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Making Sense of Health

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

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1.1. INTRODUCTION

"Lifestyle medicine" (table 1.1) has developed in the second half of the 20th century with its emphasis on the behaviour of the individual. In a historical example, Stewart et al (1955) looked at the lifestyle factors that correlated with stillbirths, and found that obesity was a major risk factor. "This new argument claimed that lifestyles, involving unhealthy behaviours such as excessive food consumption and lack of exercise, created major risks rather than life conditions such as economic inequality" (Porter 2006 p1669).

However, some have focused on environmental explanations, as in, for example, Brownell and Horgen (2004) who see the cause of obesity the "toxic environment of addictive food production, which includes the mass marketing and advertising techniques of the corporate food industry" (Porter 2006).

So, there is a situation of the "obesity wars" (appendix 1A) (Porter 2006), for instance, where environmental explanations (and life conditions) battle with "lifestyle medicine" as the cause.

Pearce (1996) has referred to the shift from traditional epidemiology to modern epidemiology as "the shift in the level of analysis from the population to the

- Behaviour change programmes have the assumption "that people have the power to choose healthy or unhealthy lifestyles, and that they are thus at least partly accountable for their health" (Lucivero and Prainsack 2015 p44). This links to the idea of healthy living or healthy lifestyle, and with the consumerisation of health-related products and services. This includes for individuals "personalised health and diet recommendations on the basis of the micro-organisms inhabiting their bodies, on their blood or on their DNA" (Lucivero and Prainsack 2015 pp44-45).

- Lucivero and Prainsack (2015) referred to a "renegotiation of the boundaries between medical and lifestyle products". They focused on direct-to-consumer genetic testing and mobile health apps, particularly the ambivalent situation of these "products" "being situated between medical devices and consumer products", which "raises challenges related to certification and quality control, reimbursement, liability, and data protection. Moreover, the place of these applications in mainstream healthcare pathways is unclear" (Lucivero and Prainsack 2015 p47).

Table 1.1 - "Lifestyle medicine".

individual" (p678). Consequently, he argued, socio-economic differences in health are rarely considered, except to adjust for social class in statistical analysis. He asserted: "Epidemiology has become a set of generic methods for the measurement of disease occurrence, and there has been a concomitant lack of distinctive theory to permit an understanding of the population patterns of disease occurrence" (Pearce 1996 p679).

Part of the change in epidemiology is the increasing importance of non-communicable diseases, like obesity, in the modern Western world. Thus, risk factor epidemiology" "in some cases led to successful preventive interventions without the need for major social or political change" (Pearce 1996 p680).

Any understanding of disease needs multi-level analysis, as in Millard's (1994) model to explain child mortality rates around the world:

- Proximate tier - Immediate biomedical conditions (eg: infection, malnutrition).

- Intermediate tier - Child care practices and behaviours that expose children to proximate tier factors.

- Ultimate tier - "the broad social, economic and cultural processes and structures that lead to the differential distribution of basic necessities, especially food, shelter and sanitation" (Millard 1994 quoted in Pearce 1996).

1.2. RISK PERCEPTIONS

Risk perceptions (RPs) are "an individual's perceived susceptibility to a threat" (Ferrer and Klein 2015), and they are involved in health decision-making. RPs can be optimistic (ie: low perceived risk) or pessimistic (ie: high perceived risk), which are distinct from, but interact with, optimism and pessimism as personality traits or dispositional characteristics (Ferrer and Klein 2015). For example, optimistic individuals with optimistic RPs minimise threats and are less likely to seek health information (Fowler and Geers 2015).

There is "unrealistic optimism" (Weinstein 1980), which involves perceiving risk as lower than it actually is. There is mixed evidence about the consequences of unrealistic optimism (eg: lower motivation to engage in health protective behaviours versus positive health outcomes) (Ferrer and Klein 2015). Individuals can show unrealistic optimism and unrealistic pessimism at the same time. For example, a high perceived risk of a disease (absolute risk), but a perceived lower risk than other people (comparative risk) (Ferrer and Klein 2015).

Other factors are also important in RPs. For example, engaging in risky behaviour is associated with higher RPs (personal experience), knowing someone with a disease increases the perceived risk (available information), increased media reporting increases perceived risk (salient information), and the immediacy of the threat (context) (Ferrer and Klein 2015).

RPs are often viewed as systematic decisions (ie: "deliberate RPs"), but emotions are involved ("affective RPs") (eg: worry) as well as "experienced RPs" (eg: "gut feeling" of risk) (Ferrer and Klein 2015). "Critically, existing frameworks tend to combine or conflate affective and experiential components, or focus on one over the other as the non-deliberative component... However, evidence suggests these are empirically distinct not only from deliberative components but also from one another" (Ferrer and Klein 2015 p86) [1].

The different aspects can interact in a way that individuals can perceive their risk as high and be worried about it, but are less motivated to engage in preventive or mitigating behaviours. Ferrer et al (2013) found this in a US sample in relation to exercise and five-a-day fruit and vegetable consumption. Worried and high RP individuals also avoided visiting the doctor when they thought they should. "This pattern may emerge

[1] Ariely and Chitus (2016) noted that fear leads to decisions that respond to the now rather than the long-term, more serious concerns.

because high levels of affective and deliberate risk perceptions, in combination, activate specific experiential perceptions related to fatalistic beliefs about disease risk" (Ferrer and Klein 2015 p87).

The understanding of terminology can vary between medical professionals and laypeople. For example, a Wellcome Trust survey [2] in England found that "anti-biotic resistance" was understood as the human body becoming resistant to anti-biotics rather than the bacteria becoming drug-resistant (Mirsky 2016).

1.3. SOCIAL INTEGRATION

Social integration (as opposed to social isolation) improves longevity more than health behaviours like obesity and alcohol consumption reduction, and such individuals have a 50% greater likelihood of survival (Hostinar 2015).

Low social support predicts mortality, including cardiovascular disease (CVD), through biological mechanisms, "not yet entirely understood", and indirectly through less healthy lifestyles (White et al 2015). Also "those living alone may be at increased risk from death to CVD due to lack of social confidantes that may help prompt immediate medical attention when needed (ie: chest pain prompting subsequent activation of emergency medical services. Additionally, social relationships may provide cardiovascular benefit via their roles as stress-buffers. Individuals with adequate social support may perceive strenuous life events as less taxing, reducing physiological arousal and overall allostatic load" (White et al 2015 p19).

In terms of the stress-buffering effects, for example, adults who reported more frequent hugs had less upper respiratory infection after periods of interpersonal tension and conflict than "no huggers" (Cohen et al 2015).

On the other hand, individuals who reported low perceived social support or higher perceived loneliness had stronger negative physiological responses to stressors in a laboratory experiment (Jaremka et al 2013).

Social isolation has a negative impact on the brain and health. For example, rats removed from a social environment for long periods have smaller brain areas, like the hippocampus, while older humans with less social

[2] Details at https://wellcome.ac.uk/press-release/antibiotic-resistance-poorly-communicated-and-widely-misunderstood-uk-public.

integration have faster memory decline than highly socially integrated individuals (White et al 2015).

1.4. INFLUENCES

1.4.1. Influence of Social Network

Health-related decision-making, like decision-making for may social behaviours, is influenced by others. For example, to join a strike or not? "When individuals are asked to participate in protests by someone with whom they have a (personal) connection, the likelihood of participation increases... When individuals must make decisions about participation, they look to their social environment for guidance... People's social networks are the basis of this environment" (Born et al 2016 p58).

A homogeneous network in one direction will either boost or hinder participation in the strike, but a variety of views [3] is more difficult. How do individuals decide when members of their social network have opposing views? One reaction is avoid making a decision (and so not participate), while the similar to or trust of individuals will be influential. In other words, who is for and who is against participation in the network. For example, "friends conform" (Macy et al 1997 quoted in Born et al 2016) - ie: "individuals follow or imitate those to whom they feel attracted" (Born et al 2016). Born et al (2016) found that trust was important in a study of Dutch workers.

1.4.2. Media Exposure

Matthews et al (2016) observed: "As a society we are increasingly exposed to numerous and disparate sources of health information, and it has been shown that this bombardment leads to a lack of clarity about which sources patients and others should trust" (p1).

This uncertainty can be seen with statins and the media coverage of side effects [4]. For example, one article in the "BMJ" (Abramson et al 2013) that questioned the overall health benefits of their use for patients at low risk of cardiovascular disease was among widely reported stories in the popular press.

But does such coverage of the side effects of

[3] Known as "opposing pressures" (Born et al 2016) or "cross-cutting ties" (Santoro et al 2012).

[4] Statins do have reported side effects, most commonly muscles aches, usually in the first six months of treatment (Nielsen and Nordestgaard 2016). A recent review of the evidence found that the efficacy and safety of statins has been established (Collins et al 2016).

statins have an impact upon the use of the drug? [5] [6] Matthews et al (2016) used data from the UK Clinical Practice Research Database (CPRD) from general practitioners to answer that question. The proportion of patients over forty years old starting and stopping statins for each month between January 2011 and March 2015 was calculated. The period of high media coverage was defined as October 2013 to March 2014 after a Google search for stories. So, three time periods were created for comparison - before media coverage (baseline) (January 2011 to September 2013), during coverage, and after (April 2014 to March 2015).

There was no change in initiation of statins (ie: new patients) after media coverage as compared to before for individuals with a high risk of cardiovascular disease (primary prevention group) or among those taking statins after a cardiovascular event (secondary prevention group). Both groups were more likely to stop taking statins after the media coverage, but this was a transient rise of no more than six months [7]. Older individuals, and those with a longer continuous prescription (>1 year) were more likely to stop.

This study used interrupted time series analysis, which "cannot confirm a causal link between the media coverage and the observed changes in the likelihood of stopping taking statins. The design avoids confounding by individual level factors such as smoking and obesity that are unlikely to vary over short term timescales, but it is possible that other external factors played a role in the observed changes" (Matthews et al 2016 p8).

Studies using other methods and in other countries have found similar results. In a Danish study, Nielsen and Nordestgaard (2016) found that patients on their first statin prescription were less likely to get a second prescription if there were negative statin-related stories in the media at the time. The researchers used the data on all individuals in Denmark taking statins between 1995 and 2010 from the Danish Registry of Medicinal Products Statistics, which records all dispenses in Danish pharmacies as all prescription-based medications are subsidised by the Danish government. Two matched groups over 40 years old were distinguished - continued statin use (n = 424 000) and discontinued use

[5] Adherence to statins generally is influenced by factors like perception and understanding of disease, socio-economic status, medical costs, understanding of medical instructions, and transportation facilities (Kocas et al 2015).

[6] The public attitude towards statins is not helped by a software error in the programme that recommends the drug in the UK. The IT company that makes the programme admitted that the risk of heart attack was overstated for some people and understated for others (New Scientist 2016).

[7] Matthews et al (2016) estimated over 2000 excess cardiovascular events over ten years as a consequence (depending on how many "stoppers" re-started statins later).

(n = 84 800). Discontinuation was defined as individuals not having a second dispense of statins in a six-month period (and not due to death). Statin-related news stories from the beginning of 1995 were determined with the search terms "statin", and "cholesterol" and "medicine".

Discontinuation was more likely with increasing negative statin-related news stories. For example, discontinuation was 6% in 1995 when there were thirty stories per year, but discontinuation was 18% when there were 400 stories per year at the end of the study period. The authors concluded: "our data suggest that media exposure during the early period following initiation on statin therapy may play a role in the patients' attitude towards statin therapy and thus the decision to discontinue or continue statin therapy" (Nielsen and Nordestgaard 2016 pp913-914).

In Australia, where a documentary programme was critical of statins, discontinuation of the drug increased in the following week (Schaffer et al 2015; table 1.2), while, in Turkey, there was a negative correlation between number of news stories about statins between 2011 and 2013 and the use of the drug (table 1.3) (Kocas et al 2015). Adherence by over nine hundred coronary patients prescribed statins before 2011 was analysed retrospectively. Number of news stories was based on the Turkish pages of Google in response to the search term "cholesterol drugs" between 2011 and 2013. Statins adherence was calculated as proportion of days covered (PDC) from health insurance records.

A questionnaire study of cardiologists in France (Saib et al 2013) found an increase in reported intention to stop statins by patients after negative media reports about the drug. All patients on statins at three specialist clinics in Paris were recruited over one month in 2013. The cardiologists completed a detailed questionnaire after consultation with 142 patients. Around a quarter of patients talked spontaneously about the controversy over statins during the consultation, and two-thirds were aware of it.

Thirty-seven patients were taking statins as primary prevention and the remainder as secondary prevention. There was no difference between them in awareness about controversy. However, 24% of the former group intended to stop statins compared to 9% in the secondary prevention group.

van Hunsel et al (2009), in Holland, found an increase in patients reporting side effects after a television programme that covered the risks of statins. In March 2007, a television documentary ("Radar") highlighted serious adverse drug reactions (ADRs) by some

- In October 2013 a documentary on ABC television questioned the link between high cholesterol levels and cardiovascular disease, and consequently the benefits of statins. This documentary called "Catalyst: Heart of the Matter" had immediate effects [8]. A survey of over 1000 patients found that 11% of viewers stopped their statins, 12% stopped but later restarted, and 12% reported changing to "natural remedies" (National Heart Foundation of Australia 2013 quoted in Schaffer et al 2015) [9].

- Schaffer et al (2015) used dispensing records from the Pharmaceutical Benefits Scheme (ie: records of subsidised access to prescribed medications) from July 2009 to June 2014 for a 10% random sample of the Australian population. Discontinuation was defined as "the absence of any dispensing for a period of at least three times the number of pills last dispensed (assuming one pill per day) plus a 5-day grace period. Nearly all statin dispensing records (99.5%) were for a 30-day supply; therefore, in most cases, a period of 105 days or more without a statin dispensing record was considered a discontinuation" (p592). Data were analysed per week, and adjusted for seasonal variations.

- After the documentary there was an average 2.6% drop in statin dispensings per week (with a 29% increase in discontinuation in the week of the programme).

Table 1.2 - Schaffer et al (2015).

Year	Number of news stories	PDC (%)
2011	2320	57
2012	6210	58
2013	3070	50

Table 1.3 - Number of news stories and PDC in Turkey.

patients taking statins. The reporting of ADRs are collected by the Netherlands Pharmacovigilance Centre Lareb. Van Hunsel et al (2009) analysed all ADR reports about statins for the period February to December 2007 (ie: one month before and ten months after the programme). There were 265 reports from patients and 111 from health professionals in the five months after the programme. The number of reports peaked in the two weeks after the programme and then returned to the normal level. Thirty patients explicitly referred to the television programme in their reports. For example, one person said: "After seeing the TV show Radar everything

[8] "Many elements of the Catalyst programme's contents were inconsistent with the recommendations of key medical advice about statins and cardiovascular disease and the ABC has since withdrawn the programme, primarily on the grounds that it breached their impartiality standards" (Schaffer et al 2015 p594).

[9] Similar effects have been reported with other documentaries and medications - eg: 2007 programme on problems with osteoporosis in the jaw and biophosphonate (Sambrook et al 2010).

became clear. I had already been going to a physiotherapist for quite a while, with little result. Now I've stopped taking simvastatin and me and my physiotherapist can see the results" (p562).

Edwards (1999) pointed out that "reports from patients and health professionals must be regarded as their concerns, even though they may not be 'clinically validated'" (Van Hunsel et al 2009 p563) [10].

On the other side, exposure to statins (direct-to-consumer) television advertising increased their use (Niederdeppe et al 2013).

Studies have found that individuals are sensitive to well-publicised stories in the popular media, especially when celebrities are involved. For example, in the sex weeks after reports of Kylie Minogue's breast cancer first appeared, there was a two-fold increase in Australian women seeking screening who had never previously sort it (Kelaher et al 2008).

In mid-May 2015 it was reported that Kylie Minogue had been diagnosed with breast cancer, and this sparked a twenty-fold increase in media stories of breast cancer in Australia in the following two weeks (Chapman et al 2005). Chapman et al (2005) also reported that among women aged 50-69 years old, there was a 40% increase in demand for screening among previously screened women and a 101% increase among previously unscreened women.

Kelaher et al (2008) concentrated on the low-risk population (women 25-44 years old) who were demographically similar to Kylie Minogue, who was thirty-six years old at the time. Data were collected on doctor-referred breast imaging (bilateral mammography and ultrasound), image-generated biopsy (fine needle and core breast biopsy and wire localisation of breast lesions), and surgical excision of breast cancer (open surgical biopsy of malignant tumour; complete local excision of malignant tumour; total mastectomy and sub-cutaneous mastectomy) from the Australian universal health insurance programme from 1st January 2004 to 30th September 2006 for 25-34 and 35-44 year-old age groups. Quarterly rates were calculated for each of the procedures.

There was a sharp increase of one-quarter to one-third in doctor-referred breast imaging in the two quarters after Kylie Minogue's news (ie: July-December 2005) from 8 per 1000 women to 12 among 25-34 year-olds, and 21 to 28 in the 35-44 year-old age group. This was not due to an increase in breast cancer because the rate

[10] Another example is the anti-depressant paroxetine ("Seroxat") and stories of severe ADRs in a BBC documentary in 2002. General reports of ADRs increased after the programme (Martin et al 2006).

of cancer detection after screening did not increase. The findings "reinforce existing evidence that both patients and doctors are susceptible to behaviour change in response to celebrity health events" (Kelaher et al 2008 p1330).

One in six articles found by Chapman et al (2005) criticised the Australian government's policy of not screening women under forty years old. Kelaher et al (2008) observed: "The coverage appears to have included very little discussion of the evidence basis for current screening policy, which may have further undermined adherence. Add the demands of anxious patients, and the pressures on doctors to screen may be considerable. Patients must weigh the risk of a late cancer diagnosis against the time, discomfort, exposure to radiation, potential for false positives associated with an unnecessary investigation. Doctors, on the other hand, from a personal standpoint, face mostly downside risk if patients' requests for screening are denied. At a health system level, there is a potentially serious organisation and cost issue: an influx of lower risk women may reduce the capacity of services to deal with higher risk women, particularly if this occurs suddenly and there is no time to plan a response" (pp1330-1331).

Matthews et al (2016) concluded about their research (and the other studies) that there is "the potential for widely covered health stories in the media to have an effect on real world behaviour related to healthcare..." (p9).

1.4.3. Social Media

Social media, like Facebook, has increased the opportunities for patient support groups, particularly for rare medical conditions. For example, the Facebook page for the Cluster Headache Support Group has 98 000 visits per month (Armstrong 2016). Such groups, as well as support, raise awareness, promote products and services, and fundraise (Armstrong 2016).

On the downside, some groups can get "a bit conspiracy based" (Graham Anderson in Armstrong 2016), and there is a risk of "misleading, superfluous, or incorrect information" (Maureen Baker in Armstrong 2016).

Science is full of uncertainty, but in relation to food and health the general public want certainty. This certainty often comes "the latest internet healthy-eating guru" (Warner 2016). For example, the Helmsley sisters, who advocate a diet "free from grains, gluten and refined sugars", or Belle Gibson, who claimed her diet (and alternative medicine) cured her cancer (Warner 2016). In the latter's case, she subsequently admitted fabricating

the cancer (Editorial 2016).

Editorial (2016) observed: "As a society, we seem less protective of our health than our wealth. While aspiring financial advisers are studying to gain proper accreditation, any wellness blogger can pick up a worthless nutritional qualification for a small fee. Pretty much anyone can declare themselves to be a diet expert. And when the only arbiter of authority is popularity, the word 'recipe' can quickly be followed by 'for disaster'".

1.4.4. Wikipedia

About half to three-quarters of doctors and medical students admit to using Wikipedia as a source of health care information (Hasty et al 2014). Studies are divided about the accuracy of Wikipedia, as shown by examples in table 1.4.

AGAINST ACCURATE	FOR
• Key omissions and factual errors for three conditions: otitis media, conjunctivitis, and multiple sclerosis (Pender et al 2009). • Statins (Kupferberg and Protus 2011): "While none of the information was incorrect, much of it was incomplete in ways that could harm patients (a lack of information on drug interactions and on contraindications for the drugs)" (Temple and Fraser 2014 p38). • Not reliable information source for gastroenterology and hepatology (Azer 2014).	• Good quality information but inferior to National Cancer Institute website on osteosarcoma (Leithner et al 2010). • Comparable to psychiatric textbooks for schizophrenia and depression (Reavley et al 2012). • Wikipedia articles roughly equivalent to those in the "Encyclopaedia Britannica" (Giles 2005).

Table 1.4 - Examples of studies for and against the accuracy of Wikipedia articles for medical information.

Comparing the accuracy of factual information in Wikipedia on ten medical conditions to the peer-reviewed medical literature, Hasty et al (2014) (table 1.5) reported significant differences that "cast serious doubt on Wikipedia's authority as a medical reference repository".

- 10 Wikipedia articles chosen on 25 April 2012.
- 10 internal medicine residents to review two articles each, so that each article reviewed by two individuals.
- "Reviewers were asked to identify every assertion (ie: implication or statement of fact) in the Wikipedia article and to fact-check each assertion against a peer-reviewed source that was published or updated within the past five years" (p369).
- There was statistically significant discordance (ie: contradictions) between facts in Wikipedia and peer-reviewed literature in nine of the ten Wikipedia articles.
- Errors of omission were not covered.

