational success, in a study of pupils in England, Gorard (2018) found that the most important factor in school test and examination results was "not the quality of teaching or leadership but who they teach, the proportion of pupils who are

disadvantaged through poverty, family circumstances or special educational needs and most crucially the length of time they have been disadvantaged" (Lightfoot 2018).

9.2. GLOBAL PUBLIC GOOD

The idea of rights, as applied to migrants, Widdows and Marway (2015) noted that "this debate collapses into a conflict between the rights of some individuals and the right of others" (p121). These authors preferred the idea of "global public good", particularly in relation to the issue of the health of migrants.

Public goods are "enjoyed collectively and, as such, are non-rivalrous (in that their use by one does not prevent their use by another)..., lack excludability (they are inclusive and available to all) and require collective management and maintenance" (Widdows and Marway 2015 p122). Global public goods "require all individuals to behave in certain ways if they are to be sustained" (p122), and if they are not protected "then all individuals (current and future) will be exposed to significant harm (and often will actually suffer harm, harms preventable by the the protection of the good)" (Widdows and Marway 2015 p123). This is the first of Widdows and Marway's (2015) criteria of global public goods. Another is that global public goods cannot be protected without collective action.

Examples of global public goods include the environment, and appropriate anti-biotic use. In both cases, failure to protect by collective action will expose everybody (current and future) to harm.

Returning to Widdows and Marway's (2015) main focus - the health of migrants, and why it should not be neglected through the refusal of treatment, say. For example, managing infectious disease is a global public good, and refusal to treat migrants is a risk to everybody because disease is "no respecter of borders". Linked to this is the "herd immunity" of vaccination. Failure to vaccinate certain groups is a risk to all.

So, in conclusion, "health goods are provided to migrants not because they are migrants but because they need to be provided to all to protect public goods" (Widdows and Marway 2015 p126).

9.2.1. Organ Transplantation

Svenaeus (2015) presented four groups of ethical issues related to organ transplantation:

i) Consent from donors - eg: should consent be explicit or presumed from dead donors.

ii) Compensation for donors - eg: payment, which opens the possibility of a trade in human body parts.

iii) Keeping individuals alive or allowing them to die in relation to use of their organs.

iv) Ethics related to recipients - eg: who deserves a new organ.

All these issues are related to "the relationship a person (a self) has to his or her body" (Svenaeus 2015 p571). The phenomenological view [61] sees organs as part of the self and donation "would equal giving away something of one's self instead of merely giving away one or several things that belong to you" (Svenaeus 2015 p572).

However, Svenaeus (2015) argued that "our embodiment connects us to the lives and sufferings of other people in a fundamental way. The connectedness by way of the body goes back to the way we are delivered to the world as fundamentally dependent on other persons, a predicament made obvious in situations in which we become ill or disabled in various ways and need the support of others... We share the same fundamental needs and desires as human beings because we are embodied in similar ways" (p572).

The first-person perspective of the phenomenological view is combined with a second-person perspective ("the dialogue with other persons") rather than the third-person impersonal perspective of science (Svenaeus 2015).

9.2.2. Mental Health

The United Nation's Sustainable Development Goals include those related to mental health, like promoting mental health and well-being, improving prevention and treatment of substance abuse, and general health coverage (Patel et al 2018).

More specifically, the Lancet Commission (Patel et al 2018) made four proposals for global mental health:

i) Global mental health is a public good, and it is linked to sustainable development. "No person should be excluded from a public good (non-excludable) and possession by one person does not deny it from others (non-rivalrous)" (Patel et al 2018 p33).

ii) Mental health problems conceptualised as a continuum from "mild, time-limited distress to chronic, progressive, and severely disabling conditions" is more

[61] Eg: Heidegger (1927/1996); Merleau-Ponty (1945/1962).

helpful than the binary categories of absent/present.

iii) The "mental health of each individual is the unique product of social and environmental influences, in particular during the early life course, interacting with genetic, neurodevelopmental, and psychological processes and affecting biological pathways in the brain" (Patel et al 2018 p1).

iv) Mental health is a "fundamental human right for all people".

Patel et al (2018) outlined six key actions to fulfil the above proposals:

- Integrating mental health with physical health services.
- More investment in mental health services.
- Break down the barriers to positive mental health, like lack of awareness of its value.
- Public policies to protect mental health.
- The use of innovations to deliver mental health interventions (eg: digital technology).
- Investment in research into mental health.

9.3. OBLIGATION TO FUTURE GENERATIONS

Making sacrifices now to limit the future consequences of climate change, say, is for the sake of future generations. "Do we, in fact, have obligations to persons who will exist only in the future and, if so, how we can coherently explain the basis for these obligations?" asked DeGrazia (2012).

DeGrazia (2012) offered "a plausible list" of obligations to future generations:

- Responsible stewards of environment (eg: preserving adequate natural resources).
- Responsible stewards of gene pool (eg: "appropriate precautions in pursuing inheritable genetic modifications").
- Avoid disastrous overpopulation.
- Protect important aspects of human culture (eg: literature; valued monuments).

- Protect important technological resources (eg: medical knowledge).
- Keep national debts manageable.
- Protect valued non-human species from extinction.
- Protect human species from extinction (eg: nuclear war).

In terms of the moral status of future individuals, as such they do not exist now, so "it follows that they do not have interests, moral status, or rights since there is really no 'they' to have these things. It may seem to follow that we cannot have obligations to future individuals. But this does not follow. After all, even though we do not know who will exist in the future, we do know — or at least we responsibly assume — that there will be future people. Once they exist, they will have full moral status with associated rights" (DeGrazia 2012 p204). DeGrazia (2012) argued that the basis of the obligation to future generations is justice.

But is the good of future individuals equal to the good of present individuals? "Pure discounting" (Broome 1994) is "the assignment of less moral importance to the interests - collectively, the well-being - of future persons" (DeGrazia 2012 p212). DeGrazia (2012) argued against pure discounting, but, at the same time, accepted that "there are limits to the sacrifices we should be expected to make for the sake of future generations" (p216). He stated: "What matters most, from the standpoint of individual lifestyle choices and public policy, is that we take the interests of future people seriously, try not to cause great harm, and conduct ourselves as good stewards of our environment, economy, gene pool, species, and so forth" (DeGrazia 2012 p215).

