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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/ and at https://kmbpsychology.jottit.com/.

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1. BEING CANCERED

1.1. LIVING WITH CANCER

The WHO (2008) estimated that 11.4 million people were diagnosed with cancer in the world in 2004, and lung cancer was the most common, followed by breast, colon and rectum, and stomach cancers.

Living with cancer is more than the disease [1]. For example, nearly half of cancer patients in the USA are called by collection agencies over their unpaid medical bills, and 60% of personal bankruptcies are due to "the catastrophic financial burden of illness" (Jain 2013). She continued: "Even if you enter the illness casino with a few coins jangling in your pocket, seeking healthcare is a gamble in which the house enjoys vastly superior odds. To add to the built-in paradox of the for-profit healthcare system, money made from treating cancer aligns a little too comfortably with the profits made from causing cancer" (Jain 2013 p11) [2].

"Cancer, as a chimera, gains different registers of meaning in different places" (Jain 2013 p12). Mauss (1966) coined the term "total social fact" "for a practice whose effects both connect and fissure through seemingly distinct areas of life, thus weaving them together" (Jain 2013), and Jain (2013) presented cancer as a "total social fact". She quoted Mauss (1966), but replaced "gifting" (gift-giving and exchange) (his example of a total social fact) with "cancer":

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[1] Some cancers are "rare diseases" (appendix 1A).

[2] Talking about the pharmaceutical industry and cancer, Jain (2013) commented that "the chances that a sector whose binding legal concern is stockholder profit will lead to adequate research and better public health are slim" (p10).

> These phenomena are at once legal, economic, religious, aesthetic, morphological and so on. [Cancers] are legal in that they concern individual and collective rights, organised and diffuse morality; they may be entirely obligatory, or subject simply to praise or disapproval. [Cancers] are at once political and domestic, being of interest both to classes and to clans and families. They are religious; they concern true religion, animism, magic and diffuse religious mentality. [Cancers] are economic, for the notions of value, utility, interest, luxury, wealth, acquisition, accumulation, consumption and liberal and sumptuous expenditure are all present (Jain 2013 pp13-14).

To sum up: "Cancer in all its complexity is not solely a biological phenomenon, but a politics with which to engage and struggle" (Jain 2013 p14) [3].

Broom et al (2017) explored the experiences of individuals living with cancer ("incurable survivors"), as opposed to those "beating" or "surviving beyond" it, with 15 individuals in Australia who kept a diary for one month.

"Across the diaries it was clear that living with advanced and/or incurable cancer fundamentally challenged participants in their everyday lives, offering a mix of contradictory and constantly changing emotions and experiences" (Broom et al 2017 p7).

The authors focused on some key themes:

i) "Terminal entanglements" - "disentangling self from the spectre of cancer" (ie: "take one's mind off cancer"). For example, "Audrey" wrote: "Hate these days as we seem to live day-to-day & scan-to-scan... You try to put it out of your mind but [you] seem to be drawn back in" (p8).

"Waiting" was a key element (eg: for clinical results) "(which promise either good news and relief or bad news and greater anxiety), while also trying to live in the meantime - to do more than just wait" (Broom et al 2017 p8). For example, "Jack" wrote: "I know this week I will be anxious waiting for the scan results... Sometime it's good to get away from cancer. I have good solid thoughts about the future. Where we will be and what we want to do, which is good" (p8).

Other studies have "drawn attention to the distinction between 'objective' clock time, by which disease progression is clinically assessed, and the ongoing flux of 'subjective' time that characterises patients' experiences of illness (Toombs 1990). In the context of cancer, some scholars have eloquently elucidated the 'creepiness' of cancer (Jain 2007) and its

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[3] "Forms of cancer-knowledge tend to push each participant to identify with one side of the equation (objective, scientific, 'neutral') or the other (subjective, emotional, 'biased')" (Jain 2013 p15).

'queer' temporality (Stacey and Bryson 2012), whereby the past and future are reconfigured through the prospect of 'living in prognosis' (Jain 2007)" (Broom et al 2017 p3).

ii) "Normality and normativity" - Part of the forgetting about the cancer was to find "normal" things to do (eg: "see the rest of my family through school"; "Karl"), and "not make cancer the centre of the universe" ("Jack").

iii) "Side-effects, suffering and the valorisation of longevity - Living with the consequences of the therapeutic programme had its own challenges, which could be worse than the cancer. For example, "Wendy" wrote: "[Cancer] does not affect me at all. I sometimes forget that it is there. If not for the side-effects of the drug, I am quite normal... Side-effects cause continuous pain + discomfort with no end in sight... I do not want to live this type of life" (p12).

The "cancer-as-clinical-experience" can "jar" with "cancer-as-a-clinically-known-biophysical-process" (Broom et al 2017) as seen in "Des's" comments: "Aside from the treatment side effects, the only way I know I have cancer is what I am told as I do not have any symptoms... Probably the hardest aspect of living with cancer is accepting that I have cancer... While I have seen the results of CT and PET scans showing cancer tumours in my chest, I have had no symptoms or even discomfort... Of course I have the medical diagnosis from the various doctors and specialists. Logic and my brain tells that I have the dreaded disease but I find it difficult to accept it" (p13) [4].

1.2. INFECTIOUS CANCERS

Though cancers are "not contagious in the sense that they are not transmitted from patients to close contacts", it is estimated that one in six cancers worldwide have an "infectious aetiology" (ie: caused by infectious agents - eg: Epstein-Barr virus (EBV) and gastric carcinoma; human papillomavirus and cervical cancer) (Chang et al 2017). These cancers afflict younger individuals in developing countries more than in the developed world (Chang et al 2017) [5].

Chang et al (2017) described seven kinds of virus

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[4] Living with pain is a common part of the experience as well as in situations (appendix 1B).

[5] "While wealthy nations in Europe and North America generally have low viral cancer burdens, infection can cause over one-half of cancers in some developing countries. The types of cancer in developing countries, however, vary widely and are influenced by concurrent patterns of AIDS immunosuppression" (Chang et al 2017 p6).

that cause cancer (oncogenic viruses), but none of them induce tumours as a "normal" part of their life cycle. "It appears that viral cancers, similar to non-infectious cancers, are biological accidents and in the natural course of disease the resultant neoplasms are just as deadly to the virus as they are to their hosts. This raises an intriguing teleological question: if viral oncogenes did not evolve to cause cancer to benefit the virus, why are they conserved?" (Chang et al 2017 p4). One answer is that viral oncogenes aid in defeating the immune responses of the host cell.

Whether exposure to a virus leads to disease, both generally and in relation to cancer, depends on factors like age, genetics, environmental factors, and prior immunity of the individual (eg: malaria in childhood increases the risk of EBV leading to Burkitt's lymphona) (Chang et al 2017).

Immunosuppressed individuals are particularly at risk (eg: certain carcinomas increased dramatically between pre- and post-AIDS males in San Francisco) (Chang et al 2017).

1.3. HAIR LOSS

The experience of being a cancer patient is further compounded by physical changes with treatment, like hair loss, for women in particular. "Hair is an important indicator of identity. Hair forms our impression of a person, and can be fashioned to demonstrate religious beliefs or music preferences. Hair is an important part of physical appearance, particularly for women, as it symbolises health, femininity and attractiveness and influences body image and identity. Consequently, hair loss as a result of chemotherapy treatment for breast cancer can have profound implications for women’s mental health and social interactions" (Trusson and Pilnick 2017).

Trusson and Pilnick (2017) performed interviews with 24 women undergoing treatment for breast cancer in the UK. Most of the interviewees reported their hair loss as distressing, including "Karen" who was more affected by hair loss than breast loss: "I was more affected by that to tell you the truth, I thought I would be fine about it but when it came to the actual, my friend came to shave it off before there was big clumps, I got really, really upset".

How others perceived them was important. "Catherine" described herself out running: "... this little child just couldn't keep their eyes off me you know. It was like my bald head... and this child said 'Mummy, is that a man or a woman?'".

"Barbara" talked about the sympathetic looks from others: "I think the worst thing that bothered me was people used to look at me and be sort of 'aah'. And then they sort of say 'for the grace of God it's not me'... I got to the stage with my hair; I'd had enough sort of that I did get a wig which was great... I wanted to move on from people knowing that I was ill to looking different, looking okay again".

On the other hand, "Phoebe", who did not have chemotherapy and thus lose her hair, reported "getting bullied" at work and having unsupportive colleagues. "Phoebe seemed incredulous at their lack of sympathy despite the fact that she had been very open about her treatment, repeating the phrase 'they knew everything that I'd had done'. Phoebe attributed it to having had no visible signs of illness..." (Trusson and Pilnick 2017).

This was an "unexpected finding" for the researchers, "that women who had not lost their hair reported traumatic experiences because they failed to conform to the stereotypical bald cancer patient and therefore were 'incongruous with our stereotype of what a given type of individual should be' [Goffman 1963]... Where the only evidence of treatment is a missing breast, which is concealed, there may be a risk of being accused of malingering as there is no visible proof of illness or treatment. Consequently they were not afforded the levels of support and sympathy which were reported by women who had revealed their baldness. Therefore it seems that visibility of the stigmatising illness is key to the way that people relate to others, whether this is in a positive or negative way" (Trusson and Pilnick 2017).

1.4. MORAL AMBIVALENCE OF INFORMAL CARERS

The "good death" or "dying well" is viewed as a "social success", and informal care (ie: by family and friends) is "central to the cultural imaginary of a good death" (Broom et al 2016).

Broom et al (2016) argued that informal care of the dying "has been prone to reification as a virtuous social practice", when the reality for carers is quite different. What Gordon et al (1996) described as "valued privately, romanticised publically and largely invisible to society" (quoted in Broom et al 2016).

The expectations that "one's significant others should be present, be involved and care" can put "social pressures on carers to undertake particular activities and roles in order to feel like they are moral beings" (Broom et al 2016 p990). But carers can be left with feelings of shame and guilt when they do not live up to the virtuous aspects of the role.

Broom et al (2016) explored the moral ambiguity of informal caring (duty, gift and virtue versus failure, shame and suffering) in thirty-seven interviews with informal carers of individuals with advanced cancer in a city in Australia.

The key themes from the interviews were summarised as:

i) "Waiting and knowing" - Although it was known that death was coming, the when of it created uncertainty for the carer. For example, a wife said: "... [death] it's been hanging over our heads sort of for two and a half years... the last six months have been the hardest I think because it's coming, it's coming... So it's just there waiting, you're just waiting, waiting, waiting. You’re expecting that it's going to be here soon, anytime you think. You just don’t know" (p992).

"Grounded in the dynamic of waiting versus knowing, stoicism and strength were viewed by participants as finite resources, and only to be performed until the patient's death (and often funeral). For the majority of participants, there was an expectation that they would 'fall in a heap' once death had occurred, and that such stoic behaviours represented a temporary enactment of duty. Stoicism, then, is enacted at least in part to avoid the shame of not caring enough (eg: admitting to thoughts of being 'fed up' with caring). Put differently, the moral ambivalence experienced around waiting versus knowing results from a discordance between the diverse experiences of caring for the dying and dominant cultural scripts around duty and dying well" (Broom et al 2016 p993).

ii) "Duty and regret" - Many respondents talked of their behaviour as "out of duty", or as "pay back" for the care the patient had provided in the past. Added to this was not wanting "to have regrets" for not spending enough time with the dying person.

iii) "Place of care, transitions, and the permissive moral boundary" - Most of the patients had moved into institutions as they became sicker, and there was "a sense of moral failure" for carers. A daughter said: "you feel as though you're abandoning them", while a granddaughter admitted: "I actually felt that I had totally failed him", and a wife responded: "I feel a bit of a rat putting him in" (p997).

iv) "Taboo feelings, hoping for death" - eg: a granddaughter said: "... mine are funny tears. Mine are tears that I'm losing someone but behind it is the sooner [he dies] the better... I've come to terms with my grandfather because it's the best for him and [living] it's not what he wants" (p998).

Broom et al (2016) summed up: "What emerged in this study of carers' diverse accounts of the dying process was a series of tensions between dominant cultural scripts and individual experiences of informal care at the end of life. Tensions around waiting and knowing, loathing and caring, duty and regret, stoicism and release, gift and withdrawal etc, reflected a series of moral and normative struggles for informal carers" (p999).

1.5. ALTERNATIVES TO TECHNOLOGY

Sullivan et al (2017) argued that the desire to treat cancer with the latest drugs and technology may not improve survival rates. For instance, in wealthy countries, more expensive drugs are trialled, but often with limited improvements, such that "the more expensive the drug, the less clinical benefit it seems to give" (Sullivan et al 2017 p325). In poorer countries, technology is often too expensive.

Survival rates vary between countries (eg: by one-third between the best and worst countries in Europe, and by nearly a half in Asia) (Sullivan et al 2017). Health infrastructure is important here, suggested Sullivan et al (2017). For example, at a cancer centre in Texas, nearly 2000 specialist staff see 33 000 patients in a year compared to around 150 specialist staff for 40 000 patients in an equivalent centre in India (Sullivan et al 2017).

Societies also vary in their response to cancer, as in stigma experience by sufferers. For example, the five-year survival rate for breast cancer in Tunisia is low because of its stigma, and fearful of divorce with a cancer diagnosis, women did not seek their husband's permission to seek help (Sullivan et al 2017). Added to this is lack of education.

Sullivan et al (2017) proposed three social, economic and structural factors that could improve cancer survival rates:

i) "Change global mindsets" - "Media hype fuels the perception that new must mean better" (Sullivan et al 2017 p326). This is not always the case.

ii) "Fund human capital and social development" - Many countries need better health infrastructures that includes education of the population, and more healthcare staff before expensive treatments.

iii) "Implement standards and systems of accountability" - Government spending on effective care, and regulation of profit-making players.

1.6. COGNITIVE PROBLEMS

Cancer survivors face the potential problem of cancer-associated cognitive decline (CACD) [6] (eg: problems with attention, concentration, memory, and multi-tasking), particularly during treatment due to factors like nausea, disturbed sleep, and side effects of non-cancer drugs (eg: sedatives) (Ahles and Root 2018). Up to one-third of survivors reported cognitive changes up to twenty years after treatment (Koppelmans et al 2012).

However, it is only a sub-set of survivors who may experience CACD. The risk factors for this group include genetics, age, stress, and socio-economic status (Ahles and Root 2018).

"Cognitive reserve" is also important. This "represents innate and developed cognitive capacity, which is influenced by genetics, education, occupation, lifestyle, cognitively stimulating activities etc" (Ahles and Root 2018 p5.9).

The most common method of data collection is self-reports (eg: half of lymphona patients reported forgetfulness in the six months after treatment; Cull et al 1996). Performance-based measures are more objective. For example, Janelsins et al (2017) compared 580 breast cancer patients and 363 controls on computer-based tests of memory and verbal fluency.

But both methods tend to lack baseline measures (ie: pre-diagnosis or pre-treatment cognitive scores). Prospective studies, however, begin with healthy individuals and follow them over time to see who becomes ill. Such studies have found cognitive problems pre-treatment and even pre-diagnosis in some breast and colon cancer patients (Ahles and Root 2018).

In terms of neuroimaging studies, structural changes in the brain (eg: reduced dorsolateral prefrontal cortex volume) and reduced cortical activation have been observed. On the other hand, greater prefrontal activity has been reported as compensation (Ahles and Root 2018).

1.7. LIFESTYLE MODIFICATIONS

Hamer and Warner (2017) reviewed lifestyle changes that benefit women undergoing standard breast cancer treatments:

i) Weight - Gaining weight during or after treatment, or being overweight/obese at the time of

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[6] Or cancer-related cognitive impairment (CRCI) (Janelsins et al 2017).

diagnosis are a higher risk for breast cancer-related death. For example, a weight gain of more than 10% of body weight before treatment, or a body mass index (BMI) of 25 or over at diagnosis increased the mortality risk.

However, there is "not yet a clear answer regarding the effect of weight loss, or prevention of weight gain, on the prognosis of patients with breast cancer" (Hamer and Warner 2017 pE269).

ii) Exercise - Physical activity (eg: 150 minutes per week) significantly reduced mortality after diagnosis for most women.

iii) Diet - High-fat intake may increase mortality risk, but a low-fat diet many not reduce the risk.

iv) Smoking - Cessation after diagnosis is generally beneficial to the women.

v) Alcohol consumption - "Overall, the results are inconclusive. Nonetheless, limiting alcohol consumption to one or fewer drinks per day is a worthwhile goal to reduce the risk of a second primary breast cancer" (Hamer and Warner 2017 pE271).

vi) Vitamin supplementation - Limited evidence for reducing mortality risk, but may be beneficial for general health in certain women.

1.8. RECENT STUDIES ON DIFFERENT CANCERS

Alcohol and tobacco smoking individually are well-established risks for oesophageal cancer (OC), but hot tea less so (Yu et al 2018). But Yu et al (2018) showed an increased risk for a combination of these factors in a study in China.

Participants were aged 30-79 years old, and were enrolled between 2004 and 2008 (baseline) in ten regions of China as part of the China Kadoorie Biobank (CKB) cohort. Over 450 000 individuals were included in the study.

Data were collected at baseline on frequency of tea drinking, type of tea, and quantity per cup, on frequency of tobacco smoking, and on frequency, amount and type of alcohol consumption. There were 1731 documented cases of OC by 2015.

The cancer risk was increased with more frequent, and, particularly, hotter tea [7], and this was exacerbated for current smokers and individuals who drank more than

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[7] The tea consumed was without milk, which would lower the temperature.

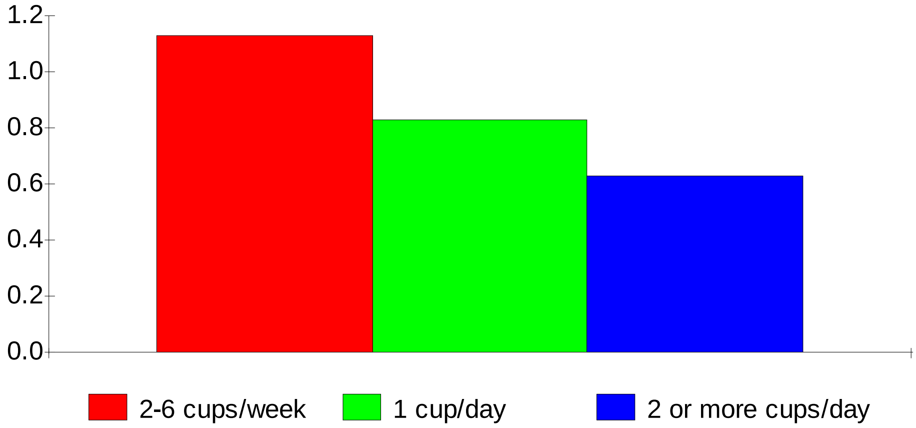
15 g of alcohol per day. The risk was five times greater with the three habits compared to none of them.

The authors offered a "biologically plausible" explanation for the findings: "Research has suggested that thermal injury may damage the epithelium and impair barrier function, subsequently augmenting the risk for damage from other risk factors, such as excessive alcohol consumption and smoking. The release of N-nitroso compounds, which are formed as a result of inflammatory processes associated with chronic thermal irritation of the oesophageal mucosa, also may contribute to oesophageal cancer development" (Yu et al 2018 pp494-495).

The study used self-reported measures, and did not distinguish between OC sub-types, but the sample was large. However, few women in the cohort smoked and drank alcohol, so the findings are best applied to men. This was a prospective cohort study.