Table 1.5 - Hasty et al (2014).

Fraser and Temple (2014) challenged this assertion because Hasty et al (2014) only looked at one Wikipedia article for each condition, whereas Temple and Fraser (2014) (appendix 1B) found several relevant articles under slightly different headings for each condition.

The inclusion of the Wikipedia articles by Hasty et al (2014) seemed to be arbitrary. For example, for the medical conditions of cancer, mental disorders, and heart disease, Wikipedia articles on lung cancer, depression, and coronary artery disease respectively were chosen (Fraser and Temple 2014).

Hasty, Garbalosa and Suciu (2014) noted that there are more than 30 000 Wikipedia articles on medical conditions, and their study (Hasty et al 2014) of ten was "designed to look for errors rather than omissions of information... [and] made no comment or criticism on the breadth of information covered on each subject or its completeness" (p766).

Hasty et al (2014) used third year medical students to compare the Wikipedia articles with the medical literature, and Leo and Lacasse (2014) questioned whether such individuals could "correctly ascertain the accuracy of claims made on Wikipedia".

Leo and Lacasse (2014) also raised the question of whether peer-reviewed literature is "an accurate reflection of the raw data". They noted that in the case of studies of anti-depressants, for instance, "there is evidence of selective reporting, ghost-written papers, and a well-documented difference between the published and unpublished clinical trial data" (p762).

Leo and Lacasse (2014) quoted an editorial from "Nature" in 2006: "scientists understand that peer review per se provides only a minimal assurance of quality, and that the public conception of peer review as a stamp of authentication is far from the truth". Chen and Xiong (2014) made a similar point: "the accuracy of peer-reviewed literature cannot be simply classified as either

correct or incorrect. Discrepancies often occur among articles regarding a certain topic. Therefore, the measurement of the accuracy of peer-reviewed literature would not just be binary" (p764).

Chen and Xiong (2014) also questioned the statistical test used by Hasty et al (2014). Gurzell (2014) agreed, and noted the irony that the Hasty et al (2014) study was "incorrectly analysed and inappropriately published through the same peer-review process that Hasty et al are holding to such high esteem" (p765).

Hasty, Garbalosa and Suciu (2014) disputed the criticisms.

1.4.5. Claims on Websites

Murdoch et al (2016) collected details of claims related to the diagnosis and treatment of allergy and asthma on 392 chiropractic, naturopathic, homeopathic and acupuncture clinic websites in ten cities in Canada. Search results were collected in March-April 2016 for mentions about allergy and asthma, and claims to diagnose and/or treat the conditions, and claims about the efficacy of complementary and alternative medicine (CAM) to treat them.

In terms of the findings:

- Allergy services mentioned on website - 68% overall; most common for naturopathy clinics;
- Asthma services mentioned on website - 61% overall; most common for naturopathy clinics;
- Claims of diagnosis of allergy or asthma - 25% and 3% respectively;
- Claims of treatment - 56% (allergy) and 52% (asthma);
- Claims of efficacy of treatment - 18% (allergy) and 13% (asthma) - eg: "Research studies show that children receiving Chiropractic care have improved: allergies"; "When treating asthma naturally... [i]f you are not in a weakened state, a colon cleanse is very beneficial" (Murdoch et al 2016 p5).

In relation to the latter claims, Murdoch et al (2016) raised concerns that evidence in support of tests and treatments were lacking from the websites, let alone lacking full stop. "Some of the proposed treatments are so absurd that they lack even the most basic scientific plausibility, such as ionic foot bath detoxification" (Murdoch et al 2016 p6). Furthermore, certain treatments

advertised were "potentially harmful" (eg: intravenous hydrogen peroxide) as well as "alterations and exclusions in diets, which can subsequently result in malnutrition and other physiological problems" (Murdoch et al 2016) [11].

It has been suggested, for example, in relation to women's health that "the popularity of CAM may be the result, in part, of a values-based rejection of modern society's intense 'medicalisation' of nearly everything related to women's health" (MacDonald and Gavura 2016) p82). But CAM products may be "the substitution of one commercialised expert understanding of women's health and bodies for another" ("alternativisation") (MacDonald 2002 quoted in MacDonald and Gavura 2016).

1.5. FEAR-AVOIDANCE AND PAIN

Chronic pain is a major health issue. For example, between one-quarter and just under half of US adults are affected by chronic pain (Zale and Ditre 2015).

The experience of pain is a combination of biological, psychological, and social factors according to the biopsychosocial view. "Whereas the medical model views disability as a direct result of disease processes that require treatment or intervention, the psychosocial model posits that environmental (eg: social, political, physical environment) and individual (eg: cognitive and affective processes) factors influence the experience of disability. Taken together, a biopsychosocial perspective on disability considers changes to body structure and function (eg: injury, disease), personal factors (eg: age, gender), activity limitations (eg: difficulty executing physical tasks), and participation restrictions (eg: problems maintaining participation in daily activities)" (Zale and Ditre 2015 p24).

The upshot of chronic pain is pain-related disability, where an individual's life is affected, including physical, occupational, recreational, and social functioning. The fear-avoidance model of chronic pain (Vlaeyen and Linton 2000), originally developed in relation to low back pain, "posits that pain-related fear activates escape mechanisms that lead to the avoidance of movement and activity. Although such behaviour may be adaptive in the context of acute pain (eg: by allowing an injury to heal), long-term avoidance of physical activity may impair functioning (eg: reduced participation in occupational and recreational activities), increase negative mood (eg: depression), and contribute to greater

[11] For example, more generally, a Canadian mother was charged with negligence after treating her son's serious strep infection with CAM rather than anti-biotics, and he subsequently died (MacDonald and Gavura 2016).

levels of disability (via disuse syndrome and physical deconditioning)" (Zale and Ditre 2015 p25). In short, avoidance behaviours are reinforced which "may contribute to the maintenance and progression of disability" (Zale and Ditre 2015).

In terms of research, fear of movement among lumbar surgery patients, for instance, was associated with long-term disability, while fear-avoidance beliefs were associated with less likelihood to return to work among sciatica sufferers (Zale and Ditre 2015). Thus, there is a place for cognitive-behavioural therapy to help with pain-related fears.

Individuals with chronic pain are regular users of pain medication, and this use takes place in a particular social context in the USA - namely, direct-to-consumer (DTC) marketing - but also consumerism (ie: the consumption of goods, including medicines, communicates social values) (Eaves 2015). "Medications carry meanings not only about those who choose to use them, but also about those who choose not to... Pills impact relationships with others and conceptions of oneself as an agent and as a moral individual" (Eaves 2015 p148).

Eaves (2015) continued: "Chronic pain, alternatively, is unique in that its experience as well as available treatments remain incompletely or ambiguously medicalised... Despite availability of opiates and analgesics, their medical necessity and legitimacy (and the legitimacy of those requesting them) is questioned by many physicians... Unlike medications that legitimate illness..., pain medication confers suspicion, particularly when mapped onto existing racial, ethnic, and gender stereotypes" (p148). For example, with the so-called "opioid epidemic" (Manchikanti et al 2012), doctors are "concerned not only about addiction, but also about inadvertently contributing to the street drug market and facing legal retribution for over-prescribing... Thus, the use of opioids for any purpose is questioned as a legitimate or even moral act" (Eaves 2015 p148).

Meanwhile, individuals who refuse pain medication are often presented as "fulfilling cultural ideals of stoicism and toughness" (Eaves 2015). But for some individuals experiencing daily pain, this is not possible. Eaves (2015) interviewed 95 US individuals with temporomandibular disorder (TMD) about their use of pain medication, particularly over-the-counter (OTC) brands. TMD involves chronic pain in the face and jaw.

Most interviewees did not use prescription pain medications or used them sparingly, but OTC analgesic use was common (eg: 90% used "Advil" (a brand of ibuprofen)). Avoidance of prescription pain medications was motivated mostly by concern about addiction, keeping them for if really needed, and to avoid further damage to the face

and jaw. "Knowing pain would return as soon as medication wore off led participants to regard prescription pain medication as a poor coping strategy. The opportunity cost of temporary relief provided by prescription medications was simply too high. Participants chose instead to use OTC pain medications, still with reluctance, to mitigate opportunity costs while still gaining some level of relief" (Eaves 2015 p149).

Aware of the stoic ideal of not taking pain medication, the interviewees referred to themselves as "not one of those people" (ie: an individual addicted to the medication) in order to distinguish themselves from the stigma of prescription pain medication use. OTC medications were viewed as not "'real' pain medication" and this allowed individuals to take them while still perceiving themselves as stoic. This can be seen in the exchange between Eaves and "Deanne":

> Deanne: I don't take medication. I never take any medicine unless, you know, I really, it's like a kind of life or death kind of thing... I take a lot of herbs... I never take pain medication.
>
> Eaves: Never? Okay. Even with the, stuff like Excedrin?
>
> Deanne: Codeine with Aspirin... yeah, but that's not pain medication. I think it's an aspirin, I don't think of Excedrin for tension headache as being pain medication (p150).

Another issue that chronic pain sufferers, particularly women, had to confront was "fear of being perceived as whiners or complainers... or violating strong prohibitions in US culture against dampening the mood in social situations" (Eaves 2015 p150), if they talked about the pain. Even not talking to significant others or doctors, rather managing the pain with OTC medications.

Eaves (2015) summed up:

> Trade-offs between physical harm reduction and reducing potential harm to one's identity involved narratives of harm justification as chronic pain sufferers described their use as minimal and responsible. Describing medications as 'just over-the-counter' or 'not real pain medication' is social harm reduction. These phrases are uttered with the intention of minimising stigma and distancing the individual from the addictive potential of prescription pain medications. Harm justification is therefore harm reduction, but in an altered sense. Navigating discourses of authentic versus inauthentic suffering..., participants reduce harm to their identities through description of medication use as 'minimal' in light of their experience of intense and ongoing pain (p152).

To understand the context of the interviewees' statements, Eaves (2015) looked at 63 television and

magazine advertisements for three OTC pain medication bands (Advil, Tylenol, Aleve) between 2012 and 2014. The themes distinguished included:

- "Taking action and responsibility for oneself" - eg: "Get relief responsibly" (Tylenol);
- "Overcoming limits" - eg: "No pain. No limit" with images of athletes (Advil);
- Fulfilling social roles - eg: "I take Advil because my kids deserve a mom without a headache";
- Getting back to "normal" - eg: "So I can be myself again, sooner" (Tylenol).

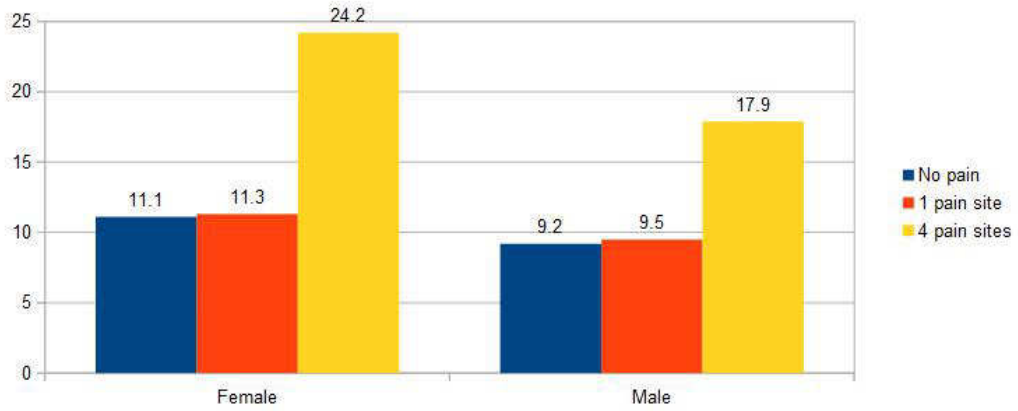
Eaves (2015) commented that the OTC medications were "often portrayed as simple solutions to problems". Applbaum (2009) has argued that "over-emphasis on consumer agency and simplicity masks the exercise of power in pharmaceutical advertising. In exercising agency, consumers are involved in the reproduction of pharmaceutical ideologies that have influenced the very definitions of normal and pathological they purport to remedy" (Eaves 2015 p152) [12].

Musculo-skeletal pain in adolescence has been found to be associated with mental health problems in adulthood (eg: mood and anxiety disorders; Shanahan et al 2015). This link has been confirmed by a recent longitudinal study in Norway (the Norwegian Arctic Adolescent Health Study; NAAHS) (Eckhoff et al 2017).

Around 4000 15-16 year-olds were asked in 2003-5 about pain in the head, neck/shoulder, arms/legs/knees, abdomen or back in the past year. Data on mental healthcare use in 2008-12 was taken from the National Patient Registry (NPR).

There was a significant association between self-reported musculo-skeletal pain in adolescence and anxiety disorders in young adulthood, and a strong trend for mood disorders, after currently for other factors (eg: adverse life events, relationship with parents, school-related stress). Overall, approximately 10% of the sample reporting no pain were mental healthcare users compared to around 20% of individuals reporting four different body site pains (figure 1.1).

[12] Advertising of pharmaceutical products is "implicated in promoting a 'global monoculture of happiness' (Kirmayer 2002) by offering pharmaceutical solutions to the cultural demands of being a pain-free and productive citizen" (Eaves 2015 p148).



(Data from Eckhoff et al 2017 table)

Figure 1.1 - Percentage of adults using mental healthcare based on number of body site pains reported as adolescents.

The researchers also found that adolescent anxiety and depression, low family income, and low physical activity were independently associated with later mental health problems.

Table 1.6 summarises key strengths and weaknesses of the study.

ISSUE	STRENGTH	WEAKNESS
Sample	Large, unselected - 292 of 293 schools in North Norway involved; equal gender respondents	83% of those invited to participate in NAAHS agreed, and 82% of those agreed to future NPR search - ie: response rate = 68%
NPR	Detailed official record of mental healthcare use with "few logical errors"	"Ideally, it would have been preferable to differentiate between primary and secondary diagnoses, but from a close inspection of the NPR data it was clear that attempting this would not be trustworthy due to the evident difference in the specialists' diagnostic coding practice" (Eckhoff et al 2017 p9)
Self-reported	Clear questions about pain	Use of twelve month period increased risk of recall bias, as well as other general issues with self-report measures (eg: honesty

Table 1.6 - Key strengths and weaknesses of Eckhoff et al (2017).

1.6. GENDER

"While gender is sometimes viewed as something that an individual is, current social science understandings of gender emphasise that it is something that an individual does through their behaviours and inter-actions with others. Thus, a person's behaviours are critical to their ability to fit into cultural gender norms" (Fleming and Agnew-Brune 2015 p72).

Gender, or more precisely gender norms, play a role in health - eg: masculinity and excessive alcohol consumption or avoidance of certain healthy foods in certain cultures (Fleming and Agnew-Brune 2015). Gender and diet is shown in men's motivation to eat meat as a sign of masculinity, or the drive for thinness in eating disorders linked to femininity and appearance (Fleming and Agnew-Brune 2015).

Power related to gender can be seen in women's lack of control of family planning in some societies, or the role of wives as food-preparers on men's eating behaviours (Fleming and Agnew-Brune 2015).

Other examples of gender and health behaviours include:

- Sexual health - eg: men who believe in traditional gender roles and norms are less likely to use a condom (Fleming and Agnew-Brune 2015).

- Substance use - eg: smoking cessation programmes that emphasise positive masculine ideals like responsibility and parenthood (Fleming and Agnew-Brune 2015).

1.7. HEALTH BEHAVIOUR INTERVENTIONS

There is mixed evidence about whether health behaviour interventions based on theory are more effective than those not based on a theoretical framework (Prestwich et al 2015).

In fact, many interventions do not use theory as their basis (ranging from 36 to 89%, depending on the study) (Prestwich et al 2015), while many interventions that use theory do not identify it (eg: 90% of "theory-based" interventions on physical activity and diet) (Prestwich et al 2014). Prestwich et al (2014) also found that only parts of a theory were tested.

Another problem is the failure "to consider how theory has informed the intervention" (Prestwich et al 2015). The ideal would be an experiment with an intervention based on theory A versus an intervention based on theory A plus an extra construct versus the extra construct alone versus control (Prestwich et al 2015).

Interventions based on theory have been found to use more stringent methodological procedures (Prestwich et al 2015).

1.7.1. Diabetes

The rising prevalence of type 2 diabetes (T2D) is a global health inequality in two ways [13]. Firstly, the majority of cases occur in low- and middle-income countries, and, secondly, the "economic cost of dealing with the consequences of diabetes is not only a threat to health systems but is a far broader economic and social problem and thus a threat to future long-term sustainable development" (Wareham and Herman 2016 p1).

Inequalities in health at an individual level could also be widened as richer individuals are better placed to afford the personal costs of the condition (eg: specialist foods), as well as being more likely to attend screening and treatment (Wareham and Herman 2016) [14].

A "Western diet" high in sugar, and little physical activity have been linked to the rise in T2D, in particular (though there is a genetic risk also; Goudino et al 2016), and so health behaviour change programmes can help. But there is a gap between the success of such programmes in studies and their use in real world settings (Wareham and Herman 2016).

Behaviour change requires the motivation to change. Communicating the individual's risk of developing T2D could be such a motivator. Goudino et al (2016) found that this was not the case.

Individuals born between 1950 and 1975 in Cambridgeshire, England, who were part of the Fenland Study, were offered the opportunity to receive information about their genetic risk of diabetes. The participants were also given lifestyle advice about diet and physical activity. The primary outcome measure was physical activity energy expenditure at eight-week follow-up.

There were 550 healthy participants, of which one-

[13] Five million deaths in 2015 were attributed to all diabetes worldwide (Chan and Luk 2016).

[14] Chan and Luk (2016) described the reality in poorer countries: "In busy outpatient clinics, doctors may have no more than 5 minutes to explain to their patients the nature of diabetes and the importance of self-discipline in diet, behaviour and medication adherence, while deciding which drugs to prescribe based on little clinical information. They realize that many patients with hypertension, the metabolic syndrome, or a family history could benefit from screening for diabetes. However, in many settings, doctors can only remind patients to improve their diet and lifestyle and repeat the drug prescriptions. Patients themselves may be unable to afford to wait in long queues in a public clinic or find an insurer to support private outpatient care. Despite possessing some knowledge about diabetes, patients often find it difficult to adopt a suitable level of exercise, take multiple pills, make healthy food choices, and interpret fluctuating blood glucose concentrations, resulting in their diabetes being left unchecked" (p1).

third received an estimation of their genetic risk of T2D as "below average", "average" or "above average". The others received risk information based on weight, or no information. There was no significant difference in physical activity at follow-up between the groups. However, women receiving genetic risk information increased their physical activity more than men as compared to the control group.

T2D is twice as common among Native Americans (American Indians and Alaskan Natives) than White Americans (Satterfield et al 2016). This health disparity goes with income disparity (eg: 23% of Native American families below poverty line; Satterfield et al 2016), and it has been blamed on the "disruption of indigenous persons' relationships with their homelands, including land, language, culture, and religious beliefs" (Satterfield et al 2016 p5). One response of the US Government has been the "Traditional Foods Project" to support traditional and local foods and practices, and physical activity.

For diabetes worldwide, the WHO (2014) advocated "multi-sectoral action that simultaneously addresses different sectors that contribute to the production, distribution, and marketing of food, while concurrently shaping an environment that facilitates and promotes adequate levels of physical activity" (quoted in White 2016).

Population approaches to health promotion can reduce risk factors in the whole population, irrelevant of an individual's level of risk. But not everyone in the population may need to change their behaviour, and sub-groups can have "differential access, uptake and compliance" (White 2016).

Another way to prevent diabetes is to stop or delay the progression from "pre-diabetes" (non-diabetic hyperglycaemia; NDH) to T2D. Lifestyle modification programmes including weight loss, a healthy diet, and increased exercise could reduce the progression by up to 58% (Gray et al 2016).

The "Let's Prevent Diabetes" programme is an example from the UK based around a day of education about diabetes and lifestyle, and subsequent three-monthly telephone support. Davies et al (2016) found a reduction in T2D in a three-year study of the programme as compared to standard care, and improvements in lifestyle.

Gray et al (2016) found that remaining or engaging in the programme was key for the success of the "Let's Prevent Diabetes" programme. Based around 43 general practice surgeries, 880 participants were involved, of which 433 were controls. Of the 447 participants in the intervention group, 346 attended the education day and

one refresher session ("engagers"), and 130 of them completed the programme ("retainers") (figure 1.2).