The contrary position is taken by Schwartz (1978), for example, who asserted that "we've no obligation extending indefinitely or even terribly far into the future to provide any widespread, continuing benefits to our descendants" (quoted in DeGrazia 2012). DeGrazia (2012) explained: "His reasoning is simple: Whatever policy we choose will be numerical-identity-affecting, so we can neither benefit nor harm those who come into being, since they would not have existed had we taken another choice. Crucial to his reasoning is the person-affecting intuition: that an action is wrong only if it wrongs someone" (p218).

9.4. HEALTH INEQUALITIES

Wester (2018) began: "Some live shorter lives and

experience more illness than others. Are such inequalities in health unfair?" (p346). She replied to her question that "health inequalities are unfair when they are the result of unfair distribution of resources" (Wester 2018 p346).

Health inequalities are in part due to differences in healthcare services, but also to a wide range of material and social factors, like living conditions, and income equality/inequality.

For some authors, health has a special place, and so health inequalities are morally worse than other types of inequalities. For example, Descartes (1953/1637) noted the "preservation of health is... without doubt the first good and the foundation of all the other goods of this life" (quoted in Wester 2018).

Wester (2018) outlined the options: "If health is believed to be a particularly important determinant of our life prospects or overall well-being, then that would constitute a rationale for being particularly concerned with the distribution of health and for providing principles of justice that apply specifically to health. Treating health as a separate sphere is one way in which we may award health a special status in a theory of justice. In contrast, if we reject this view of health as special, considering its contribution to our overall life prospects as on par with, and to some extent compensable by, other goods, we should primarily be concerned with health inequalities where they correlate with inequalities in other important goods because such clustering of inequalities gives a better indication of people's overall life prospects" (p349).

She took the latter position, arguing that "the importance of health for our overall well-being is generally comparable to that of other components, and that we should mostly be concerned with health inequalities where they correlate with inequalities in other important goods" (p353).

So, "we should see fairness in the distribution of health as generally derivative of, or secondary to, the fair distribution of other important social goods" (Wester 2018 p353).

9.5. MIGRANTS

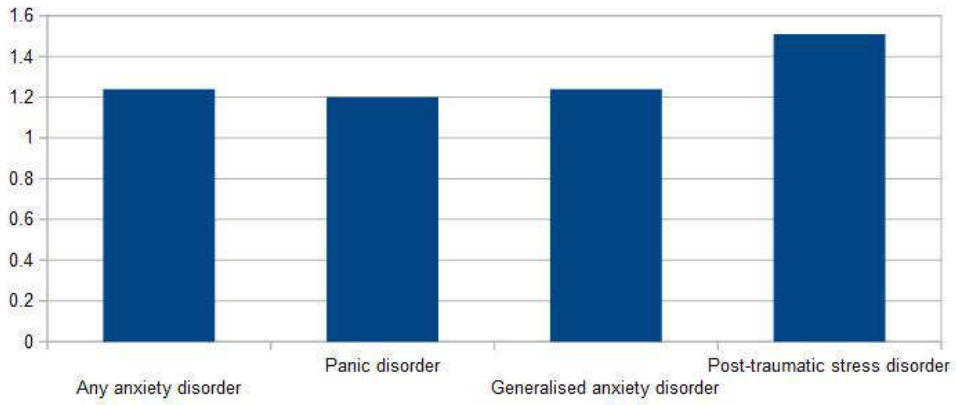
The prevalence of anxiety disorders among migrants to a country has been studied. The majority of studies find a higher rate among first-generation migrants (1GMs) than the native population, and some studies higher among second-generation migrants (2GMs). But there is a "healthy migrant effect" observed in some cases, where the prevalence of anxiety disorders is lower in 1GMs than the natives. Furthermore, studies find differences

between 1GMs and 2GMs (Pignon et al 2018).

Pignon et al (2018) investigated these differences between studies, and anxiety disorders among third-generation migrants (3GMs) using data from France. The World Health Organisation's Mental Health in General Population (MHGP) survey interviewed over 38 000 individuals in France between 1999 and 2003. Anxiety disorders were diagnosed by ICD-10 criteria [62]. Migration status was as follows:

- 1GM - individual born in another country.
- 2GM - parent(s) born in another country, but individual born in France.
- 3GM - grandparent(s) born in another country, but parents and individual born in France.

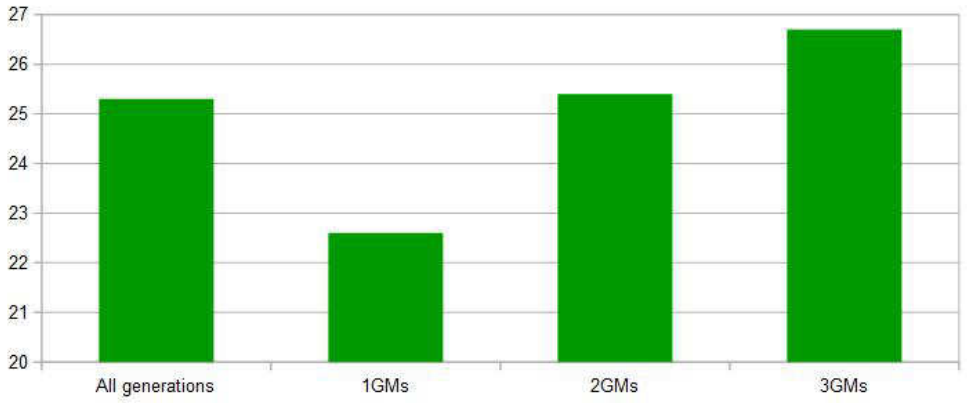
Overall, 22% of the sample were diagnosed with an anxiety disorder [63], but among any generation migrants the rate was significantly higher than the natives (figure 9.2). The rate increased across the generations (figure 9.3). In terms of specific anxiety disorders, the "risk increased across the three migrant generations for SAD [social anxiety disorder] and GAD [generalised anxiety disorder], while remaining stable for PD [panic disorder] and decreased for PTSD [post-traumatic stress disorder]" (Pignon et al 2018 p40).