On the other hand, Geybels et al (2013a) found that tea consumption reduced the risk of prostate cancer with data from Washington State, USA. Tea and coffee consumption for the previous two years was compared for 892 cancer cases and 863 controls.

Comparing the highest tea drinkers (2 or more cups per day) and the least (1 cup or less per week), the former group had a one-third less risk for prostate cancer (figure 1.1). There was no association for coffee consumption.



(Data from Geybels et al 2013a table 2)

Figure 1.1 - Odds ratio of prostate cancer based on tea consumption (where 1 = 1 cup or less per week).

These findings support those of the Netherlands Cohort Study (Geybels et al 2013b), for example. However, a meta-analysis of eleven studies did not find the same association (Zheng et al 2011).

Microbes in the human body can influence the efficacy of cancer therapies (eg: gecitabine metabolised into an inactive form) (Geller et al 2017).

1.8.1. E-Cigarettes

E-cigarette smoke (ECS) is seen as safer than conventional cigarettes because of the lack of more than 7000 carcinogenic incomplete combustion byproducts of tobacco smoke. "However, the question as to whether ECS is as harmful as TS, particularly with regard to carcinogenicity, remains a serious public health issue that deserves careful examination" (Lee et al 2018 pE1560).

Lee et al (2018) reported DNA damage in the lungs, bladder and heart of ten mice exposed to ECS three hours per day, five days per week for 12 weeks. E-cigarettes deliver nicotine dissolved in "relatively harmless organic solvents", but a small portion of the inhaled nicotine is metabolised into nitrosamines and these can induce tumours. Further metabolisation of nitrosamines can produce the DNA damage (Lee et al 2018).

The question is how applicable is the e-cigarette smoking in this experiment to that of humans in everyday life (appendix 1C).

Miyashita et al (2018) reported that e-cigarette vapour may increase airway infections and enhance that environment for the bacterial infection [8]. This has already been established with cigarette smoking (eg: four times more likely to have invasive pneumococcal disease than non-smokers; Nuorti et al 2000).

E-cigarette vapour impairs pulmonary bacterial host defences and delays the clearance of pneumococci from the lung (Miyashita et al 2018).

1.9. APPENDIX 1A - RARE DISEASES

Individuals who experience "rare diseases" have been called "health orphans" (Wolf 2004 quoted in Duysens 2018). "Moreover, beyond this low prevalence rate, rare diseases are commonly defined by some situations, lived experiences, and problems often faced by patients and their relatives: delay or lack of access to correct

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[8] Miyashita et al (2018) collected e-cigarette vapour from eleven vaping adult males, and the exhalation of six control males.

diagnosis, lack of scientific knowledge on the disease, lack of quality information, lack of appropriate healthcare, difficulties and inequalities in access to treatment and care, heavy social consequences, or even lack of focused political awareness" (Duysens 2018 p3).

Huyard (2009) proposed that the rare diseases category is "boundary object" (Leigh Star and Griesemer 1989) - ie: an object "that contributes to the co-ordination of different social worlds, combining both a blurred meaning in its common use and a specific meaning in its local use" (Huyard 2009 quoted in Duysen 2018). The different social worlds include the patients and their families, doctors, pharmaceutical companies, and public health bodies (Duysens 2018).

The use of the term "boundary object" highlights "the existence of different social worlds around the rare diseases object, the contradictions and lack of consensus between the motivations of these stakeholders groups, their attempts at coordination in order to facilitate the communicability despite their heterogeneity in regards to some issues they all address, and finally the contours and the role of the whole infrastructure, that is 'the rare diseases community' according to the expression commonly used in the field" (Duysens 2018 p5).

1.10. APPENDIX 1B - LIVING WITH PAIN

Bryant (2007) defined pain in medicine as "felt when a stimulus, usually mechanical, thermal or chemical, is strong enough to exceed patients' normal pain threshold" (p6).

"Pain is an essential sense that has evolved in all complex organisms to minimise tissue and cellular damage, and hence prolong survival. The onset of pain results in the adoption of behaviours that both remove the organism from a 'dangerous environment' and allow for tissue repair; for example, resting a broken limb so that new bone can form. Pain also protects us from our environment, by teaching us what situations and behaviours are likely to lead to injury. Pain pathways operate at numerous levels in the nervous system and are under both voluntary and involuntary control" (Cox et al 2006 p894).

The traditional theories of pain include (Curtis 1999):

i) Specificity theories - Based on Descartes' ideas in the seventeenth century, it is believed that there is a special system of nerves that carries only messages from the skin's pain receptors to the pain centre in the brain. So, there is a direct relationship between the physiology of pain and the experience of it.

This ignores the fact that the experience of pain changes with psychological factors, while subsequent research has shown that nerves respond to other sensations that just pain.

ii) Pattern theories - Stimulation of receptors in the skin produces nerve impulses to the brain, and a particular pattern/type of stimulation produces the experience of pain.

The best known version of these theories is the gate control theory (Melzack and Wall 1965), which includes biological, psychological, and social factors in the experience of pain. A "gate" that allows nerve impulses to reach the brain as pain can be varied by psychological and social factors. In other words, the same physiological pain response can be experience differently depending on the situation.

Anxiety, for example, is a key psychological factor in the experience of pain, particularly in hospital (Bryant 2007). Byrne (1997) noted factors like not knowing what will happen, uncertainty about diagnosis, and undergoing uncomfortable procedures as relevant factors here.

1.10.1. Too Much

Chronic pain, like low back pain and osteoarthritis, is common. But how common?

Fayaz et al (2016) set out to answer this question for the UK with a meta-analysis. Chronic pain was defined as "pain in one or more body locations, lasting for a period of three months or longer", and nineteen relevant studies (up to 31st May 2015) were found. The mean prevalence rate was 43.5% of a total of 139 933 respondents. If this finding is generalised, this is estimated to be around 28 million individuals in the UK. This compares to estimates of 40% in the USA by the Institute of Medicine, and 37% in developed countries and 41% in developing countries according to the World Health Organisation (Fayaz et al 2016).

Fayaz et al (2016) found that chronic pain prevalence increased with age, from 14% of young adults (18-25 years old) to 62% of over 75s. There were also gender differences: females (37-52%) and males (31-49%).

The prevalence rates were also higher for newer studies - ie: 45% (studies published after 2010) vs 41% (20th century studies). Prevalence was higher in Scotland than South-East England, for instance (47% vs 44%).

Using the diary method, Broom et al (2015) explored the experiences of women in their 60s in Australia with chronic back pain.

The "sick role" (Parsons 1951) is presented as temporary, and society "accepts" individuals within this, "dependent on a discrete diagnosis, identifiable organic pathology and time-to-wellness social expectations" (Broom et al 2015 p713). But the "intractability and perpetuality of much chronic illness eluded such opportunities for legitimacy (either external or internalised), positioning sufferers in a highly liminal and often stigmatised illness space... These disruptive relations of illegitimacy, in the context of chronic illness, have often been accompanied by similarly normative notions of individual deservedness (of care) and responsibility (for achieving wellness)" (Broom et al 2015 p713).

Concentrating on the lived experience of sufferers of chronic back pain within this social context, Broom et al (2015) recruited volunteers aged 61-66 years old from the Australian Longitudinal Study on Women's Health. Seventeen volunteers completed the one-month daily diary-keeping.

The researchers' analysis of the diaries produced the following themes:

i) "Disrupted lives and social relationships" - The women were involved in dilemmas "situated around the extent to which they should 'let their back pain dominate' or 'give in' in terms of their daily routines, lives and their relationships" (Broom et al 2015 p719). This permeated all aspects of the women's personal and social lives, varying from avoiding social events to difficulties doing everyday tasks.

For example, "Participant 9" wrote: "Day 1: I washed and detailed my car. I know my back will pay for it later but I still need to be able to do these things for my own satisfaction. Day 2: My thoughts are always 'I know these activities bother my back' but what life will I have if I don't go out and interact with family and friends?" (p720).

ii) "Perpetuality and dilemmas around revealing suffering" - The suffering was "intimately connected to the cultural reception of chronic pain" (Broom et al 2015 p721), particularly in how much to tell others. For example, "Participant 2" wrote: "On a few occasions today I have deliberately not talked about my pain or general state of health. Sometimes it's better not to tell people how bad you feel" (p721).

Similarly, "Participant 5" wrote: "Spoke on phone with a friend tonight who asked about my health and treatment (very supportive). I still made light of it though but having someone to talk to is very helpful" (p722).

iii) "Entrapment, withdrawal and invisibility" -

"The perpetuality of their back pain was interpreted by these women as a form of gradual but persistent entrapment. In some respects this was physical (ie: being trapped in a dysfunctional, painful body) but crucially it was also emotional and social in character" (Broom et al 2015 p723) (ie: constant, ceaseless pain).

For example: "Physically feel weak. Emotionally or spiritually very sad as I feel housebound... I am feeling upset as I have a lot to do. Not much for anybody else but it takes me so long and when pain bad it takes longer" ("Participant 6") (p723).

iv) "'Others have it worse': On guilt and being a fraud" - The women were concerned with "feeling guilty for 'bothering people with it'" or that it "not being serious"(eg: "I don't have real problems like cancer", wrote one woman).

While another writer summed up another fear: "I always feel like a fraud". "The fraud or imposter narrative in relation to their own pain – and associated guilt for drawing attention to it – in turn tended to prompt depression or low mood. For at least one of the participants, this then led to questioning the legitimacy of taking antidepressants for 'my minor problem'. In this sense, layers of stigma and illegitimacy can be seen in the women's dairies, as they subtly undermined – and felt undermined by – their illness experiences, often internalising an identity as 'better off than others'" (Broom et al 2015 p724).

v) "Families and the 'relative' aspects of pain" - The women experienced their pain within a gendered context - ie: as women with the social expectations of caring for their husbands/families. For example, "Participant 15" wrote as much about her concerns over her husband's health problems as her pain in parts of the diary.

Overall, this study highlighted how the experience of pain was embedded in social relationships, social context and expectations. So negative emotions, Broom et al (2015) wrote, like "indignity, shame, guilt and suffering threaten to push these (and other) women underground in terms of their experiences of chronic illness and pain. Often unwilling to accept chronic illness as their pervasive identity, and despite often being overwhelmed by pain at points, they often wrote about opting for silence. Removing expressions of, and attempts at recognition, from social interaction solved the potential stigma of being outed as 'fraud' or 'imposter', but perpetuated their isolation and suffering" (p728).

The assessment of the level of pain is difficult generally for medical professionals, but even more so in cases of individuals with little or no language, as in children. Specialist measures have been developed for such situations, including (Atkinson et al 2009):

- Faces, legs, activity, cry and consolability (FLACC) (Merkel et al 1997) - For use with non-verbal children, and the physician observes the behaviour of the child (eg: facial expression, leg position, presence of crying).

- Wong Baker faces (Wong and Baker 1988) - Five line drawings of faces showing emotions like happy or crying, for use with pre-school children.

1.10.2. Too Little

Cox et al (2006) reported the case study of seven individuals from northern Pakistan, who otherwise healthy had inherited a condition involving the complete inability to sense pain. This is a rare condition, originally called "congenital general pure analgesia" (Dearborn 1932), but later "congenital indifference to pain", "autosomal recessive congenital analgesia", or "congenital insensitivity to pain" (though these are all now seen as slightly different conditions) (Cox et al 2006).

Cox et al (2006) preferred "channelopathy-associated insensitivity to pain" for their cases, "in whom all other sensory modalities were preserved and the peripheral and central nervous systems were apparently otherwise intact" (p894).

The index case was a ten year-old boy who performed "street theatre" involving putting knives through his arms, and walking in burning coals without pain. He died at age 14, jumping off a house roof. Six affected genetically-related individuals were found in three families. Cox et al (2006) described them: "All six affected individuals had never felt any pain, at any time, in any part of their body. Even as babies they had shown no evidence of pain appreciation. None knew what pain felt like, although the older individuals realised what actions should elicit pain (including acting as if in pain after football tackles). All had injuries to their lips (some requiring later plastic surgery) and/or tongue (with loss of the distal third in two cases), caused by biting themselves in the first 4 yr of life. All had frequent bruises and cuts, and most had suffered fractures or osteomyelitis, which were only diagnosed in retrospect because of painless limping or lack of use of a limb" (p894).

The gene involved (SCN9A) mutates to produce no pain sensation at one end, and too much pain at the other (Dobbs 2007). Erythromelalgia (or "burning man syndrome") involves "searing heat in the feet and lower legs and sometimes in the hands" (Dobbs 2007). It is an inherited condition that afflicts only a few people worldwide, and is caused by defective sodium channels in pain-sensing neurons due to the SCN9A mutation, which means they are "too quick to open and too slow to close" (Dobbs 2007).

1.11. APPENDIX 1C - MOUSE MODELS

Cancer research depends on models that mirror human tissue biology, like cultured cells, and animal studies.

Ben-David et al (2017) raised concerns about the use of patient-derived xenografts (PDXs) and mice. These are human tumours that are transplanted into mice to see how they develop, and/or respond to drugs. The genetic instability of PDXs meant that they changed in the mice in ways different to in humans, which has implications for the applicability of mouse models to humans.

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2. INJURY CULTURE

2.1. INJURY CULTURE

"Patient safety" or "iatrogenic injury" (ie: "injuries caused by medical management as opposed to the patient's underlying disease process"; Mello et al 2005 quoted in Ocloo 2010) is a growing concern in healthcare (eg: medical harm in hospital). Estimates for the UK suggest that around one-tenth of hospital admissions end in patient safety incidents, while as many as 100 000 death per year in hospital in the USA could be the result of preventable medical errors (Ocloo 2010).

The response to such figures is the development of a "safety culture", particularly a "blame-free culture when harm occurs" (Ocloo 2010). Marx (2001) proposed a distinction between "recklessness" ("conscious disregard of substantial and unjustifiable risk") and "intentional rule violation" (ie: blameworthy) from "human error" and "negligence".

Jain (2006) explored "deep-seated anxieties about the body, technology, consumption, agency, and injury" in a book about litigation in the USA after injury. Going beyond the legal text, it is possible to see "how physical injuries are made material (made to count), how they circulate, and how their distribution creates the material conditions of everyday life" (Jain 2006 p2).

An "injury culture" is linked to two powerful discourses - the "small guy" versus the "vast corporation", and the "valid" versus the "frivolous" claim (Jain 2006).

Emile Durkheim (1897/1951), writing about suicide, described a paradox (subsequently called the "Durkheimian paradox" [9]) - "although we cannot know in advance how many people will commit suicide each year, we can predict with tremendous accuracy that several thousand people will" (Jain 2006 p7). Jain (2006) applied the idea and accidents and injuries, observing that "if we understand human wounding to be a central feature of capitalism, the

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[9] There is another paradox in relation to cigarettes with "free will" and compulsion - "the powers of our 'free will' are always already vitiated by the 'truth' of compulsion, while the powers attaching to an acknowledged compulsion are always already vitiated by the 'truth' of our free will" (Sedgwick 1992 quoted in Jain 2006).

'accident' or 'side effect' lens of injury laws affects how suffering is both distributed and made legible" (p8).

But injury law struggles with such possibilities - as "plaintiffs' lawyers tend not to believe in accidents or acts of god — they locate the person who made a decision to save some money and make the tunnel too narrow, resulting in a client’s paralysis; or someone (or an institution) who decided not to warn about or add a colouring to a poisonous gas, resulting in a client's chronic asthma; or someone who carelessly replaced a brake pad, resulting in a fatal car accident. The plaintiff's job is to show precisely how messages of danger 'should' have been encoded into products and how the consequences of materialised decisions were visited on specific, real people and not statistical futures. In other words, the various theorisations of personal injury law offer different moral codings of how agency in design will be determined and accepted" (Jain 2006 p10).

On the other side, plaintiffs may have "impure" motives for their court actions (eg: profit; fame) as Francois Ewald (1991) noted: "The fact that bodily damage can... be transformed into a cash price may lead an insured person to speculate on his or her pain, injury, disease or death, so as to extract the maximum profit from them" (quoted in Jain 2006).

2.1.1. Harming the Self

Individuals with type 1 diabetes have a high risk of an eating disorder (ED) because "these patients have to select the food they eat carefully in an early period of their development and because both entities, type 1 diabetes and ED, often affect adolescents and young adults" (Larranaga et al 2011 p190). For example, among 143 adolescents with type 1 diabetes on the Assessing Health and Eating among Adolescents with Diabetes survey, over one-third of females and one-sixth of males admitted to unhealthy weight control practices (including skipping insulin injections or taking less to control weight) (Neumark-Sztainer et al 2002).

Rydell et al (1997) found that 14% of 91 12-18 year-old female diabetics deliberately omitted insulin (when asked at the beginning of the study), but over 30% did so when questioned four years later. Altogether, it is estimated that 30-40% of adolescents and young adults with type 1 diabetes skip insulin injections after meals as a strategy to lose weight (Larranaga et al 2011) [10].

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[10] "Reducing insulin to lose weight increases the risk of dehydration, break down of muscle tissue and high risk of developing infections and fatigue. If this behaviour continues, it may also result in kidney failure, eye disease leading to blindness, vascular disease and even death" (Larranaga et al 2011 p191).

2.2. SPOTTING DISEASE

"The detection of sick individuals has been proposed to serve as a first line of defence allowing individuals to avoid being contaminated by sick peers. The central premise of disease avoidance is that infections pose a major threat to individuals, and that humankind and other animals, through evolution, have developed an ability to limit contagion by avoiding potentially sick peers" (Axelsson et al 2018 p1).

Many animals use smell to detect sick conspecifics, even possibly humans (eg: less "healthy" body odour; Olsson et al 2014). More commonly, humans use facial cues, including lighter or less red skin (Axelsson et al 2018).

For example, in an online experiment, Tskhay et al (2016) found that viewers could detect individuals with HIV on a dating website at above chance levels. But the photographs were self-selected, and noting that "dating sites are affected by deceptive self-presentations, and some of the subjects classified as healthy may actually have been sick, these results may not be generalisable" (Axelsson et al 2018 pp1-2).

Axelsson et al (2018) tried a more controlled experiment. Twenty-one health volunteers' faces were photographed before and after an injection of a bacterial stimulus inducing an immune response. Then sixty-two naive participants from Sweden were shown 32 photographs (half before the injection), and asked, "is this person sick or healthy?". The raters could identify thirteen of the sixteen faces as being sick better than chance (50%).

Another sixty naive participants were asked about the characteristics that distinguished the sick faces. Pale skin and lips were key, followed by more hanging eyelids, more swollen face, droopier corners of the mouth, and redder eyes. Altogether, these are signs of looking tired.

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3. EUTICALS

3.1. "ELECTROCEUTICALS"

Vagus-nerve stimulation (VNS) involves an implanted device emitting tiny electrical signals to stimulate the vagus nerve that runs from the brainstem to major organs in the body. It was initially tried in the 1990s to treat epilepsy, and then in the 21st century with depression (Fox 2017) [11].

"Electroceuticals" (a name for devices that stimulate nerves) are being considered for wider use (eg: autoimmune diseases) after work with rats (eg: Borovikova et al 2000) [12]. "These experiments seemed to show that when the vagus is zapped with electricity, a signal pulses down it to the abdomen, and then through a second nerve into the spleen" (Fox 2017 p21). The spleen plays an important role in the immune system. The upshot is that autoimmune diseases (where the immune system is causing the damage to the body) can be suppressed.

Koopman et al (2016) reported improvements in rheumatoid arthritis in twelve individuals over six weeks with VNS, while five of seven individuals with Crohn's disease had benefits over six months (Bonaz et al 2015).