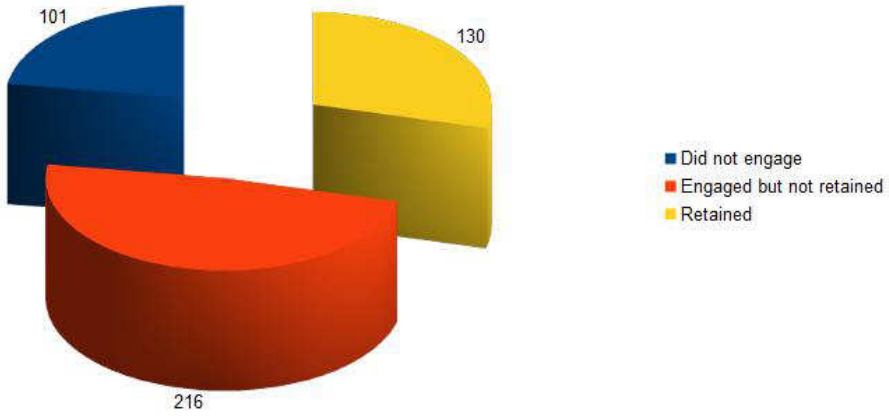
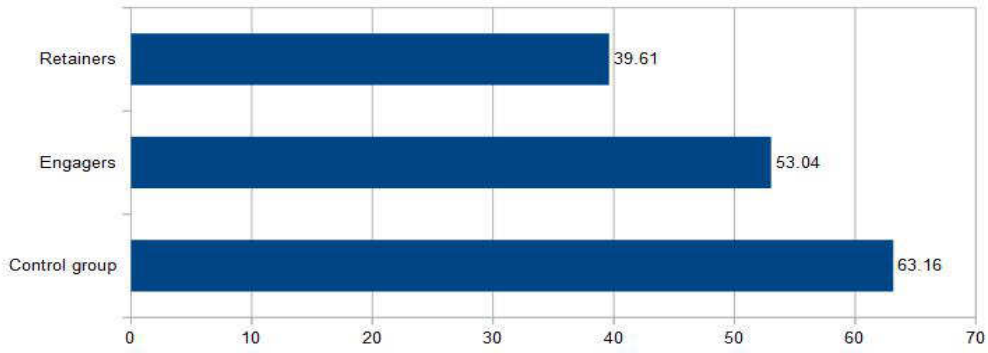


Figure 1.2 - Engagers and retainers.

"Retainers" were significantly less likely to develop T2D from NDH than the control, as were "engagers" (figure 1.3). There was an 88% reduction in T2D incidence over three years for "retainers" and 62% for "engagers".

In terms of the characteristics of "retainers" and "engagers", there were older, lower weight, non-smokers, male, and from less socio-economically deprived areas than non-retainers and non-engagers.



(Data from Gray et al 2016 table 3)

Figure 1.3 - Incidence rate per 1000 person years for T2D.

Mexican Response

The prevalence of T2D in adults in Mexico is around one in six, and the country is the fourth largest per-capita consumer of energy-dense ultra-processed food and

drinks (ie: "junk food" and sugar-sweetened beverages; SSBs) (Batis et al 2016) (appendix 1C). In response the Mexican government in January 2014 introduced the equivalent of a 10% tax on SSBs, and 8% on non-essential energy-dense (NEED) foods (eg: snacks, sweets, ice cream) [15].

Batis et al (2016) evaluated the effectiveness of the purchase tax on NEED foods in reducing their consumption after one year [16]. They used data from a Mexican consumer panel, which included diaries of purchases, receipts of food purchases, and empty product packages (for over 6000 households [17]). The period January 2012 to December 2014 was covered to give a comparison of pre- and post-tax purchases [18].

It was found that the purchase of taxed foods declined by around 5% after January 2014, while untaxed food purchases did not change (figure 1.4). The decline was greater for poorer households (-10%) with no change for the richest [19].

Batis et al (2016) summed up: "The present results show that, at least in Mexico, a relatively modest tax can, in the short run, result in a substantial decline in volume purchased of taxed foods. However, it is important to consider that taxes could affect purchases with other mechanisms in addition to the increase of price. Press coverage or public discussion of the tax can help discourage the consumption of the taxed products in the population; but, for the nonessential energy-dense tax in Mexico, the coverage has been small relative to the SSB tax. On the other hand, the presence of the SSB tax could have had an effect on the purchases of non-essential energy-dense foods, because these items might be complementary and consumed together" (p10) [20] [21].

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[15] The tax was based on a cut-off point of energy density ≥275 kcal/100g. But in the example of sweet bread, small bakeries were exempt from the tax (Batis et al 2016). Also, "the use of a single energy-dense cut-point in the Mexican tax without other nutritional attributes left out foods that are otherwise considered unhealthy (eg: most ice creams were untaxed), whereas foods like peanuts and nuts were taxed" (Batis et al 2016 p11).

[16] The consumption of SSBs was reported as declining by 6% (Batis et al 2016), while untaxed beverage purchases increased (Colchero et al 2016).

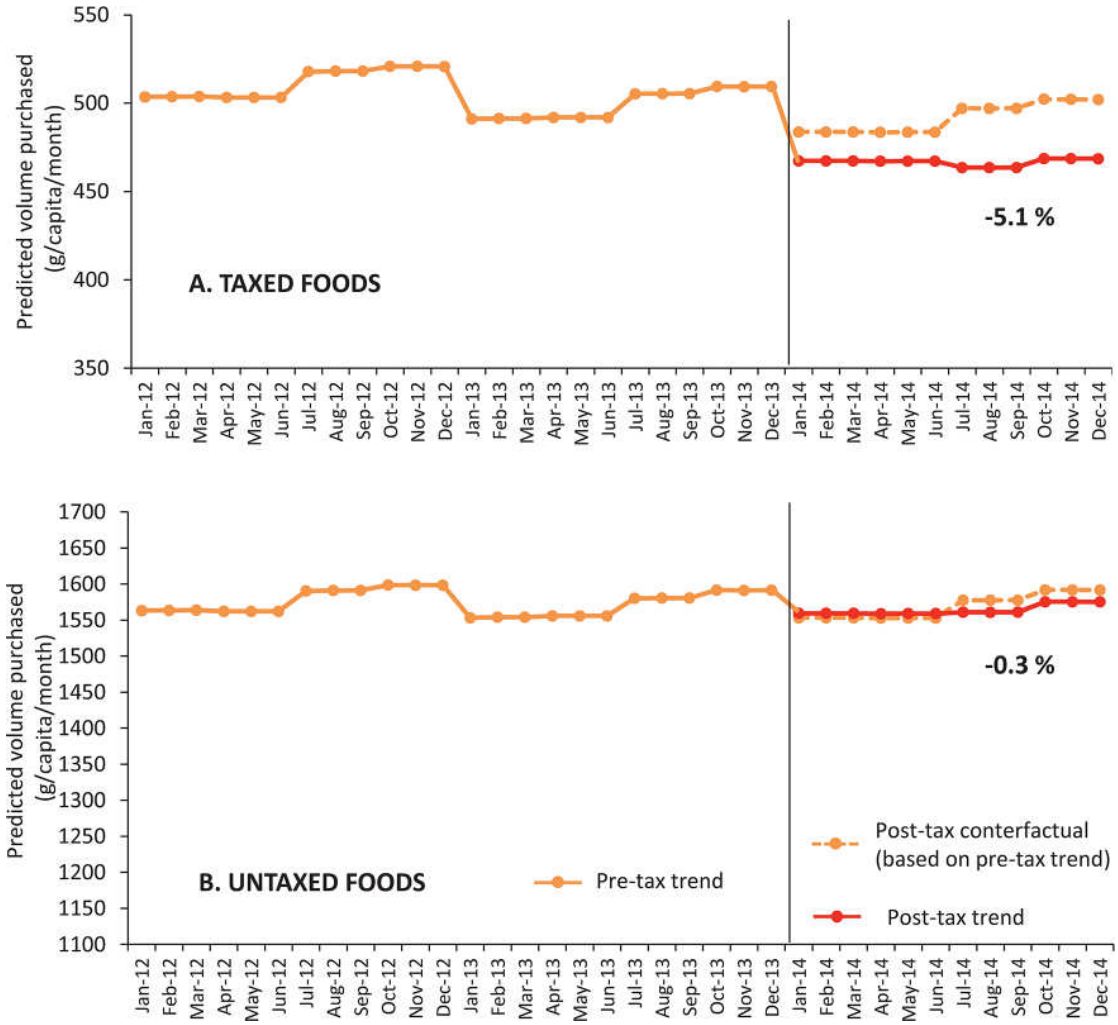
[17] The sample only represented urban areas (Batis et al 2016).

[18] The study did not include food purchased and consumed away from home (Batis et al 2016).

[19] But the prevalence of obesity and diabetes is higher among richer households in Mexico, whereas in the USA obesity rates are higher in lower income households (Batis et al 2016).

[20] "The changes in taxed foods were for salty snacks and cereal-based sweets. Interestingly, for salty snacks, all the change was due to changes in probability of purchasing, suggesting that, for this item, people prefer to decrease the frequency of purchases rather than the amount. Moreover, we saw smaller-than-expected increases in the volume of sugar and sugar substitutes, suggesting that households are not necessarily substituting sugary home-prepared foods or beverages for pre-packaged taxed sweets" (Batis et al 2016 p10).

[21] This study was not able "to infer causality because the taxes were implemented at the national level (lack of control group)" (Batis et al 2016 p1).



(Source: Batis et al 2016 figure 2)

Figure 1.4 - Monthly trend in purchases for taxed and untaxed foods.

A few other countries have introduced similar "unhealthy" food-related taxes. For example, the Danish government, in 2011, increased the price of saturated fat products by up to 20% for a short period, and purchases of these products declined by 10-15% (Jensen and Smed 2013). This tax was criticised for discouraging traditional cooking by focusing on ingredients used like butter (Batis et al 2016).

"A great complexity of implementing a food tax is to define the characteristics of the foods subject to it. If only selected unhealthy foods are taxed, individuals can substitute with other unhealthy untaxed foods; on the other hand, if the tax categorisation is too broad, many relatively healthy products will also be affected, increasing the cost of food without the public health benefit (Batis et al 2016 p10).

Sorting foods into "essential" or "non-essential", and/or defining which ones to tax can be difficult, as

well as the response of the food industry. For example, in Hungary, a tax on foods high in salt, sugar or caffeine (introduced in 2011) led to food manufacturers reformulating their products to avoid taxation (Batis et al 2016).

1.7.2. Blood Pressure

Raised blood pressure is a risk factor for cardiovascular diseases and kidney disease, and the WHO has set targets to reduce it. Raised blood pressure is defined as systolic blood pressure of 140 mm Hg or higher, or diastolic blood pressure of 90 mm Hg or higher (NCD-RisC 2017).

NCD-RisC (2017) pooled the data from 1479 studies measuring blood pressure of 19.1 million adults (18 years and over) worldwide between 1975 and 2015.

Overall, globally, age-standardised adult mean systolic blood pressure was unchanged for men over the study period, but slightly decreased for women, while mean diastolic blood pressure increased slightly for both sexes. The male-female difference was largest in high-income countries, and central and eastern European countries, and was due to differences between younger individuals (under 50s).

Blood pressure decreased in the high-income western countries, but increased in south and south-east Asia, and sub-Saharan Africa, and central and eastern Europe over the study period.

The estimated number of adults with raised blood pressure increased from 594 million in 1975 to 1.13 billion in 2015, due, in the main, to population growth and ageing. In terms of age-standardised prevalence, there is a decline from 30% to 24% for men and 26% to 20% for women over the forty years of the data.

NCD-RisC (2017) summed up: "Raised blood pressure has transitioned from a risk factor largely affecting high-income countries to one that is now most prevalent in low-income countries in south Asia and sub-Saharan Africa, while being a persistent health issue in central and eastern Europe" (p45).

They continued: "Blood pressure is a multi-faceted trait, affected by nutrition, environment, and behaviour throughout the life course, including foetal and early childhood nutrition and growth, adiposity, specific components of diet, especially sodium and potassium intakes, alcohol use, smoking, physical activity, air pollution, lead, noise, psychosocial stress, and the use of blood pressure lowering drugs. Changes in risk factors and improvements in detection and treatment of raised blood pressure have, at least partly, resulted in the decrease in blood pressure in high-income countries..." (NCD-RisC 2017 p47).

The researchers accepted the following key limitations to the data used:

- Data scarce from some countries (eg: sub-Saharan Africa, Caribbean).
- Data more plentiful globally after 1990.
- Many sources did not include older adults (ie: over 70s).
- Different studies used different ways of measuring blood pressure.

1.7.3. Cholesterol Levels

Low-density lipoprotein (LDL) cholesterol level is a modifiable risk factor for cardiovascular disease (CVD), and monoclonal antibodies (eg: evolocumab) are drugs able to lower the level (Sabatine et al 2017) [22].

Sabatine et al (2017) reported data from the Further Cardiovascular Outcomes Research with PCSK9 Inhibition in Subjects with Elevated Risk (FOURIER) trial. Over 27 000 40-85 year-olds with high LDL cholesterol levels in forty-nine countries were randomised to receive ecolocumab or a matching placebo for two years.

There were significantly less CVD deaths, heart attacks and strokes, and related hospitalisations in the evolocumab than in the control group (9.8% vs 11.3%; $p<0.001$) [23].

1.7.4. Physical Activity

Walking is a safe physical activity to help older adults remain physically active, and to overcome the negative health effects of physical inactivity. Wearing a pedometer helps the individual to see how many steps are taken and to set goals.

Harris et al (2017) found that a pedometer-based walking programme (Pedometer and Consultation Evaluation (PACE-UP) increased step-counts by 10% for a group of predominantly inactive 45 to 75 year-olds. Around 1000 volunteers were recruited in south London for the three-month study, and randomised into three groups. Two groups

---

[22] Monoclonal antibodies inhibit proprotein convertase subtilisin-kexin type 9 (PCSK9), and this is associated with lower LDL cholesterol levels, and consequently less risk of heart attacks and problems (Sabatine et al 2017).

[23] Note that the participants were also taking statins.

were given a pedometer with step-count goals (eg: "3000 steps in 30 min") (one by post, the other with nurse support), and the third group was a control.

Both pedometer groups had increased their steps per day between baseline and three months (mean increase of 692 in postal group and 1172 in nurse support group), and these were significantly different from each other and the control group. At a twelve-month follow-up, both pedometer groups walked significantly further than the control group and at their baseline, but not significantly different between themselves. No change was found in body mass index.

The findings were compared to other studies:

- Similar at twelve months to PACE-Lift trial (Harris et al 2015) with 60-75 year-olds;

- Less improvement than found in systematic reviews (eg: Kang et al 2009), but often the studies included are small-scale (Harris et al 2017).

1.7.5. Adherence

From the clinical point of view, adherence is simply about taking the medication for the benefits, and non-adherence is a "'problem' to be alleviated" (Gibson 2016). But for the individual, medication adherence is embedded in their lived experience and there are a variety of reasons for taking it or not.

Parkinson's disease (PD) is an interesting example here. Medication can only alleviate the symptoms, not cure it, but adherence is low. Over a five-year period, only 3% of sufferers had full adherence (Kulkani et al 2008). The most common cause of non-adherence was forgetting to take the medication at the correct time or as prescribed (Gibson 2016).

Gibson (2016) used a "lived body perspective" in his research. This "situates bodies as having a physiological reality while also being constituted through social relations explores medication adherence at the level of the body-self... Within such an approach medication adherence can be understood in terms of the consequences medications may have for an embodied self and its position in the world" (Gibson 2016 p28).

Gibson (2016) interviewed fifteen men with PD in north-west England and North Wales. Medication was reported as beneficial (but with limits) - eg: "David" said: "When (medications) kick in, you feel, as if a weight comes off your body, and you feel, ahh, I can move. But it isn't a weight, it's like a restriction, and it frees itself, and all of a sudden you find you can

move your legs much more easily, and you can walk more naturally. It comes on very quickly, but then it dies down slowly after that. I could be here now, and I could work for about three hours. If I keep taking my tablet at the right time, it keeps me going" (p29).

"David" then continued about the medication wearing off: "Well imagine holding a potato, and peeling it, and you haven't got any strength to press the peeler against the potato, you can't do that, you are at the sink. I couldn't peel a potato now. Then you're looking for a saucepan and you go (imitates walking) whereas if you are alright you go much quicker. Everything slows down. And you sometimes feel your feet are like lead weights, they're there, but they seem to stick to the floor. So you kick yourself" (p30).

The medication regimen created a new structure to the day, as described by "Henry": "I've got my tablets, my time alarm all in one go. Now what I've done with that Stalevo (a stronger version of levodopa), is 6 o clock, 2 o clock, 6 o clock, as is mirapexin, so I take two tablets out of that box, 6(am), 2(pm) and 6(pm). And that one is Stalevo with Azilect (An adjunct medication prescribed to lessen levodopa's side effects), and that's once a day, so that one again is once only in that combination. Now the Madopar ('standard' levodopa) is three times a day, 8(am), 12(pm) and 4(pm). And then that one there is at 10 o clock, and that's the last Stalevo of the day" (p30).

Gibson (2016) observed that the medication was the "centre ground of the lifeworld". "Crucially much of PD's lived experience emerges through the confounding of the pathological mechanisms of PD and side effects emerging from PD's treatment. From the perspectives of patients, the iatrogenic effects of PD therapy; dyskinesia, off periods or impulse control disorders are as much a part of PD as its motor and non-motor symptoms. Indeed for many they were part of PD; a symptom rather than an iatrogenic effect resulting from its therapy. Unsurprisingly then, for those taking them PD medications came to hold complex and deeply problematic meanings" (Gibson 2016 p32).

Furthermore, Gibson (2016) said: "Initially expecting miracles from medicine in its ability to treat PD, as treatment progressed patients quickly learned that the benefits gained from medications and therefore medicine's wider therapy were transitory, time limited, subject to trial and error, and for some eventually led to problems as severe than the disease" (p32).

1.8. SATISFACTION AND CORRUPTION

Satisfaction (often called customer satisfaction)

with health care providers leads to better adherence and outcomes. On the other hand, corruption within a health care system (eg: bribes to doctors) is associated with less use of health services when needed, and negative health outcomes, especially for the poor. This is corruption as "sand in the wheels" (Habilov 2016).

Alternatively, corruption can "grease the wheel", and be experienced as a positive thing. "Healthcare professionals consider their remuneration low and expect informal payments, while patients expect that they would have to pay out-of-pocket to underpaid professionals for additional or better quality services... When expectations of healthcare professionals and patients match, then a transaction of paying and receiving unofficial payments takes place" (Nabilov 2016 p119) (ie: corruption increases satisfaction).

A third view is corruption as a cultural norm with no link to satisfaction (Nabilov 2016).

Habilov (2016) tested these three relationships between corruption and satisfaction with health care services using 2011 data on twelve former Soviet countries (eg: Georgia, Moldova, Belarus). The data came from the Life-In-Transition survey (by the European Bank of Reconstruction and Development), which involved interviews with nearly one thousand individuals in each country.

Satisfaction with the public health care system was the outcome measure on a five-point scale, while corruption (ie: an unofficial payment or gift to public health care personnel) was rated as present or absent.

It was found that corruption correlated with lower satisfaction. The mean level of satisfaction when corruption was present for a majority of respondents was 2.45 compared to 3.72 when mostly absent. In terms of differences between countries, Georgia had the highest mean satisfaction level (3.7) with less than 10% of respondents reporting corruption, compared to over 60% in Azerbaijan with a satisfaction level of 3.1.

This study has the following limitations:

- Use of secondary data.
- Measured petty corruption rather than large-scale.
- No information collected on reasons for paying bribes etc.
- Wider factors like spending per capita on health care, and individual-level factors were not controlled for in the statistical analysis.

1.9. HEALTH AS RELIGION

Philipson and Uddenberg (1989 quoted in Peiters and Wijma 2016) stated that health is "the religion of our time". Peiters and Wijma (2016) explored this idea further, making use of Vanderpool's (2007) ten criteria of a religion:

i) A concept of the sacred/transcendental ("the set-apart") - The World Health Organisation in its constitution defined health as "a state of complete physical, mental and social well-being" (quoted in Peiters and Wijma 2016). This depicts an ideal state, almost transcendent, though it has been criticised as "being utopian and rendering practically everybody ill" (Peiters and Wijma 2016 p132).

ii) A comprehensive world-view - The biomedical approach/institutionalised health provides "answers to the questions 'wherefrom?' 'where to?' and 'what is the meaning of life?' Therefore it exhibits a comprehensive world view that is materialistically rooted" (Peiters and Wijma 2016 p134).

iii) Moral values - "Leading a good, healthy life is connected to certain 'qualities of character or personality believed to support healthy behaviours' (Crawford 2006). This connection allows members of the health society to judge a personality and its derived social status by looking at the quality of a person's health and life as the visible expression and consequence of these personality traits. This opens up space for social distinctions and inequalities, stigmatisation and discrimination, as well as simultaneously securing 'the good order of the social body' (Rose 1999) by societal agents" (Peiters and Wijma 2016 p136).

iv) A protective screen from feared but uncontrollable events - The "evil is here represented by disease, suffering or impairment" (Peiters and Wijma 2016), and following the healthy life is presented as protection against these, particularly preventive health behaviours.

v) Salvation/liberation for believers/adherents - Salvation is "divine health" (ie: without impairment or disease and optimising the potential for a satisfying life) (Peiters and Wijma 2016).

vi) The use of meaningful symbols that embody the beliefs - eg: gyms ("fitness temple") (Peiters and Wijma 2016).

vii) The use of meaning-ridden rituals - eg:

behaviour at the "fitness temple".

viii) The invocation of certain moods and emotions - eg: "a mindset of optimism that obliges everybody to keep on thinking positively in order not to endanger actual health or recovery but to advance it, an attitude portrayed in the descriptive title 'smile or die' [Ehrenreich 2009]" (Peiters and Wijma 2016 p141).

ix) A conviction in the truth of beliefs despite others' disbelief - eg: a "dogmatic exclusiveness" by biomedicine towards alternatives (Peiters and Wijma 2016).

x) A community connected by shared beliefs - eg: patient support groups.