(Data from Pignon et al 2018 table 1 p40)

Figure 9.2 - Odds ratio of anxiety disorders among all generation migrants (where 1.00 = natives).

[62] World Health Organisation's International Statistical Classification of Diseases and Related Health Problems (10th edition) (http://apps.who.int/classifications/icd10/browse/2016/en).
[63] This compares to 29% in the USA (Kessler et al 2005).



(Data from Pignon et al 2018 table 1 p40)

Figure 9.3 - Prevalence of any anxiety disorder (%) among three generations of migrants.

Explanations for the higher rate among migrants include stressful life events pre-, per-, and post-migration, acculturation issues (ie: differences between host culture and country of origin), and socio-economic conditions (including discrimination) (Pignon et al 2018).

9.5.1. Climate Migrants

Long-term seal level rise from climate change may see the migration of entire populations of small and low-lying islands. These individuals will be "future climate change migrants". Farbotko et al (2016) investigated how individuals felt about this scenario in Tuvalu and Kiribati.

The researchers noted an increase in "a sedimentation of sedentarist feelings" -ie: "an intensity of voiced commitment among some members of the population to staying rooted in place, even in the face of possible inundation of their islands..." (Farbotko et al 2016 p535).

Tschakert et al (2013) used the concept "solastalgia" to describe a kind of homesickness among individuals who have not left their home but see their land degrading through climate change. This is a sense of helplessness, while Farbotko et al (2016) noted a feeling of empowerment in Tuvalu and Kiribati.

The inhabitants of these islands are contesting the "climate refuge discourse". Farbotko and Lazrus (2012) criticised this discourse as assuming that the individuals are from the developing world moving to the industrialised world, whereas movements are expected to

be within national borders.

These authors stated that "the image of the climate refugee is sustained as a sort of victim-commodity, providing news value, political point-scoring, and a human embodiment of climate change 'evidence' for western environmental activists concerned with saving the planet (Farbotko 2010). Climate refugee narratives have evoked a particularly narrow range of subject positions for inhabitants of Tuvalu – either a helpless victim or a climate hero - in a dependent relation with powerful groups in the developed world" (Farbotko and Lazrus 2012 p386).

Farbotko (2005) analysed over thirty stories about Tuvalu and climate change in an Australian daily newspaper in 2001-2. Tuvalu was presented as "paradise" in "imminent peril", while Australia was represented as "a secure place, capable of offering a 'lifeline' to 'drowning Tuvalu'" (Farbotko 2005 p284). An identity for Tuvalu was constructed in terms of "tragedy and displacement".

9.6. PSYCHOLOGICAL KIDNAPPING

Referring to their own country, Xu et al (2018) began with the question: "How does a good official become corrupt in China?" (p1).

A simple answer is the rent-seeking theory (Buchanan et al 1983). An official will seek "rent" (bribe) when they have power over others (eg: decision to allocate public resources), and the economic benefits are large (eg: lucrative public service contract). Furthermore, "low relative earnings, high unemployment, and advertising will also influence the acceptance of bribes" (Xu et al 2018 p2).

Xu et al (2018) rejected the rent-seeking theory as an explanation for China as "for some corrupted officials, the benefits gained from bribery were so small that their value was far less than the risk of being caught" (p2). Furthermore, many officials avoid bribes initially, and, in time, are "enticed or seduced into corruption through an interpersonal process under certain social norms in which psychological factors play a very important role" (Xu et al 2018 p2).

These researchers emphasised specific cultural factors in the psychology of corruption in China, which they described as "psychological kidnapping". Key is the nature of interpersonal relationships where "an individual attempts to influence another person by means of 'renqing' (norm of reciprocity) and 'mianzi' (face)" (Xu et al 2018 p2). This involves three stages - initiating the relationship, building on it, and using

that relationship for gain ("guanxi").

Xu et al (2018) summed up: "The process by which officials become corrupt is gradual. The bribee feels comfortable at the beginning, as with the frog swimming in warm water, unaware of the risk. After receiving many small-value 'gifts' from the briber, when being asked to allocate public resources unfairly, the bribee is likely to become aware of the danger. However, by this time, they have already been trapped and have no chance of escaping from a deeply embedded social reciprocal dilemma" (p3).

Psychological kidnapping can thus be defined as "a process in which the kidnapper, in order to attain his/her desired benefits and instrumental goals, develops an affective bond with the kidnapped, who gradually lowers defences and risk perceptions, allowing the kidnapper to use the established relationship to get special considerations and help from the kidnapped. The core of psychological kidnapping is the renqing dilemma (reciprocity)" (Xu et al 2018 pp3-4).

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10. THEORETICAL AND METHODOLOGICAL ISSUES

10.1. LOCAL BIOLOGIES

Lock (1993) introduced the idea of "local biologies" to refer to "the way in which the embodied experience of physical sensations, including those of well-being, health, and illness, is in part informed by the material body, itself contingent on evolutionary, environmental, social and individual variables" (Niewohner and Lock 2018 p684). This idea came from studying the very different experiences of North American and Japanese women at the end of menstruation.

One possible mechanism of local biologies is epigenetics (or specifically environmental epigenetics) [64], where the environment affects gene expression.

Niewohner and Lock (2018) took the idea of local biologies further with the concept of "situating biologies". This wider concept situates the material body in:

- Time - different time frames (evolutionary, generational, biographical, metabolic).
- Space - "the human body needs to be situated within its physical surroundings in multiple ways" (p689).
- Patterns of practice - individuals move globally today more than ever, so placing individuals in a single culture and its social relations is not enough.

"Local biologies" can be seen as a way of overcoming "the conventional twentieth century separation of the social from the biological" (Meloni et al 2016 p11).