But Constantini et al (2015) found that the human genome has key differences to that of the rat, which means that some humans do not respond to VNS for immune system suppression (Fox 2017).

3.2. ELASTRONICS

The "bodyNET" (Yang 2006) is "a network of sensors, screens and smart devices woven into our clothing, worn on our skin and implanted in our bodies" (Chu et al 2017 p328), like a pregnant woman wearing a tiny sensor to

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[11] Work by Angela Sirigu and team, which stimulated the vagus nerve, produced a small reaction (eg: track object with eyes) in 35 year-old man who had been in a vegetative state for fifteen years (Devlin 2017).

[12] Tracey (2015) used the term "bioelectronic medicine" to describe nerve-stimulating electric devices to reduce inflammation. Such stimulation reduces the inflammatory reflex, which is the basis on conditions like rheumatoid arthritis (Tracey 2002).

monitor the heart rate of the foetus.

The bodyNet is based on "elastronics" - electronics that stretch "made from soft plastic circuits thinner than paper that can deform without tearing, biograde and even heal themselves" (Chu et al 2017 p328).

Chu et al (2017) highlighted eight technical and five cultural challenges for elastronics. The former relate to the manufacture of the devices, while the latter include:

- Making the data collected useful - Just producing raw data about the body will only be useful if translated into alerts, say (eg: increasing skin temperature = sign of heat stroke).

- Concerns about body modification.

- Data security.

3.3. PHARMACEUTICALS

Gerattini (2017) noted that "the law currently states that new drugs should be approved on the basis of their quality, safety and efficacy, and although these are all important considerations, they do not take into account what the public actually expects of new drugs: that they should improve on the old ones. In fact, simply adding the three words 'therapeutic value added' to the current legislation would be enough to show up most of the 40 drugs currently available" (pviii).

Giraldi (2017) developed this argument about the influence of the pharmaceutical industry with anti-depressants and depression. "More SSRI [selective serotonin uptake inhibitor] anti-depressants are being prescribed partly because of pressure from the pharmaceutical industry, and partly because of the procedures for authorising the marketing of new anti-depressants. New drugs can now be authorised by providing results from a limited number of clinical trials sponsored and effectively conducted by pharmaceutical companies. Pharmaceutical companies do not even have to publish all their results: they can keep them secret and simply choose the studies they want published. In fact, all studies need to show is that a new compound causes a modest reduction on the psychometric scale compared to placebos. It is not necessary to show they are more or even equally as effective as the drugs already on the market. New drugs are therefore authorised for market on the basis of only modest clinical efficacy" (Giraldi 2017 p168).

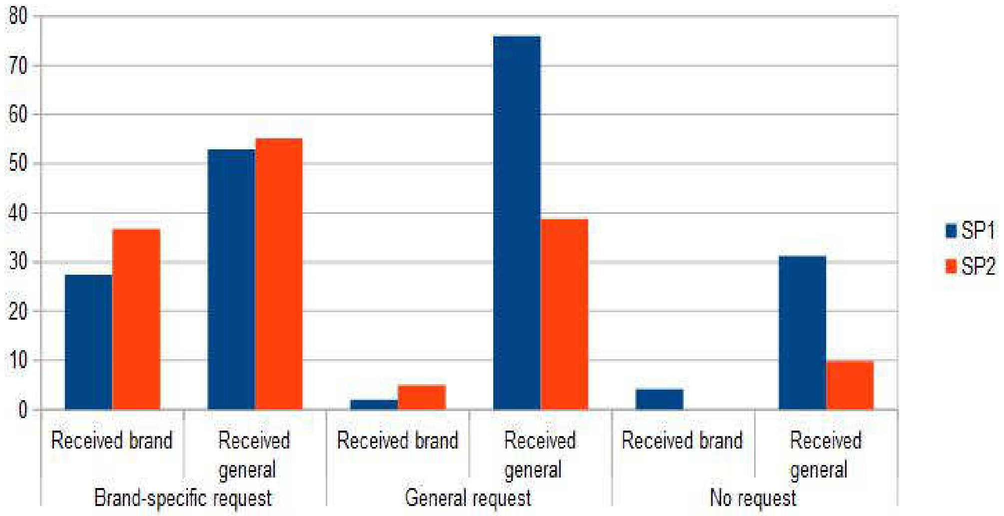
Why should electroceuticals (or any new treatment) be different when private companies are involved, and there is money to be made?

In the USA, direct-to-consumer (DTC) advertising of pharmaceuticals can lead to "over-prescribing of unnecessary, expensive, and potentially harmful medications" (Kravitz et al 2005). Anti-depressant medication is the most DTC advertised drug (Kravitz et al 2005).

Kravitz et al (2005) assessed the response of doctors to patients' requests for medication by actors playing "standardised patients" (SPs). SP1 was a middle-aged woman who presented as feeling "kind of down" and showed the symptoms of major depression, while SP2 was a woman of the same age portraying adjustment disorder (eg: insomnia, depressed mood). Participants were given training for their role. The two SPs made one of three requests of the doctor - for a brand-specific anti-depressant ("I saw this ad on TV the other night. It was about Paxil..."), for any medication, or no request (control).

Between May 2003 and May 2004, eighteen individuals playing the two SPs made 298 visits to 152 doctors in three US cities.

SP1 was prescribed an anti-depressant in 54% of visits compared to 34% for SP2. The brand-specific request for "Paxil" was accepted in about one-third of cases (figure 3.1).



(Data from Kravitz et al 2005 table 1 p1998)

Figure 3.1 - Percentage of SPs receiving anti-depressants.

SP1s who requested "Paxil" were over twice as likely to get it and thirteen times more likely if SP2 compared to no request. A request for medication generally was answered 6-7 times more often than no request. These were significant differences.

Kravitz et al (2005) observed: "Brand-specific requests had a differentially greater effect in adjustment disorder compared with major depression. This supports the hypothesis that DTC advertising may stimulate prescribing more for questionable than for clear indications" (p2000).

The use of SPs (ie: individuals playing a role) was a clever way to study the effects of DTC, but the external validity of "SP-based research might be threatened if SP roles are unrealistic or extreme, SP portrayals are of poor quality, or physicians 'detect' the presence of an SP and act differently as a result" (Kravitz et al 2005 p2000) [13]. Furthermore, Kravitz et al (2005) admitted, "we cannot determine whether DTC advertising actually produces the kinds of behaviours in real patients that were portrayed by our SPs" (p2001).

3.3.1. Anti-Depressants

There are estimated to be 350 million people in the world affected by depression (Cipriani et al 2018). The main treatment is anti-depressant drugs. Their success is contested.

Cipriani et al (2018) concentrated on anti-depressants (ADs) as acute treatment for adults with unipolar major depressive disorder in their meta-analysis. They found 522 relevant double-blind [14], parallel [15], randomised controlled trials [16] performed between 1979 and 2016, and twenty-one different ADs were involved. In a meta-analysis, the data from different studies is pooled and reanalysed as one sample (n = 116 477 patients).

"Efficacy" was defined as "the total number of patients who had a reduction of ≥50% of the total score on a standardised observer-rating scale for depression", and "acceptability" as "treatment discontinuation measured by the proportion of patients who withdrew for any reason" (Cipriani et al 2018).

All ADs were more effective than the placebo, and overall an odds ratio of 1.15 to 1.55 times more effective (where 1.00 is improvement with the placebo). This is a modest effect size. "Some anti-depressants, such as "escitalopram, mirtazapine, paroxetine, agomelatine, and sertraline had a relatively higher

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[13] After the study, doctors visited were asked if they had been suspicious of any patients - 13% said "definitely" or "probably".

[14] Neither the participant or the administrator of the drug know whether the drug is active or placebo.

[15] The groups receiving the active drug and the placebo are studied at the same time.

[16] The decision as to who receives the drug or the placebo is randomised.

response and lower dropout rate than the other anti-depressants. By contrast, reboxetine, trazodone, and fluvoxamine were associated with generally inferior efficacy and acceptability profiles compared with the other anti-depressants, making them less favourable options" (Cipriani et al 2018 pp1362-1363). In head-to-head studies comparing different ADs, there were few differences between them in terms of efficacy.

Overall, acceptability ranged from odd ratios of 0.64 to 0.83 (where 1.00 is drop-out in the placebo group) (ie: ADs less drop-out than placebos).

Cipriani et al (2018) offered the following points of evaluation:

i) The difference between the AD and the placebo could be reduced by higher placebo response rates, which is influenced by, for example, "the expectation of receiving an active treatment, the therapeutic setting, or the frequency of study visits" (Cipriani et al 2018 p1363).

ii) "Depressive symptoms tend to spontaneously improve over time and this phenomenon contributes to the high percentage of placebo responders in anti-depressant trials" (Cipriani et al 2018 p1363).

iii) "Anti-depressants usually take full effect only after weeks of treatment; therefore, participants who dropped out earlier tend to have poorer responses than those who remain on treatment..." (Cipriani et al 2018 p1363).

These factors could produce an underestimation of the "true efficacy" of the ADs.

The researchers claimed to have included "the largest amount of unpublished data to date", and these data are often less favourable for ADs (and thus why they were not published).

The data varied in quantity and quality between ADs. For example, bupropion studies were rated as low or very low quality. Generally, many studies were poor in reporting details of randomisation (Cipriani et al 2018).

Furthermore, individuals recruited for clinical trials tend to highly selected (eg: exclusion of psychotic or treatment-resistant depression) (Cipriani et al 2018).

Discontinuation Withdrawal

In "The Times" on the 24th February 2018, Wendy Burns (President of the Royal College of Psychiatrists) and Daniel Baldwin (Chair of Psychopharmacology Committee of the Royal College of Psychiatrists) stated that "in the vast majority of patients, any unpleasant symptoms experienced on discontinuing anti-depressants have resolved within two weeks of stopping treatment" (quoted in Read et al 2018).

Read et al (2018) believed that this statement (in an official capacity) is "not evidence-based, is incorrect and has misled the public on the important matter of public safety".

Fava et al's (2015) review, for example, of fifteen randomised controlled trials, four open trials, four retrospective investigations, and 38 case reports suggested that withdrawal symptoms lasted a few weeks, even up to a year.

Read et al (2018) reported a recent study that found that one-third of over 700 individuals surveyed by a British mental health charity took at least three months to withdraw from anti-depressants, and one-sixth took at least six months.

3.3.2. "Alternative" Treatments

Singing

Singing can be beneficial to physical and mental health. Fancourt and Perkins (2018) concentrated on the benefits for women with post-natal depression with a study of 134 individuals in the London area.

The women were randomised to one of three groups for a ten-week period:

- Group singing workshops learning and singing songs with their babies.
- Creative play workshops with their babies.
- Control.

Measures of post-natal depression (using the Edinburgh Post-Natal Depression Scale; EPDS; Cox et al 1987) were taken at baseline, and at weeks 6 and 10 of the study. All the women showed an improvement over time, but the singing group had a significantly faster improvement than the control group.

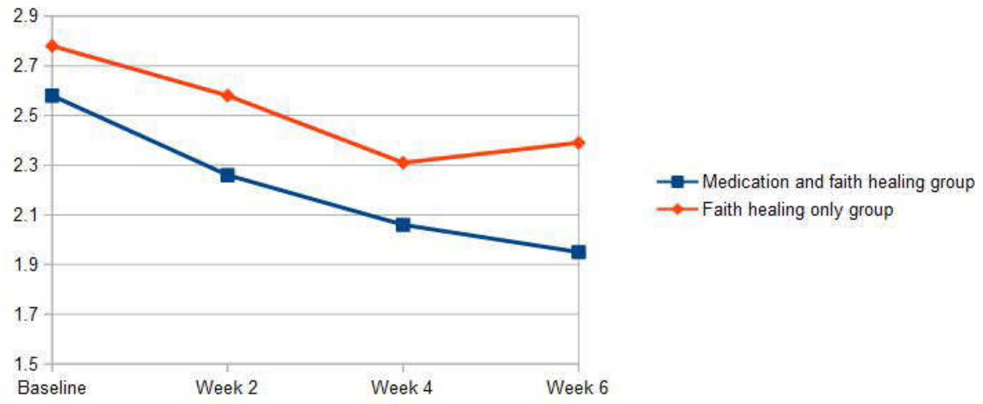
Medicine and Prayer

Low-income countries lack professional mental health staff (eg: Ghana, with a population of 25 million people, has 25 psychiatrists, 30 clinical psychologists, and 900 psychiatric nurses; Ofori-Atta et al 2018).

Consequently, faith-based healing centres are commonly used, particularly where mental illness is seen as having a supernatural or spiritual cause.

Ofori-Atta et al (2018) looked at the combination of psychiatric care and faith healing at the Mount Horeb (Evangelical Pentecostal) prayer camp near Accra in Ghana. During the six-week study, 57 randomised participants received psychotropic medication as well as faith healing, and they were compared with 53 individuals (as controls) who received faith healing only (prayer, Bible study, and fasting) [17].

The medication group had significantly lower mental illness symptom scores (as measured by the Brief Psychiatric Rating Scale; BPRS; Overall and Gorham 1962) at week 6 than the controls (mean: 1.95 vs 2.39) (figure 3.2).



(Data from Ofori-Atta et al 2018 table 3 p39)

Figure 3.2 - Mean number of symptoms.

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4. MAKING SENSE OF ANTI-BIOTICS

4.1. PRESCRIBING ANTI-BIOTICS

The concern over anti-biotic resistance has grown in recent years with the emergence of "resistant superbugs" [18], and "the prospect of an 'anti-microbial perfect storm' in the next few decades" (Broom et al 2014 p81) [19].

One response in many hospitals is to restrict anti-biotic prescribing. But "sub-optimal prescribing" is hard to change - ie: inappropriate choice of anti-biotic, route of administration, and/or duration of dosage. For example, 40% of Australian hospital inpatients received anti-biotics, and half of these were sub-optimal (Broom et al 2014).

Why are doctors choosing sub-optimal prescribing? Broom et al (2014) provided an answer based in the "social relations of medicine". Sub-optimal prescribing, for them, is "a logical choice within the habitus of the social world of the hospital. That is, the rules of the game within the field [20] are heavily weighted in favour of the management of immediate clinical risks, reputation and concordance with peer practice vis-a-vis longer-term population consequences. Anti-microbial resistance is thus a principal of limited significance in the hospital" (Broom et al 2014 p81).

Broom et al's (2014) view of prescribing is based on

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[18] Resistance has also occurred in relation to other medications - eg: head lice (appendix 4A).

[19] "It is anticipated that within decades, our currently available anti-microbial agents will no longer have potency, and multi-resistant organisms will offer a greater threat to humanity than cancer. Although anti-microbial resistance is an entirely normal evolutionary process, it is currently being dramatically accelerated by prolific overuse of antimicrobial agents in livestock, communitycare, and in hospitals" (Broom et al 2017 p1).

[20] "Habitus" and "field" are ideas from Bourdieu's (eg: 1990) theory of practice. Medicine is a "field" with its "rules" (ie: informal practices as well as formal rules), and "habitus" is a set of "dispositions which a social actor acquires through processes of socialisation, providing a mechanism for highlighting the generative principles of action or practice... Habitus is both an individual embodied reality and an organising principle, describing the ways by which the external (social) is internalised resulting in collective patterns of thinking and doing, without necessarily rational or conscious reasoning..." (Broom et al 2014 pp82-83).

Bourdieu also used the idea of "social capital", which is "associated with status, professional relationships, experience and reputation within the hospital..." (Broom et al 2014 p83).

their thirty interviews with doctors at a hospital in Queensland, Australia, in 2013. The researchers highlighted the following themes from their analysis of the transcripts:

i) "Everyday sensitivity toward resistance" - Concern about anti-biotic resistance was "theoretically important", but "of limited concern vis-a-vis other day-to-day issues" (ie: "down the list of considerations"; female oncologist) (Broom et al 2014 p84).

ii) "Risk, fear and uncertainty" - Doctors were more concerned about "fear of relapse", "not making a mistake", and "not missing something", which led to "over-treatment". One male emergency medicine consultant said: "I'm aware that I don't want to be criticised for being either a cowboy or too cautious [in prescribing]. So, I want to do what is recognised as the standard of care" (p84).

iii) "Time, pressure and uncertainty" - Time pressures meant prescribing was an "easy" option. As a female oncologist admitted: "... sometimes you're busy... you've kind of heard half the story and you haven't fully done everything yourself, and it sounds like good going infection... [so you prescribe]" (p85).

iv) "Benevolence and emotional prerogative" - The focus of the doctors was the patient now. This is seen in a male respiratory medicine doctor's comment: "[My concern is] someone who's going to die in the next hour, or someone who's bleeding to death, or someone who's had a major pulmonary embolus. So antibiotic prescribing I think isn't viewed in the same light... we worry about this patient, and we don't have the big picture, so we don't worry as much about what's happening in the community, about resistance patterns, about community-wide use of antibiotics..." (p86).

v) "Habitus and the internalisation of peer practice norms" - eg: "Oh I think [antibiotics prescribing is] peer-related practice, it's habit, and you learn from your peers, and presume there's a leadership issue, but our behaviours are heavily influenced by what we see, and people do around us, and by [the] modelling [of] others..." (male consultant paediatrician; p86).

vi) "Hierarchies and the localisation of anti-biotic prescribing" - Prescribing practice was a product of "organisational and professional cultures", and hierarchy was important in that. A female oncologist summed up the uncertainty here: "In terms of challenging them [consultants], as a junior doctor you're also not so confident with your own knowledge, and you have to look a lot of things up. So having the confidence in my own knowledge, to kind of say something to someone who is more senior than me - I probably wouldn't, unless I thought that - unless I knew, or thought that it would negatively impact the patient, or something like that" (p87).

So, altogether, Broom et al (2014) concluded that, "it is clear that decisions around antibiotics are (at least in this context) governed less by stewardship initiatives, therapeutic guidelines and other techniques of bureaucratic routinisation, than by what constitutes appropriate behaviour within professional hierarchies, and the securing of professional reputation" (p87).

Broom et al (2017) developed this work with an interest in "the significance and potency of such things as ritual and drama, etiquette and manners, and obligation and responsibility in the hospital" (p2).

a) Ritual and drama - simplistically, certain behaviours that are performed because they have always been done, like "a cricketer refusing to change her winning gloves, ritualised behaviour in medicine might be superstitious, involving repeating acts which result in positive outcomes, and might be simple or elaborate. Ritualised acts in medicine might emerge from particular historical situations for an individual or community of clinicians (eg: loss/cure of an individual patient), or due to the security they provide a clinician within a particularly risky therapeutic atmosphere and their association (intuitively) with successes across one's professional life" (Broom et al 2017 p2).

b) Etiquette and manners - "Etiquette, or the manners of medicine, articulate the principles of care, responsibility and duty, and the limits of an Other to intervene in an exchange between carer and cared-for. Etiquette also allows ritual, and enables the seemingly irrational or illogical act to occur without necessarily being questioned" (Broom et al 2017 p3).

c) Obligation and responsibility - eg: "Anti-biotic practices..., articulate dilemmas around new forms of responsibilisation within medicine (eg: enhanced litigation, greater pressure on doctors to avoid adverse events, desire for juniors to pass on overall responsibility) and are complicit in forms of (anti-microbial-driven) risk reduction and anxiety amelioration" (Broom et al 2017 p3).

Broom et al (2017) explored these social processes in the transcripts of five focus groups of medical professionals in two teaching hospitals in Australia. The analysis was adapted from Charmaz's (1990) approach and revolved around four questions: "What is the basis of a particular experience, action, belief, relationship, or structure? What do these assume implicitly or explicitly about particular subjects and relationships? Of what larger process is this action/belief and so forth a part? What are the implications of such actions/beliefs for particular actors/institutional forms?" (Broom et al 2017 p4).