Peiters and Wijma (2016) ended with examples of religious language - "mercy (for example, of having won 'good genes' in the holy lottery) or vengeance (for example, for not behaving 'healthily'), practices such as mortification (for example, for the greater good of long-lasting health) or holy wars (for example, against obesity as a sign of late-onset disease), actors such as initiated or converts and their gurus (for example, concerning a special diet) and concepts such as resurrection (for example, from the brain-dead by 'mind jogging'), sins (for example, regarding one's diet), remission (for example, by 'normal' test results during medical check-ups in primary care) or redemption (for example, by engaging in a certain sports activity)" (pp144-145).

1.10. APPENDIX 1A - STIGMA AND VICTIM BLAMING

Scrambler (2006) referred to the "greedy bastards hypothesis" (GBH) to explain widening health inequalities in the UK with reference to "to the sociological and causal linkages between the logics of the regime of capital accumulation [24] and of the mode of regulation of the state and their respective relations of class and command and morbidity/mortality" (quoted in Monaghan

[24] Terms like "bubble economy" (Hudson 2012) and "madoffised society" (Monaghan and O'Flynn 2013) (after Bernie's Madoff's multi-billion dollar Ponzi scheme in the USA; addendum) have been used to describe the financial behaviour of the rich and powerful; "what is being denoted here is a highly unstable and crisis generating system wherein various corrosive processes and fictions are institutionalised.... such as accumulation by debt expansion, mass deception, efforts to maintain secrecy and silence, obfuscation and scapegoating.... Viewed through a critical sociological lens, such processes have roots in a deeply structured/divided world-system wherein financialised regimes of capital accumulation are increasingly untenable and oppressive (inter-)state apparatuses are marshalled in order to shore up dominant class interests at public expense" (Monaghan 2016 pp13-14) (table 1.7).

2016). Put another way, "illness behaviours" (ie: profit-seeking) of the wealthy and powerful "unintentionally increase health inequalities" (Monaghan 2016). But this takes place in a climate of personal responsibility, which, again unintentionally, leads to stigma against the overweight and obese, for example (Monaghan 2016).

Monaghan et al (2010) referred critically to "obesity epidemic entrepreneurs", including "obesity researchers, campaigners and opportunists" (Monaghan 2016) who benefit from the moralising note that "hold obesity individuals culpable for their obesity" (Farrell et al 2016).

Williams (2013) noted the tendency to blame "lifestyle choices" in the UK rather than the "economic activities of robber barons" (quoted in Monaghan 2016). Poor lifestyle choices are a "moral deficit", or what Goffman (1968) called "achieved deviance", rather than "an imperfection of being as might be the case for the person with an underlying biological disorder ["ascribed deviance"; Goffman 1968]" (Monaghan 2016).

- Prechel and Zhang (2016) investigated the conditions in the US FIRE sector (finance, insurance, and real estate) that lead to FM, which they defined as "acts that violate (1) a law or the intent of a law established by government agencies responsible for ensuring the integrity of the financial system, and (2) the public's understanding of the business code of conduct that consumers and investors use when making financial decisions" (pp655-656). They chose FM rather than crimes to cover violations both convicted and settled without admission. The researchers focused on seventy-three companies between 1995 and 2004.

- The likelihood of FM was higher in companies with more subsidiaries, in larger companies, with lower dividend payout per share, and higher bonuses paid to top executives.

- Prechel and Zhang (2016) noted that "when organisations establish incentives designed to ensure that its members conform to external expectations, these arrangements may decouple means from ends... and create perverse incentives to engage in financial malfeasance" (p658). Add to this the size of the organisation, where "governance structures (eg: accounting, auditing, reporting and monitoring systems) contain structural holes that create opportunities for financial malfeasance and that trust is insufficient to ensure that financial transactions are conducted through legitimate means" (p660).

Table 1.7 - Financial malfeasance (FM).

1.11. APPENDIX 1B - TEMPLE AND FRASER (2014)

Temple and Fraser (2014) collected thirty-two "common misconceptions" related to health - ie: statements that recent research has disproved, or ideas based on speculation (table 1.8).

STATEMENT	EVIDENCE
"Tea and coffee have a diuretic action which may therefore lead to dehydration" *	Not so (eg: Maughan and Griffin 2003)
"People should drink at least seven glasses of water a day for health" *	Most people gain enough water from food and regular drinks (Temple and Fraser 2014)
"Sugar can sometimes make children hyperactive" **	Only weak support (eg: Kanarek 1994)
"Adding olive oil to the diet lowers the blood cholesterol level and helps prevent heart disease" **	Some benefits in lowering cholesterol if olive oil replaces saturated fat, but not in preventing heart disease (eg: Flock and Kris-Etherton 2012)
"Stomach ulcers are caused by stress" *	Major cause is a bacterium called Helicobacter pylori (Temple and Fraser 2014)

(* = rated as 5; ** = rated as 4)

Table 1.8 - Examples of statements and evidence.

Forty-nine Wikipedia entries in November 2013 covering the 32 statements were rated from (1) "major errors" to (5) "very accurate (including the inclusion of all important information)". Nineteen statements were rated as "5", eleven as "4" ("mostly correct (but has a minor error or significant information is missing)"), and the other two statements were "3" ("neutral (or no information given)").

Temple and Fraser (2014) concluded that the findings "suggest that Wikipedia is a 'work in progress': while it is mostly quite accurate it should not be relied on as an authoritative source of information... Wikipedia should therefore not be relied on as a primary source of scholarly work. However, it can be a useful resource as a starting point for searches or as a supplement to other sources" (p42).

1.12. APPENDIX 1C - SUGAR AND JUICE

"Free sugars" are those added to food and drink as opposed to sugars naturally present. "Free sugars" are common in beverages, and are linked to health issues like dental decay and weight problems (Boulton et al 2016). But consumers underestimate the sugar content of beverages - eg: by about half for fruit juices, juice drinks, and smoothies (FJJDS) [25], and about 10% for sugar-

[25] The British Soft Drinks Association uses the following definitions - fruit juices ("100% pure juice

sweetened carbonated drinks (SSCD) (Gill and Sattar 2014). FJJDS can, thus, be perceived as healthier than SSCD.

Boulton et al (2016) calculated the amount of sugars in 203 FJJDS marketed towards children in the UK in 2014. The mean sugar content overall was 7.0 g per 100 ml, but this varied from 0 to 16 g per 100 ml depending on the product. For smoothies the mean was 13.0 g, 10.7 g for fruit juice, and 5.6 g per 100 ml for juice drinks.

Presenting the data in a different way, a 200 ml serving would contain half a 4-6 year-olds' recommended daily sugar allowance (19 g) for two-thirds of the FJJDS, and the full day's allowance for 42% of products.

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made from the flesh of fresh fruit..."), and juice drinks ("1% to 99% juice, nectars, still flavoured waters, sports drinks and iced teas") (Boulton et al 2016)

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ADDENDUM

The Ponzi scheme involves paying the rate of return for one investor with the money from other investors. The first investor puts £100 in the scheme, say, and receives £10 return each month, and this money comes from the second investor's £100 and so on. The scheme organiser keeps the difference. The problem is that there is always a need for more investors, which will eventually stop, and the "pyramid" collapses (Basu 2014).

"Financial bubbles" in the price of assets or shares have been called "naturally occurring Ponzi" - ie: "a bubble that forms not in response to a manipulator's baton but to natural market forces, with one person's expectations stoking the next person's" (Basu 2014 p57). "Loan juggling" where companies (or individuals) pay off one loan with another loan is an example of "camouflaged Ponzi" (ie: legal) (Basu 2014). This is only a problem if the company's income drops or ceases.

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2. SELF-RATED HEALTH AND WELL-BEING

2.1. Differences
2.2. Subjective well-being
2.3. Personality
2.4. Stress and mental health
2.5. Active ageing
2.5.1. Well-being
2.6. Scouting as a protective factor for mental health
2.7. References

2.1. DIFFERENCES

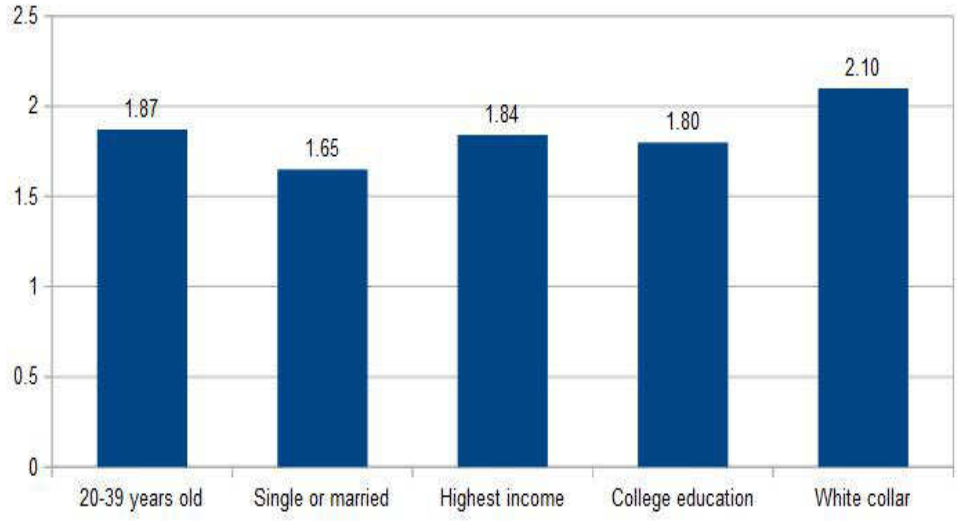
The World Economic Forum compares countries on gender equality in four areas - economic participation and opportunity, educational attainment, health and survival, and political empowerment (Lee et al 2016).

Women tend to have poorer health than men, and lower self-rated health (SRH), and SRH is associated with declining health and higher mortality (Lee et al 2016) [26].

Lee et al (2016) compared SRH and gender in South Korea and the USA. In the former country, data were taken from the fourth and fifth Korean National Health and Nutrition Examination Surveys (KNHANES IV and V, 2007-12), which covered over 30 000 individuals. The US data came from the National Health and Nutrition Examination Surveys (NHANES 2007-12) with 14 000 individuals. SRH was measured by the question, "how do you rate your health in general?", and with the response options of "excellent", "very good", "good", "fair" and "poor". For analysis purposes, the first three responses were combined as "good SRH", and "fair" and "poor" as "poor SRH".

Overall, 81.2% of South Korean respondents were classed as "good SRH" and 83.7% in the USA. Only in South Korea were significantly more men in the "good SRH" group than women. Women in the age group 20-39 years in both countries had the highest "poor SRH". Women in South Korea had more "poor SRH" in all sub-group analyses compared to men - age groups, marital status, household income, education level, and occupation class (figure 2.1).

[26] Inequity is defined by the World Health Organisation as "systematic biases in the conditions of daily living that are produced by social norms, policies, and practices that tolerate or actually promote unfair distribution of, and access to, power, wealth, and other necessary social resources" (Lee et al 2016 p12).



(Data from Lee et al 2016 table 3 p18)

Figure 2.1 - Odds ratio for women in South Korea in selected sub-groups (where men = 1.00).

2.2. SUBJECTIVE WELL-BEING

Subjective well-being (SWB) is a commonly used measure, which is seen as covering life satisfaction, positive affect, and the absence of negative affect (Lamu and Olsen 2016).

SWB correlates well with friends' reports, and with SRH measures, but less so with objective measures of health (eg: doctors' reports; diagnoses) (Lamu and Olsen 2016).

The relationship between income and SWB is "positive, but diminishing" (Lamu and Olsen 2016). Easterlin (1995) stated that "raising the incomes of all, does not increase the happiness of all, because the positive effect of higher income on subjective well-being is offset by the negative effect of higher living level norms brought about by the growth in incomes generally" (quoted in Lamu and Olsen 2016). Put another way: "People either adapt to their circumstances..., and hence end up no more satisfied than they were before, or they raise their financial aspirations..., which will make them feel less satisfied with their increase in income" (Lamu and Olsen 2016 p177).

Social relationships are also important to SWB and health, but what is the relative importance of health, income, and social relationships to SWB? Lamu and Olsen (2016) set out to answer this question using data from an online survey in 2012 of 1760 healthy individuals and

6173 individuals with diseases from seven major groups (eg: asthma, diabetes).

SRH had the strongest association with SWB, while household income was lowest. Health was more important to individuals with lower than higher SWB. Social relationships were consistently related to life satisfaction.

Lamu and Olsen (2016) summed up: "Subjective well-being (SWB) is more than having a good financial standing and the absence of disease. It is an asset that allows people to realize their aspirations, and enhance their social ties. This study provides empirical evidence that health, income and social relationships are positively associated with SWB even after controlling for individual, household and national-level control variables" (p183).

2.3. PERSONALITY

Personality characteristics can be associated with health outcomes, particularly neuroticism (N) (where high scorers have worse health) and conscientiousness (C) (where high scorers have better health) (Murray and Booth 2015). These relationships are mediated by behaviours like C predicting participation in health screening, physical activity, and having a good diet. While health can influence (eg: reductions in extraversion after chronic illness) (Murray and Booth 2015).

This is evidence for many mediating mechanisms, and the mechanisms my vary between personality traits. For example, C influences health through self-regulation, while N is mediated by reactivity to stress (Murray and Booth 2015). Different aspects of the same personality trait can also play a role. For example, C includes self-control and industriousness, of which the former links to excessive alcohol consumption or not and the latter to physical activity/inactivity (Murray and Booth 2015).

Furthermore, personality traits will interact as in "healthy neuroticism" (Friedman 2000) (high C and high N), where health-related worrying motivates good health behaviours. Turiano et al (2012a) found that such individuals were protected against high alcohol consumption, but not for smoking (Turiano et al 2012b). This difference may be down to methodology, though (Murray and Booth 2015).

Interventions to improve health could be tailored to personality traits (eg: more structured exercise programme for low C individuals), or, more controversially, to changing personality (eg: a change to more C to improve self-control). But "it is not clear that intervening at the level of an individual's personality would be more effective or efficient than

intervening at other stages in the causal pathway, for example, targeting downstream health behaviours or population-level social policies and norms... [and]... it is unlikely that all aspects of traits such as N and C are equally important for health; it's also unlikely that it would be equally appropriate or productive as targets of intervention" (Murray and Booth 2015 p52).

2.4. STRESS AND MENTAL HEALTH

Stressful life events do not impact on everybody in the same way, and the effect depends upon intervening factors that can protect against or enhance the negative effect. Self-efficacy is one such factor and is part of the cognitive appraisal process. It is "an individual's capabilities to perform appropriately in challenging situations" (Schonfeld et al 2016 p2). Perceived self-efficacy (ie: the belief that the individual can perform) is positively correlated with positive mental health (eg: general feelings of well-being) and negatively correlated with negative mental health (eg: depression) (Schonfeld et al 2016).

Schonfeld et al (2016) found that self-efficacy was a mediator of the effects of daily stress on mental health. Data were used from the Bochum Optimism and Mental Health study programme (BOOM), which includes 1031 members of the general population in Germany, and student samples in Germany (n = 394), China (n = 8669) and Russia (n = 604). Four main questionnaires were used:

- Depression Anxiety Stress Scales (DASS-21) (Henry and Crawford 2005) - 21 negative emotional states rated 0-3 in last week.

- Positive Mental Health Scale (PMH) (Lukat et al 2015 quoted in Schonfeld et al 2016) - Nine items about well-being (eg: "I enjoy my life").

- Brief Daily Stressor Screening (BDSS) (Scholten et al 2014 quoted in Schonfeld et al 2016) - Nine stressful events in last year (eg: health problems, financial difficulties).

- General Self-Efficacy Scale (GSE) (Schwarzer and Jerusalem 1995) - Ten items (eg: "I am confident that I could deal efficiently with unexpected events").

Schonfeld et al (2016) summed up: "The most important result of our study is that general perceived self-efficacy was a mediator between the effect of daily stress on positive and negative mental health, including symptoms of depression, anxiety and stress. In

conclusion, these findings suggest that prevention aimed at positive indicators of functioning and coping is essential to minimise the subjective stress" (p7).

2.5. ACTIVE AGEING

In recent years, concepts like "healthy ageing", "productive ageing", and, in particular, "active ageing" (AA) have become important. Boudiny (2013) asked what AA actually meant.

The WHO (2002) originally defined AA as the process of "optimising opportunities for health, participation and security in order to enhance quality of life as people age". Subsequent definitions can be divided into types (Boudiny 2013):

i) Unidimensional approaches focusing on employment or physical activity.

Boudiny (2013) described these approaches as reductionist and narrow-focused, while ignoring "older adults' own perceptions, as many of them resist an exclusive emphasis on 'youthful' physical activities" (p1080) [27]. The old-old (ie: 75-80 years and above) tend to be ignored by these approaches. Clarke and Warren (2007) described AA here as "little more than empty rhetoric".

ii) Multi-dimensional approaches that refer to "the continuous participation of older adults in several domains of life" (Boudiny 2013), and can include physical and mental activities. Houben et al (2004 quoted in Boudiny 2013), for example, developed an AA index based on paid labour, care and voluntary work, sports and active recreation outdoors.

Boudiny (2013) criticised such approaches: "These conceptualisations thus appeal primarily to the young-old, while deviating from the day-to-day reality of many of the old-old. This is especially clear in definitions restricted to productive activities. Several studies indicate that the old-old tend to focus more on non-productive leisure activities than on productive ones. While external structural (eg: upper age limits for

[27] Active ageing can be threatened by falls, which are common among older adults (eg: one-third of over 65s fall at least once a year; Sherrington et al 2008). There are a number of predictable risk factors, like reduced muscle strength, impaired balance, and poor vision, and prevention programmes. Exercise is one of these, and can reduce falls by around one-fifth, particularly higher levels of exercise and balancing exercises (Sherrington et al 2008).

volunteers) and situational (eg: grown-up grandchildren no longer in need of care) constraints may contribute to this tendency, changes in health and preferences apparently play a key role in advanced old age" (pp1082-1083).

iii) "Transcending the behavioural level" and including health and economic circumstances. For example, Bowling (2005) defined AA as "continuing physical, psychological, social health, participation, independence, autonomy, control for the enhancement of quality of life".

But Boudiny (2013) suggested that "such definitions fail to make a clear conceptual distinction between the constituents of active ageing and its determinants" (p1085). Furthermore, AA, unintentionally, becomes "unattainable for many of those who are already frail and dependent" (Boudiny 2013).

Boudiny (2013) emphasised the need for AA to include "all groups and all meaningful activities". This could include concepts like adaptability (to age-related changes), that "the meaning of social engagement may change", and agency (as far as possible).

Boudiny (2013) concluded: "Diversity-thinking..., in which both extremes (ie: an overly negative and an overly positive view of old age) should be avoided. To take diversity truly into account, we must discover how to promote and realise active ageing throughout various phases of life. A crucial point in this regard involves acknowledging that the meaning of an active life may change throughout the lifecourse and that gains might also be seen in the context of loss, as older adults may unfold unexpected substitute skills, collaborative relationships or creative strategies to overcome limitations..." (p1093).

There will also be gender differences. Spector-Mersel (2006) noted that "Western masculinity scripts are not designed for elderly men, and thus are concluded somewhere before 'old age'". Saxton and Cole (2012) continued: "Older men thus lack an alternative to midlife masculine ideals, depriving them of guidelines for being a 'real' man and limiting their ability to fashion effective and culturally respectable identities" (p98). There is even an cultural "invisibility" of older men (Thompson 2006).

2.5.1. Well-Being

Siegrist and Wahrendorf (2010) observed: "Most

people in early old age are still in good health, and free from physical dependency – but also free from earlier responsibilities for work and family, which opens opportunities for individual freedom, hobbies and other options of self-realisation. At the same time, this phase lacks a clear societal definition in terms of social roles and social status, legitimised expectations, norms and values. While most middle-aged people experience a secure sense of social identity by maintaining core social roles (such as the work role, family roles or civic roles), social identity during the third age [Laslett 1989] becomes more fragmented and insecure – often in combination with a reduced intensity of contacts in social networks and with reduced income opportunities" (p109).

There is an opportunity for older adults to "gain" a role with "socially productive activity" (eg: paid work, volunteering), which is beneficial for well-being. Using the Survey of Health, Ageing and Retirement (SHARE) study data, which covers around 7000 older adults in ten European countries, Siegrist and Wahrendorf (2010) found that being "socially productive in informal work in early old age, in a situation in which reward and control are experienced, is associated with better well-being in terms of quality of life" (pp123-124).

But the ability to continue in work is influenced by health, and health is influenced by income (Siegrist and Wahrendorf 2010). Social inequalities in well-being among older adults have been found in the same way as differences in health and mortality (Siegrist and Wahrendorf 2010).

The SHARE data showed that "poor quality" work (eg: insecure, low control) was associated with increased depressive symptoms and poor self-rated health, and this linked to declining objective health (Siegrist and Wahrendorf 2010).