Others have argued for "the necessity of a dissolution of the 'conventional divisions between body,

[64] The discovery of epigenetics led to the idea of a "reactive genome" (Gilbert 2003). Keller (2014) explained: "The role of the genome has been turned on its head, transforming it from an executive suite of directional instructions to an exquisitely sensitive... system that enables cells to regulate gene expression in response to their immediate environment" (quoted in Lock 2018).

mind and culture'" (Ingold 1999 quoted in Meloni et al 2016).

Ingold and Palsson (2013) proposed a biosocial approach that "challenges the reductionisms of sociobiology and cultural constructionism alike (dissolving the pole of nurture into nature and vice versa, respectively), and puts forward an integration of 'the social and the biological... ontogeny and phylogeny, organism and context, being and becoming'" (Meloni et al 2016 p11).

Rose (2013) talked of "biology in two senses": "(1) biology as the field of positive knowledge of living beings that we give that name; and (2) biology as the reality of those beings themselves – humans who are, after all, animals, living creatures, who are born, live, sicken and die" (p3).

Rose (2013) outlined three features of biology that are important today:

i) Genomics has been able to "reveal multiple affinities between humans and other creatures, and throw new light on their differences" (p5).

ii) The "'technologisation' of vitality in the life sciences - "Life itself – that is to say, the living of the living organism – seems to have become amenable to intervention and open to projects of control" (p6).

iii) The "salience that the biological and the biomedical has achieved in practices of self-management and self-governance" (p6). To expand, "individuals are coming to understand themselves in the language of contemporary biomedicine, to judge themselves in terms of the norms articulated by biomedical experts, to modulate their bodies and minds with products that are the product of biomedical belief systems, to use new reproductive technologies to manage procreation, to consider replacing worn out body parts with artificial hips and knees, to think about reducing risks of disease with diet and exercise, and to worry, individually and collectively, about Alzheimer's and the dementias, maybe even to take up Sudoku and mind gyms in the belief that if they act this way, they may be saved. In this sense, personhood itself is becoming increasingly somatic" (Rose 2013 pp6-7).

10.2. FEMINIST APPROACH TO BIOETHICS

Sherwin (2008) began: "Humanity is facing a terrifying array of threats to its continued existence. A non-exhaustive list includes: climate change; air and water pollution; rapid disappearance of growing numbers

of species, including many that are crucial to human food supplies; a desperate shortage of (clean) water for many people; enormous disparities between the rich and the poor, both nationally and internationally deeply entrenched religious and ethnic hatreds; proliferation of nuclear, chemical, biological, and conventional weapons; emergence of new infectious diseases (eg: HIV/AIDS, SARS, and a potential bird flu pandemic); and reappearance of 'old' infectious diseases in new, more resistant forms (eg: tuberculosis). Each of these problems on its own has the potential to produce catastrophic consequences for human (and other) life; in combination, the dangers are multiplied" (pp7-8). Thus, the need for bioethics to guide humanity through the many issues involved.

Sherwin (2008) argued for a "public ethics" that is "explicitly collective" (ie: "institutional changes to create the infrastructure that will facilitate choices that protect rather than threaten human life on the planet and ensure that all levels of organisations act in accordance with appropriate norms"; p9). Feminist theories can help here, for Sherwin (2008), and particularly the concept of "relational autonomy" (MacKenzie and Stoljer 2000).

This is the idea that individuals are not entirely autonomous, but are influenced by those around them, like in social norms. For example, the individual decision of a woman to choose cosmetic surgery to change their appearance takes place "within a culture that makes physical appearance important to how others treat them and correspondingly, to how most feel about themselves. As liposuction, tummy tucks, and botox injections among middle-aged women and breast enlargement becomes an increasingly popular graduation gift for high school girls, it is useful to explore the forces that are at work. Given the risks and costs inherent in such interventions, it is worth trying to find ways to make such procedures less attractive redirect preferences into healthier" (Sherwin 2008 p13).

This approach also takes account of power structures. Sherwin (2008) stated: "Repeatedly, bioethicists either: (1) focus on questions of individual responsibility and individual rights and ignore discussion about the moral dimensions of public policy, or (2) they take existing public policy as the norm and ask about how to modify it for improvement. They (we) are sidetracked, again and again, from examination of important but larger ethical questions by the apparent need to attend to narrower issues that get put in our paths through the terms of a debate that others have initiated" (pp23-24).

Gender and biomedical research can be seen in (Ballantyne et al 2008):

a) The inclusion of participants - "The decision to include or exclude women who are pregnant, breastfeeding, or not using contraceptives raises questions about the relevance of data gathered in such research to significant sub-populations that are likely to need access to the treatments being tested" (Ballantyne et al 2008 p2).

Rogers and Ballantyne (2008) found that one-third of 113 sex-specific clinical research studies in Australia (published between 2003 and 2006) had inappropriately excluded either men or women.

b) Gender stereotypes and research design - eg: male-only sports injury prevention studies or female-only falls prevention studies with older adults (Ballantyne et al 2008).

c) Gender equity in health research - eg: governance framework for clinical trials.

In relation to fertility research, Ballantyne and de Lacey (2008) argued that the "reliance on infertile women as sources of eggs breaches the principle of just participant selection because the vast majority of such research is not related to fertility. Research participants should be selected from the population that stands to benefit from the research, not from a sub-population that is convenient and accessible. Ballantyne and de Lacey conclude that it is preferable to recruit healthy donors from the general population for stem cell research that investigates general medical conditions" (Ballantyne et al 2008 pp3-4).

10.2.1. Female Fitness

Physical activity and fitness are associated with subjective well-being for women, yet there are "significant impediments to women's flourishing associated with fitness talk" (Isaacs and Brennan 2016 p2). Isaacs and Brennan (2016) highlighted four themes:

i) Equality - Females are less active than males from school age to adult participation in sports. Isaacs and Brennan (2016) commented that "the level of participation in sport and physical activity matters because (1) active lifestyles are good for women's well-being; (2) it's good for children to see their mothers as physically active and competent; and (3) it's good for women's agency for them to experience themselves as embodied and competent" (p3).