Four themes were thus distinguished:

i) "'Dirty' medicine, the 'Betadine blessing', and 'Gentamicin fairy dust': Myth, ritual and medical performances" - eg: One surgeon described using an anti-biotic as "part of the cleansing ritual after surgery" (Broom et al 2017): "we would put Betadine in the wound. Whether or not we should do or not do, but we all do it because it's just part of the culture" (p4).

ii) "Judicious anti-biotic use as 'courage under fire', fear and responsibility" - eg: One junior doctor said: "It takes real courage under fire to say, 'No, we're not going to start something', because you've got a family there... I think it’s hard and I think when the odds are like that, like someone's delirious, where they're acutely unwell, it's very hard not to try and treat something" (p6).

iii) "Norms, reputation, and (learning) defensive medicine" - Anti-biotics were used as "defensive medicine", because, for example, "the junior doctors wished to avoid any impression that the patient had (unnecessarily) worsened 'on their watch'" (Broom et al 2017 p7) (as compared to the consultants who prescribed anti-biotics).

iv) "Autonomy, 'medical good manners', and the right to intervene - Doctors did not want to contradict other doctors, as shown by this comment: "I think [changing antibiotics] it's an ethical issue... I will not write on another physician's drug chart unless specifically invited to... it's up to that person whether they take that advice or not" (p8).

Broom et al (2017) summed up: "In seeking to manage the practice of medicine, (many) doctors are therefore opting for the anti-microbial-as-security, to protect themselves and, by extension, to protect their patients and the institution. By deploying this security (of reputation, of surgical track record, of job), however, it/they lose their efficacy. It seems that doctors might feel disempowered or exposed without the armour of anti-biotics, given that this is the norm designed to shield them from the vagaries of medical risks" (p10).

4.2. VIEWS OF LAYPERSONS

Brown and Nettleton (2017) analysed forty-two threads about anti-biotic resistance on "Mumsnet", and distinguished five themes:

i) "Temporal constraints and technological fixes" - Anti-biotics were discussed in the context of "the unstoppable demands of parenting, work and other daily obligations" (Brown and Nettleton 2017) (eg: "... truth is, work is piling up and I have to go on a business trip, so I have got the prescription..." (ID13 [21]) (p308).

ii) "Restorative bodies" - Contributors to the discussion talked of "allowing an illness to 'run its course'", or of "unwarranted expectations of 'instant' recovery" (Brown and Nettleton 2017). For example: "ID18": "Expectations need to change as well. Sometimes you can't get instantly well... I think people do expect to get instantly well. Which is why they take anti-biotics for a virus rather than sitting it out" (p309).

iii) "Spatial othering" - Concerns about anti-biotic resistance were often linked to misuse ("off label use") by others ("'foreign' practices"). For example, "ID6" reported "a particularly annoying au pair from France" who "told me proudly that she had her own supply of anti-biotics in her bedroom and she used than frequently" (p311).

Davis et al (2015) described "an emergent 'immuno-cosmopolitanism' within which infections, vaccines and anti-biotics are embedded in global flows and perturbations. Here, the threat of resistance is frequently presented as an incoming incursion from an alien without, or already within, the body and bodies of the nation" (Brown and Nettleton 2017 p311).

As seen in "ID4's" comment: "This is not an anti-immigration thread... I believe that the UK is richer and better for its tolerance, openness, and diversity... However, has anyone noticed that there are far more varieties of 'bugs' around in recent years? Not necessarily serious but just different... Symptoms just seem to be more varied" (p311).

iv) "Moral accountabilities" - Linked to the previous theme is the attribution of blame to others, including older generations. "'Overuse' or inappropriate prescribing is conceived as the legacy of a passing generational population for whom anti-biotics were ubiquitously available" (Brown and Nettleton 2017 p312).

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[21] Individuals were anonymised with "individual (ID) number".

For example, "ID22" wrote: "An old lady I used to know told me proudly that her GP would write her a prescription for anti-biotics if she just rang 'and not many nowadays will do that'" (p313).

Individuals who were deemed as "demanding" anti-biotics from doctors or illicitly buying them online were criticised as "selfish".

v) "Domestic immunity environments" - Anti-biotics were viewed by some contributors as compromising "natural immunity" - eg: "ID26": "Anti-bacterial cleaners and sterile environments are bad; you need your immune system to be primed, particularly through childhood. Our body is covered in bacteria, and we need them, most are harmless and out-compete other harmful micro-organisms. [...] We need to get sick" (p316).

A "nostalgia" for "productive encounters with 'dirt' and traffic with foreign microbial life" (Davis et al 2015) is another characteristic of "immuno-cosmopolitanism" (Brown and Nettleton 2017).

Altogether, Brown and Nettleton (2017) observed an "immunity moralism" "where decisions and practices relating to anti-biotics resonate with notions of self, other, community and immunity" (p317). The authors noted that official reports that increase fear about anti-biotic resistance as a means to reduce use may, thus, lead to "unintended, stigmatising and socially diverse consequences" - ie: the threat of anti-biotic resistance is "often seen to originate from without (from elderly generations, foreign au-pairs, self-interested patients and brow-beaten practitioners spoiling patients like indulged infants)" (Brown and Nettleton 2017 p318).

4.3. PROMISING ALTERNATIVE?

Community-acquired pneumonia (CAP) is a common infection requiring hospitalisation, particularly in the West and with the elderly, and having an inpatient mortality of one in ten (Chalmers et al 2010) or even one in two with complications (Grudzinska et al 2017). Anti-biotics have been the main treatment since the 1950s, but with the development of anti-biotic resistance, there is the fear that CAP may be untreatable.

In terms of alternative treatments, there is promising interest in statins, which are normally prescribed to reduce cholesterol.

Chalmers et al (2010) found three case-control studies published before 2010 that showed that prior statin use was associated with lower risk of developing CAP, but one study found the opposite. This is the prevention of CAP.

In terms of prior statin use and outcome in individuals hospitalised with CAP, Chalmers et al (2010) found fourteen studies (eleven retrospective, three prospective). Generally, there was reduced mortality for individuals using statins. But these studies were observational, and thus "show association rather than causation and only data from randomised control trials will establish conclusively if statins are effective in preventing or treating CAP" (Chalmers et al 2010 p1088).

There have been randomised controlled trials for statins with sepsis, but no benefits were found. Grudzinska et al (2017) raised methodological concerns with these studies - eg: varying dose of statins; varying age of participants; prior statin use or not.

Returning to observational studies, more recently, Grudzinska et al (2017) reported a significant [22]improvement in survival after hospital admission with CAP with statin use. Their prospective study analysed the data of 2067 patients at a hospital in Birmingham, UK (of whom 633 individuals were taking a statin on admission). Of statin users, 83% survived compared to 76% of non-statin users, but the former had significantly longer hospital stays.

The authors noted: "The mechanism by which statins reduce risk of in-patient death in this cohort remains unclear. Statins influence multiple anti-inflammatory pathways; it may be that stopping statin therapy at a time of hyper-inflammation could cause rebound inflammation and adversely affect patient outcomes. There is also evidence to suggest that statins are able to modulate immune cell function, which could reduce the damaging inflammation associated with organ dysfunction. Alternatively, it is estimated that cardiovascular events account for up to 30% of the mortality associated with CAP, and hence the beneficial effect we have observed could be directly related to the lipid-lowering effects and plaque stabilisation" (Grudzinska et al 2017 p406).

Limitations with this study include (Grudzinska et al 2017):

- Retrospective (which limits the control of

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[22] There is concern that the statistical significant cut-off point of 0.05 may have produced false positives in science, especially because of "p hacking", where "researchers gather data without first creating a hypothesis to test, and then look for patterns in the results that can be reported as statistically significant" (Chawla 2017 p16). For example, in biomedical research published between 1990 and 2015, over 90% of studies were statistically significant at the p<0.05 threshold, but replication rates were much lower (Benjamin et al 2018).

Benjamin et al (2018) argued for a threshold of p 0.005. But this risks increasing false negatives, and the "file-drawer problem" (where non-significant results are not published) (Chawla 2017).

confounders);

- Only cases that sought help;

- No control over timing and dose of statins;

- Depended on accuracy of hospital's database.

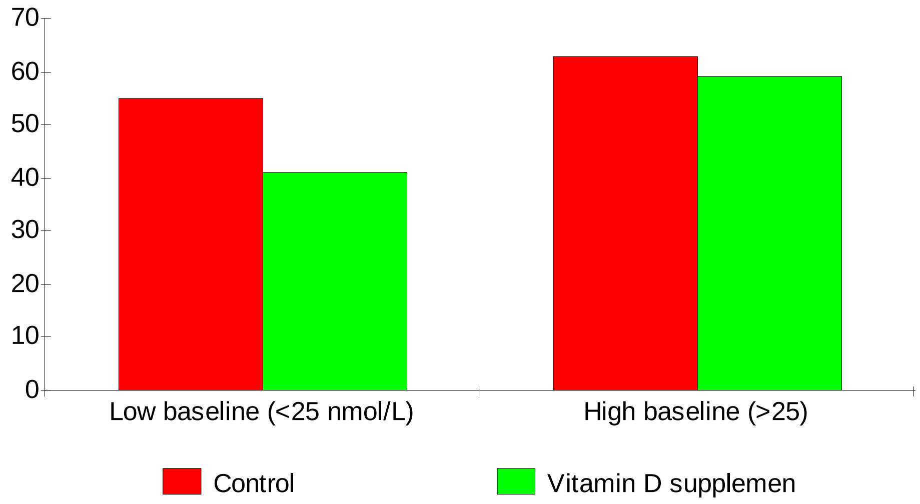
4.3.1. Prevention

Acute respiratory tract infections may be prevented by vitamin D supplementation. Randomised controlled trials (RCTs) have "yielded conflicting results" (Martineau et al 2017). Five meta-analyses that aggregated data from up to fifteen RCTs were also conflicted, particularly because of "statistically significant heterogeneity of effect between primary trials" (Martineau et al 2017).

This heterogeneity includes differences in participants between studies (eg: age, weight), differences in vitamin D dosing regimen, and baseline vitamin D levels of participants (Martineau et al 2017).

Martineau et al (2017) proposed the use of individual participant data (IPD) meta-analysis of 25 RCTs published before 2016. Rather than aggregating the data from studies, IPD meta-analysis concentrates on combining data from similar sub-groups (eg: baseline vitamin D status, vitamin D dosing regimen, dose size, age, and body mass index). IPD meta-analysis involves reanalysis of the studies included.

Overall, with aggregated data, vitamin D supplementation led to a statistically significant reduction in the proportion of individuals experiencing acute respiratory tract infection. In terms of sub-groups (IPD meta-analysis), vitamin D supplementation was especially beneficial for individuals with low baseline vitamin D (vs high baseline) (figure 4.1), and those receiving daily or weekly dosage (vs single dose or additional doses to regular dosing). Other variables, like age, were not statistically significant (ie: in terms of the difference between the treatment and control groups).



(Data from Martineau et al 2017 table 2)

Figure 4.1 - Percentage of participants with acute respiratory tract infection based on baseline vitamin D level.

4.3.2. Vaccination

Poliomyelitis (polio) is an infectious disease which the World Health Organisation is attempting to eradicate (eg: eight confirmed cases in the world in the first half of 2017; Sepulveda 2017). Vaccination is key to this aim, but certain countries still have a high polio risk because of the difficulty of implementing vaccination programmes (eg: Pakistan, Afghanistan, Nigeria) (Sepulveda 2017).

Leaving aside armed conflict and poor sanitation, the polio vaccination programme itself can be an issue. Habib et al (2017) reported a comparison of three programmes in Pakistan [23].

One group of pre-school children in one polio high-risk district of the country received the oral poliovirus vaccine (OPV) (live but attenuated strains of the virus taken in an oral dose). The OPV is low cost and easy to administer, but very occasionally the strains of the virus used can mutate leading to polio outbreaks (Sepulveda 2017).

A second group in Habib et al's (2017) trial received an integrated health package including educational materials for the community, OPV, and other immunisations. A third group received this health package, but with an inactivated poliovirus vaccine (IPV)

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[23] In total, 90 000 children were involved.

(ie: injected rather than oral). These two groups had better community acceptance of the programme, and thus increased coverage as compared to the first group. An increase of 6-9% in coverage [24].

Integrated health packages with OPV have proved effective in other countries, like Mexico, which included vitamin A provision, oral dehydration therapy, and health education as well (Sepulveda 2006).

4.4. APPENDIX 4A - HEAD LICE

Approximately one in five children in the developed world have head lice (Weintraub 2017).

Traditionally "special shampoos" to combat head lice have contained plant-derived insecticides called pyrethrins (or synthetically, pyrethroids). But lice are becoming immune to these (eg: up to three-quarters of lice in the USA; Weintraub 2017).

Pyrethrias and pyrethroids interfere with sodium pores in cell membranes and trigger fatal overfiring of the cells. Genetic mutations that protect against insecticides (eg: "knockdown resistance-type mutations") has produced the resistance (Weintraub 2017).

Alternative popular treatments include "Ulesfia" in the USA, which is alcohol-based and kills the lice by suffocation, or silicone and other synthetic oils in Europe, which envelop the lice and prevent water excretion (Weintraub 2017) [25].

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[24] Routine immunisation with OPV in Pakistan can be as low as one-third of the population in certain regions (with a national average of 72%) (Sepulveda 2017).

[25] "In Europe, such synthetic oil treatments are considered medical devices rather than drugs and so are subject to fewer regulations; in the US, they are viewed as medications and have not passed regulatory hurdles..." (Weintraub 2017 p19).

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5. DATAFICATION OF HEALTH

5.1. DATAFICATION

Ruckenstein and Schull (2017) began: "Over the past decade, the capacity to gather, store, and analyse individuals' physiological, behavioural, and geolocational data has come to affect a wide array of everyday life domains, from policy making to policing, corporate marketing to electoral forecasting, entertainment to education, urban planning to epidemiology. So-called big-data fundamentalists promote the view that large data sets, properly mined for correlations and patterns, will render up previously elusive insights, predictions, and answers to long-standing challenges of individual and collective life, replacing the need for theory and science..." (p262). This process has been called "datafication" (Van Dijck 2014).

The application to health is seen in "a number of different scales and registers, including data-driven medical research and public health infrastructures, such as biobanks and governmental databases; clinical health care, as in continuous patient monitoring, implantable biosensors, the use of the Internet for doctor-to-patient interaction, and personalised or 'precision' medicine — practices collectively described as digital health, eHealth, mHealth, or Health 2.0; and self-care practices, as in the use of direct-to-consumer genetic and microbiomics testing websites, health-related peer-to-peer social media, and a vast array of wearable fitness and health devices and smartphone applications (apps)" (Ruckenstein and Schull 2017 p262).

In Western countries, this fits with the concept of the "ideal citizen" as "digitally literate and self-advocating" (Ruckenstein and Schull 2017). Datafication applied to health is most prominent in relation to preventing "lifestyle diseases" (like obesity-related ones), which can be managed by the citizens with technology rather than professionals (Ruckenstein and Schull 2017).

Ruckenstein and Schull (2017) highlighted three issues related to the datafication of health in their review of ethnographic studies:

i) "Datafied power" - Those that have the data (governments and particularly, corporations) seeking to monetise it. Illiadis and Russo (2016) noted how "data are surreptitiously extracted from data subjects. hijacked to serve agendas that benefit research and industry" (quoted in Ruckenstein and Schull 2017).

Individuals perform "unpaid and invisible 'digital labour'" in providing the data, which becomes "biocapital" (Ruckenstein and Schull 2017). Thus, individuals are "sliced and diced into decontextualised parts, and bought and sold" (Nafus and Neff 2016 quoted in Ruckenstein and Schull 2017).

Digital tracking devices, like wearable monitors, combine both the "medical gaze" and the "surveillance society" (Lupton 2012), to give "dataveillance" (Raley 2013). "Rather than originating from a singular source positioned 'above', dataveillance is distributed across multiple interested parties — in the case of health, including caregivers, insurance payers, pharmacies, data aggregator and analytics companies, and individuals who provide information (either wittingly or unwittingly). Another feature that distinguishes dataveillance from surveillance is its predictive telos; its aim is not to 'see' a specific behaviour so much as to continuously track for emergent patterns..." (Ruckenstein and Schull 2017 p264).

Greenfield (2016) described a "pixelated person", "a subject ever divided into finer granularity, but also whose partial datasets can be joined with others" (quoted in Ruckenstein and Schull 2017).

ii) "Living with data" - The "Quantified Self" (QS) is a name to describe a movement whose members want to use data about themselves to learn about themselves - "self-knowledge through numbers" as a QS website says (Ruckenstein and Schull 2017).

Smith and Vonthethoff (2017) studied QS videos as individuals "narrate personal experiences and stories in a public forum via the 'companion' medium of their data" (quoted in Ruckenstein and Schull 2017).

Lomborg and Frandsen (2017) saw this data (self-) tracking as a form of communication, as "datasociality" (Ruckenstein and Schull 2017). Surveying apps and websites, Maturo and Setiffi (2016) viewed this sharing of knowledge as a way to bypass or challenge professional medical expertise. So, "self-tracking can balance or adjust the power dynamics of the doctor– patient relationship by giving rise to forms of therapeutic alliance in which patients and providers are both seen as experts... Self-generated data can mediate between subjective experiences of physical and mental health and the medical profession's protocols and diagnostic categorisations... In some cases, patients use the data to second-guess or subvert medical expertise and intervention; those with chronic conditions such as diabetes might start self-tracking when pushed by doctors and later refuse to share the data..." (Ruckenstein and Schull 2017 p267).

The collected personal data and its technologies "enable individuals to make meaning of their life experiences and relate to their bodies and selves" (Ruckenstein and Schull 2017 p266). In the case of individuals living with medical conditions, the data makes the "somewhat inaccessible world of feelings and problems more tangible and comparable" (Sharon and Zandbergen 2016 quoted in Ruckenstein and Schull 2017).

But there is an ambivalence as self-trackers report "a wish both to take charge of themselves and to delegate that task, burdensome and confounding as it is; they speak of feeling cared for by the automated interventions of their devices and released from hard-to-meet demands for self-regulation..." (Ruckenstein and Schull 2017 p267).

iii) "Data-human mediations" - This is the "non-human element" (ie: the devices and data collecting methods - algorithms). Nafus and Neff (2016) talked of the data as a "prosthetic of feeling [that can] help us sense our bodies or the world around us" (quoted in Ruckenstein and Schull 2017). While Williamson (2015) described "health-tracking data act as a kind of active, algorithmic skin that not only sheathes but animates and orders the body" (quoted in Ruckenstein and Schull 2017).

More negatively, Smith and Vonthethoff (2017) felt that bodily intuition was "being outsourced to, if not displaced by, the medium of unbodied data" (quoted in Ruckenstein and Schull 2017).

The algorithms that make sense of the raw data are not neutral, but are "invested with social norms, cultural values, and governance agendas" (Ruckenstein and Schull 2017 p269). For example, digital pedometers are programmed with a daily target (eg: 10 000 steps) irrelevant of the user (ie: general norms rather than individual targets). Likewise online weight-loss services calculate an individual's "personalised" calorie intake based on averages from large populations (Ruckenstein and Schull 2017). "Sexual activity tracking apps are designed with gendered assumptions: Those marketed to women tend to be framed in terms of reproductive risks and sexually transmitted diseases, whereas those for men typically focus on sexual performance, allowing users to record number of thrusts to orgasm, audio decibels, and the like..." (Ruckenstein and Schull 2017 p269).