2.6. SCOUTING AS A PROTECTIVE FACTOR FOR MENTAL HEALTH

The focus of research is often on childhood risk factors for adult mental health problems, but there is also evidence of protective factors.

In relation to this, Dibben et al (2017) found that participation in Guides or Scouts in childhood was associated with better mental health at 50 years old. The researchers used data from the National Child Development Study (NCDS) in the UK, which began with 17 500 individuals born in a single week in 1958. In 2008 9790 participants were interviewed at age 50.

Current mental health was measured by five general questions covering how much in the last month (eg: "felt downhearted and low"), and the responses were converted into a score between 0-100, where a higher score was

better mental health, and 65 or less was the cut-off point for potential mood or anxiety disorders.

Membership of the Scouts (boys) or Guides (girls) in the 1970s was self-reported. Membership of other voluntary groups or church organisations was also collected as a form of "negative control" exposure (Lipsitch et al 2010) (ie: to check if membership of any community group or Scouts/Guides only associated with mental health). Frequency of attendance was also measured for a dose-response relationship (ie: to see if longer attendance associated with better mental health). The socio-economic background of the children was recorded based on father's occupation to see if Scouts/Guides membership reduced inequalities in adult mental health derived from socio-economic background (ie: individuals from lower backgrounds have poorer mental health).

Around 28% of respondents had been Scouts/Guides members, and this group had a significantly higher mean mental health score than non-members (76.7 vs 74.0). Members had a one-fifth lower odds of a mood or anxiety disorder than non-members.

Membership of other groups was not associated with better mental health compared to non-membership. There was no dose-response relationship to Scouts/Guides attendance, but members from lower socio-economic backgrounds showed less inequality in mental health (ie: smaller gap between lowest or highest socio-economic groups) than non-Scouts/Guides.

The researchers concluded that "Scout–Guide attendance may be protective, instituting a resilience to stressful life events that may lead to mental ill health or increase the chances of achieving states in adult life that are associated with better mental health. The relationship does not appear to be explained by potential confounding factors, notably familiar characteristics such as parental attitudes to education or familial history of mental health which might have affected the likelihood of a child being a Scout–Guide and mental health in later life" (Dibben et al 2017 p279).

The key protective factor of Scouts/Guides membership seems to be "progressive self-education". "During the 1970s, the Guide 'method' had evolved into an 'eight point plan', aimed at developing not only the traditional ideas of: character, out-of-doors skills and challenges, fitness, home-craft skills and service, but also creative ability, mind and relationships, and a focus on personal development then rather simply character development. Similarly, the Scouts were focusing on a system of progressive self-education based on: promises (laws), active learning, interactions within small groups and stimulating individual-driven self-learning through awards" (Dibben et al 2017 p279).

The researchers continued: "Scouts–Guides use small groups to enable young people to learn about

relationships, understand their own competences and to become more self-reliant. It may be that this early exposure to the skills needed to work with small group enables adults to more effectively develop later life social networks. Social interaction, in particular having friends, has been identified as being beneficial for emotional well-being for adults of a range of ages. It may also help individuals to engage with 'local sociability' and 'community organisation', if it exists in places they have lived, and thus benefit from informal reciprocity and social capital, more generally" (Dibben et al 2017 p279).

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3. MATERNAL HEALTH AND PREGNANCY ISSUES

3.1. Maternal health and mortality
  3.1.1. Encouraging health service use
  3.1.2. Differences in experience and social status
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3.1. MATERNAL HEALTH AND MORTALITY

Millennium Development Goal 5 (MDG5) from the United Nations was to reduce the maternal mortality ratio (MMR) by 75% between 1990 and 2015. Based on data from 181 countries, Hogan et al (2010) found that maternal deaths had decreased over the period 1980 to 2008, but only 23 countries were on track to meet MDG5 by 2015. The authors stated: "Progress overall would have been greater if the HIV epidemic had not contributed to substantial increases in maternal mortality in eastern and southern Africa" (Hogan et al 2010 p1619).

Ceschia and Horton (2016) began: "It is tempting to see progress towards better maternal health in linear terms. If only, the argument goes, one could scale up evidence-based interventions and policies in all countries for all women, maternal mortality would fall and maternal health would advance. The past year has shown the desperate fallacy in this argument". The authors referred in particular to the Zika virus infection in Latin America, and conflict-induced displacement around the world.

Ceschia and Horton (2016) emphasised important factors in the "fragile and non-linear" progress of maternal health, including access to modern contraception, maternal undernourishment during pregnancy, strengthening health systems, education and equality, and mental health. "And while saving the lives of mothers is important, much greater attention needs to be paid to what women need after the safe delivery of a healthy newborn baby. Maternal and newborn health programmes need to be considered as an integrated whole, and these programmes also need to be linked to practices that ensure good early child development— eg: effective parenting programmes" (Ceschia and Horton 2016).

Graham et al (2016) commented that "while elimination of preventable maternal mortality should remain a priority, it is also timely to recognise death as the tip of the iceberg beneath which lies the true diversity of the burden or consequences of pregnancy-related health problems – ie: poor maternal health" (p2165). Poor maternal health is a key issue for "marginalised women" - "those women who are vulnerable by virtue of where they live or who they are" (Graham et al 2016).

The World Health Organisation (WHO) has defined maternal morbidity as "any health condition attributed to and/or aggravated by pregnancy and childbirth that has a negative impact on the woman's wellbeing", and identified 121 diagnostic criteria (Graham et al 2016). Maternal mortality is defined as the death of the woman during pregnancy, childbirth, or in the following 42 days (Hogan et al 2010).

Graham et al (2016) emphasised two points:

i) The diversity in causes of poor maternal health - For example, fragile health system issues [28] for first-child young mothers in low-income countries compared to obstetric complications and non-communicable diseases (eg: diabetes) for older mothers in high-income countries.

The main causes of maternal death are haemorrhage giving birth, complications of abortions, and sepsis (and infections), and hypertension disorders (Graham et al 2016).

ii) The widening inequalities in experience - Maternal mortality is around 12 per 100 000 live births in high-income countries compared to 546 in sub-Saharan Africa, or, put another way, a lifetime risk of 1 in 36 in the latter case versus 1 in 4900 ("more than a 100 times different") (Graham et al 2016) [29].

Graham et al (2016) also noted: "Rich–poor gaps in women's uptake of maternity services persist across rural and urban areas within countries, and across very different national levels of maternal mortality" (p2172).

Education is also an independent variable with the least educated twice as likely to have sever maternal health problems and six times as likely to die as the highest educated (Souza et al 2013).

Obesity is a recent problem for all women in the wealthier countries, but also wealthy women in low-income

[28] The Fragile State Index (Messner et al 2015) ranks countries based on twelve indicators, including deterioration of public services, security threats, and economic decline (Graham et al 2016).

[29] It is estimated that 98% of maternal deaths are "preventable" (Graham et al 2016).

countries and middle-income women in South America (appendix 3A) (Graham et al 2016).

The United Nations has recently moved from Millennium Development Goals (MDGs) to Sustainable Development Goals (SDGs), of which one of the seventeen (SDG3 - health promotion) is "ensure healthy lives and promote well-being for all at all ages" (United Nations Social and Economic Affairs 2015) [30].

3.1.1. Encouraging Health Service Use

Conditional cash transfer (CCT) is a programme to encourage the use of health services or health behaviour adherence by paying individuals if they complete certain goals.

For example, in Afghanistan between 2009 and 2011 the Ministry of Health introduced CCT to encourage mothers to take their children for diphtheria-pertussis-tetanus (DTP) vaccination. Lin and Saleh (2013 quoted in Witvorapong and Foshanji 2016) found that CCTs increased use of the target services, while Witvorapong and Foshanji (2016) found some increased use of other services by women and their households compared to households that did not receive CCTs.

But should payment go to the women or to the household as a whole (Witvorapong and Foshanji 2016)?

Witvorapong and Foshanji (2016) had doubts about "whether CCTs have long-term effects on generalhealth seeking behaviour of beneficiaries in a context where non-financial barriers exist" (p94). Women's use of health services in Afghanistan depends on cultural factors - eg: "they have to ask for permission from their husbands or mother-in-laws, who may be unwilling to allow them to seek care at a medical facility. The situation is less severe for women whose husbands are better educated, wealthier or at least have access to the credit market as well as for those who live close to their birth families (Witvorapong and Foshanji 2016 p94).

3.1.2. Differences in Experience and Social Status

"Medicalisation" is where "behaviour or conditions that had previously been understood to be forms of moral deviance were transformed into treatable illnesses" (Chazan and Faro 2016 pp2-3), while "biomedicalisation" (Clarke et al 2003) refers to the central role of techno-

[30] Other key SDGs include poverty eradication (SDG1), food security (SDG2), and education gender equality (SDG4) (Nilsson et al 2016).

science (technology and science) leading to change in the organisation and practices of (bio)medicine.

Social stratification influences the experience of medicine, and it is "closely linked to the commodification of health and, as an essential focus of health assistance, health care becomes delineated and shaped through its transformation into an object of consumption" (Chazan and Faro 2016 p5).

Chazan and Faro (2016) reported an ethnographic study of ultrasound scans [31] in three different "universes" in Brazil involving three private medical clinics, a public maternity hospital, and a teaching hospital. Women from different social classes had different experiences of the scanning procedure based on variations in time waiting and with the doctor, privacy around the procedure, and actual technology used, for instance.

Chazan and Faro (2016) stated that "the intertwining of technology and social interactions, ultrasound constructed three different objects, in conjunction with sub-products that reinforced the stratification underlying their production, in a process of ongoing feedback" (p18):

i) At private clinics, for the wealthiest women, the "object was a fetus-baby-person with a name, photos, and videos, which could be summed up in the expression 'meio quilo de gente!' (literally, half a kilogram of person), and this fed the consumption of scans" (Chazan and Faro 2016 p18).

ii) At the teaching hospital, used by poor women, "a fetus-patient-model was constructed and transformed into medical knowledge; here, as an object of study, the mother-to-be was the 'roadway' for obtaining knowledge and the very reason for the existence of the ultrasound department" (Chazan and Faro 2016 p18).

iii) At the public maternity hospital, for poor women, "through the exame bento (holy scan), a fetus-number and terse diagnostics were produced to feed statistics" (Chazan and Faro 2016 p18).

3.2. STILLBIRTHS/PRE-TERM BIRTHS

Stillbirth is higher among disadvantaged groups in society. One aspect of disadvantage is low educational

[31] Ultrasound scans have been associated with selective abortion of female foetuses in India (appendix 3B).

attainment, and focusing on one country, Amegah et al (2017) "hypothesised that household use of biomass fuels and consumption of unsafe water related to low educational attainment could explain the stillbirth burden in Ghana attributable to socio-economic disadvantage" (p2).

The researchers analysed the data from the 2007 Ghana Maternal Health Survey (GMHS), which is a nationally representative population-based survey that includes over 10 000 women. Education level was self-reported, along with details of type of fuel use for cooking, source of drinking water, and lifetime experience of stillbirth.

Overall, 6% of women had experienced stillbirth, but the rate was 32% for mothers who had never attended school and 26% for those with less than four years education. The increased risk for stillbirth among these women was partly predicted by increased use of biomass fuel (eg: charcoal, firewood) and unsafe water consumption (eg: wells, rivers). Goldenberg et al (2011) argued that each geographical area will have local causes of stillbirth. Individuals from disadvantaged groups are also more likely to have sub-optimal medical care (eg: delayed access to pre-natal care services), and nutritional issues (Amegah et al 2017).

Hinkle et al (2016) reported that "morning sickness" (nausea and vomiting) (which as many as four-fifths of pregnant women experience) was associated with reduced risk of the loss of the pregnancy. This conclusion was based on 797 pregnant women on the Effects of Aspirin in Gestation and Reproduction (EAGeR) trial. All had a history of pregnancy loss. Nausea alone or nausea with vomiting was associated with a 50 to 75% risk reduction of pregnancy loss.

Physical activity (PA) during pregnancy is viewed as beneficial to the woman's health, but there may be a risk of pre-term birth. The studies are unclear (Wen et al 2017).

For example, increased total PA is not significantly associated with risk of pre-term birth (eg: Barnes et al 1991). But a total score includes occupational, leisure-time, and domestic PA. When they are studied individually, leisure-time PA reduces the risk of pre-term birth, while commuting PA increases it (eg: Misra et al 1998).

The type of occupational PA is also important - eg: prolonged standing in late pregnancy and increased risk (Wen et al 2017).

Wen et al (2017) performed a meta-analysis on non-occupational PA level in thirty-seven studies up to August 2016. Overall, leisure-time PA reduced the risk

(17 studies), but there was no significant association between pre-term birth and domestic PA (ten studies) or commuting PA (six studies).

3.3. ANTI-BIOTIC USE

Use of oral anti-biotics (ABs), like the penicillins, by pregnant mothers and young children has been associated with later illness in the children. For example, ABs use in the first years of life and later childhood allergies, obesity, or poorer cognitive abilities (Leclercq et al 2017).

ABs use during pregnancy and breastfeeding is reported as a risk factor for offspring allergy and potential asthma (Leclercq et al 2017).

Studies with humans are observational, and so it is not possible to establish cause and effect. This has been done with animal experiments. For example, Cox et al (2014) gave pregnant mice low-dose penicillin from one week before birth until weaning (21 days old), and the offspring were heavier/obese in adulthood. It is suggested that the mechanism involved is gut microbiota. Penicillin changes the make-up of the gut microbiota, and this has consequences for the immune and metabolic systems (Leclercq et al 2017).

Leclercq et al (2017) confirmed this idea with their work. Pregnant mice given penicillin as in Cox et al (2014) had offspring with lasting changes in gut microbiota, greater permeability in the blood-brain barrier, and changes in behaviour. Males were more aggressive, and both sexes showed less social behaviour.

The penicillin was given in drinking water. One group received that (AB), the control group only water (CT), and another group received penicillin and a probiotic that counters the anti-biotic (AB/JB1). At six weeks old the pups were given various tests, including:

i) Open field test - A mouse was placed in the middle of an open enclosure and their amount of movement was recorded. This measured general locomotor activity, and no differences were found between the three groups.

ii) Elevated plus maze - A mouse was placed in the middle of an elevated maze with four arms (two closed, two open). The amount of exploration of the arms was taken as a measure of anxiety-like behaviour. AB males, but not females, explored significantly more than CT individuals (ie: less anxiety-like behaviour), as did AB/JB1 mice.

iii) Three-chamber sociability test - A mouse was placed in the middle chamber of three plexiglass chambers. in one adjoining chamber was an unknown mouse,

while the other was empty. Sociability was measured as the time spent in the chamber with the other mouse. The AB mice spent less time with the other mouse than the other two groups. So, AB treatment was shown to reduce social behaviour, while the probiotic countered it as the AB/JB1 mice were as sociable as the CT ones.

Preference for social novelty was tested by adding another unknown mouse later. The AB mice spent less time with the second mouse than the first suggesting a decrease in preference for social novelty.

iv) Stress test - This was used to measure aggressive behaviour by forcing a mouse into the territory of a larger and aggressive mouse. The CT invaders showed a submissive posture (typical behaviour), but AB males were more likely to fight.

Leclearcq et al (2017) concluded: "While all these data obtained in rodents cannot be directly extrapolated to humans, they add support to the necessity to carefully consider the potential negative long-term effects of early-life ABs exposure" (p9).

3.4. APPENDIX 3A - PREGNANCY AND OBESITY

The Academy of Nutrition and Dietetics (2016) stated the concerns about pre-pregnancy obesity, excessive weight gain during pregnancy, and weight retention post-birth:

a) Getting pregnant - Obesity and reduced fertility as adipose tissue involved in the metabolism of sex hormones. Obese women's fecundity ratio (probability of conception during a specific menstrual cycle) is half of normal-weight women. Pregnancy rates with assisted reproductive technology are also lower.

b) Foetus - An association between pre-pregnant obesity and pre-term birth, for example.

c) Mother - Increased risk of gestational hypertension, and gestational diabetes, and difficulties during labour and delivery for obese women.

So, weight management programmes are the answer. The evidence is not clear-cut for obese women (Academy of Nutrition and Dietetics 2016):

i) Weight loss during pre-conception period - No studies found.

ii) Weight management during pregnancy - Lifestyle-intervention most effective.

3.5. APPENDIX 3B - FEMALE FOETUSES IN INDIA AND GENDER ISSUES

Selective abortion of female foetuses in India is increasing. The Indian census of 2011 found 7.1 million fewer girls than boys aged 0-6 years old (Jha et al 2011).

Jha et al (2011) commented that "the exact contribution of selective female abortion to the measured gender imbalance at ages 0–6 years in the censuses also depends on child mortality rates (appendix 3C). However, only in recent years did slightly more girls die compared to boys...".

Jha et al (2011) plotted the "missing" girls with data from three National Family Health Surveys (NFHS) in 1992-3, 1998-9, and 2005-6. Each NFHS interviewed around 100 000 women in over twenty Indian states. Female interviewers collected a complete birth history from each woman.

Women with a first-born girl were at most risk of aborting subsequent female foetuses.

3.5.1. Gender Inequalities in Health Care Use by Immigrants

In some parts of the world, female babies are treated worse than males ones varying from less frequent immunisation, poorer nutrition and shorter breast feeding to infanticide (Pulver et al 2016).

Explanations based in culture are given for these gender inequalities, including perceived lack of economic benefits of daughters, and expensive dowries (Pulver et al 2016).

Are immigrants from countries with such biases in Western, high-income countries taking gender inequalities in child health care with them? Provisionally, the answer seems to be yes. This is seen in higher male to female birth ratios among immigrants to North America from India, South Korea and Pakistan, for instance (Pulver et al 2016).

The general assumption is that if "parents originate from societies where gender preferences for family composition and female disadvantage through the life-course exist, they may be less motivated to facilitate their children's health care encounters" (Pulver et al 2016 p56).

However, there are few studies on this question. Pulver et al (2016) found only twelve peer-reviewed articles on health care use for pre-school children by immigrant families in Western, high-income countries between 1980 and 2014. Five studies covered use of emergency health care services, and seven general health

care service use (eg: vaccination).

In the former case, a higher rate of emergency service use was found for male than female children. For example, Berg et al (2004) found that Latino boys with asthma in San Diego, California, were three times more likely to visit an emergency department than girls, but there was no significant difference for hospitalisation. This study did adjust for health care need (Pulver et al 2016).

In terms of general health care service use, primary care visits (eg: to general practitioner) and prescription medication use were found to be less frequent among immigrant female than male children. However, there were two studies in the USA showing greater use of doctors for girls (Pulver et al 2016).

There were a number of methodological issues with the studies, which limited the conclusions of the researchers. These included heterogeneity in immigration group, and in children's ages, and lack of non-immigrant comparison groups. Only four of the twelve studies were rated "high" for methodological quality. Table 3.1 summarises the methodological and wider issues.

Immigration should also be distinguished from travelling to another country for treatment - ie: "medical tourism", defined as "the private movement of patients across national borders for the purpose of accessing medical care" (Crooks et al 2016).

Patients travel for orthodox treatments, which may be too expensive or unavailable at home, including because of long waiting lists, and for unproven interventions (including those illegal at home) (Crooks et al 2016).

"Health tourism" is a term covering "medical tourism" and non-medical health-related services (eg: spa therapies), while patients referred to health cre providers in another country by their home health care services are, technically, "out-of-country care". All these terms can be conflated. Also "medical tourists" are not individuals who become ill and seek medical care while travelling, or ex-patriates receiving care in the country where they live (Crooks et al 2016).

Methodological issues	Wider issues
1. Source of data - eg: surveys of emergency departments or households. 2. Type of data - eg: primary (eg: interviews) or secondary (health record databases). 3. Study population - variations in age of children included, and even children and adults together. Some studies did give details of age. 4. Definition of immigrant - eg: birthplace of child or parents. 5. Statistical analysis in relation to gender - eg: data stratified by gender vs gender as descriptive. 6. Health care service- eg: primary care vs emergency department use. 7. Duration of residence of immigrants. 8. Use of non-immigrant comparison group. 9. Distinguishing between refugees, short or long-term migrants. 10. Each parent may come from a different country. 11. Details of health status of child. 12. Adjusting for other variables and confounders. 13. Analysing gender differences	1. Access to health care services varies, irrelevant of gender bias - eg: health insurance coverage in USA around half of non-citizen immigrants (Pulver et al 2006). 2. Longer parental migration has been found elsewhere to benefit girls more than boys (eg: Mexicans in the USA; Donato et al 2003). 3. The presence of siblings - eg: Mishra et al (2004) found greater discrimination against girls in health care use and feeding in families with no sons. 4. How to define health care use - Pulver et al (2016) stated: "For instance, do more frequent primary care visits mean that a child is receiving the recommended schedule of care or that they require more frequent monitoring because they are unwell? Deciding to take a child to an emergency department could similarly represent a serious acute issue requiring swift care, or it could be more accessible to a family than scheduling an appointment with the child's regular physician" (p57). 5. The behaviour of the child themselves - "Boys may be more risk-oriented and therefore more often require medical attention for injuries than girls... However, elevated risk-taking among boys is not an innate sex characteristic, but is a result of socialisation and parenting... and therefore it may vary across cultures with different gender

Table 3.1 - Methodological and wider issues in studies of gender inequalities of health care service use by immigrant families.