Burrow (2016) highlighted the "masculinised values of athleticism", such that "women in sport face a double bind that compromises their autonomy and creates barriers, prejudice, and bias against them" (Isaacs and

Brennan 2016 p4).

ii) Inclusivity - "Fitness culture" (ie: representations in fitness media) tend to be of non-disabled, younger, White men. So, "it seems that only those who already appear to be 'fit'... are welcome to participate. As our population ages, it is essential that we not promote the idea that fitness is only for the young" (Isaacs and Brennan 2016 p5).

iii) Empowerment - "Where dieting is characterised by deprivation and restriction, participation in intense and demanding activity, including lifting heavy weights, requires people to fuel their bodies appropriately and adequately with high quality food in sufficient amounts. This approach leads to feelings of empowerment and strength, quite different from the impact of severely restricted diets" (Isaacs and Brennan 2016 p6).

iv) Aesthetics and feminine embodiment - "Aesthetic goals may encourage women to become active, but they are just as likely to undermine women's self-respect and self-esteem and discourage them from continuing to pursue physical fitness once the fit body ideal is found to be unattainable... The fit body that we see in 'fitspiration' or 'fitspo' imagery is also young and thin and beautiful. Many women find it demoralising to work hard and not 'see' visible results in the way their bodies look. Thus, inspiration and motivation can turn to demoralisation and disillusionment over time" (Isaacs and Brennan 2016 p8).

10.3. EVOLUTIONARY IDEAS AND MENTAL DISORDERS

Del Giudice (2016) noted some "innovative trends" in the study of mental disorders from an evolutionary perspective, including:

a) Developmental psychopathology - This focuses on "the interplay of personal and environmental factors in the origin of mental disorders, including genotype-environment interactions, epigenetic encoding of life events (eg: prenatal stress, early neglect or abuse), and their role in the development of neurobiological systems" (Del Giudice 2016 p44).

b) Computational psychiatry - The use of mathematical models of cognitive processes (eg: decision-making) and neurological processes (eg: synapses) to understand the mechanisms involved in mental disorders. For example, a general "p factor" (general susceptibility to psychopathology; Caspi et al 2014).

c) Evolutionary psychopathology - Understanding mental disorders in the context of the evolution of behaviours.

Del Giudice (2016) distinguished three themes in the above approaches:

i) Trade-offs and conflicts - Psychopathologies are the product of trade-offs between competing traits and conflicts of interest between individuals. For example, autism spectrum disorders are the result of the overdevelopment of "mechanistic cognition" (eg: visuo-spatial skills) and the underdevelopment of "mentalistic cognition" (eg: theory of mind) (Crespi and Badcock 2008; diametrical model).

Another example is psychosis, which Del Giudice et al (2010) hypothesised as a trade-off between short-term mating with multiple partners (as in the risky behaviour associated with psychosis like impulsivity) and long-term romantic relationships.

ii) The evolution of developmental mechanisms - eg: "differential susceptibility" (Belsky 1997). "In a nutshell, individuals can be more or less sensitive to the effects of experience owing to a combination of genetic and early developmental factors, so that those who are more susceptible to adverse conditions are also more responsive to safe, supportive ones" (Del Giudice 2016 p46). Differences in serotonin transporter genes is one possible mechanism (Del Giudice 2016).

iii) Life history theory - This theory understands organisms in terms of the time and energy allocated to activities in their life cycle (eg: growth; reproduction). Strategies are, broadly, fast or slow depending on the environment. "In humans, dangerous and unpredictable environments tend to favour faster strategies characterised by early maturation and reproduction, sexual promiscuity, unstable relationships, impulsivity, risk taking, aggression, and exploitative tendencies, whereas safe and predictable environments tend to entrain slower strategies characterised by late maturation and reproduction, stable relationships, high self-control, aversion to risk, and pro-sociality" (Del Giudice 2016 p48). Mental disorders could be a (maladaptive) side effect of fast strategies (Del Giudice 2014).

10.4. BIPOLAR RATING SCALES

Rating scales for bipolar disorders aim to distinguish the presence of the disorder or not, and the severity of symptoms. "Many mania and depression rating

scales were developed some 30–40 years ago and demonstrate considerable heterogeneity in the range of assessed symptoms and in underlying assumptions about the nature of bipolar disorder episodes" (Scott and Murray 2018 p628).

Particularly important is that the criteria for the presence of bipolar disorder have changed in recent years (eg: "abnormally and persistently increased activity or energy" in the mania phase in DSM-5 in 2013) (Scott and Murray 2018).

Scott and Murray (2018) considered the commonly used rating scales (eg: Young Mania Rating Scale; YMRS; Young et al 1978) (table 10.1) and contemporary diagnostic criteria. The preliminary finding was that increased activity and energy was less important in the rating scales than in the DSM-5 criteria, which "raises concerns about the content validity of the most widely used symptom rating scales" (Scott and Murray 2018 p628).

Other researchers have also questioned the "most established" rating scales for bipolar disorder. For example, Scott et al (2017) reported non-significant correlations between YMRS scores and objective measures of mania (obviously when significant correlations are expected for the validity of this scale).

Prisciandaro and Tolliver (2016) criticised items on the YMRS as poorly constructed and inefficient - ie: "several items that provided little or no psychometric information and only measured a narrow band of severity of symptoms" (Scott and Murray 2018 p628).

- Elevated mood

0 Absent.
1 Mildly or possibly increased on questioning.
2 Definitive subjective elevation; optimistic, self-confident; cheerful; appropriate to content.
3 Elevated; inappropriate to content; humorous.
4 Euphoric; inappropriate laughter; singing.

- Sleep

0 Reports no decrease in sleep.
1 Sleeping less than normal amount by up to one hour.
2 Sleeping less than normal by more than one hour.
3 Reports decreased need for sleep.
4 Denies need for sleep.

- Insight

0 Present; admits illness; agrees with need for treatment.
1 Possibly ill.
2 Admits behaviour change, but denies illness.
3 Admits possible change in behaviour, but denies illness.
4 Denies any behaviour change.

(Source: https://dcf.psychiatry.ufl.edu/files/2011/05/Young-Mania-Rating-Scale-Measure-with-background.pdf; accessed 17 December 2018)

Table 10.1 - Example of 3 of 11 items from YMRS.