5.2. MORTALITY DATA

In 2013, the NHS in England published data for the first time on the mortality rates of individual surgeons. Advocates of this move emphasised transparency and the ability to improve standards (Harrison et al 2016).

There is the issue, however, of the extent to which an operating surgeon is responsible for the outcome of an individual patient - for example, in cardiac patients the whole care process is involved (Westaby et al 2015).

Critics of the data raised the concern of "whether surgeons performed particular procedures frequently enough to enable those with an excess mortality to be reliably identified" (Harrison et al 2016 p1). For example, acceptable performance could be defined within two standard deviations of the national mean or median of mortality. But the ability to detect this depends on caseload and statistical power.

Harrison et al (2016) showed that not enough operations are performed for detection of unacceptable performance. They analysed UK data from 2010 to 2014 on six procedures using both 30-day and 90-day post-operation mortality.

The average surgeon volume was between 23 and 75 cases depending on the procedure, but over 200 procedures would be needed to accurately detect a 90-day mortality rate three times the national median for higher risk procedures, and 500 cases for a lower risk procedure to detect a mortality rate five times the national average.

5.2.1. Interpreting Data

Gigerenzer and Edwards (2003) noted three numerical representations of risk that "foster confusion":

i) Single event probabilities - eg: "There is a 30% chance of a side effect from the drug". To avoid misunderstandings, the authors recommended use of a frequency statement, like "three out of every 10 patients taking this drug have a side effect".

ii) Conditional probabilities - The probability of a positive test result when the individual has the disease is the sensitivity of the test, while the probability of a negative test result when the individual does not have the disease is the specificity. But the probability of the disease if the individual has a positive test score is different (positive predictive value).

For example, one thousand women screened for breast cancer with a 0.8% prevalence of the disease and 90% test accuracy: true positives = 7, false positives = 70, true negatives = 922, and false negatives = 1. Those who test positive only 1 in 11 (9%) actually have disease (Gigerenzer and Edwards 2003).

iii) Relative risks - For example, undergoing screening reduces the risk of dying by 25% (relative risk), but the absolute risk is less (eg: 4 in 100 not screened die vs 3 in 100 who screened). Absolute risks are easier to understand, recommended Gigerenzer and Edwards (2003).

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6. ETHICAL ISSUES RAISED BY MODERN GENETICS

6.1. CHOOSING BABY

A deaf lesbian couple in the USA (Sharon Duchesneau and Candy McCulloch) found a sperm donor with five generations of congenital deafness in his family in order to "produce" a deaf baby. The women did not see deafness as a disability. "They see being deaf as defining their cultural identity and see signing as a sophisticated, unique form of communication" (Savulescu 2002 p771). Savulescu (2002) saw no ethical issue here as "the couple have the right to procreate with whomever they want" (p771).

But what could be more problematic is the use of pre-natal genetic testing of a foetus or pre-implantation genetic diagnosis (PGD) [26] in in vitro fertilisation (IVF) to "guarantee" a particular "type" of child. Savulescu (2002) stated, in reference to the selection of a deaf embryo, the "deaf child is harmed by being selected to exist only if his or her life is so bad it is not worth living. Deafness is not that bad. Because reproductive choices to have a disabled child do not harm the child, couples who select disabled rather than non-disabled offspring should be allowed to make those choices, even though they may be having a child with worse life prospects" (p772). If individuals are a given a choice, then they may well choose something that the majority do not agree with. "The only legitimate ground for interference in reproductive decisions would be an important detrimental social impact of such choices. But it is unlikely that many people would make a selection for disability" (Savulescu 2002 p773).

6.1.1. Eugenics

Any discussion of altering genes takes place in the context of the history of eugenics and compulsory sterilisation. Nourse (2016) described eugenics as a

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[26] PGD involves testing cellular material from early human embryos cultured in vitro for genetic abnormalities. It was developed particularly for couples with reproductive risks (Braude et al 2002).

PGD can be used for three groups of genetic disorders (Braude et al 2002):i) A known single-gene disorder (recessive or dominant);ii) X-chromosome linked disorders which can be avoided by sex selection;iii) Chromosomal rearrangements.

"pseudo-science focused on the notional 'improvement' of human populations by halting the reproduction of supposedly lesser genes".

The main target, certainly in the USA, was individuals classed as "imbecile" (which is today described as learning disability or intellectual disability), who ended up in asylums. Though individuals could be in this places for many reasons. Historical research on a famous 1920s "feebleminded" woman, Carrie Buck, found that she had been raped and made pregnant by a relative of her foster parents, and this was her reason for being in the asylum (Nourse 2016).

Compulsory sterilisation was legal in a number of US states in the early 20th century [27], beginning with Indiana in 1907, and including Virginia that forcibly sterilised around 7500 "unfit" people between 1927 and 1979 (Ings 2016). In total, at least 60 000 US citizens (Nourse 2016).

Ings (2016), reviewing a new book on eugenics (Cohen 2016), summarised its conclusion that "eugenics fails because it looks for genetic solutions to what are essentially cultural problems".

6.2. PARTICIPATORY GENOMIC RESEARCH

Aungst et al (2017) gave this overview: "Interest in individual health management, advances in mobile technologies, and the ubiquity of social media platforms have led to heightened expectations for individuals to acquire more self-knowledge with the aim of managing their health. Whether through wearable biomonitoring tracking devices, direct-to-consumer genetic testing, or emerging models of shared decision making in the clinic, health care is moving from top-down paternalism to a patient-centred focus — no longer asking just 'What's the matter with you?' but also 'What matters to you?'" (p358).

In relation to genomic research, the partnership between medical professionals and laypeople has been called "public-participation", "citizen-driven", "crowd-sourced", or "participant-driven" genomic research, among other terms (Aungst et al 2017). Woolley et al (2016) saw a continuum from "bottom-up citizen-science initiatives designed to liberate scientific inquiry from the constraints of traditional research institutional contexts and professional practices to top-down investigator-initiated research designed to acquaint the

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[27] Nearly half of states (Nourse 2016).

public with scientific research processes and build its support and enthusiasm for them" (Aungst et al 2017 p358).

Aungst et al (2017) presented examples along with the ethical issues of "participatory genomic research":

a) "Do-it-yourself (DIY) genomic sequencing" - Individuals and groups learning to sequence their own genomic data. Advocate of this bottom-up approach, Clive Brown stated: "With self-sequencing you are in control. Part of that means asserting your right to understand your own biology, and, in this case taking ownership of your own genetic profiles" (quoted in Aungst et al 2017). This emphasises the personal responsibility for monitoring and managing one's own health [28].

b) Patient advocates - Particularly in relation to rare diseases, advocacy groups are going beyond supporting their members, and giving voice to their concerns to professionals, to "finding their own investigators and raising funds for research, searching a growing number of open databases to find others whose children have a mutation in the same gene, leveraging direct-to-consumer genomic test results, and even conducting the research or experiments on their own as citizen scientists" (Aungst et al 2017 p360) [29].

For some medical professionals, this is "a direct challenge to the existing order of scientific knowledge production in which the research process and data quality can be managed by certified experts" (Aungst et al 2017 p360).

Parents are especially active here. For example, Chong et al (2016) described the case study of website "Milo's Journey" (and associated social network campaign) set up by the family of a child with symptoms (eg: developmental delay; distinctive facial features) linked to an unknown KDM1A gene variant. The aim was to recruit other families, and to encourage research on this gene.

c) Top-down approaches - Larger investigator-led, and government-initiated genomic research projects are needed in some cases to aggregate the large databases, and to involve large numbers of citizens. But how much control will individuals have over their own data, and how to deal with declining trust in government agencies?

While Giroux (2008-9) has made the criticism that academics as biotechnology entrepreneurs fits a neo-liberal ideology. "Within the neo-liberal university,

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[28] What Foucault et al (1988) called "technologies of the self".

[29] Collins (2017 quoted in Aungst et al 2017) talked of "coalitions of convenience" and "coalitions of conscience".

research ideas are assessed instrumentally and deemed successful if they obtain external funding and increasingly strong ties between academic researchers and corporate entities are promoted" (Aungst et al 2017 p364).

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7. BIO-CAPITALISM IN THE MIDDLE EAST: TWO DIFFERENT STUDIES

7.1. ISRAEL

Vertommen (2017) used the phrase "reproductive-industrial complex", particularly in relation to Israel, to describe the growth of biotechnology related to fertility. Within "a neoliberal world economy, the capitalism of bare biological life has become a very lucrative globalised business" (Vertommen 2017 p284), and Israel is at the forefront.

Vertommen (2017) explained this situation "as a political project driven by state – and global market-making practices and shaped by histories of settler colonialism and bio-capitalism" (p284). "Settler colonialism" refers to "a demographic logic of elimination of the indigenous population as a way to re-populate the country with the newly arrived settler population" (Vertommen 2017 p284). Also a "pro-natalism" stance is seen in State support and the general popularity of reproductive technologies, like in-vitro fertilisation and donor insemination [30], at the expense of treatments that "potentially restrict family size" (eg: family planning, abortion).

Bio-capitalism (or "tissue economies"; Waldby and Mitchell 2006 [31]) is "a new economic model built on the speculative promise of creating commodities from existing forms of bare life" (Vertommen 2017 p285). "Biological matter" ("'res nullius' or nobody's property") is transformed into "patentable products" (Vertommen 2017). In relation to reproductive technologies, feminist critics have highlighted how women are marginalised as "tissue donors", treated as "open sources of biological material which can be readily disentangled in ways that favour the rights and profits of biotechnology companies" (Waldby and Mitchell 2006 quoted in Vertommen 2017).

Likewise, a scientist involved in the development of "Rebif" (for multiple sclerosis) spoke of blood donors

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[30] Prainsack and Firestine (2006) noted a "fearless, liberal but not immoral embrace of biomedical technologies" in Israel (ie: "a remarkable absence of public controversies about the moral permissibility of technologies such as cloning, genetic modification or human embryonic stem cell research"; Vertommen 2016). In fact, Prainsack and Firestine (2006) referred to "doing it the Israeli way".

[31] "Red" biotechnology is used to described biotechnology applied to medical processes (Vertommen 2016).

involved in the process thus: "I remember during our research there was a case of blood donors who claimed that they were inventors. They are not inventors, they are just blood donors. The scientists made the invention. So I do not think that it would be wise to extend the intellectual property rights to people who are just donating an organ or tissue" (quoted in Vertommen 2017).

Intellectual property rights allow the importance of "monopolised knowledge and information for the extraction of rent" (Zeller 2008 quoted in Vertommen 2017). For example, egg cells are "a highly desirable commodity" in bio-capitalism (Vertommen 2016). "Brown and Webster (2004) noted, egg cells together with other female reproductive tissues such as placentas, embryos and umbilical cord blood 'are increasingly used by contemporary biomedicine as a generative site separate from the production of children, through which biological materials and information is harvested for scientific, medical and commercial purposes'" (Vertommen 2016 p178).

While Nehman (2013) stated: "Extracting oocytes out of women's bodies is mining bodies for the creation of surplus value, through the development of new techniques generating more research papers for scientists and developing new pharmaceuticals associated with reprotech" (quoted in Vertommen 2016).

7.2. EGYPT

The "organ trade" (ie: buying and selling of human organs) is treated in many countries as part of "organised crime", but this marginalises the "majority of individuals who due to their poor socio-economic status have little choice but to consider an organ sale" (Columb 2017 p1301).

Cairo, Egypt, has a "reputation as one of world's largest organ bazaars", even with a 2010 Act prohibiting the commercial exchange of organs, and Columb (2017) studied Sudanese migrants involved in this trade. In 2014, interviews were made with organ sellers and brokers via "snowball sampling".

Sudanese brokers recruit migrants who want to sell organs from local street markets. One of them, "Shaker", talked of "just trying to get by, like everybody else", and of providing a service (eg: taking the seller to a tissue typing lab).

Negotiating the fees is an important part of the broker's work. "Kariem" bragged: "There was a girl from France [who needed a kidney] whose father contacted me. I saved him a lot of money. He got the kidney for £45,000 GBP [British £]. Without me he could have paid more than £100,000 GBP" (Columb 2017 p311).

The brokers do more. "All of the respondents who had sold a kidney were accompanied by a broker(s) while attending the clinics. Apart from collecting their recruitment fee, the presence of the broker(s) ensured that the donors did not reconsider their 'donation'. While the majority of respondents did not experience any overt violence compelling them to donate, it was clear that once they had agreed to sell a kidney they had little choice but to proceed with the operation" (Columb 2017 p312). "Patrick" (donor) described the difficulty if an individual changed their mind: "They [the brokers] told me that they would never let me change my mind. They said, if you change your mind you will pay for all the health checks, and we will never leave you alone. We will take your money and your passport. We will never let you go. Every day they paid me 50 or 150 LE [Egyptian £]. They told me that I owe them now. I couldn't pay them back so I had no choice but to continue" (p1313).

Columb (2017) felt that criminal sanctions pushed "the trade further underground. This has increased the role of intermediaries and reduced the bargaining position of organ sellers, leaving them exposed to a greater risk of harm. While organ markets continue to operate, the process of organ trading has become more hidden, making it more difficult to assess the extent of the problem and identify individuals targeted for organ sale" (p1317).

He summed up: "The organ brokers and organ sellers interviewed as part of this study were responding to the same set of circumstances and conditions. With limited access to employment, residency and/or education respondents were left with little choice but to find ways to help themselves. In this context, selling or arranging the sale of a kidney was an option worth considering. Contrary to popularised reports that link organ trafficking to the operations of transnational crime groups, the informal/formal relations that underpin Cairo's organ markets are based on modern modes of collaboration, trading and communication, across the illegal/legal divide. In this sense, the organ trade is better understood as an emerging sector of the informal economy, as opposed to a trafficking offence" (Columb 2017 p1317).

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8. GENDER TOPICS

8.1. DISEASE AND GENDER INEQUALITY

Varnum and Grossman (2016) linked changes in gender equality/inequality in the USA and the UK since the 1950s to the rates of infectious diseases (pathogen prevalence). "Higher levels of pathogen prevalence are associated with more conformity, more authoritarianism, less openness and tighter social norms. Given that most human societies have relatively patriarchal traditions, it seems possible that higher pathogen prevalence might also promote behaviours, norms and values that foster gender inequality. That is, as men have traditionally held more power in most societies, if pathogens push people towards more traditional values, then one might expect individuals and institutions to accord women fewer rights and opportunities when pathogen loads are higher" (Varnum and Grossman 2016 p1).

The researchers used data on equal pay, and sexist work attitudes (eg: preference for a male boss) along with official records on the prevalence of nine common infectious diseases. There was a significant positive correlation between pathogen prevalence and level of gender inequality. This first study concentrated on the USA (1951-2013).

For comparison Varnum and Grossman (2016) looked at similar data for the UK (1945-2014) in their second study, and confirmed the significant positive correlation of Study 1.

Varnum and Grossman (2016) argued that specific events and social movements (eg: women's liberation) are "partly responsible for temporal variations in gender equality, [but] they provide fairly intermediate explanations void of a comprehensive framework" (p1), and pathology prevalence is the comprehensive framework.

Technically, the secondary data used did not allow the establishing of causality.

Varnum and Grossman (2016) ended with a positive observation that "efforts to reduce infectious diseases, such as vaccinations, free health care, public sanitation and water treatment, might also increase equality among the sexes" (p3).

8.2. LIFE EXPECTANCY

Of the 58.8 million deaths estimated in the world in 2004, 31.1 m were males and 27.7 m were females; 51% were individuals 60 years and over and 18% four years and younger. In terms of causes - 60% were non-communicable diseases, 30% communicable, maternal, perinatal and nutritional conditions, and the remainder injuries (WHO 2008).

The "female survival advantage" describes the fact that the average life expectancy of women is longer than that of men.

Is this gender gap down to biological or social factors? For example, a social explanation might be that men experience more risks in their lifetime than women, and consequently die earlier.

Finding a biological explanation for the difference requires studying populations where men and women have similar lifestyles (eg: cloistered monks and nuns; Luy 2003). "Findings indicate that, even though men and women in these groups have more similar lifestyles and men are exposed to fewer risk factors than men in the general population, a gender gap in life expectancy still persists" (Zarulli et al 2018 pE832).

Zarulli et al (2018) took a different approach and studied the survival of both sexes in populations under extreme conditions. Data on seven documented high-mortality populations were analysed:

- Slaves - freed Liberian slaves between 1820 and 1843; plantation slaves in Trinidad in the early 19th century.
- Famines - Ukraine 1933; Sweden 1772-73; Ireland 1845-49.
- Epidemics - Iceland 1846 and 1882.

Life expectancy for women was higher than for men in all these populations, except the Trinidad slaves. "The conditions experienced by the people in the analysed populations were horrific. Even though the crises reduced the female survival advantage in life expectancy, women still survived better than men. In all populations men had equal or higher mortality than women across almost all ages. A substantial part of the overall female advantage in life expectancy was due to survival differences among infants" (Zarulli et al 2018 pE836).

Zarulli et al (2018) ultimately argued for a biological explanation to the female survival advantage. For example, sex hormones are involved, in that oestrogen enhances the immune system while testosterone "seems to increase the mortality risk for certain diseases, although the evidence on this point is mixed" (Zarulli et al 2018 pE838).

Studies with non-human animals confirm the difference. "Female mammals not only seem to be better at dealing with infection but also survive better than male mammals under harsh environmental conditions — an observation confirmed by a large comparative study on 26 ungulate populations [Toigo and Gaillard 2003], among others" (Zarulli et al 2018 pE838).

8.3. OLDER FATHERS

Older mothers can be a risk to the child (eg: greater risk of Down's Syndrome), and so are older fathers in the form of more inherited genetic mutations (Arsian et al 2017).

These mutations will decrease offspring fitness in the form of reproductive success. Arsian et al (2017) explored this idea in terms of number of grandchildren with a study of four historical populations (eg: isolated French settlers in Quebec 1670-1750).

Siblings born to the same father with at least ten years difference were compared. Children of older fathers had around one-tenth less offspring themselves who survived to five years old.

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9. MISCELLANEOUS BEHAVIOURS

9.1. THIRST

Thirst motivates fluid intake to compensate for water loss from sweating, breathing, and urination. Loss of only 1-2% of the body's water triggers the desire to drink (Gizowski and Bourque 2017). This is homeostatic thirst (ie: to re-establish the balance), and is explained by the "drive reduction" hypothesis (ie: dehydration promotes water intake to reduce the drive) [32].

Decreases in blood volume (hypovolemia) [33], for example, can promote homeostatic thirst ultimately through activating forebrain areas, particularly the hypothalamus (Gizowski and Bourque 2017). Recently, Allen et al (2017), using mice, discovered neurons that respond to the intensity of thirst in the median pre-optic nucleus (MnPO) of the hypothalamus [34]. The MnPO neurons were highly active in response to thirst and lowered their activity with quenching. It was shown that "the activity of MnPO neurons is proportional to thirst and is sufficient to drive water intake" (Gizowski and Bourque 2017 p1093).

Also it was shown that the activation of these neurons was unpleasant (which fits the "drive reduction" hypothesis). Mice learned to press a lever to turn off stimulation of these neurons when not thirst (Gizowski and Bourque 2017).

After drinking begins in response to thirst, there needs to be a mechanism to signal satiety. Changes in mouth dryness as well as gastric and intestinal factors are involved, but Saker et al (2016) recently highlighted the importance of swallowing inhibition.