3.6. APPENDIX 3C - ESTIMATING CHILD MORTALITY

Infant mortality is usually calculated for the period birth to five years old (also called under-five mortality rate; U5MR; Walker et al 2012). HIV/AIDS transmission from mother to foetus, and the subsequent death of the child can bias child mortality calculations

(Walker et al 2012).

In low- and middle-income countries which lack accurate registration of births and deaths, estimates of child mortality come from surveys of mothers of reproductive age (15-49 years old in practice) about the survival of their children. If the sample is representative, then estimates can be made for the whole group/country. "It is unlikely that this condition is ever perfectly met: births to mothers who have died or migrated out of the population will not be reported. Moreover, for periods long before the survey, births to older mothers will not be represented because these mothers will have been age 50 or over at the time of the survey and therefore not included" (Walker et al 2012 p2). HIV-positive mothers are more likely to die and thus unable to report the survival or not of their offspring.

One way to overcome this problem is to calculate child mortality in three groups - HIV-negative births to HIV-negative mothers, HIV-negative births to HIV-positive births, and HIV-positive births to HIV-positive mothers (Walker et al 2012).

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4. INDIVIDUAL VERSUS POPULATION HEALTH

4.1. The issues
    4.1.1. Life course
4.2. Air pollution
4.3. Lead pollution
4.4. Industrialisation
4.5. Individual experience of illness
4.6. Appendix 4A - Non-communicable diseases
4.7. Appendix 4B - "Global health"
    4.7.1. Preparedness
4.8. Appendix 4C - Large datasets
    4.8.1. Mental health
4.9. References

4.1. THE ISSUES

The key question for medicine is "why did this patient get this disease at this time?" (Rose 1985). One way to answer the question in research terms is with the case-control method, which compares cases (ie: those with the disease already) and healthy controls for past differences. On the other hand, the cohort method follows a group of healthy individuals over time to see who gets the disease and thus the risk factors for the susceptibility to the disease.

Rose (1985) offered another option - the difference between the questions: why do some individuals have a disease, and why do some populations have more of the disease? Depending on the question used, different answers will emerge - ie: the cause of individual cases is not necessarily the same as the cause of the population incidence of the disease. Add to that the fact that incidence rates vary over time (Rose 1985) (appendix 4B) [32].

The implications of the focus taken is in the prevention strategy adopted. Either concentrating on high-risk susceptible individuals ("high risk" strategy) or producing a strategy to control the causes of the disease in the whole population (population strategy) [33].

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[32] Talking about the ethics of the decisions to ration certain treatment by the NHS in England and Wales, Charlton et al (2017) highlighted the difference between individual or population health: "Budget impact is essentially the price per patient multiplied by the number of patients treated. Yet the prevalence of someone's condition should not determine their access to treatment. The principle of equity means that like cases should be treated as like; the NHS Constitution requires the NHS to respond to the clinical needs of patients as individuals. The new test requires NICE to treat patients in one group less favourably than those in another solely because there are more in the first group than the second. It is numerical discrimination. And if large numbers of patients experience delays, the policy threatens widespread harms".

[33] Distributive justice on scarce resources can be framed as identified (individual) lives versus

The former includes screening, and has the advantage of motivated patients (table 4.1).

ADVANTAGES	DISADVANTAGES
1. Intervention appropriate to the individual. 2. Motivated patients to change behaviour or take medication. 3. Cost-effective use of	1. Problems with screening accuracy. 2. Cost of screening. 3. Does not alter the underlying causes of disease.

(Source: Rose 1985 table 1 p429 and table 2 p430)

Table 4.1 - Main advantages and disadvantages of the "high-risk" preventive strategy.

This approach, however, can lead to the situation of "a large number people at a small risk may give rise to more cases of disease than the small number who are at a high risk" (Rose 1985 p431).

The population strategy involves "mass environmental control" (eg: encouraging everybody to eat less fatty foods), and has the strength of seeking to control the underlying cause of the disease, but at the cost of the "prevention paradox" (Rose 1981) (table 4.2). "A preventive measure which brings much benefit to the population offers little to each participating individual" (Rose 1981 quoted in Rose 1985). Rose (1985) said: "In mass prevention each individual has usually only a small expectation of benefit, and this small

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statistical lives (ie: many). In relation to who to treat when there is an enforced choice, it is the use of high-cost high-technology medicine to save individuals or less expensive primary and preventative care to save many people. Moore (1996) argued that "less expensive primary care, as opposed to high-tech medicine, is positively correlated with improved life expectancy, decreased infant and neonatal mortality, and fewer cases of low birth weight. However, shifting resources from high-tech medicine to primary care will be difficult because people find it psychologically painful to deny care to identified lives. People value identified lives more than statistical lives because we are influenced by certain cognitive preferences inherent to human nature. Natural selection has primed these cognitive preferences" (p379).

benefit can easily be outweighed by a small risk" (p432) [34].

ADVANTAGES	DISADVANTAGES
1. Seeks to control underlying causes of disease. 2. The use of social norms to change behaviour (eg: the majority are doing something).	1. "Prevention paradox". 2. Less motivated individuals to change behaviour etc.

(Source: Rose 1985 table 5 p431 and table 6 p432)

Table 4.2 - Main advantages and disadvantages of the population preventive strategy.

Social determinants of health include the social and physical context, and the "larger political-economic organisation of society" (Short and Mollborn 2015). These are sometimes presented as "upstream" (or macro) factors as opposed to "downstream" (or micro) factors (eg: individual, body), while "meso" level factors interact between these other two (eg: family) (Short and Mollborn 2015).

Table 4.3 gives three examples of studies of the social determinants of health behaviour.

STUDY	DETAILS
Harrison et al (2014)	HIV risk for women in Lesotho linked to wider context (eg: kinship, family responsibilities, economic vulnerability).
Wodtke (2013)	Relationship between neighbourhood poverty in childhood and becoming a teenage parent.
Boardman et al (2010)	Likelihood of smoking across generations in the USA and the social acceptability of the behaviour.

Table 4.3 - Three examples of studies on the social determinants of health behaviour.

The World Health Organisation's "Global Action Plan for the Prevention and Control of Non-Communicable Diseases 2013-20" covers seven areas - harmful use of alcohol, insufficient physical activity, tobacco use, high blood pressure, salt intake, diabetes, and obesity. It is sometimes called the "25 x 25 risk factors" as the goal is to reduce premature mortality from non-communicable diseases by 25% by 2025 (Stringhini et al

[34] Non-communicable diseases lack "charisma" according to Herrick (2017) (appendix 4A).

2017).

Stringhini et al (2017) argued that the "25 x 25 risk factors" ignored low socio-economic status (SES), which is a stronger predictor of premature death than the other factors. These authors provided evidence with data from forty-eight cohort studies from Europe, USA, and Australia.

SES was measured as an individual's last known occupation, and occupations were categorised into nine hierarchical groups (according to the European Socio-Economic Classification; ESEC).

It was calculated from the data on 1.7 million individuals that low SES was associated with 2.1 years of life lost (YLLs) [35] between 40 and 85 years compared to 0.5 for high alcohol intake, 0.7 for obesity, 3.9 for diabetes, 1.6 for hypertension, 2.4 for physical inactivity, and 4.8 for current smoking.

The authors accepted that the risk factors were interconnected "making it difficult to establish their independent contribution. For example, low socio-economic status might induce changes in one or more risk factors, but risk factors for chronic diseases might also reduce labour supply and earnings, thereby lowering socio-economic status. Furthermore, factors other than those considered in the 25 × 25 list could be involved in the pathways between socioeconomic status and mortality" (Stringhini et al 2017 p1234).

If lower SES is associated with poorer health, what is the underlying mechanism involved? One possibility relates to the immune system. Lower SES individuals acquire persistent infections earlier in life, and also have poorer immune response to these pathogens across the lifespan. This leads to a clear difference in chronic diseases in old age based on SES (Meier et al 2016).

Kuh and Ben-Shlomo (2004) outlined the critical period model, where an infection/illness early in life (ie: during a critical period) has a lasting effect on health in later life. SES influences the infection/illness exposed to, as well as the immune system. "For persistent infections, which once acquired are never cleared from the body, impaired immune control later in life may manifest as increased production of anti-bodies targeted against these infections and are reflective of impaired cell-mediated function" (Meier et al 2016 p78).

Kuh and Ben-Shlomo (2004) also described the chain of risk model, where one exposure/experience is linked to another and so on to influence health in later life. Low

[35] YLLs were calculated as "the difference of the areas under the survival curves (from age 40 years to 85 years) comparing the population exposed to a given risk factor with the reference population with no exposure" (Stringhini et al 2017 p1231).

SES in childhood leads to exposure to illness, which leads to low SES in adulthood, and this contributes to poor immune function in later life.

Meier et al (2016) tested these two models with data from the Sacramento Area Latino Study of Ageing (SALSA), which began in 1988-89 with 1789 Mexican Americans in California aged 60 years and above. Early life SES or social economic position (SEP) was based on mother's and father's education and occupation, and the individual's own occupation was used for later life SEP. The immune response was measured by anti-body levels in a blood sample.

The data supported the chain of risk model as "early life SEP influences later life SEP, which in turn, impacts immune control of... infections... Early life SEP was not independently associated with immune response in older age for any of the four persistent infections included in the study" (Meier et al 2016 p82).

Meier et al (2016) summed up: "This study adds to the growing literature showing that childhood may not be an independent critical period for SEP exposures in relation to later life health outcomes, and instead the beginning of multiple mediating pathways that ultimately influence adult health" (p84).

4.1.1. Life Course

The idea of cumulative exposure to disadvantaged circumstances and the duration of the exposure leads to poorer health in later life, according to the life course approach, particularly if the disadvantage is evident early in life. Cumulative exposure to advantage can work the other way (Corna 2013) [36].

In terms of evidence, longitudinal studies, for example, showed rates of decline in health in later life among persistently rich than poor individuals (eg: Americans Changing Lives survey; Kim and Durden 2007).

Corna (2013) noted weaknesses with the life course approach, including:

- SES or SEP is seen as "a rather fixed, taken for granted attribute that can be measured at particular moments across the life course" (p152).

- The "tendency to evaluate how disadvantage influences subsequent health at one point in time, rather than conceiving of health as a dynamic construct that may,

[36] This is often called cumulative advantage/disadvantage (CAD) theory, or specifically "cumulative inequality theory" (Corna 2013).

along with markers of SEP, change over time" (p152).

- Establishing how "socio-economic inequalities are sustained, exacerbated or attenuated over time" (p153).

- Problems with defining SES or SEP (eg: income or occupational class).

- A failure to consider "how gendered experiences may shape SEP differently for men and women over time" (p153).

- Ignoring the social policy contexts, so that "by not linking individual experiences that shape SEP to the social policy contexts that influence resources and shape opportunities, we discount their influence, or at best, assume that they have similar implications for different social groups within and across contexts... This runs the risk of over attributing life course outcomes to individual choices or preferences, placing emphasis on the proximal determinants of health inequalities, rather than the broader, institutional factors that are consequential for SEP and health over time" (Corna 2013 p153).

The age-as-leveller (AAL) hypothesis offers an alternative view. It describes "a process whereby socio-economic inequalities in health and mortality that are evident earlier in the life course converge or attenuate as individuals enter later life... The potential mechanisms driving this convergence include the idea that by a certain age, biological factors play a stronger role in shaping health decline relative to social factors; the potential for welfare state supports associated with retirement to level economic inequalities and their subsequent influence on health (eg: state pensions, subsidised health care etc); and the possibility that inequalities fade out as older adults disengage from important stratifying systems, such as the labour market" (Corna 2013 p152).

Dupre (2007) provided support for both CAD and AAL hypotheses in a study of the effects of education on health in later life. At an individual level, less educated individuals had greater disease in retirement than higher educated ones (ie: widening health gap) (support for CAD), but at a group (aggregate) level, socio-economic differences in health are lessened with age (support for AAL) (Corna 2013).

Corna (2013) argued for a life course theory that emphasised the "dynamic interaction between individual biography, structural context and historical time... Central to this work is the study of trajectories in multiple life course domains, and the transitions or

turning points that shape them... Importantly, individual trajectories do not unfold in isolation; rather, the various social roles that individuals occupy as workers, partners, and parents are interwoven to create what Elder and colleagues refer to as 'social pathways (Elder et al 2003). In turn, social pathways are influenced by the time and place in which they are located, including the structural features of that context, and through their relationship to the social pathways of those around them" (p154).

Three issues emerge from this theory, which are often overlooked in studies (Corna 2013):

a) Individual agency vs structure - "For instance, decisions about educational attainment, extent and type of labour market participation, and involvement in care work are likely influenced by individual preferences, but also by prevailing social policies and provisions with respect to work and family that either provide or restrict resources and opportunities. To attribute observed work patterns among men and women entirely to choice would be erroneously overlooking the contextual factors that shape these decisions" (Corna 2013 p154).

b) The individual's life takes place in a particular historical time and place.

c) Interdependencies within the family - "labour market experiences and their relationship to SEP cannot be fully understood without also considering family roles, both because there are likely to be differences between men's and women's activities owing to the gender division of labour, but also because individuals are often a part of family units where their experiences are best understood in conjunction with those with whom they live and make decisions" (Corna 2013 p154).

Corna (2013) concluded: "Viewed in the context of the life course, the evidence suggests that regardless of the specific mechanism involved, health disparities between the most and least disadvantaged are not levelled with age" (p156).

4.2. AIR POLLUTION

It has been established that outdoor air pollution exposure is linked to increased cardiovascular disease risk (Brook et al 2010), but what is the relationship with hypertension?

Experimental studies have shown that short-term increases in air pollution lead to higher blood pressure (BP), while cross-sectional studies show that long-term exposure increases systolic and/or diastolic BP (Fuks et

al 2016). However, a meta-analysis of cross-sectional studies of fifteen European cohorts (Fuks et al 2014) found "no consistent associations of air pollutants and BP" (Fuks et al 2016). Long-term noise exposure tends to be a confounder as road traffic noise exposure by itself increases hypertension (van Kempen and Babisch 2012) [37].

Fuks et al (2016) used longitudinal data from the European Study of Cohorts for Air Pollution Effects (ESCAPE) [38] (appendix 4C) to study the effects of long-term exposure to air pollution and road traffic noise on hypertension. Fuks et al (2016) included seven cohorts [39] from five countries - Norway, Sweden (2 cohorts), Denmark, Germany (2 cohorts), and Spain. Between 2008 and 2011, measures of air pollution were taken at forty sites in three separate two-week periods to give concentrations of particulate matter. Road traffic noise levels were based on EU data. The main two outcome measures were self-reported hypertension and measured hypertension.

There were over 41 000 participants, who were free of self-reported hypertension at baseline, and follow-up covered 5-9 years. At follow-up, overall self-reported hypertension was 15% and measured hypertension 33%. Air pollution and traffic noise exposure were positively associated with self-reported hypertension, and with taking of blood pressure lowering medication, but not measured hypertension.

The researchers noted the weakness that a "one-time office-based BP measurement in the framework of a cohort study is subject to large intra-individual variability. This variability, as well as the potential misclassification of medication as anti-hypertensive, if indeed the indication was otherwise, might have led to a low specificity of the measured hypertension definition with many false positives" (Fuks et al 2016). Table 4.4 summarises the main strengths and weaknesses of the study.

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[37] "The suggested biological mechanisms for the cardiovascular effects of air pollution include the elicitation of local and systemic inflammation and oxidative stress, autonomic imbalance, and endothelial dysfunction. Road traffic noise, on the other hand, is a stressor affecting the endocrine system and the autonomic nervous system, therefore, it is possible that air pollution and noise affect different pathophysiologic pathways, or at least, not completely overlapping ones" (Fuks et al 2016).

[38] Information at http://escapeproject.eu/.

[39] Eg: Stockholm diabetes preventive programme (Sweden), and Co-operative Health Research in the Region of Augsburg (KORA) (Germany).

STRENGTHS	WEAKNESSES
1. Large prospective study of both air pollution and traffic noise on hypertension. 2. Standardised protocols and definitions "enabled a high degree of harmonisation" (Fuks et al 2016). 3. Diverse populations.	1. Differences between cohorts/studies included. 2. Measured hypertension was not available in all cases, and so self-reported hypertension could not be verified. 3. The risk of the "healthy survivor effect" where participants with the illness drop out of the study during the

Table 4.4 - Main strengths and weaknesses of Fuks et al (2016) study.

4.3. LEAD POLLUTION

Establishing thresholds for public health is often based on the "precautionary principle" - "the idea that when an activity raises threats of harm, we should take measures to stop it, even if some cause-and-effect relations are not fully established scientifically" (Shell 2016 p19).

One example is the threshold for official action in the USA of childhood blood lead levels - 5 micrograms per decilitre (µg/dL). This was set in 2012, not because blood lead levels at this threshold lead to permanent harm, but because 97.5% of young children fell below it (Shell 2016). With this particular health issue, establishing a causal link between low blood lead levels and cognitive deficits is confounded by poverty, for example (Shell 2016).

Studies with rats, say, tend to use very high levels of lead - eg: 80 µg/dL (Shell 2016).

4.4. INDUSTRIALISATION

"Through industrialisation the economy of a country is dramatically transformed so that the means whereby it produces material commodities is increasingly mechanised since human or animal labour is increasingly replaced by other, predominantly mineral sources of energy in direct application to the production of useful commodities" (Szreter 2004 p75). Such a process has negative health implications, including related to urbanisation and migration, and increased interactions through trade, as well as health benefits from technological developments.

Szreter (1997) distinguished "four Ds" of rapid economic growth: disruption, deprivation, disease, and

death. "They can only be addressed through political mobilisation of the society to devise new structures, which can respond to the forces of disruption and remedy their consequences. This typically requires, at a minimum, massive investment in urban preventive health infrastructure, and an accompanying regulatory and inspection system, along with a humane social security system" (Szreter 2004 p82).

Szreter (2004) went on: "The lessons of history, therefore, are that all economic exchange entails health risks and that industrialisation typically results in a particularly concentrated cocktail of such health risks. From a policy point of view, it is particularly important that currently non-industrialised societies are neither encouraged nor forced to enter the industrialisation process without a clear understanding of the difficult prospects which they face for at least a generation while undergoing this profoundly disruptive process. It may well be possible to avoid the undesirable fourth 'D' of death and possibly even the third 'D' of disease, given a sufficiently careful and thoroughgoing effort to manage and respond to the forms of deprivation which rapid economic growth produces as it transforms communities and relationships..." (p84).

Health in later life can be influenced by the socio-economic circumstances experienced in periods of life, including individual job loss and insecurity, and broader economic upturns and downturns.

Hessel and Avendano (2016) looked at the latter with economic data from 1945 to 2010 in eleven European countries involved in the Survey of Health, Ageing and Retirement in Europe (SHARE). Adult life between 25 and 54 years was divided into five-year intervals, and the experience of an economic downturn in these was compared to an individual's health aged 55 to 80 (SHARE data). Health was measured as physical functioning (ie: the ability to perform basic self-care and everyday tasks - eg: dressing, preparing hot meals, using a map).

Experiencing an economic downturn at 40 years old and above was significantly associated with poorer physical functioning in later life.

Hessel and Avendano (2016) offered this explanation for the findings: "adverse financial circumstances and job loss can decrease resources for healthy behaviours such as exercise and nutrition, and may trigger use of alcohol or drugs as a coping mechanism to face adversity" (p769). This is exacerbated for job loss in middle age.

Lu et al (2017) explored paid employment history and frailty in later life using data from the English Longitudinal Study of Ageing (ELSA). From the data on 2765 women and 1621 men over 50 years old when the study began, different employment history profiles were

distinguished (table 4.5).

MEN	WOMEN
• Full-time paid employment throughout working life (FTT) • Non-employment throughout working life (NET) • Full-time employment with retirement at 60 (FTE60) • Full-time employment with retirement at 49 (FTE49) • Late start to paid employment, retired at 60 (LSE60)	• FTT • NET • Little work, early exit (WA) • Long career break for family (LCB) • Short career break for family (SCB) • Family care, then full-time employment (FC/FT) • Family care, then part-time employment (FC/PT)

Table 4.5 - Employment history profiles for men (5) and women (7).

For women, the SCB group had the lowest levels of frailty in later life than FTT, while FC/PT, FC/FT, and NET groups had higher frailty at 60 years old followed by a slower decline. Among men, the FTE49 and FTE60 groups had higher frailty at 65 years old than the FTT group. But men who left employment early for poor health had a slower decline in frailty in retirement.

Though job loss is associated with illness and premature death, unemployment benefits (UB) can reduce the negative consequences. Cylus and Avendano (2017) provided evidence from the Panel Study of Income Dynamics between 1984 and 2009. This involves data collected annually or biennially from households in the USA. In the USA UB vary between States and eligibility criteria differ.

Individuals receiving UB were found to be less likely to report poor health in the year following job loss than non-recipients of UB (18% vs 26%).

However, differences were found between those who received UB and who did not. Recipients were more likely to be married, White, male, and to have higher income, while non-recipients were more likely to be single and Black. This led the authors to note that "unemployment benefits disproportionately favour socio-economically advantaged workers more than vulnerable workers with lower socio-economic status" (Cylus and Avendano 2017 p294).