10.5. DIAGNOSING PUBLIC FIGURES

In 1964, the American Psychiatric Association (APA) stated that "it is unethical for a psychiatrist to offer a professional opinion unless he or she has conducted an examination and has been granted proper authorisation for such a statement" (quoted in Gartner et al 2018). This statement was made in reference to US Presidential candidate, Barry Goldwater, and so became known as the "Goldwater principle" for psychiatrists. However, the debate about this principle has become more important with the election of President Trump.

Gartner et al (2018) considered the arguments for and against the Goldwater principle, including:

FOR:

a) "Desisting from speculation about diagnoses of public figures is an important and powerful demonstration of ethically informed practice. It also goes some way to addressing some of the more shameful historical practices of psychiatry, and brings us closer to a less stigmatising, more educated and ultimately hopeful future" (Gartner et al 2018 p635).

b) Mental health terminology often takes a pejorative meaning when used freely in the public arena, and this is detrimental to ordinary individuals suffering from mental disorders.

Furthermore, Alex Langford commented: "The saddest irony of attacking politicians we do not like by calling them mentally ill is that it risks turning our young people away from politics because they have mental health problems of their own. There may be an incredible 50th president of the USA out there, deciding not to join the party of her leaning because she fears that her teenage psychotic episode will be discovered" (Gartner et al 2018 p636).

c) The duty to maintain confidentiality about the private information of patients.

AGAINST:

a) The "duty to warn" the public about a potentially dangerous patient can be applied here. Lee (2017) observed that "possibly the oddest experience in my career as a psychiatrist has been to find that the only people not allowed to speak on an issue are those who know the most about it. Hence, truth is suppressed" (quoted in Gartner et al 2018).

b) There is plenty of public material available in order to observe the individual. John Gartner stated: "In the case of Donald Trump, I have observed literally hundreds of hours of Donald Trump's behaviour. I have read thousands of his tweets. And I have read the testimony of dozens of informants. I would dare say I have a stronger basis for diagnosing Trump than most of the patients in my practice" (Gartner et al 2018).

c) The Goldwater principle benefits the APA and psychiatrist's self-interest - eg: fear that the President would retaliate with financial restrictions on psychiatrists (the "pocket book" explanation).

10.6. BOURDIEU AND FIELDS

Bourdieu (eg: 1993) had the concept of "field" [65] to describe "a social space of relations or social configuration defined by struggle over capitals. That is, it is an arena of struggle in which actors compete for a variety of valued resources" (Go and Krause 2016 p8). These resources are different forms of "capital" (eg: economic, political, symbolic [66]). Fields consist of "the objective configuration of actor-positions", and the subject meanings ("rule of the game") guiding the struggle for "capital" (Go and Krause 2016).

Go and Krause (2016) emphasised five points of Bourdieu's work here:

i) Actors may be competing for more than one form of capital at a time depending on the field.

ii) Fields and capitals are a combination of the objective and subjective dimensions.

iii) In any given field at any given time, some actors will be dominant and others subordinate. "The 'rules of the game' are most often set, and protected, by the dominant actors, while subordinate actors eventually come to challenge those rules and impose new ones. The latter become 'heretics': they challenge the existing rules, or 'orthodoxy' of the dominant players who cling to their privileges through their 'conservation' strategies in the face of the 'subversion' strategies of challengers" (Go and Krause 2016 p9).

iv) Individual fields can have their own rules for

[65] Eg: political, artistic, literary, religious, and intellectual and academic fields.
[66] Different form of symbolic capital include "academic capital" and "juridical capital" (Go and Krause 2016).

their struggles.

v) The autonomy of a given field varies over time.

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11. DEMENTIA AND RELATED ISSUES

11.1. DEMENTIA

Fletcher (2018) stated clearly: "Dementia is a collective term for the symptoms of multiple conditions causing ultimately fatal progressive cognitive impairment. This results from long-term brain cell damage caused by varied factors. AD [Alzheimer's Disease] accounts for around 60% of dementias. AD is widely attributed to the protein beta-amyloid (Ab) forming plaques in the brain" (p173). This is often called the molecular model of AD, or the process of "Alzheimerisation" (Fletcher 2018).

"Whilst successful at attracting funding, the molecular model has been therapeutically unfruitful. Drug trials have removed Ab from the brains of people with AD, yet they have subsequently continued to experience cognitive decline... Furthermore, many older people exhibit AD pathology without corresponding symptoms. This pathology/symptom disparity undermines the differentiation of abnormal AD pathology from normal ageing physiology" (Fletcher 2018 p174). This is the "Alzheimer Conundrum" (Lock 2013).

Fletcher (2018) noted three reactions to this conundrum:

a) Earlier diagnosis, including the adoption of "mild cognitive impairment" as a preceder of AD. "As early intervention progresses, the medical gaze extends into younger populations" (Fletcher 2018 p174).

b) Genetic research, particularly in relation to Ab aggregation predisposition. "Being labelled a pre-clinical person with dementia may have negative repercussions, such as heightened insurance premiums" (Fletcher 2018 p175).

c) The entanglement model which explains cognitive decline in older adulthood as only partly due to pathology. "Separating AD from ageing becomes meaningless, as an amalgamation of complicated age-

related 'crap' (as researchers often refer to it) permeates the overall process... Therefore, entanglement understands AD as the result of many diverse factors. It encourages the interrogation of numerous strands to construct holistic approaches, incorporating the 'social, political and environmental' [Lock 2013] alongside the molecular" (Fletcher 2018 p175).

Fletcher (2018) developed this latter idea by combining the entanglement model with symbolic interactionism (SI) (Blumer 1969) to emphasise the social aspects of dementia. SI can be summarised as three principles: "people act based on the subjective meanings that things hold for them; these meanings are produced in interaction with others; meanings are negotiated in an interpretative process" (Fletcher 2018 p176).