Twenty healthy Australian adults exercised for one hour to produce thirst before drinking liquid to excess while in a FMRI scanner. This was done by delivering 5 mL of liquid by a tube to the mouth automatically every 47

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[32] "Classical theories of learning and motivation suggest that deviations from homeostatic set points are aversive and that animals perform motivated behaviours to reduce such aversive states" (Allen et al 2017 p1154).

[33] Also cellular dehydration, and changes in sodium concentration in the cerebral spinal fluid (Saker et al 2016).

[34] The MnPO integrates information on blood volume, osmolarity (cell water balance), and hormonal inputs, as well as regulating body temperature, sleep, cardiovascular function, and sodium excretion, along with thirst (Allen et al 2017).

seconds to a maximum of 50 mL. The ratings of the pleasantness of the taste of the liquid (water or sugar water) significantly decreased with overdrinking, while the rating of the effort to swallow increased. Changes in brain activity in the motor cortex, prefrontal cortex, posterior parietal cortex, striatum, and thalamus were observed between thirst and overdrinking.

9.2. ALEXITHYMIA AND THE TROLLEY DILEMMA

The trolley dilemma (Thomson 1985) is commonly used to investigate moral reasoning and harm aversion. An out-of-control trolley (tram, train) is going to hit/kill five people on the track who cannot escape, but the viewer can press a lever and the trolley will change track and only hit/kill one person. Most people feel that the sacrifice of one person to save five is permissible, and this is a utilitarian position (ie: benefit to the greatest number).

The footbridge version of the trolley dilemma changes the option from pressing a lever to pushing a person off an overhead bridge to block the track, and save five people. The outcome is the same as before, one person's death to save five people, but listeners are less likely to agree with this behaviour. This is a deontological position, which "argues that individuals have inviolable right and duties which can't be infringed upon even if doing so would maximise welfare of more number of individuals" (Patil and Silani 2014 p1).

Greene et al (eg: 2001) explained the differences in response with the dual-process model involving two competing processes:

- Deliberative reasoning (utilitarian position taken)
- Emotional or automatic response (deontological position taken).

The upshot is that many moral decisions are based on the emotional response. But "one can find it morally acceptable to personally harm someone in order to achieve the greater good either because they are better at cognitive deliberation (eg: abstract reasoning, problem-solving etc) and find it pragmatically more acceptable after cost-benefit analysis or because they have a blunted sense of harm aversion due to reduced empathic concern for the victim" (Patil and Silani 2014 p2).

Patil and Silani (2014) investigated moral decision-making in relation to the latter with individuals with alexithymia. This is "characterised by reduced capacity to experience emotions, absence of tendency to reflect on one's own emotions, difficulty in identifying feelings and bodily sensations associated with emotional arousal, and describing those feelings to others" (Patil and Silani 2014 p3). It was predicted that such individuals will have less empathy and thus choose the utilitarian option in moral dilemmas.

Three hundred and thirty-one Italian adults (mostly students) completed the study online, which included measures of alexithymia (eg: "It is difficult for one to find the right words for my feelings"), empathy (eg: "When I see someone being taken advantage of, I feel kind of protective toward them"), and the trolley dilemma.

Thirty respondents were categorised as alexithymic, sixty as possibly, and the remainder as not. It was found that "trait alexithymia influenced moral judgments via empathic concern such that it led to reduction in empathic concern which reduced the affective aversion to the prospect of personally harming someone for the greater good" (Patil and Silani 2014 p6).

9.3. ALCOHOL AND EMOTIONS

"Alcohol consumption has a long-standing association with mood, with evidence showing that people consume alcohol to help regulate emotional experiences, reduce negative emotions and enhance positive emotions" (Ashton et al 2017 p2). Individuals report drinking to increase positive mood and reduce negative mood, as well as for social bonding (Fairbairn and Sayette 2013).

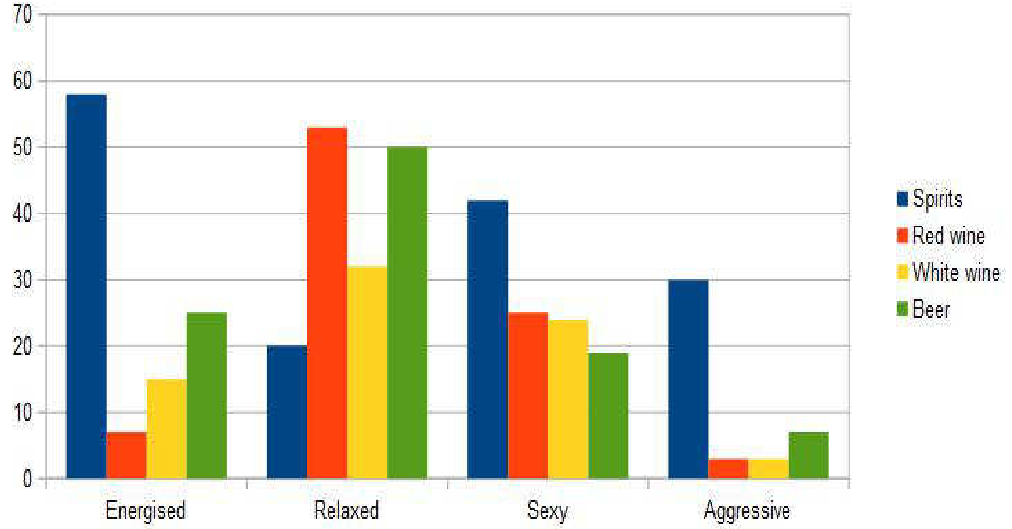
Ashton et al (2017) looked at emotions and different types of alcohol consumed by analysing data from the online Global Drug Survey 2016 (GDS), which covers 88 000 individuals in twenty-one countries. This self-reported survey includes type of alcoholic drinks consumed in the last twelve months, and emotions associated with this - positive (energised, relaxed, sexy, confident) and negative (tired, aggressive, ill, restless, tearful).

Drinking spirits was associated with energy, confidence, and feeling sexy by around half the respondents, but these drinks were more likely to be linked to negative emotions than other types. Relaxation was reported with red wine and beer (figure 9.1).

Women reported all emotions, except aggression, more than men, and younger age groups likewise. Male beer drinkers were less aggressive than spirit drinkers.

Individuals classed as dependent drinkers were five times more likely to feel energised after drinking than low consumers, and six times more likely to report aggression. "These findings suggest that individuals inadvertently select drinks which are known to elicit negative emotions because they crave the positive emotions that go with them and link with existing evidence that those dependent on alcohol drink alcohol as a coping mechanism rather than drinking for pleasure. This was evident particularly among heavier drinkers.

This highlights a potential emotional gap which individuals may be looking to fill by drinking alcohol. This gap can be a concern, particularly with exploitation by the alcohol industry with advertising focused on pushing the positive emotions associated with alcohol use without outlining the negatives which go alongside them" (Ashton et al 2017 p10).



(Data from Ashton et al 2017 table 1)

Figure 9.1 - Percentages of individuals reporting selected emotions based on type of drink.

Though the sample was large, it was opportunist (ie: not representative). "As the sample was self-selected, there may be an over-representation of individuals who are more likely to participate in drug and alcohol use. The sample may also be biased towards those with access to the internet" (Ashton et al 2017 p12).

The data on alcohol consumption were self-reports as were details of the emotions. Alcohol consumption "may have been affected by confounding factors such as mood prior to drinking and mixing of alcohol drink type in individual drinking sessions which were unable to be controlled for. Additionally, without knowledge about the amount of alcohol consumed and the rate at which it was drunk, such inferences remain speculative. Respondents may have also undertaken other activities while consuming specific drinks such as dancing, socialising and drug use, which may have affected emotions reported to be associated with each drink type. We also cannot rule out the impact of recall bias and the deliberate misreporting of results" (Ashton et al 2017 p12).

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10. THE PROSPECTIVE STUDY AND SOLID FUEL USE AS RISK FOR DEATH

"Solid fuels" include biomass (eg: wood, charcoal, dung) and coal, and it is estimated that towards three billion people worldwide use them for domestic purposes (Yu et al 2018). "When combusted indoors, solid fuels generate a large amount of pollution such as fine particulate matter (PM $_{2.5}$)" (Yu et al 2018 p1352).

The World Health Organisation estimated that household air pollution from solid fuels resulted in 2.5 million cardiovascular-related deaths in 2016 (Yu et al 2018). But research is limited - usually cross-sectional or case-control design (table 10.1), not prospective studies [35] (appendix 10A) - and little distinction is made between solid fuel use for cooking and heating. Furthermore, variables like appropriate ventilation (eg: chimney; extractor fan), and switching to clean fuel use are overlooked (Yu et al 2018).

CROSS-SECTIONAL DESIGN	CASE-CONTROL DESIGN
Comparison of different groups at one point in time. Advantages: 1. Allows comparison of different groups on variable of interest. 2. Short-term study, which makes it usually cheaper and less time-consuming than longitudinal studies. Disadvantages: 1. Data collected at one point in time, and so misses what happens on other occasions and long-term trends. 2. Problems with matching individuals in different groups, in order to control for confounders.	A retrospective study of factors that differ between cases (with relevant variable - eg: disease) and controls (without variable - ie: healthy). Advantages: 1. Focus on outcome (eg: illness) and work backwards looking for potential causes. 2. Use existing cases rather than waiting for individuals to become ill. Disadvantages: 1. Risk of recall bias with retrospective data. 2. Problems with finding matching controls on potentially confounding variables.

Table 10.1 - Two main advantages and disadvantages of cross-sectional and case-control designs.

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[35] Yu et al (2018) referenced two other prospective studies:

- Kim et al (2016) (Shanghai Women's Study) found that coal use for cooking among 75 000 women in Shanghai, China, was associated with increased death;
- Mitter et al (2016) (Golestan Cohort Study) reported an increased risk from use of kerosene/diesel (but not wood) among 50 000 Iranians.

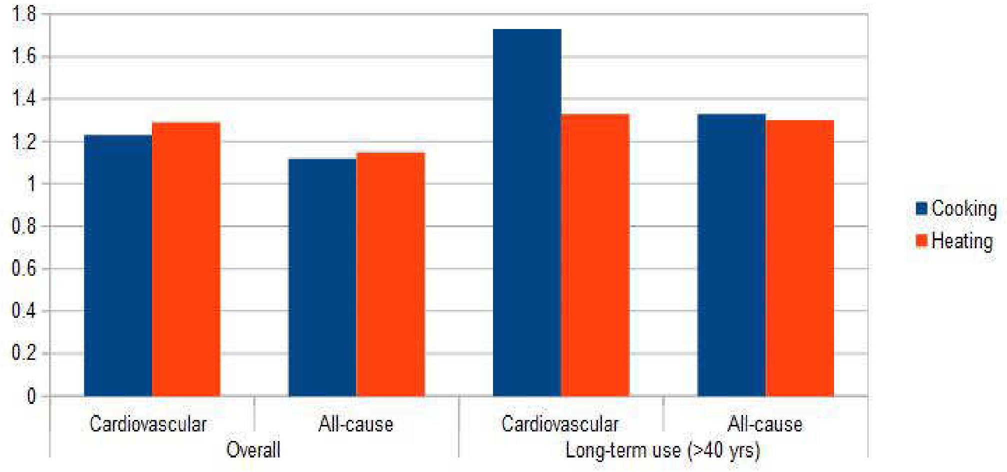
Yu et al (2018) sought to overcome these weaknesses with data from the China Kadoorie Biobank, which studied over half a million adults in ten areas of China between 2004 and 2008.

Relevant information on solid fuel exposure was collected in questions about cooking frequency, use of heating, cookstove ventilation, and primary fuel used. "Solid fuels" were defined as "wood" (wood and charcoal) and coal, while "clean fuels" included gas and electricity. This information was collected at baseline (June 2004) and again in 2008.

The outcome measures were cardiovascular and all-cause mortality collected from baseline until the end of 2013.

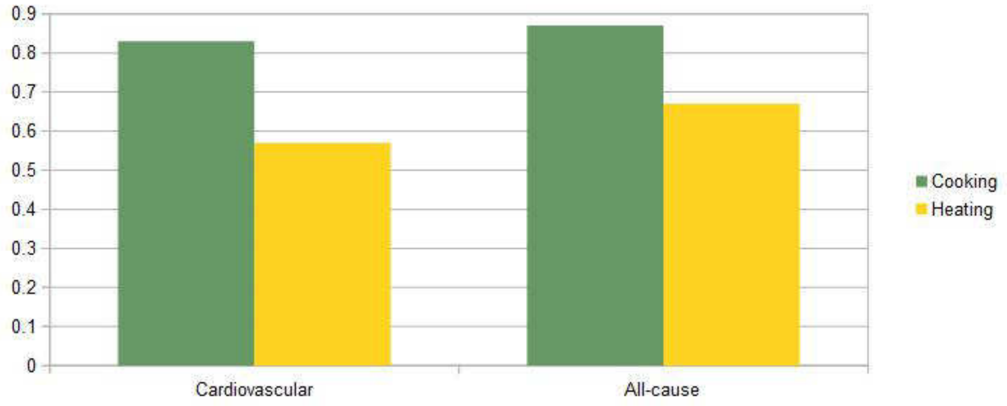
Yu et al (2018) focused on five rural areas (Gansu, Henan, Hunan, Sichuan, and Zheijang) (n = 271 217), and adults older than 35 years. A total of 15 468 deaths occurred during follow-up.

Reported solid fuel use was significant associated with increased cardiovascular and all-cause mortality compared to clean fuel use, both for cooking and heating (figure 10.1). A significant associated also existed for wood use, but not coal use separately. Longer use of solid fuels was associated with higher risks of death, but switching to clean fuels reduced the risk as did appropriate cookstove ventilation (figure 10.2). Solid fuel use and cigarette smoking were together the highest risk for death (figure 10.3).



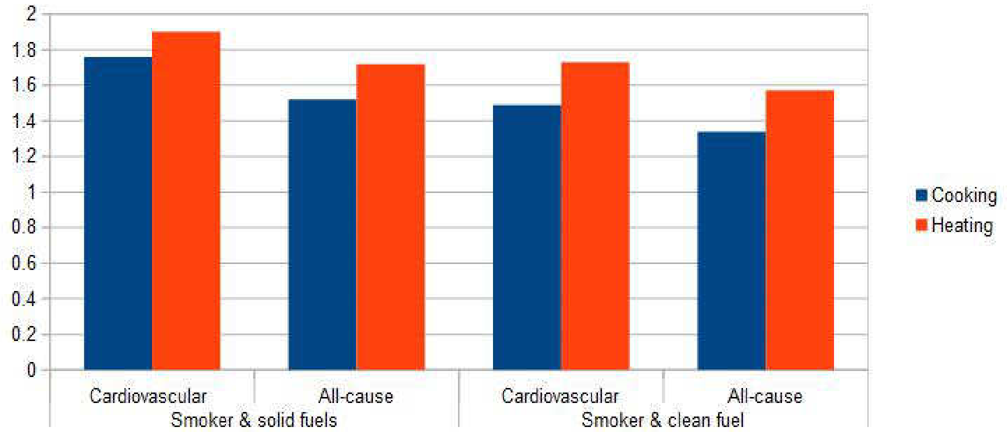
(Data from Yu et al 2018 table 2 p1356 and figure 1 p1357)

Figure 10.1 - Selective hazard ratios for death with solid fuels use (where 1.00 = clean fuel use, and other variables adjusted for).



(Data from Yu et al 2018 table 3 p1358)

Figure 10.2 - Selected hazard ratios for death with switch to clean fuel (where 1.00 = continued solid fuel use, and other variables adjusted for).



(Data from Yu et al 2018 figure 3 p1359)

Figure 10.3 - Selective hazard ratios for death with solid fuel use and cigarette smoking (where 1.00 = clean fuel use and non-smoker, and other variables adjusted for).

Yu et al (2018) commented on the findings: "The exact mechanisms through which solid fuel use may contribute to mortality risk are not well understood. Burning of solid fuels releases substantially higher levels of various gaseous pollutants and PM $_{2.5}$ than clean fuel, and it might increase cardiovascular disease and mortality risk through pathways such as cardiac autonomic dysfunction and atherothrombosis" (pp1358-1359).

Evaluation of Yu et al (2018)

Strengths:

1. Large sample.

2. Prospective study.

3. Five diverse rural areas.

4. Assessed solid fuel use for cooking and heating separately.

5. Controlled for variables in analysis, including appropriate ventilation, switch to clean fuels, occupation, and family history of cardiovascular disease.

6. Face-to-face interviews by trained health workers using standardised electronic questionnaires.

7. Mortality data taken from China's Disease Surveillance Point System, health insurance database, and local records. Cause of death categorised by trained staff blind to study.

Weaknesses:

1. Self-reported data.

2. Fuel use was "used as a proxy for household air pollution exposure, which could vary by level and efficiency of ventilation, climate, and fuel properties" (Yu et al 2018 p1360). Direct measurement of household air pollution would be ideal.

3. The "domestic fuel choice is closely related to socio-economic status, which itself is associated with the risk of cardiovascular and all-cause mortality. Despite extensive adjustment for related variables (education level, household income, and various dietary variables) in this study, residual confounding remains likely" (Yu et al 2018 p1360).

4. Some difference in reported fuel use at baseline and resurvey, which represents actual changes, but also random measurement error (eg: recall errors; administrative errors).

5. A small number of deaths had no official information, and trained health workers determined probable cause by asking family members or caregivers.

6. Participants younger than 35 years old were excluded.

7. Cigarette smoking and solid fuel use were assumed to be additive in effect in analysis.

APPENDIX 10A - PROSPECTIVE STUDY METHOD

The prospective longitudinal cohort method follows the same individuals into the future to see who develops a disease, for example.

Advantages:

1. Study set up before illness develops, and this minimises observer bias.

2. Allows for real time to elapse (Fleming and Hsieh 2002), and can show the temporal sequence of events (ie: what comes before what).

3. Can estimate disease incidence rates in those exposed and not exposed (Weich and Prince 2003).

4. Compared to retrospective study, no risk of recall bias

Disadvantages:

1. Time-consuming and expensive to carry out.

2. Problems of follow-up, and incomplete follow-up produces risk of bias.

3. Unsuitable for rate outcomes (Weich and Prince 2003).

4. Periodic examination of participants may influence their behaviour.

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11. "SCHIZOPHRENIA"

11.1. LABELS

The variety of experience with schizophrenia can be seen in the fact that one-third of individuals do not respond to medication, and less than one-fifth have full symptom remission within five years of onset of first psychotic experience (Brennand et al 2014).

The language used to diagnose an "illness" is more than just a convenient label, especially in the case of "mental illness". The name given to a condition is a "signifier" (Barthes 1977). Signifiers, however, "are not simply a neutral reflection of some self-evident reality. Instead, although it may appear that their meaning is anchored by their relationship to some phenomenal entity, their power to signify may actually derive from their positioning relative to other signifiers within a wider chain of signification. This chain may operate so as to 'divide reality' in a certain way and thereby impose a particular order onto what is signified and 'naturalise' this as a culturally embedded and taken-for-granted way of making sense of the phenomenal world" (Tew 2017 p111).

Derrida (1967) emphasised that the meaning of a signifier is seen "both how it differed from other related signifiers within its discursive context, and how it deferred to a history of pre-existing meanings" (Tew 2017 p111).