Also non-recipients were more likely to report poor health in the year before the job loss (21% vs 15%).

In terms of the benefits of UB for health, the most obvious is through income - to maintain consumption (of healthy foods, for example), to limit financial-related stress, and to pay for healthcare. Psychologically, UB may provide "comfort and security to job losers" (Cylus

and Avendano 2017). There is another benefit: "people who are not working may have more leisure time available that can be used for health-promoting, time-consuming activities such as exercise. Unemployment benefits may therefore protect health by subsidising time out of work and providing the unemployed with additional time to engage in health-promoting leisure activities" (Cylus and Avendano 2017 p295).

4.5. INDIVIDUAL EXPERIENCE OF ILLNESS

The "neoliberal consensus in modern welfare capitalist states is characterised by an emphasis on individual responsibility, consumer choice, market rationality and growing social inequalities" (Vassilev et al 2017 p349). The upshot is that the individual can feel responsible for their illness. Vassilev et al (2017) found this among individuals with diabetes in the UK, particularly in relation to the self-management of the illness and feelings of failure.

"Self-management practices have been viewed as a politically sponsored project towards individual self-governance and the acquisition of a new ethical relationship to the self predicated on an individual's empowered and proactive management of their life and an investment in a new set of knowledge and skills... Within this discourse, scientific and evidence- based knowledge is understood as a neutral collection of facts passed down to lay people, leading to the emergence of 'informed patients' (Henwood et al 2011)" (Vassilev et al 2017 p350).

Vassilev et al (2017) undertook thirty semi-structured interviews in the Greater Manchester area (and 30 in Bulgaria as comparison where neoliberal ideas are less influential). Analysis of the transcripts produced four themes around the experience of diabetes management in the context of neoliberalism:

i) Struggling with diet - UK respondents emphasised healthy lifestyles (ie: individual-level factor), but, a the same time, struggling with diet. One person admitted to have "to sometimes cut corners and get quick meals on the table" (ie: "unhealthy" food), while another respondent referred to problems with food labelling - "I don't know what the hell's in it". "Implementing lifestyle changes for our UK respondents was a moral dilemma of ([not] doing the right thing) and identity (being [in]capable or [un] willing to do the right thing), framed in terms of making a personal choice between a life that was healthy and a life that was pleasurable and compatible with one's wishes, identity and social contacts" (Vassilev et al 2017 p355).

Among the Bulgarian respondents, affordability od diet changes was the main issue.

ii) Diabetes as a personal failure - Body weight and diabetes were absent from Bulgarian respondents, but common among the UK ones. For example, an older woman in the latter sample was at pains to present herself as a "good patient", not eating the wrong thing and so controlling weight, as compared to her "daughter's mother-in-law".

iii) Integrating illness management with valued activities - Good diabetes management was discussed in the UK in relation to wellbeing and doing valued activities rather than in the context of narrowly defined health goals.

iv) Trustworthiness of the healthcare system - UK respondents' trust was greater than in Bulgaria.

Overall, "the UK narratives of poor health are associated with two types of moral failure: a failure of character, will, restraint and knowledge; and being a 'burden' to society. These failures were experienced as shameful and inspired little sympathy in others. In Bulgaria, where the emphasis in CIM [chronic illness management] is biomedical, the main focus of respondents is on the lack of a cure. Having diabetes was a form of disability ('being ill' and thus 'less capable' to do 'normal' things), and was therefore primarily experienced as a crisis in which the causes were of little relevance. Being ill in Bulgaria is an irreparable problem that evokes sympathy. This only opens space for what could be described as incapacitated agency, where problems cannot be resolved through rational action whether or not one practices effective self-management" (Vassilev et al 2017 p360).

4.6. APPENDIX 4A - NON-COMMUNICABLE DISEASES

Using a quote from the popular media, Herrick (2017) asked why "the biggest global health challenges are not necessarily those that make the biggest headlines". She quoted her experience of working on a project to reduce alcohol consumption in southern Africa, and this being viewed as unimportant by the locals compared to the fear of the spread of Ebola.

Certain diseases "become imbued with sufficient charisma to garner public attention, material resources and political prioritisation, while others do not" (Herrick 2017 p100). Those that don't are usually lifestyle-related non-communicable diseases (NCDs). For example, they account for 80% of premature deaths in low-

and middle-income countries, but only 2% of global health spending by the Gates Foundation (Herrick 2017). Ironically, "the burgeoning NCD rate in the global south is an unintended 'paradox of success' from efforts to reduce infectious disease mortality and morbidity, infant and maternal mortality, and gains made in life expectancy at the expense of years of life lived in good health" (Herrick 2017 pp101-102).

NCDs are often viewed as the fault of individuals in wealthy countries in their lifestyle choices (ie: "victim blaming"). But Farmer et al (2013) pointed out that "boundaries between communicable and non-communicable diseases are often indistinct" (quoted in Herrick 2017). "New syndemics are emerging where NCDs such as, for example, cervical or liver cancer have infectious aetiologies and chronic conditions such as type-2 diabetes can significantly increase the risk of otherwise infectious diseases such as TB... These co-infections are most marked amongst the NCDs of the world's 'bottom billion', many of whom live in locations where TB is endemic, HIV rates are high and rates of obesity (as a risk factor for type-2 diabetes) are rapidly rising" (Herrick 2017 p103).

In trying to explain the limited interest in NCDs, Herrick (2017) made use of the concept of "charisma", originally understood by Weber (1947) as possessed by individuals. Blom Hansen and Verkaaik (2009) added "mythical" charisma that cities can "create" and endow on their users (residents), and "performative" charisma that occurs in the city: "special forms of knowledge, networks, connectedness, courage and daring that enable some individual – politicians, gangsters, business tycoons and the everyday hustler – to assume leadership, or to claim hidden and dangerous abilities and powers" (quoted in Herrick 2017).

Applied to diseases, mystical charisma is "generated by the interactions between popular and scientific knowledge, facts and anecdote, observations and rumour that come to circulate and characterise disease" (Herrick 2017 p104), and performative charisma "evokes the types of knowledge, language, tools of persuasion and aspects of legitimation that enable certain individuals to talk of disease in ways that confer power and agency on that disease" (Herrick 2017 p104). A prime example is HIV/AIDS. Mythical charisma is seen in the references to "plague" or the imagery of "AIDS orphans", and performative charisma in the behaviour of famous and "heroic" campaigners and sufferers, for example (Herrick 2017).

Lorimer (2007) introduced three other forms of charisma when talking about animal species:

i) Ecological - This "relates to the ways in which

organisms intersect with and can be comprehended by human bodies in ways that exhibit varying degrees of 'detectability' and therefore the ease with which they might be mapped, researched and understood" (Herrick 2017 p105).

ii) Aesthetic - This emerges from short-lived and emotional encounters with rare species, for example.

iii) Corporeal - This is the product of more common interactions with common species.

"Both aesthetic and corporeal charisma are inherently malleable and dynamic and, importantly for this paper, can 'certainly be magnified through marketing and [are] open to a degree of construction', which may also be 'constrained by the ecological characteristics and particular agencies of the species themselves' [Lorimer 2007]" (Herrick 2017 p105).

NCDs have a "charismatic gap", argued Herrick (2017). They do not evoke fear of "plague" (mythical charisma), they are not associated with "heroic" individuals (performative charisma), and they do not have the thrill of glimpsing a rare, endangered species (aesthetic charisma). Put in ordinary language, NCDs are mundane, even boring in their image.

Furthermore, "non-communicable disease means nothing to ordinary people. Nevertheless, it seems as if the term - or rather its acronym, NCD - is becoming the accepted category" (Smith 2011 quoted in Herrick 2017). NCD is a category in public health to cover non-infectious diseases with "modifiable" risk factors. Certain assumptions are made about NCDS: "(1) that individuals have and can exercise choice; (2) that choices exhibit varying degrees of responsibility; (3) that behaviours are modifiable and (4) that the 'wrong' behaviours reflect individual or class culpability" (Herrick 2017 p107).

Using the term "lifestyle disease", particularly in relation to the last assumption, can lead to "voyeuristic class disgust" (Piper 2013), "and subsequent 'reflexive positioning' [Piper 2013] in that they become mechanisms to judge the quotidian behaviours that we so often deny or discount in ourselves, rather than vehicles for the realisation of health equity and social justice" (Herrick 2017 p108).

The risk factors for NCDs are "socially normalised activities" (eating, drinking and exercising) that "become ambivalent 'sites of social anxiety (Ungar 2001) that we binge on food and alcohol, are irreparably distanced from the origins of our mass-produced, toxin-loaded food, lead automated and automobile-reliant lives and allow children to be addicted to screens" (Herrick

2017 p7).

Add to that "the relationship between diet, exercise and body weight and between body weight and health are both unclear and, furthermore, intensely contested" (Herrick 2017 p108).

Herrick (2017) concluded: "Without charisma, that is, the possession of an exceptional status that incites affective responses such as fear, anxiety, awe or disgust (Lorimer 2007), the potential political and popular salience of NCDs will remain limited, regardless of the power of the advocacy community's credibility claims" (p14). She continued: "The 'cultural narratives' (Treichler 1988) that characterise individual chronic diseases can therefore be lost when they are demarcated as NCDs. There is no shared history of NCDs, no high-profile advocacy and few cultural connotations beyond the association of risk behaviours with lifestyle. This association, in turn, only evokes notions of individual and collective culpability that undermines the case for global action in the common good" (Herrick 2017 p112).

4.7. APPENDIX 4B - "GLOBAL HEALTH"

Any understanding of health takes place today within the context of globalisation, which Deacon et al (2009) said: "(a) sets welfare states in competition with each other, (b) raises social policy issues to a supranational level, and (c) generates a global discourse on the best way to regulate capitalism in the interests of social welfare East and West, North and South" (p23).

"International" public health focuses on the control of epidemics across countries, whereas "global" public health "in general, implies consideration of the health needs of the people of the whole planet above the concerns of particular nations" (Brown et al 2006 p62). The World Health Organisation is key in the development of both. Brown et al (2006) stated: "Between 1948 and 1998, WHO moved from being the unquestioned leader of international health to being an organisation in crisis, facing budget shortfalls and diminished status, especially given the growing influence of new and powerful players. We argue that WHO began to refashion itself as the coordinator, strategic planner, and leader of global health initiatives as a strategy of survival in response to this transformed international political context" (p62).

Fried et al (2010) stated that "global health is public health", but Myer (2015) pointed out that "global health" as a field has emerged at North American academic institutions, having links to "tropical medicine" and "international health". But there is the "retaining

traces of European and/or North American conquest, imperialism, and colonialism that create a legacy of ongoing ethical challenges for global health" (Myer 2015 p5). The response is that "global health" is entering into "'true' partnership with poor countries" (Crane 2010). Sanchez and Lopez (2013) countered that "existing... global health [literature] - its evolving definitions, scope and, very importantly the values and competencies required for ethical practice - reveals a troubling imbalance: there is little contribution from Southern authors based in the South" (quoted in Myer 2015).

The use of the concept of "global health" has a good motivation with its "emphasis on disenfranchised populations who do not enjoy the advantages of the medical systems of developed countries. By drawing attention to the issues that affect billions of disadvantaged people around the world, global health campaigns attempt to reduce the moral distance that makes many in developed countries neglect the needs of those most in need in other countries" (Shaw and Rich 2015 p1).

There is a binary perspective here (rich-poor, developed-developing), and a comparison of country averages (Shaw and Rich 2015). Rosling (2006 quoted in Shaw and Rich 2015) pointed out the danger of average data, "because there is such a lot of difference within countries.… [For example, we can split countries into quintiles and compare, say, the poorest 20 percent of Niger with the richest 20 percent of South Africa], and yet we tend to discuss on what solutions there should be in Africa. Everything in this world exists in Africa".

Another issue for Shaw and Rich (2015) is global health inequalities of future generations, particularly with health implications of climate change. They made this point about health programmes today: "The simple fact that successful global health campaigns can transform the lives of millions of people raises serious issues for future generations. If hundreds of thousands of people are saved from famine and disaster, that in turn means that hundreds of thousands of babies will be born who otherwise would not have been. In addition to the direct impact this will have on climate change, will the health care of these future generations be of the same or better standard available to their parents?" (p2).

4.7.1. Preparedness

In recent years, the WHO has spearheaded the idea of preparing to deal with future pandemics, particularly influenza. "Pandemic 'preparedness' embodies a pre-

emptive approach to the regulation and control of emerging infectious disease that involves generating responses to predictions concerning a future event that is both exceptional and highly uncertain" (Sanford et al 2016 p19).

Sanford et al (2016) explored the concept of "preparedness", and performed a discourse analysis of four key pandemic planning documents produced by the WHO between 1999 and 2009.

Being prepared is part of the "securitisation of disease" (eg: Elbe 2005), which presents a "new normal" or "newly insecure" world (Hooker and Ali 2009). "Representations of the emergence of novel infectious diseases (for example, SARS) and re-emergence of previously controlled disease (for example, tuberculosis) reflect deep-seated cultural values about geopolitical relations. Notably, pathogens are thought to originate somewhere other than the global North and exert their threat through interconnectedness within the globalised economy... and through international migration, with consequences for nationalist identities and economic agendas..." (Sanford et al 2016 p20).

Specifically, the "new normal" "emerges in the context of both neo-liberal policies that emphasise and prioritise individual freedom in relation to risk management, and neo-conservativism that 'justifies the reimposition of authoritarian government in order to maintain security' (Hooker and Ali 2009)" (Sanford et al 2016 p21). Connecting infectious diseases with bioterrorist threats allows interventions in the name of "public health" (Thaker 2006). "In the context of declining government intervention and the individualisation of responsibility for health and well-being, there has been a corresponding investment of public funds into the stockpiling of vaccines by wealthy countries, which has contributed billions of dollars to the pharmaceutical industry... These kinds of public health agendas have replaced social programs that target the underlying causes of health inequalities, and can be understood, further, as creating new speculative possibilities for profit by private interests..." (Sanford et al 2016 p21) [40].

So the focus has moved from dealing with known diseases to those predicted to occur at some point in the future. Fear of the potential rather than the actual. Foucault (eg: 1975) used the concept of "biopolitics" to describe how poor is used to control the body (in the case the social body). "In this regard, the biopolitical security apparatus organises and regulates the 'natural' features of the populations in relation to the liberal

[40] For example, the production of a global stockpile of anti-virals - the UK government had spent over $700 million by mid-2014, it was estimated, on an influenza anti-viral stockpile (Sanford et al 2016).

conceptualization of society, in which individual freedom is problematised as the objective of government and as inextricably bound up with mechanisms of unfreedom, control and constraint required to protect the population from internal threats..." (Sanford et al 2016 p23) [41].

Put another way, the threat of future diseases requires the government to take certain necessary measures for protection, which may restrict the individual's freedom [42], in association with the free market [43].

Returning to the WHO documents, Sanford et al (2016) gave an example of "pandemic potentiality" in discussion of influenza viruses living in wild birds, "which normally do not infect people, could transform into a pandemic virus" (WHO 2009 document; Sanford et al 2016 p28). This potential transformation is a threat because it transgresses boundaries, not only between animals and humans, but also nation states. It is the latter that is the basis of the WHO's decision to call a spread of an infection, a pandemic.

Thus, a need for an "early warning" approach (part of preparedness) to allow time to develop vaccines, for example. But this "early warning" approach requires vigilance all the time, even when there are no obvious signs of infection - ie: "to collect, interpret, and disseminate information on the risk of a pandemic before it occurs" (WHO 2009 document; Sanford et al 2016).

"Pandemic preparedness discourse operates as a technology of (in)security that renders the uncertainty of pandemic emergence governable. The threat of pandemic influenza to the health of the global population is conceived of, and responded to, through specification of the very features of the virus and its potential to disrupt society in numerous ways. The construction of the virus, both in terms of its pandemic potentiality and its capacity to transgress corporeal and territorial boundaries, is key in this regard; these features reveal the interconnectedness of territories, and how such interconnectedness constitute zones of vulnerability to pandemic emergence, and thus threats to global health" (Sanford et al 2016 p35).

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[41] According to Foucault, biopower operates through the "microscopic management of life" (Morris 2007).

[42] For example, freedom of movement could increase the circulation of the virus.

[43] "Discipline, according to Foucault's historical and philosophical analysis, is a form of power that tells people how to act by coaxing them to adjust themselves to what is 'normal'. It is power in the form of correct training. Discipline does not strike down the subject at whom it is directed, in the way that sovereignty does. Discipline works more subtly, with an exquisite care even, in order to produce obedient people. Foucault famously called the obedient and normal products of discipline 'docile subjects'" (Koopman 2017).

4.8. APPENDIX 4C - LARGE DATASETS

The growth in the availability of digital health data and biobanks is a benefit for researchers, but it also raises ethical issues. For example, Aicardi et al (2016) distinguished between anonymous and anonymised data: "Anonymisation is a process performed on identifiable data or material, which makes the data or material no longer identifiable. This concept is categorically distinct from 'anonymous', which signifies a status of data or material, namely that which never was identifiable at the origin" (p210).

Another issue is how the data are used. Aicardi et al (2016) stated that "it may be possible to establish a probabilistic correlation of clinical relevance between two characteristics A and B (eg: a biomarker and late onset disease). The sheer volume of data and the relative ease with which digital data can be mined would make this possible. For any individual exhibiting characteristic A, the hypothesis of them also possessing or developing characteristic B could lead to tangible implications, even if the quality of the data and the robustness of the correlation were never verified" (p210).

4.8.1. Mental Health

Socio-economic status (SES) and differences in mental health are evident. Socially deprived areas (taken as low SES) have a greater prevalence of mental disorders, while individuals from these areas make less use of mental health services including therapy, and have poorer outcomes for psychological treatments (Delgadillo et al 2016).

Delgadillo et al (2016) analysed publicly available data in England from the government-funded "Improving Access to Psychological Therapies" (IAPT) from 211 clinical commissioning groups (CCGs) for July to September 2014. The CCG locality was scored on an index of multiple deprivation (IMD), where a lower score is greater deprivation.

New referrals for therapy were negative correlated with IMD (ie: more referrals in poorer areas and less referrals in richer areas), and poorer areas had lower average recovery rates, though take-up of therapy was less and/or drop-out higher in deprived areas.

The researchers did not have for information for individual patients, but they were sure that a "range of other factors including employment status, baseline symptom severity, functional impairment and variability between therapists are likely to influence clinical outcomes in psychological care" (Delgadillo et al 2016 p430).

Thus, Delgadillo et al (2016) "put forward an argument that 'recovery targets' [44] should be adjusted for social deprivation, at the same time they rightly inveigh against using the term 'recovery' to refer to what may be a short-term improvement in reported mental health at the end of therapy" (Parry and McCrone 2016 p431).

Parry and McCrone (2016) noted the wider context of IAPT: "Local authority spending on social care has been reduced in recent years and this has likely had an impact on the ability of mental healthcare services to function efficiently and to provide an optimum level of service. Cuts to other local authority services and grants to third-sector providers is also going to have a detrimental effect. Such impacts not only reduce the amount of service provision but they may themselves have an impact on the occurrence of mental health problems in the first place" (p431).

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5. PLACEBO EFFECT

5.1. Placebo and pain
5.2. Increasing placebo effect?
5.3. Placebo and psychiatry
5.4. References

5.1. PLACEBO AND PAIN

Beecher (1955) was the first person to formally show that in clinical trials, one-third of individuals in the control (placebo) group improved [45] [46]. Thus, the "placebo effect", where an individual's health condition improves with no formal treatment but by the belief that they are receiving treatment.

Levine et al (1978) showed a biological effect to placebos. Individuals in pain were given an intravenous infusion of saline, which was presented as morphine, and dental pain was reported as reduced. Then a substance that blocks the action of painkillers was added secretly to the saline, and the patients reported the return of pain. This study showed that "a placebo response could be biochemically blocked" (Marchant 2016) - ie: the placebo effect is not pretending or imagined. It produces a release of endorphins. This has been confirmed subsequently by neuroimaging (Marchant 2016).

The placebo effect has also been found to activate endocannabinoids, dopamine, and prostaglandins (Marchant 2016).

Pain is the most commonly studied symptom in relation to placebos, which alter the perception of it. While social factors and learning influence the placebo effect (Marchant 2016). In the case of learning, Colloca and Benedetti 2006) used the idea of "pre-conditioning" [47]. Initially, patients are given a real painkiller before an electric shock [48], and surreptitiously the amount of painkiller was reduced. Eventually, individuals reported the same level of pain with no painkiller as with the full amount [49]. Pre-conditioning also worked even when individuals knew it was a placebo (Schafer et al 2015) (table 5.1).

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[45] Beecher (1955) reviewed fifteen "illustrative studies" chosen at random (covering over 1000 patients), and including seven in which he was involved.

[46] On the other side, participants in placebo groups report side effects (eg: 10% of cases; Beecher 1955), both minor and major.

[47] Or "response conditioning" (Schafer et al 2015).

[48] Pain was induced by a mild electric shock to the back of the hand of thirty healthy volunteers.

[49] The placebo effect was found to last 4-7 days.

- Forty volunteers at a US university were divided into two groups - long conditioning and short conditioning - for the experiment. Pain was induced by a hot needle to the forearm. Participants in the long conditioning group had four sessions of pain and analgesic cream, while the short conditioning group had one session. This was the conditioning phase of the experiment.