Fletcher (2018) described the SI of dementia in stages:

i) Transformative nature of the dementia object - ie: the power of the label of dementia. "The dementia object arrives in a pre-existing social context, introducing instability into existing relationships and challenging existing worlds of objects. This arrival threatens both existing meanings and the negotiation of new ones" (Fletcher 2018 p177). Goffman (1963) talked of the stigma of certain labels.

ii) Continuity and change, agency and determinism - The tension between wanting to continue as before by individuals diagnosed with dementia, and to maintain their agency, versus the need for help, and the loss of agency. Meanwhile, other individuals are confronted with the demands of multiple roles (eg: wife and nurse).

iii) The language used during these processes - Fletcher (2018) gave this example: "Imagine a woman named Norma. If everybody besides Norma referred to Norma as 'Demetria' it would likely not take long until Norma began to answer to 'Demetria'" (p179). Put simply, language constructs relationships and objects, particularly if individuals, struggling with speech, cannot contest it. "As the condition progresses, speech is increasingly considered indicative of disease... Deemed symptomatic, the linguistic divide between the person with dementia and others emphasizes their abnormality... Linguistic misunderstandings fuel agitation, which is likewise deemed symptomatic... Declining ability to contest interpretations reinforces their potency" (Fletcher 2018 p180).

iv) Being symptomatic - "Actors interacting with the person with dementia increasingly interpret the person with dementia's self-object in light of the dementia

object, transforming the meaning of the person... Interpreting action as symptomatic removes agency from the person with dementia... The stigmatised actor's indignant response is commonly interpreted as additional evidence of abnormality, justifying discrimination" (Fletcher 2018 p181). As others act on behalf of the individual, there is "a loss of self" (Beard and Fox 2008). "The person is replaced by the dementia sufferer and thus dehumanised" (Fletcher 2018 p183).

11.2. IMPROVING MEMORY

There is some evidence that lithium may improve memory (eg: in rats; Nocjar et al 2007), and reduce the risk of dementia (eg: individuals with bipolar disorder; Kessing et al 2008). While, in a placebo-controlled randomised trial over two years, Forienza et al (2011) found that low doses of lithium reduced the rate of cognitive decline in individuals with mild cognitive impairment.

Could lithium in drinking water, then, reduce the incidence of dementia? Kessing et al (2017) reported a study from Denmark which compared the levels of naturally-occurring lithium in drinking water in different areas, and the rates of dementia. It was a case-control study of over 73 000 individuals with dementia and over 730 000 non-dementia individuals (ie: ten age- and sex-matched controls to one case).

The researchers "confirmed the hypothesis that higher long-term lithium exposure from drinking water may be associated with a lower incidence of dementia, although this association was non-linear" (Kessing et al 2017 p1008). For example, among the sample exposed to the highest levels of lithium, the incidence rate ratio of dementia was 0.83 (eg: eastern regions of Denmark) compared to 1.00 for the lowest level of lithium (eg: western regions of Denmark).

This was a large-scale study covering many years, but "because all inhabitants in a given municipality are assigned the same level of lithium exposure, it cannot be excluded that other, unobserved environmental or social care factors related to individuals' municipality of residence might have confounded the association between lithium exposure and dementia rate" (Kessing et al 2017 p1008). Other methodological issues included:

- Full population-based data available, but focus on 50-90 year-olds.
- Extensive records available - eg: Danish National Patient Register, Danish Psychiatric Central Research Register.

- Dementia data for 1986 to 2013, but lithium in drinking water based on samples from 2009-10 and 2013 covering less than half of the country.

- Validity of the diagnosis of dementia high (ie: agreement between researchers and original diagnosis in 86% of sample checked), but less so for dementia sub-types.

- Adjustment made for urbanicity as a confounding effect, but not for access to health care services.

- It "cannot be excluded that there may have been some long-term changes in lithium levels in drinking water during the study period from 1986 to 2013, although the level of lithium in groundwater and drinking water is most likely stable over time because of the chemical properties of lithium and its slow release from the soil and sediment" (Kessing et al 2017 pp1008-1009).

11.3. ANXIETY

What is the relationship between anxiety and cognitive decline/dementia? Becker et al (2018) provided an answer based on a review and meta-analysis of longitudinal studies (up to 2018). Ten relevant articles met the inclusion criteria, which most importantly included a minimum period of two years, and clear criteria for anxiety, and dementia.

Anxiety at baseline was predictive of Alzheimer's disease or vascular dementia at two years later (figure 11.1). Individuals with anxiety and depression had an even higher risk of Alzheimer's disease. Becker et al (2018) stated: "Independently of age, anxiety is likely to damage the brain directly by permanent stress and indirectly by avoiding behaviour, inactive lifestyle and loss of cognitive reserve and resiliency" (p659).

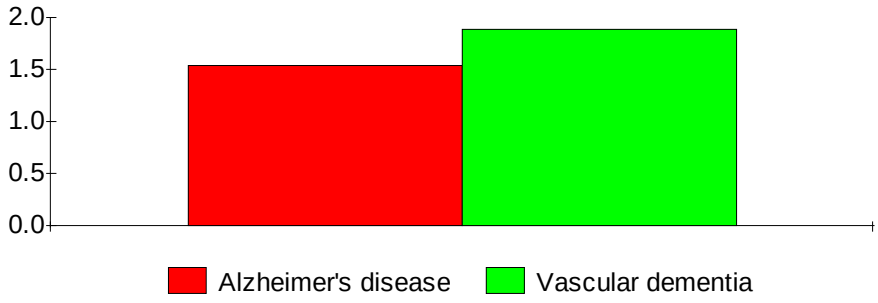

Figure 11.1 - Hazard ratio for dementia with anxiety (where 1.00 = no anxiety).

As with any meta-analysis, the studies included tended to vary in aspects of methodology. This included:

- Sample size - from 185 to 12 083.
- Case-control or cohort study.
- Length - from 3 to 40 years.
- Age of participants at start of study.
- Definition and measurement of anxiety - eg: trait anxiety or anxiety disorders.
- Study sample - eg: volunteers, clinic patients.
- Measurement of dementia.