Concentrating on the label/signifier "schizophrenia", Tew (2017) argued that "'society can very well refunctionalise it' [Barthes 1977], thereby accruing a range of other connotations, including ones which serve to stigmatise and construct people as 'other', or to justify policies of segregation or compulsory treatment" (p112). An individual's self-identity and their relationships with others are also "powerfully influenced" by the label. While, on the positive side, "schizophrenia" "can operate as a social permission to be distressed and to be relieved of excessive responsibility – and many people describe a sense of relief when they receive a formal diagnosis. It can provide 'a means for people to externalise their problems rather than feeling that they [are] personally responsible for them' [Pitt et al 2009]. Craddock and Mynors-Wallis [2014] suggest that it may provide reassurance 'that their situation is not unique', and perhaps more controversially, that their experience is no longer 'mysterious or inexplicable'" (Tew 2017 p112).

Modern psychiatry with the emphasis on the biological basis to mental illness anchors signifiers with the promise that soon the genetic and/or physiological basis will be found by researchers (Tew 2017).

Larkin et al (2017) speculated about if schizophrenia were cancer to highlight the differences between the services available for the two conditions. They stated: "Adverts from cancer charities talk about human-kind pulling together to beat the disease – if we support each other, or if we collaborate to raise money for research and treatment, for example... By contrast, campaigns from mental health charities focus on encouraging the individual with the mental health difficulties to talk about their experiences (such as in the 'Time to Talk' campaign). The emphasis seems to be less on 'cure' and more on individual responsibility" (Larkin et al 2017 p119).

In terms of parity between services for physical illness and mental illness/disabilities, and the position of these conditions in society, Bartlett (2017) finds himself in a "rather bleak place" - "It is impossible to look at the current system regarding mental disability without profound dismay. It is not at all clear that we have successfully integrated people with mental disabilities into our communities" (p133).

11.2. SELF-STIGMA

Referring to individuals with mental disorders, Morris et al (2018) commented that "for some, the burden of stigma actually outweighs that of the illness" (p169). This stigma can also be experienced by family members [36], particularly with self-stigma (or internalised stigma). This is "a process whereby affected individuals endorse stereotypes [...], anticipate social rejection, consider stereotypes to be self-relevant, and believe they are devalued members of society" (Livingston and Boyd 2010 quoted in Morris et al 2018). Such self-stigma can cause negative consequences for the mental health of relatives (eg: suicidal thoughts) (Morris et al 2018).

Morris et al (2018) developed a measure of self-stigma among relatives of individuals with serious mental

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[36] "Courtesy stigma" (Angermeyer et al 2003) or "stigma by association" (Morris et al 2018).

illness (eg: schizophrenia) called the "Self-Stigma in Relatives of people with Mental Illness Scale" (SSRMI).

The researchers began with six semi-structured group interviews with relatives, and 130 quotes were ascertained as relevant. These quotes were divided into five areas (table 11.1), and 74 items were found from them These items were presented to eleven close relatives and thirty items emerged for the pilot SSRMI.

Two hundred relatives completed this questionnaire at two points in time (one month apart). Full data were available for 169 individuals. The data were approximately normally distributed, and about a quarter of respondents scored about the mid-point.

The researchers pointed out that "the SSRMI is the first and only self-stigma measure to be developed with direct input from family members to specifically and comprehensively measure self/internalised stigma among first-degree family members of individuals with mental illness" (Morris et al 2018 p173).

- Stereotyping - undesirable characteristics assumed to be held by all members of a group.
- Separation - family members see themselves as different to other people (leading to feelings of, for example, isolation).
- Devaluation - emotional response (eg: feelings of shame; anger).
- Culpability - feeling responsible for family member's mental illness (eg: blame; guilt).
- Status loss/discrimination - feeling of moving downwards in status hierarchy.

(Information from Morris et al 2018 table 2 p171)

Table 11.1 - Core components of self-stigma.

11.3. RESEARCH METHODS

Different methods have been used to study schizophrenia (table 11.2).

Chen et al (2006) admitted: "Although it is impossible to recapitulate the full spectrum of schizophrenia symptoms in animal models (appendix 11A), hypothesis-driven genetic mouse models have been successful in reproducing several schizophrenia-like behaviours and uncovering the roles of specific genes in dopamine and glutamine neurotransmission systems in mediating schizophrenia-like behaviours" (p1180).

Mouse models have been used in different ways including (Chen et al 2006):

Method	Main advantage	Main disadvantage
Human post-mortem	Manipulate brain (eg: cut sections) without consequences	Confounded by patient history
Neuroimaging	See live brain "in action"	Requires individual to be inside scanner
Animal studies	Interfere with brain in way unacceptable with humans	Applicability to humans
Cell cultures (eg: hiSPC)	Live human neurons studied	Individual cells may react different to networks inside the brain

(After Brennand et al 2014 table 1)

Table 11.2 - Main methods used to study schizophrenia.

- Abnormal neurodevelopment - eg: cortical development.

- "Candidate genes" - eg: brain-derived neurotrophic factor (BDNF) related.

- Hyperdopaminergic hypothesis - ie: excess dopamine (eg: dopamine transporter (DAT) knockout mouse [37]).

- Hypoglutamatergic hypothesis - ie: low glutamate levels (eg: calcineurin knockout mouse).

- Susceptibility genes - eg: catechol-o-methyltransferase (COMT) gene.

"Schizophrenia is a polygenic disease likely related to complex gene-gene and gene-environment interactions. Genetic mouse models with single gene mutations do not address the interactions among susceptibility genes" (Chen et al 2006 p1185).

Brennand et al (2014) outlined the benefits of human induced pluripotent stem cells (hiPSCs) for studying schizophrenia. HiSPCs are adult (skin) cells that can be "reprogrammed" to become different types of cells, and thus used for modelling complex genetic conditions like schizophrenia.

This is useful because schizophrenia has been linked to aberrant activity in certain brain cells (eg: midbrain dopaminergic neurons) (Brennand et al 2014).

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[37] Knockout mouse are genetically engineered to lack a certain gene.

11.4. APPENDIX 11A - ANIMAL MODELS IN MENTAL HEALTH RESEARCH GENERALLY

Milton and Holmes (2018) justified the importance of mental health research: "Mental health disorders now account for more than 15% of the disease burden in developed countries, more than all forms of cancer. Even our best mental health treatments demand improvement — for example to increase the proportion of patients who achieve a clinically meaningful reduction in symptoms or full remission. Mental health science has an important role to play in improving treatments of all types, whether psychological, pharmacological or their combination" (p2).

One way to do this is by basic and clinical science working together. For example, a theory about animal learning that is translated into a therapy for humans as in Pavlov's classical conditioning work which is the basis of exposure therapy for phobias.

Another example of translational research is the rodent work on memory reconsolidation (eg: Nader et al 2000), and its application in programmes to help individuals with post-traumatic stress disorder (PTSD). But "some aspects of mental health disorders — such as the experience of involuntary intrusive memories of a traumatic experience, or 'flashbacks' in post-traumatic stress — may not be readily amenable to study in rodents" (Milton and Holmes 2018 p2).

Animal models can be useful in "their simplification of complex phenomena into underlying components that can be more readily understood", as in substance abuse disorder and drug addiction, which is "the result of a number of dysfunctional psychological processes, some of which predate drug use and others which are the result of drug toxicity" (Milton and Holmes 2018 p3). For example, Huang et al (2018) highlighted dysfunction in the thalamus in addicted patients, and in animal models of the disorder, which manifests in salience attribution, say (ie: the tendency to link all cues to the drug) (Milton and Holmes 2018). This type of work is sometimes called backtranslational research (ie: testing a clinical observation in an animal model) (Milton and Holmes 2018).

A transdiagnostic approach, meanwhile, is the same animal finding that can be applied to two psychiatric conditions (Milton and Holmes 2018). For example, a particular knockout mouse model of compulsive grooming showed changes in neurochemistry relevant to obsessive-compulsive disorder and food addiction (Wood et al 2018).

Milton and Holmes (2018) added a note of caution: "mental health disorders are complex and heterogeneous, and that individual animal models should not be 'reified' as fully encapsulating a mental health disorder. We need to be honest about what our favoured models really are, and are not, modelling" (p4).

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12. SUICIDE IN TWO DIFFERENT SITUATIONS

12.1. PILOT EXTENDED SUICIDE

"Extended suicide" is murder-suicide where an individual kills others before themselves, as in public shootings or suicidal pilots of passenger aeroplanes (Gunn 2017).

A recent example of the latter is the crash of Greenwings flight 9525 in March 2015 that killed 150 passengers. It was caused by co-pilot Andreas Lubitz, who had a history of depression (Maden 2017).

The Interpersonal Theory of Suicide (Joiner et al 2009), for instance, describes three factors that come together in suicide (Maden 2017):

- "Thwarted belongingness" - Feeling rejected and/or not part of a desired group.

- "Perceived burdensomeness" - See themselves as burden to others.

- "Acquired capability" - "purposeful exposure to traumatic situations to reduce one's innate fear of death" (Maden 2017 p389).

Maden (2017) wondered: "Lubitz's suicide per se may not be particularly difficult to understand and had he chosen a less destructive method it would not have made world news. His decision to take 149 strangers with him is more complex" (p390).

The characteristics reported in studies of murder-suicide include (Maden 2017):

- Depression (Eliason 2009).

- A significant precursor (Palermo et al 1997) (eg: recent separation by Lubitz and his girlfriend; Maden 2017).

- Unemployment and financial issues (Bossarte et al 2006) (eg: Lubitz fearful of losing his pilot's licence because of worsening eyesight; Maden 2017).

- Revenge for perceived grievance (as a feature of narcissism).

- A "special opportunity" to do the behaviour (Maden 2017).

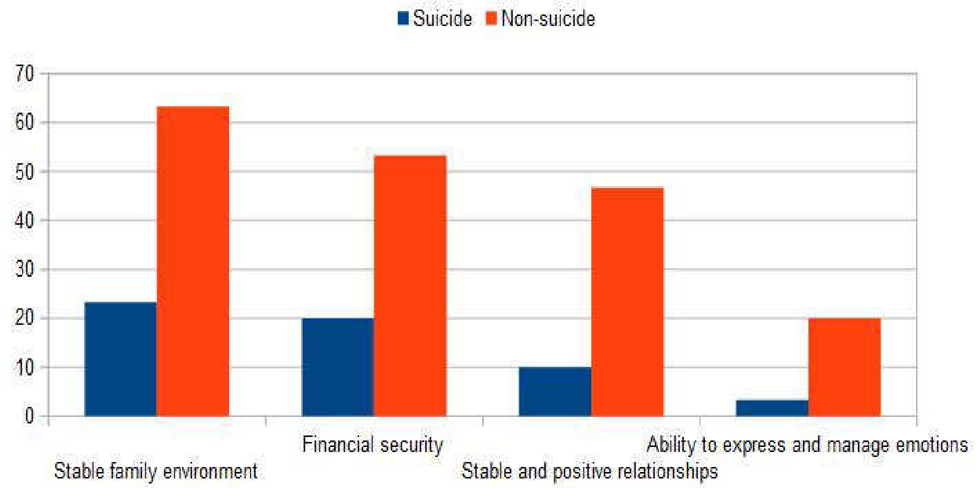
12.2. SUICIDE AND INDIGENOUS GROUPS

There are higher rates of suicide in Aboriginal communities than in their country's general population in Canada, New Zealand, Australia, and the USA (Beaudoin et al 2018). For example, in Canada, the suicide rate in the Aboriginal population is three times higher than the general population (around 30 per 100 000 vs around 11 in the early 21st century), and even higher among the Canadian Inuit in Nunavut (127.1 per 100 000 in 2013) (Beaudoin et al 2018).

"As individuals attach great importance to elements of their environment (people, land, animals), historical events that led to the destruction of the land, territorial appropriation, relocation of certain communities, changes in governance, physical inactivity, and spatial restrictions are believed to have contributed to weakening the integrity of communities and individuals" (Beaudoin et al 2018 p2).

Beaudoin et al (2018) concentrated on the protective factors in a study of 120 suicides between 2003 and 2006, and 120 controls in Nunavut. From medical and other records, scores were given for the presence of 33 variables from six groups of protective factors (eg: positive family ties; cultural pride and identity).

People who never attempted suicide had significantly more protective factors than those who had committed suicide. In particular, stable family environment, financial security, stable and positive relationships, and able to express and manage emotions, for instance, were more common in the non-suicide group (figure 12.1). "The results showed that there was no significant difference between groups for the variables referring to enculturation and cultural identity (traditional language, traditional activities, and cultural pride/identity). According to the literature, it seems that the relationship between enculturation and the mental health of Aboriginal individuals is complicated and the results of this study could be explained by the complex nature of this relationship" (Beaudoin et al 2018 p11).



(Data from Beaudoin et al 2018 table 4 p9)

Figure 12.1 - Percentage of suicides and non-suicides showing selected protective factors which are significantly different between the two groups.

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13. PARENTING BOOKS DON'T REALLY HELP

Burkeman (2018) described the vast number of parenting advice books as loosely divided into "two opposed camps". The "Baby Trainers" "who urged us to get our newborn on a strict schedule as soon as possible", and "Natural Parents" "for whom all schedules... were further proof that modernity had corrupted the purity of parenthood" (Burkeman 2018 p10).

Interestingly, different cultures around the world have baby-rearing practices that would not fit either type of (Western) advice book approaches. For example, among one West African group mothers are strongly discouraged from eye contact with their child, but this has no long-term negative consequences (Burkeman 2018). This has led some to reject all advice books: "Our mistake... isn't one of employing the wrong techniques, but of thinking in terms of techniques at all - in imagining that anything as complex as a relationship between humans could be reduced to a set of consciously manipulated variables" (Burkeman 2018 p11).

Ultimately, Burkeman (2018) argued that "baby advice isn't only about raising children: "Rather it is a vehicle for the yearning that if we could only track down the correct information and apply the best techniques, it might be possible to bring the terrifying unpredictability of the world under control, and make life go right. It's too late for us adults, of course. But a brand-new baby makes it possible to believe in the fantasy once more" (p10).

"First time mothers must transition from an independent life to one that incorporates being a mother" (Harries and Brown 2017 p1). Many such women have little experience with newborns (eg: three-quarters have never held a newborn; Oakley 1992). "Many feel significant pressure to get it 'right' and to be a 'good mother'..., especially in a society that can be critical of mother's approach to infant care... Mothers are often held responsible for the health and development of their child, with a belief that these early interactions are often deterministic in affecting the child" (Harries and Brown 2017 p1).

"Infant parenting books", as one source of advice to help mothers, tend to be "infant-led" (ie: respond to infant's needs), "parent-led" (ie: promoting parent-led routines), or "ambivalent" (Harries and Brown 2017).

Harries and Brown (2017) investigated the experience of new mothers who used "infant parenting books". Three hundred and fifty-four mothers of infants less than one year old in the UK completed questionnaires. These included measures of parental stress, depression, and maternal self-efficacy (ie: confidence in own mothering ability).

Over half (53%) of the women reported feeling anxious after reading the books, while one-quarter (24%) were made to feel "like I am doing it 'right'". Those mothers who read strict parent-led books had significantly higher depression scores than individuals who had not read any books, and reading more books was associated with higher depression scores.

Reading any type of these books was associated with stress compared to not reading, and the number of books read correlated with parental stress, except when the mothers perceived the books as having a positive impact. Reading the books was also associated with lower self-efficacy.

Harries and Brown (2017) summed up: "Overall, the findings showed that reading these books was associated with lower well-being including increased postnatal depression symptoms, higher parenting stress, and lower self-efficacy. However, on closer inspection of the findings, the maternal experience played a significant role. If mothers read these books and found them a positive and useful tool, well-being was higher, whereas those who found them not useful or a negative experience had lower well-being" (p7).

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14. INTERNET GAMING DISORDER

DSM-5 (APA 2013) includes a potential psychiatric condition called "Internet Gaming Disorder" (IGD). It is a contested concept - for example, is it akin to a substance abuse disorder, or to an impulse control disorder (Weinstein et al 2017)?

Weinstein et al (2017) investigated IGD with a US online sample of 5777 adults recruited via the YouGov website [38]. Data were collected at two points six months apart between October 2015 and March 2016. Of the sample, 2316 individuals played Internet games at both data collection points.

IGD was scored by a nine-item checklist (previously used by Przybylski 2016) - eg: "I felt moody or anxious when unable to play"; "I felt that I should play less but couldn't" [39]. Endorsement of five or more items is taken as IGD, which was 1.5% and 1% of participants at the two points in time. "Contrary to expectations, none of the participants who met the diagnostic threshold, that is, endorsed five or more items and experienced distress as a result of their game use at the start of the study also did so at follow-up. This unexpected result suggests formal diagnoses might not be stable over time" (Weinstein et al 2017 p11).

An alternative view on online gaming comes from South Korea. The concern is lack of sleep, and the negative consequences from that, for young online gamers. In November 2011, the government legalised the blocking of access to online games between 12 and 6 am for under 16s ("shutdown policy") (Lee et al 2017).

The policy has received criticisms including the ability to circumvent it by using an adult's account, for instance,; the rights of the individual; and the fact that it is "not the ultimate solution to alleviate Internet or online game addiction or lack of sleep duration" (Lee et al 2017 p1578).

Lee et al (2017) investigated the shutdown policy and sleep by analysing data from the Korea Youth Risk Behaviour Web-based Survey covering 13 to eighteen year-olds in 2011 and 2012.

The shutdown policy was calculated to increase sleep duration by an average of 1.5 minutes per night overall (but 2.7 minutes for females). Surprisingly, hours of Internet use increased for under sixteens after the policy was implemented, but it did reduce the possibility

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[38] Previously studies (eg: Pontes et al 2014) tended to use volunteers from online gaming forums.

[39] Other measures were completed on the frequency of Internet gaming, health, and psychological and social aspects of their lives.

of Internet addiction by forcing the individuals to stop their use at night. None of the findings were statistically significant.

Two key limitations of this study were:

- The question asked was about number of hours on the Internet, and this was taken as a proxy for online gaming hours.

- Because data collected by another research project were used, there was no information on timing of Internet use in the day.

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15. FEMALE GENITAL MUTILATION AS A CRIME IN EUROPE

Female genital mutilation (FGM) is practised in many countries (eg: thirty in Africa), but is viewed negatively around the world, "being an object of a global prohibition regime" (Johnsdotter and Mestre i Mestre 2017). "Transnational moral entrepreneurs" (Nadelmann 1990), in the form of governmental and non-governmental organisations, have attempted to stop it.

In the West, there are stories of FGM among particular migrant or ethnic minority groups (eg: 2016 BBC News story of "FGM parties" in England; "girls are mutilated on the kitchen table" - Italian story) (Johnsdotter and Mestre i Mestre 2017). The accuracy of such stories is difficult to establish, and Johnsdotter and Mestre i Mestre (2017) tried to do so using court cases and European Commission data.

Johnsdotter and Mestre i Mestre (2017) applied Loseke's (2003) concept of "social problem" to FGM. A "social problem" is about "conditions that we believe are troublesome, prevalent, can be changed, and should be changed" (Loseke 2003 quoted in Johnsdotter and Mestre i Mestre 2017). "Objective conditions must be infused with meaning; they must be explicitly described as troublesome and as being situations that ought to be changed for the better. To put it simply, a social problem does not exist until it is defined and widely accepted as such" (Johnsdotter and Mestre i Mestre 2017 p15).

FGM in Europe has been defined as a "social problem" by experts, including activists and academics, since the 1980s. The process can be seen as having four stages, according to Andreas and Nadelmann (2006):

1 - A behaviour is widely accepted.

2 - Influential groups recommend banning of the behaviour.