11.4. ALZHEIMER'S DISEASE

Clarfield and Dwolatzky (2013) began: "Alzheimer disease (AD), first described more than a century ago, continues to challenge our generation. If we compare the therapeutic progress that modern science has made in this condition with that achieved in treating bacterial infectious diseases, we are unfortunately still in the pre-anti-biotic era with respect to AD" (p901).

For example, drugs that slow down mental deterioration by targeting amyloid-beta protein that accumulates in the brain (Reardon 2015).

There are those who question the development such drugs when the "amyloid hypothesis" (Hardy and Selkoe 2002) is still disputed (ie: amyloid-beta protein build-up as a cause or a symptom), and when behavioural interventions may be as effective [67] (eg: Lon Schneider in Reardon 2015).

It is possible that such drugs have failed because "they have treated people too late" (Reardon 2015). For example, Bateman et al (2012) reported details of a longitudinal study in the USA with individuals carrying mutations for autosomal dominant Alzheimer's disease (which accounts for around of 1% of total cases). This study concluded: "Changes begin the brain at least two decades before the estimated onset of clinical symptoms" (Bateman et al 2012 p802).

11.5. COMMON NEUROLOGICAL DISEASES

Licher et al (2018) calculated the lifetime risk of common neurological diseases from the Rotterdam Study data. The Rotterdam Study began in 1990 with all

[67] In a Finnish study, Pitkala et al (2013) showed benefits for physical functioning of an exercise programme with individuals with dementia. The generalisability of the findings, however, were limited because the participants were volunteers (Clarfield and Dwolatzky 2013). Regular exercise may also have cognitive benefits (Clarfield and Dwolatzky 2013).

inhabitants aged at least 55 years in a suburb of Rotterdam in the Netherlands. In 2000, all individuals now 55 were added to the cohort, and in 2006 all over 45s. In total, 14 926 individuals.

Concentrating on dementia, stroke and parkinsonism, there were 1489, 1285 and 263 cases respectively during the 26 years of the Rotterdam Study. Of which, 438 individuals had multiple diagnoses. The risk of the diseases was greater for women (1 in 2) than for men (1 in 3).

11.6. FAMILY CAREGIVERS

Individuals who provide care for an adult family member with a long-term health problem or disability face financial, health, and social consequences. Keating et al (2017) concentrated on the social consequences in the form of the social relationships of carers.

The researchers found sixty-six related articles to review under three headings:

1. Relationship between the carer and the care receiver or cared-for person - In the case of the marital relationship, for instance, the changing relationship between the partners is key, and this includes declines in emotional connectedness, and sexual intimacy. Other issues include lack of emotional support for the carer, and reduced help in social and household activities.

Among family carers generally, strained relations with the care receiver, and loss of previous roles for the carer (eg: child carers "becoming a parent") were mentioned in the literature.

2. Changed relationships with other family members - The "spillover effect" on the carer's own family was reported. For example, the more time involved in caring for an older parent means less time for the carer's own children. Saban et al (2015) found that female carers of veterans with traumatic brain injury in the USA were worried about their children receiving insufficient attention, and having increased responsibilities (eg: caring for younger siblings).

Carers often felt unappreciated by other family members as well as having conflict over the best way to manage care.

3. Changes in social networks - Overall, "to varying degrees, carers were isolated. Consequences included: experiencing social exclusion because others distance themselves; becoming socially isolated through keeping others away; and having truncated opportunities for social engagement" (Keating et al 2017 p163).

Caregiving of adults has a profound impact on the carer. It is "a process of transformed identities and reconstructed relations" (Karner and Bobbitt-Zeher 2006 quoted in Keating et al 2017).

11.7. AGEING AND COGNITION

Cognitive changes in older adults are best studied with a longitudinal design. One such example is the Religious Orders Study involving older Catholic nuns, priests and brothers in the USA (beginning in 1993). Baseline evaluations were made, including of clinical history, neurological examination, and twenty-one tests of cognitive functioning, personality measures, and assessment of physical functioning.

Around 950 participants, with an average age of 75 years old, had been recruited by 2002. Overall, cognitive decline was varied: "Some persons experienced precipitous cognitive decline, some declined more gradually, and many others stayed the same or improved" (Wilson et al 2004 p287). Furthermore, these authors noted that "part of age-related cognitive decline is global in nature but another substantial proportion appears to be domain-specific" (Wilson et al 2004 p287).

Wilson et al (2004) continued: "About 3.5 years before death, the average rate of global cognitive decline increased more than six-fold. Terminal cognitive decline was evident in nearly all of those who died, but at highly variable rates" (p288). This conclusion was based on follow-up with 800 participants after eight years.

In terms of specific use of the data, Wilson et al (2002) reported that the risk of Alzheimer's disease (AD) was halved among individuals involved in frequent cognitive activity (seven common activities - eg: reading a magazine with a frequency of every day or about every day). Participation in physical activity (eg: walking for exercise) was not significantly related to risk of AD.

The key strength of the longitudinal design is the ability to measure changes over time with multiple measurements. But, in the case of the Religious Orders Study, it was limited to a specific population, who "differ in lifestyle and socio-economic status from older persons in the general US population" (Wilson et al 2004 p299).

A similar longitudinal study in the USA is the Memory and Ageing Project, which began in 1997 with participants from retirement communities in north-east Illinois. Assessments were made as home visits to avoid the "healthy volunteer effect" (Lindsted et al 1996) when

studies involve attendance at a clinic. Retirement communities are predominantly White and affluent, so a deliberate effort was made to include low-income, and ethnic minority individuals, though with limited success (12% of sample not non-Hispanic White) (Bennett et al 2012).

Cognitive tests similar to the Religious Orders Study were used with the approximate 1500 individuals (average age 80 years old) at baseline, and at annual follow-ups.

With data up to 2011, Bennett et al 92012) reported that participation in cognitively stimulating activities throughout life was associated with less cognitive decline, as well as current social engagement, and current physical activity was associated with less decline in physical abilities.

Cognitive and social activities are classed as a "natural reserve" - ie: "factors that increase the ability of the brain to tolerate the pathology of AD without manifesting clinical signs of cognitive impairment" (Bennett et al 2012).

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