3 - Suppression of the behaviour (and local criminalisation).

4 - International criminalisation of the behaviour.

"Very few people in Europe have personal experience of illegal circumcision of girls" (Johnsdotter and Mestre i Mestre 2017 p16). During the 2nd stage above, terms like "girls at risk" are used when actual cases cannot be found. "The usual method for calculation of the number of 'girls at risk' is to see how many girls in a European country have parents originating from countries where female circumcision is practiced, and to multiply that number with the prevalence percentages among the populations in the concerned African countries... Such calculations have been used in anti-FGM campaigning in ways that remind about processes labelled 'moral panics' ... because of the tendencies to exaggerate the scope of a problem. In short, a moral panic is characterised by a fear or a concern that is out of proportion to the actual threat posed by the behaviour, or supposed behaviour, of a certain group of people" (Johnsdotter and Mestre i Mestre 2017 p16).

In terms of court cases related to FGM as a criminal behaviour in Europe, Johnsdotter and Mestre i Mestre (2017) noted fewer than fifty (most from France in the 1980s and 1990s).

Johnsdotter and Mestre i Mestre (2017) distinguished the court cases as:

i) Fitting the stereotype of illegal FGM in Europe (eg: "kitchen table circumcision") - A practitioner from the "home country" is called to perform FGM (eg: Somali parents in Switzerland in 2008). "In sum, there is evidence from Switzerland, Italy, and France that illegal circumcision of girls has occurred on European soil" (Johnsdotter and Mestre i Mestre 2017 p17).

ii) Not fitting the stereotype - eg: an obstetrician in the UK stitched an already circumcised woman during delivery, but he was acquitted in the only FGM criminal case in that country (Johnsdotter and Mestre i Mestre 2017).

iii) Circumcisions performed in African countries - One stereotype is the "school holiday mutilation", where children are taken back to their parents' home country for FGM.

This was the bulk of recent criminal cases in Europe, and involved "European African parents' failure to protect their daughters from circumcision during stays in Africa" (Johnsdotter and Mestre i Mestre 2017 p21). For example, a Spanish-Gambian mother whose daughter was circumcised by the grandmother's authority despite the mother's opposition. The mother was acquitted in a Spanish court (Johnsdotter and Mestre i Mestre 2017).

Johnsdotter and Mestre i Mestre (2017) noted "a discrepancy between public discourse and what can be concluded after assessing the court cases. The key question would be how to explain the scarcity of criminal court cases given that allegedly concerned immigrants in Europe amount to many millions. Is it the case that all European states fail; that the legal systems are not efficient enough?" (p21). These researchers answered that the lack of court cases "should be seen not as 'the tip of an iceberg' but as evidence that migration - and perhaps absence of the social pressure of the home communities - leads to a general abandonment of this practice and to new parental strategies" (Johnsdotter and Mestre i Mestre 2017 p21).

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16. FRIENDSHIPS AND ALCOHOL

16.1. FRIENDSHIPS CONSTITUTED THROUGH ALCOHOL

There is talk about "new forms of relationships" in the 21st century (eg: liquid love"; Bauman 2003). "Friendship offers a haven against an increasingly globalised and impersonal social world, lending us a sense of ontological security or stability in how we understand ourselves. Friendships are characterised by intimacy and trust and have become the 'central coordinates' (Pahl 2000) of our lives" (MacLean 2016 p94).

Friendships are different to other relationships in that "there are no rules or contracts to bind us to our closest friends, we simply have to trust them" (Pahl 2000 quoted in MacLean 2016). This means that "friendship-making practices" are required to build trust and intimacy. But there is a balance between respecting the individual autonomy of friends and caring for them. Managing this tension is one of four friendship-making practices that MacLean (2016) discussed in her study. The others being: producing and affirming intimacy, demonstrating trust, and establishing the parameters of the relationship.

MacLean (2016) explored these practices, in relation to alcohol consumption on nights out, in interviews with sixty 18-24 year-olds in Melbourne, Australia.

i) Producing and affirming intimacy - "Drinking alcohol together seems to enable friends to affirm their relationships through generating a different sociality to that which is possible when sober" (MacLean 2016 p96). One aspect of this was "keeping up" with others in terms of drinks consumed (ie: state of intoxication), as in "Thanh's" comment: "When you keep on drinking with your friend and you not stop, it's like I feel loyalty to my friend, close to them, yeah" (p97).

ii) Demonstrating trust - Paying attention to friends' whereabouts and well-being was important - eg: "Honey" stated: "Getting home is a big thing. If someone is quite drunk you know everyone will watch them and make sure that it's okay. Yes we really look out for each other" (p98).

While "Sol" said: "We encourage people to get drunk, but once someone gets drunk we will help them, like take care of them. Like you know, make sure he doesn't do anything stupid. Like you keep an eye on him, make sure he gets back home. So that's kind of nice. That's why we actually hang out, like why we go out together instead of just going out alone" (p99).

But this trust can be betrayed if a friend "hooked up" with someone, as "Emma" lamented: "The shit thing was that she left me by myself in the street; I had no one to go home with and I was really scared" (p99).

iii) Establishing the parameters of the relationship - Agreements were made beforehand about the care provided (eg: call on mobile phone if separated). "Amy" described some of the "rules": "It's like: 'Don't let me go home with someone; you don't go home with someone. If someone seems like they're pestering you, come over'... 'Don't go to the bathroom alone, don't leave the club without, you know [telling me]... Don't leave your drinks [where they could be spiked]'" (p100). These aspects were more specific to women friends than men.

iv) Managing tension between autonomy and responsibility - Accepting "Amy's" rules, disputes can arise about them. The right to tell a drunken friend to go home was a tightrope, and "Emma" reported long periods of not talking with friends after disputes. Intervening when a friend had "hooked up" was another issue. "Clara" admitted about her friend "Fleur" who had "hooked up" despite agreeing beforehand not to: "You generally just let them get on with it, if it doesn't seem too dangerous. Yeah, it's hard to stop someone when they're drunk" (p101).

MacLean (2016) summed up: "The provision of care is both a responsibility of friendship and also a point where friendship can be damaged. This is further complicated by dissonance between the desires of the sober and drunken selves that friends are caring for. Many participants were anxious not to intervene to protect a friend's safety in a way which might be perceived as intrusive. Conversely, others were angry and hurt that care which was due from a friend was not provided. Friendships were also eroded when people felt that responsibilities had become burdensome, for example when someone repeatedly became so drunk as to ruin others' nights" (pp102-103).

16.2. BENEFITS OF RELATIONSHIPS

Feeney and Collins (2015) outlined the model of "thriving through relationships" to explain how relationships promoted well-being (eg: psychological, social and physical). "Thriving" is an optimal state of well-being and personal growth which relationships facilitate in and out of adversity.

In relation to adversity, Feeney and Collins (2015) noted a "useful metaphor is that houses destroyed by storms are frequently rebuilt, not into the same houses that existed before, but into homes that are better able to withstand similar storms in the future. So too are people able to emerge from adverse life circumstances stronger and better off than they were before with the support of significant others who fortify and assist them in the rebuilding. In this sense, relationships can provide a source of strength [SOS], in addition to a refuge, in adverse circumstances" (p23).

For example, Kane et al (2012) got participants to walk across a dangerous cliff in an immersive virtual world while a romantic partner was present. The partner was either supportive or unresponsive (or absent in the control condition). Participants were less anxious with the supportive partner.

In situations without adversity, the function of relationships is "relational catalyst (RC) support" (ie: acting as catalyst for thriving) - including "nurturing a desire to create and/or seize life opportunities for growth; providing perceptual assistance in the viewing of life opportunities; facilitating preparation for engagement in life opportunities by promoting the development of plans, strategies, skills, and resources for approaching opportunities; and providing a launching function during actual engagement in life opportunities, which includes providing a secure base (being encouraging, available, and non-intrusive) during exploration, supporting capitalisation by celebrating successes and accomplishments, assisting in tune-ups and adjustments (eg: in perceptions, skills, and strategies) as needed, and sensitively responding to setbacks" (Feeney and Collins 2015 pp24-25).

For example, a romantic partner's support for the ideal self helped the individual move closer to that (Rusbult et al 2009).

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17. ORTHOSOMNIA

Around 1 in 10 Americans have a wearable fitness/sleep tracking device, like "Fitbit" (Baron et al 2017). "Despite the growing interest among consumers, sleep professionals have been wary of incorporating these devices into treatment because of low concordance with polysomnography and actigraphy" (Baron et al 2017 p351).

However, Baron et al (2017) noted the increase in individuals seeking treatment over concerns with sleep quality and duration due to the tracking device's information. The researchers coined the phrase "orthosomnia" to describe the preoccupation with improving the sleep data - "ie: "the perfectionist quest to achieve perfect sleep" (Baron et al 2017).

Baron et al (2017) described three case studies to support the concept of "orthosomnia":

a) "Mr.R" - "He stated his average sleep duration was '7 h and 45 minutes' based on the tracker data and that he felt pressure every night to ensure his tracker would display at least 8 h of sleep" (Baron et al 2017 p351).

b) "Ms.B" - In a sleep laboratory she showed a relatively normal pattern of sleep, but afterwards she asked: "Then why does my Fitbit say I am sleeping poorly?".

Her "belief that she was not getting enough 'deep sleep' was unchanged even after seeing data from her in-laboratory polysomnogram. It is well known that laboratory studies are often different than sleep at home. However, most studies demonstrate worse sleep in the laboratory (ie: the 'first night effect' [Agnew et al 1966]). There have also been reports of 'reverse first night effects' [Hauri and Olmstead 1989] and data suggesting that objective sleep parameters are worse at home among individuals with bed partners... With Ms. B, the clinician hoped that she would be reassured that she was indeed receiving deep sleep, in fact higher than average for her age. However, her belief persisted" (Baron et al 2017 p353).

c) "Mr.S" - Paid more attention to his sleep tracker than the advice of the medical professionals to change his sleep schedule to help with his sleep problems.

Baron et al (2017) pointed out that their case studies showed how sleep trackers may "reinforce sleep-related anxiety or perfectionism for some patients". All the individuals trusted the sleep tracker despite concerns about their accuracy by sleep researchers. "For example, all three patients were spending excessive time in bed in attempts to increase the sleep duration reported by the sleep tracker, which may have exacerbated their insomnia. Given that these devices tend to overestimate sleep, they may have served to reinforce poor sleep habits by encouraging extending time in bed" (Baron et al 2017 p353).

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18. PRE-CONCEPTION HEALTH AND THE PERI-CONCEPTIONAL PERIOD

18.1. PRE-CONCEPTION HEALTH

Stephenson et al (2018) proposed that the pre-conception health (PCH) of the mother is key to not only pregnancy success, but the health of the offspring. The 2-3 months before and after conception is "a critical period for optimising gamete function and early placental development" (Stephenson et al 2018).

Folic acid supplementation, for example, is beneficial during this period (eg: decreased risk of low birth weight, miscarriage, and neonatal death) [40], while materno-fetal (mother and child) iron deficiency is a risk (eg: impairment to foetal brain development) (Stephenson et al 2018).

PCH is focused on three aspects (Stephenson et al 2018):

i) Maternal body composition - underweight and overweight.

Maternal obesity has been associated with inability to conceive, complications of pregnancy (eg: gestational diabetes) and delivery, birth issues (eg: low birth weight), and even maternal death. Paternal obesity is not irrelevant (eg: impaired sperm quality). "The cumulative effect of maternal and paternal obesity on the risk of obesity in future generations has been proposed by several studies and causal pathways involving interaction between genetic, epigenetic, and environmental factors are emerging" (Stephenson et al 2018 p2).

In a Canadian study with over 200 000 women, Schummers et al (2015) showed a pre-conception weight loss of 10% of body mass index for obese individuals reduced the risk of pregnancy issues like stillbirth, and gestational diabetes. The risk of the latter was also reduced by exercise in the pre-conception period (eg: four hours or more of brisk walking per week; Zhang et al 2006).

ii) Maternal nutrition and diet - Deficiencies in

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[40] In a Chinese study, folic acid supplementation three months before pregnancy was associated with significantly lower risks of low birth weight (odds ratio: 0.74), miscarriage (OR: 0.53), and stillbirth (OR: 0.70), for example (He et al 2016).

micronutrients (vitamins and minerals) is a problem in poorer countries through nutritional undernourishment, but also in richer countries with a "processed diet" (eg: refined grains and sugars) (Stephenson et al 2018).

Data from the UK National Diet and Nutrition Survey (Bates et al 2014) showed that "many women of reproductive age will not nutritionally prepared for pregnancy, since they do not meet even the lower reference nutrient intake (RNI) amounts" (Stephenson et al 2018 p3) (eg: 77% of 18-25 year-olds below daily RNI for iodine).

In fact, diet up to three years before pregnancy can be relevant (eg: Australian Longitudinal Study on Women's Health; eg: Gresham et al 2016).

Stephenson et al (2018) summed up that "interventions to improve diet in pregnancy lead to modest reductions in gestational weight gain, but (with few exceptions) they have not improved important maternal or newborn health outcomes. Micronutrient supplementation starting in pregnancy can correct important maternal nutrient deficiencies with modest effects on increasing birth weight, but no subsequent improvement in child health outcomes" (p6).

iii) Maternal lifestyle - eg: smoking. Reduction during pregnancy is beneficial. In terms of reduction pre-conception, Stephenson et al (2018) reported no specific evidence, but "indirect evidence of the effect at population level comes from introduction of smoke-free legislation in different countries, which has been associated with substantial reductions in pre-term births" (p4).

The pre-conception period is usually defined as the three months before conception (ie: the average time to conception for fertile couples; Stephenson et al 2018) in most studies. Occasionally, one year prior to initiating unprotected sex is used, but this is difficult in practice (Stephenson et al 2018).

Stephenson et al (2018) suggested a combination of three definitions:

- A biological perspective: weeks around conception;
- An individual perspective: "whenever a woman or couple decides they want to have a baby" (Stephenson et al 2018);
- A public health perspective: relevant sensitive phase in the lifecourse - adolescence.

Ultimately, a healthy diet and lifestyle is the answer.

Barrett et al (2015) distinguished three groups of women in relation to PCH:

- High levels of pregnancy planning and uptake of interventions, like supplementation schemes;

- Pregnancy planning, but little awareness of PCH;

- "women for whom the pre-conception period has little meaning" (Stephenson et al 2018).

The Southampton Women's Study (Dodd et al 2014) in England found that level of education was important here. It suggested that "more educated women might improve their diet once a decision has been made for pregnancy but less educated women do not, highlighting the effect of disadvantage on the ability of women to change their behaviours" (Stephenson et al 2018 p8).

This also assumes pregnancy planning as opposed to unplanned pregnancies, or women lacking control of contraception or choice. Two measures used here are the London Measure of Unplanned Pregnancy (LMUP) (Barrett et al 2004), and the Desire to Avoid Pregnancy (DAP) (Rocca et al 2016).

Barker et al (2018) argued for strategies to improve health of men and women planning pregnancy, and the general population as a whole in order to benefit PCH. The authors reviewed fourteen studies around three strategies:

i) Supplementation and food fortification - This involves providing energy supplementation (ie: extra food) and micro-nutrients to undernourished women. For example, in Taiwan, undernourished women who were given an extra 800 kcal and 40 g of protein per day extra after the birth of their first baby had an increase in heavier second babies than controls (McDonald et al 1981).

ii) Cash transfers and incentives - This strategy has not been used directly for PCH, but it has improved school attendance among girls, and household food consumption, for instance, which indirectly affects PCH (Barker et al 2018).

iii) Behaviour change intervention - eg: alcohol consumption and smoking. In an Australian study (Lumley and Donohue 2006), doctors counselled couples planning pregnancy on risk factors for low birth weight. The researchers "speculated that improved pre-conception health meant that previously unsustainable pregnancies were sustained for longer, resulting in increased preterm births and decreased birth weights. If true, this would be an unexpected and adverse effect of preconception intervention" (Barker et al 2018 p3).

Barker et al (2018) noted a problem with pre-conception interventions in that they "often require engagement from individuals who are not thinking about becoming pregnant in the near future, and are unlikely to be using maternal health services. Interventions to improve health behaviours in adolescents and young adults might, therefore, have to be placed outside maternal and child health services and appeal to motivations unrelated to health, such as self-image" (p3). Ultimately, laying the foundations for a healthy life in adolescence would help. This is the first phase of four phases where interventions could be targeted (Heckhausen 1991). The other opportunities for improving PCH are with adults with no immediate intention to become pregnant, adults intending to become pregnant, and those intending to become pregnant again (table 18.1) (Barker et al 2018).

- 1. With adolescents - Ntshembo intervention in rural South Africa to reduce obesity among 14-19 year-olds (Bhutta et al 2017).

- 2. With adults not immediately intending to become pregnant - Jom Mama project in Malaysia added pre-conception nutrition advice to pre-marital HIV screening and wellness programmes for pre-marital and newly married couples (Norris et al 2016).

- 3. With adults intending to become pregnant - "Smarter Pregnancy" (van Dijk et al 2011): digital programme.

- 4. With adults intending to become pregnant again - "Fit Moms" ("Mamas Activas") with low-income women to help weight loss in California (Poston et al 2017).

Table 18.1 - Examples of interventions to improve PCH at different phases of life.

18.2. PERI-CONCEPTIONAL PERIOD

The "Developmental Origins of Health and Disease" concept (Hanson and Gluckman 2014) suggests that "poor developmental experience can increase the risk of non-communicable diseases in later life, including cardiovascular and metabolic co-morbidities (such as hypertension, obesity, and type 2 diabetes), atopic conditions [eg: eczema], cancer, and neurological impairment" (Fleming et al 2018 p1). The few weeks around conception, known as the peri-conceptional period (PCP), is key, and the "peri-conceptional parental influences could have particular and differing effects on male and female offspring" (Fleming et al 2018 p2).

Fleming et al (2018) outlined the influences during the PCP:

i) Maternal overnutrition and obesity - eg: high maternal body mass index and childhood obesity.

In experiments with mice, obese mothers had small foetuses and pups which overgrew and became overweight later (Jungheim et al 2010). While in sheep, female embryos of obese mothers transferred to non-obese mothers still became obese (Nicholas et al 2013).

"Why might the peri-conceptional period be causal for obesity-related conditioning? Obese women have higher circulating concentrations of inflammatory cytokines, and hormones and metabolites, which accumulate within the ovarian follicular fluid and can adversely affect oocyte [egg cell] maturation and potential. Thus, maternal BMI is positively associated with increased follicular fluid insulin, lactate, triglycerides, leptin, and other metabolic regulators" (Fleming et al 2018 pp3-4).

ii) Maternal undernutrition - eg: children conceived during famine have an increased risk of cardiovascular problems and hypertension in adulthood (eg: Chinese Great Famine 1959-61; Wang et al 2012).

Experiments with mice and sheep which deliberately manipulate the maternal diet have confirmed these observations (eg: low protein diet (LPD) for 3-4 days during the PCP, but normal nutrition otherwise) (Fleming et al 2018).

iii) Paternal diet - "both direct (sperm quality, epigenetic status, DNA integrity) and indirect (seminal fluid composition) paternal mechanisms have been identified; in mice these mechanisms have been shown to affect offspring development across multiple generations" (Fleming et al 2018 p5).

iv) Parental contributions - Fleming et al (2018) performed a meta-analysis on three studies with mice that manipulated a LPD. Parental LPD in the PCP increased offspring birth weight by around 8% with the maternal LPD having the greater effect, while only maternal LPD increased offspring hypertension.

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