- During the testing phase, pain followed by cream continued, but halfway through all the participants were told that the cream was a placebo ("placebo reveal").

- The painkilling benefits of the placebo cream were reported by the long conditioning group even after the "placebo reveal". The short conditioning group reported more pain after the "placebo reveal".

- This study shows that multiple sessions of conditioning with a real painkiller can continue to reduce perceived pain even when individuals know a placebo painkiller is being used.

Table 5.1 - Schafer et al (2015).

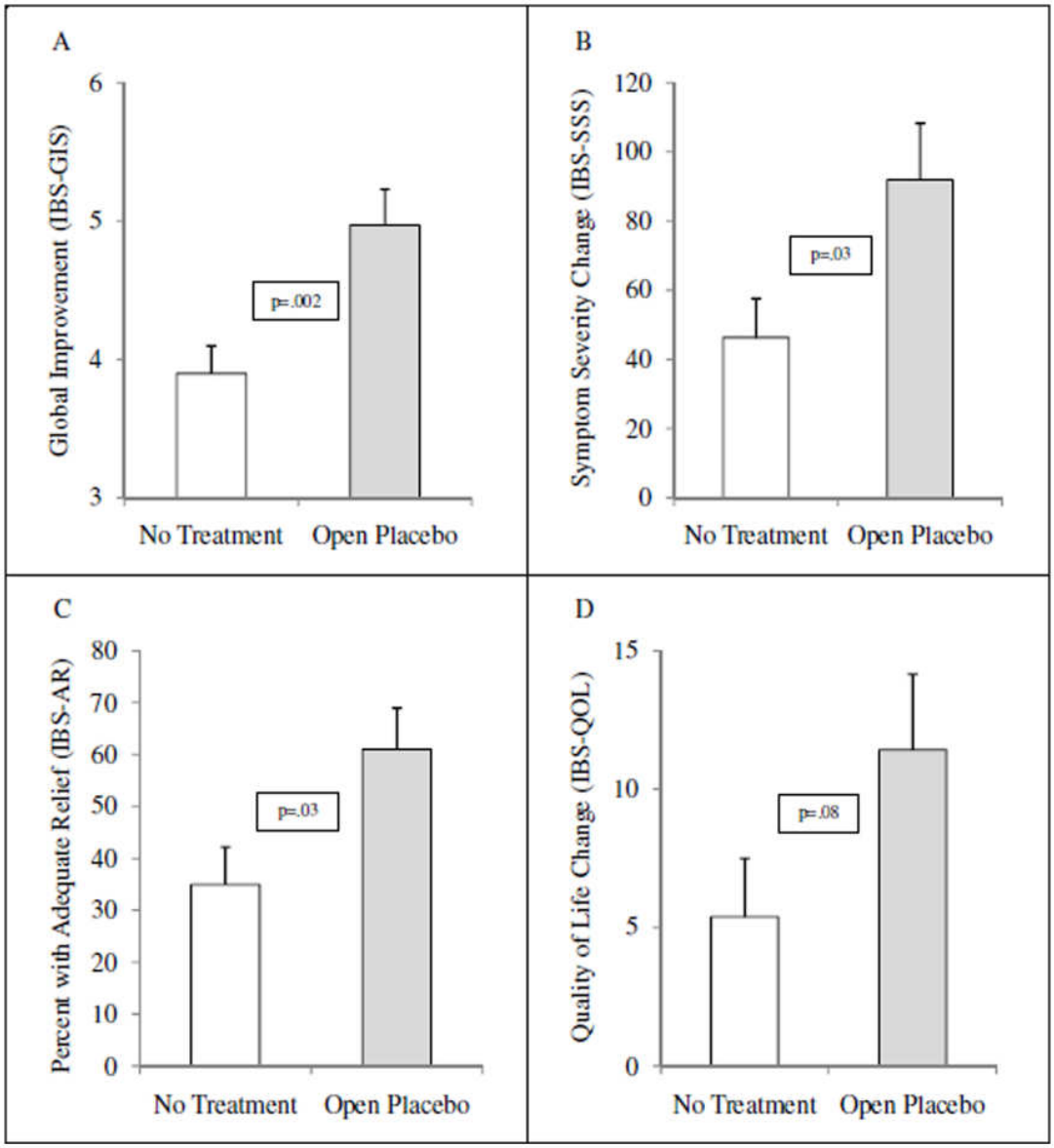
There are ethical issues that limit a doctor from secretly giving a patient a placebo. But telling a patient that a container of medication contains both active and inert painkillers could make use of pre-conditioning. Colloca et al (2016) reviewed twenty-two studies using such a technique [50]. The researchers made the following points based on their review: "(1) placebo effects exist whenever an active medicine is given, (2) conditioning in replacing an active medicine with a placebo can target and boost endogenous placebo mechanisms (beyond what a placebo alone can do) and, finally, (3) it may be possible in this way to reduce the overall dose of active analgesics, costs, and potentially side effects and tolerance, all in an ethically acceptable manner" (Colloca et al 2016 p1596).

In relation to ethical concerns for doctors, Colloca et al (2016) gave an example of a way of gaining consent and telling the truth. The patients would be told - "you will be given a blister pack of painkillers and placebos and at some point during the course of treatment you will receive placebo rather than medicine, but you won't know when" (p1596).

Kaptchuk et al (2010) went one step further. They told patients with irritable bowel syndrome (IBS) that the medication was placebo. Around 60% of the patients reported adequate relief from symptoms compared to 35% of the no-treatment group (figure 5.1) - "better than most IBS drugs" (Kaptchuk in Marchant 2016). Eighty volunteers were recruited with an advertisement for "a novel mind-body management study of IBS", and they were told that

[50] Fourteen studies with humans and eight with non-human animals.

"placebo pills, something like sugar pills, have been shown in rigorous clinical testing to produce significant mind-body self-healing processes" (Kaptchuk et al 2010). IBS symptoms were self-reported overall and individually at baseline and after three weeks.



(a) IBS Global Improvement Scale (IBS-GIS): "Compared to the way you felt before you entered the study, have your IBS symptoms over the past 7 days been": (1) "substantially worse"... (7) "substantially improved".

(b) IBS Symptom Severity Scale (IBS-SSS): 100 point scale for individual symptoms (eg: severity of abdominal pain). Higher score = improvement.

(c) IBS Adequate Relief (IBS-AR): "Over the past week have you had adequate relief of your IBS symptoms?" yes/no.

(d) IBS Quality of Life (IBS-QoL): 34 items scored on five-point scale and transformed into 0-100 improvement score.

(Source: Kaptchuk et al 2010 figure 2)

Figure 5.1 - Outcomes measures at 21 days.

Carvalho et al (2016) reported improvements over three weeks in chronic lower back pain among individuals receiving their normal painkillers and an openly given placebo compared to the normal painkiller only.

Eighty-three adults at an outpatient pain unit of a public hospital in Lisbon, Portugal, completed the three-week randomised controlled trial that was advertised as "a mind-body clinical study of chronic low back pain". Randomisation was done by a computer programme. After all the participants viewed a presentation about placebo, those in the open label placebo (OLP) group received a bottle of gelatin capsules with the label "placebo pills - take two pills twice a day" to go with their normal medication, and the treatment-as-usual (TAU) group were given instructions to continue with their normal medication.

Outcomes were taken at baseline, and eleven and 21 days later. Pain intensity was scored for the previous week on a scale from 0 ("no pain") to 10 ("worst pain imaginable"). This was used for maximum pain, minimum pain, and usual pain. Disability in relation to 24 daily activities (eg: getting dressed) was scored as yes or no, giving a total of 0-24 [51].

The OLP group reported significantly less pain and disability at 21 days compared to baseline and to the TAU group. Mean ratings of pain declined by 1.5 points in the OLP group compared to 0.2 points (out of ten) in the TAU group, and by 2.9 and less than 0.1 (out of 24) respectively on the Roland-Morris Disability Questionnaire. Roelofs et al (2008) reported that non-steroidal inflammatory drugs (NSAIDs), usually given for back pain, have a mean reduction of 1 point on the pain scale.

5.2. INCREASING PLACEBO EFFECT?

In the first systematic study of placebo-controlled anti-depressant trials up to 2000, Walsh et al (2002) found that the placebo group response rate in seventy-five studies had increased with time (ie: higher in newer studies).

However, Furukawa et al (2016) found that the average placebo group response rate in anti-depressant randomised controlled trials had been stable over the last few years (at 35-40%). These researchers found 252 double-blind studies since 1978, and divided them into five-year periods of publication for analysis. The overall response rate of placebo was 36%, and the range was 28% (1986-90) to 40% (2001-15).

[51] A Portuguese version of the Roland-Morris Disability Questionnaire (Roland and Morris 1983).

Furukawa et al (2016) explained the difference between their findings and those of Walsh et al (2002) as down to methodological factors in the studies included (eg: duration of trial; number of sites involved in a study; severity of depressive symptoms at baseline). Thus, Furukawa et al (2016) stated: "the myth of increasing placebo response was due to the exceptionally low rates in 1980s and before, which were confounded especially by the shorter duration of the trials and the preponderance of single-centre studies" (p1064).

Another methodological issue is the type of the outcome measure used. For example, Rief et al (2009), using doctor-reported measures of depression, found a rise in placebo responders in studies before the year 2000, whereas patient-reported outcomes did not (Furukawa et al 2016).

5.3. PLACEBO AND PSYCHIATRY

Iovieno et al (2016) investigated the studies of treatment for bipolar disorder between 1980 and 2015. Twenty relevant randomised, double-blind, placebo-controlled trials were found. Meta-analysis of the data produced a response rate [52] of 55% for medication and 40% for placebo. Iovieno et al (2016) took this finding as "further confirmation that the placebo response is, to a greater degree, nested within the drug response group" (p41).

Studies with higher placebo response rates had lower improvements in symptoms from medication, and vice versa. The researchers interpreted this finding as a product of the quality of the design of the study. Iovieno et al (2016) wondered whether "placebo response rates are uniform throughout the entire duration of the conduct of a clinical trial (ie: from first to last patient enrolled), although no studies, thus far, have demonstrated this" (p41).

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6. ORGAN TRANSPLANTATION AND DIAGNOSIS: CONTESTED HEALTH

6.1. Organ transplantation
6.2. Disability desire
6.3. Appendix 6A - Diagnosis and negotiated order
6.4. Appendix 6B - Blom et al (2012)
6.5. References

6.1. ORGAN TRANSPLANTATION

Aspects of the health care system that are not available to all are explained by "scarcity discourses" (eg: shortage of transplantation organs). Brassolotto and Daly (2016) concentrated on kidney treatment and transplantations in British Columbia, Canada.

The demand for kidneys outweighs the supply, and thus the shortage (eg: 1 in 10 Canadians has some level of kidney disease; Brassolotto and Daly 2016). Scheper-Hughes (2006) described such shortages as "an artificially created need" that was "invented by transplant technicians, doctors, and their brokers, and dangled before the eyes of an ever expanding sick, aging, desperate, and dying population" (quoted in Brassolotto and Daly 2016). Her argument was that "focus on the need to increase organ donation limits discussion of why transplants are becoming increasingly routine and required in the first place" (Brassolotto and Daly 2016 p139). So, the shortage of kidneys is not too few organs, but "that the pool of potential recipients has become too large" (eg: infants, patients over 70 years old, and patients with co-morbidities) (Brassolotto and Daly 2016) [53].

The increased demand for kidneys is often presented as down to the increasing rates of diabetes, high blood pressure, and obesity, and the ageing population. Lock and Nguyen (2010) preferred to talk of "diseases associated with poverty and social inequality, many of which could be prevented" (quoted in Brassolotto and Daly 2016). Thus, Brassolotto and Daly (2016) argued that to "look at kidney failure in isolation from the social, political, economic, environmental, and cultural contexts in which people become ill is to ignore the origins of kidney scarcity" (p139).

The use of the organ scarcity discourses influences health care policy and practices [54], and affects the

[53] Receiving an organ transplant depends on diagnosis of illness, and with some conditions this is not clear-cut (appendix 6A).

[54] Sharp (2007) used the term "organ transfer" to cover the practices of organ donation and transplantation.

experience of individuals. But it is part of a "narrow clinical biomedical focus" that treats "human parts as scarce medical resources" and commodifies human bodies (Brassolotto and Daly 2016).

The decision as to who receives treatment and who not has been called "lifeboat ethics" (Koch 2002). It is "a term that has been used historically to refer to the dilemma of determining who will live when not everyone can live. Or rather, '[w]here scarcity reigns, who is to be sacrificed so that others might live? (Koch 2002). The term describes a class of problems in which, 'the presumably inflexible limits of existing resources are assumed to create a special circumstance in which otherwise sacrosanct principles are greatly relaxed if not wholly in abeyance' (Koch 2002). This presents the idea that crisis situations are times and/or spaces of ethical exception" (Brassolotto and Daly 2016 p139) [55].

Brassolotto and Daly (2016) undertook a case study in a rural dialysis clinic in British Columbia in 2013, which included thirty in-depth interviews with patients, family carers, and health care professionals. Publicly-available official documents were also examined.

The findings on the effect of the scarcity discourses were observed at three levels:

i) Macro level (policy and province) - "scarcity of transplantable kidneys" - eg: documents from charitable organisations emphasised the death of patients from the shortage of kidneys and encouraged donation (eg: "give the gift of life"). The cause of the increase in demand for kidneys was underplayed. Thus the policy solution was to secure more kidney donations.

ii) Meso level (health system and region) - "scarcity of health care and human resources" - eg: the problems of providing renal care in rural areas. One nurse described the patients seeing different nephrologists who suggested different treatments: "So the next guy comes along and says, 'Well, I don't know why that nephrologist did that'. So then they stop whatever medication, it's usually a medication, they stop that medication and give them something else. So our poor patients' heads are just spinning because they're getting

[55] Brassolotto and Daly (2016) observed: "It is interesting that lifeboat ethics have been evoked in this context, given that renal transplants are not life-saving procedures in the way that heart transplants are. No other therapy can replace the function of the heart. A kidney transplant may improve and/or extend a life, but a patient can still live for years on dialysis. This underscores the fact that kidney transfer is not strictly a matter of life and death, but rather, a practice that occurs within particular social, political, and economic systems and reflects the different relationships that have been institutionalised between the individual, the market, and the state" (p139).

sometimes... In six weeks, they can get three different prescriptions" (p142). Another nurse described the workload with too many patients to see: "I see patients from 8 in the morning until 6 at night, every 20 minutes, with no lunch or bathroom breaks" (p142).

iii) Micro level (clinic and patient) - "scarcity of health and life-sustaining resources". This related to the socio-economic status of the patients. "Not only were nurses aware of the limited funds and health care resources that they were working with, they were also acutely aware of the limited socio-economic resources available to their patients. The nurses recognised the high costs of travel and transportation to dialysis, the expensive nature of the kidney-friendly diet for those on low incomes in isolated areas, the lower levels of formal education and health literacy, the limited access to supports and services, and the social and/or financial hardships that many of their patients experience" (Brassolotto and Daly 2016 p143).

For example, one patient could only afford the petrol to come for dialysis twice a week, when three-four times was needed. Another patient lost his transplant opportunity because he could not afford the time off work for all the tests (before and after) involved. One health care professional believed that transplantations were turned down because of the time required to recover (ie: time off work).

Brassolotto and Daly (2016) highlighted how the macro level policies and practices were different from the micro ones (ie: the experiences of poor, rural patients, in particular). They stated: "Our findings suggest that the kidney scarcity discourse benefits the health care system through cost savings; benefits transplant surgeons and related organizations by expanding their visibility, funding, and practice; and benefits transplant recipients by restoring renal function and improving quality of life. However, transplants are not universally accessible. Rural residents, people with multiple health conditions, people with low incomes, and people who experience various forms of social and geographic marginalisation are less likely to be able to access transplantation services. Efforts to reduce dialysis expenses can offload costs and care from the system onto patients and their families. In terms of power relations, our findings reveal that some of the most influential parties in renal care (government, policy-makers, members of policy sub-systems) are at a distance from the micro level struggles associated with renal health and everyday care" (Brassolotto and Daly

2016 p144) [56].

6.2. DISABILITY DESIRES

Body integrity identity disorder (BIID) [57] is where "some people have a profound dissatisfaction with what is considered an able-bodied state by most others" (Brugger et al 2016 p1176). In other words, these individuals desire limb amputation, or paraplegia in the most profound cases, but also deafness, blindness, or the status of eunuch.

Brugger et al (2016) preferred to call it "disability desires" (DD), and such individuals "describe a profound mismatch between their actual and their desired body, with respect to its shape and functionality" (p1176), using the term "overcompleteness" often (table 6.1). The onset is between 5-15 years old, and "the desire for a specific disability is not stronger than the desire to compensate for it by use of prosthetics, such as crutches, a wheelchair, or hearing aids" (Brugger et al 2016 p1176) [58]. DD is not listed in DSM-5 or ICD-10.

QUOTE	STUDY	DETAILS
"I feel myself complete without my left leg... I'm overcomplete with it"	First (2005)	Telephone interviews with 52 individuals
"My soul feels as though it belongs to a body with only one leg. The body does not correspond to this inner reality"	Kasten (2009) quoted in Brugger et al (2016)	Postal survey with personality inventory to nine men in Germany
"I am using a wheelchair 'full-time' when I'm in public. I walk at home. This is the only way how to remain somewhat	Blom et al (2012) (appendix 6B)	Internet-administered tests with 54 individuals

(Source: Brugger et al 2016 panel 1 p1177 and table 1 p1178)

Table 6.1 - Examples of quotes from individuals with "disability desires".

[56] Talking about surrogacy by women in poorer countries, which has many similarities to organ donation by such individuals, Davies (2017) commented that " long before the potential hazards of childbirth, surrogates have to endure the side-effects of the drugs ingested in embryo transfer" (p44). Pande (2014) described commercial surrogates in India as "reproductive labourers", and she advocated a "fair-trade surrogacy" with labour laws and protection.

[57] Also called "xenomelia" and "transability" ("transableism") (Brugger et al 2016).

[58] Blom et al (2012) commented that "BIID individuals typically avoid healthcare and often act out their desires by pretending they are disabled or perform actual self-amputation".

BIID has been compared to gender identity disorder (GID), and is distinct from psychotic-related self mutation, brain injury and estrangement from own limbs, somatoparaphrenia (denial of ownership of functionally impaired limbs), and body dysmorphic disorder (which has a greater concentration on the visual appearance of the body or part). In the past, DD was viewed as a paraphilia (eg: sexual arousal by disability) (Brugger et al 2016).

In terms of the research, 15% of 52 individuals with DD had sexual arousal as their primary motivation in one study (First 2005) compared to 90% of 54 individuals recruited via the Internet (Blom et al 2012). Brugger et al (2016) admitted that "sexual undertones are often part of the bigger picture of corporeal identity" (p1178).

Neuroimaging of individuals with DD has found a strong lateralisation to the right hemisphere of a network of regions, namely the parietal lobe ("corporeal awareness"), insula ("integration of body and mind"), and premotor cortex ("unity of body and self"). Often left-sided amputation is desired, and non-righthandedness is higher in DD individuals (Brugger et al 2016) [59].

6.3. APPENDIX 6A - DIAGNOSIS AND NEGOTIATED ORDER

Receiving a diagnosis has implications, not least it "allows individuals to validate their illness experience as real, both to themselves and to the wider social world... Diagnosis thus marks the transformation of illness to disease..., and a contestable subjective state thereby achieves a more authoritative objectivity. Hence, a diagnosis is both a 'category and an event' (Kokanovic et al 2013). The diagnostic event may, however, be a complex process, as medical diagnoses are 'contested, socially created, framed and/or enacted' and are influenced by 'social, political, technological, cultural and economic forces' (Jutel and Nettleton 2011)" (Madden and Sim 2016 p89).

Diagnosis can be seen as an example of the "negotiated order", which comes the symbolic interactionism approach. Social meanings are created through the "negotiation" between individuals. In this case, patients and doctors "negotiate" a diagnosis. The patient, in this scenario, can reject the diagnosis "because symptoms fail to respond in an expected manner... or because the individual's beliefs about the illness experience do not reflect the meaning associated with the diagnosis offered" (Madden and Sim 2016 p91).

Madden and Sim (2016) used the example of

[59] The right hemisphere controls the left side of the body.

fibromyalgia syndrome (FMS), which includes the symptoms of chronic widespread pain, tender points on the body, and fatigue. FMS is "not defined by identifiable pathological abnormalities and hence diagnosis relies on the subjective reporting of symptoms. The lack of objective diagnostic evidence has been the basis of much speculation as to whether FMS is a distinct clinical syndrome" (Madden and Sim 2016 p91).

Interviews were undertaken with seventeen individuals in the UK who had received a diagnosis of FMS. These individuals described their illness experience vividly, as with this interviewee: "Sometimes it feels like your body just wants to explode. You know, it can go numb at times, you can get burning sensations and then you get the pain. And it's very difficult to say 'oh my legs have gone numb', 'cause the next minute they're burning and then you feel as though your muscles are contracting inside; it's like everything is fighting inside you" (Interviewee 9) (p94).

Initial diagnosis by doctor was often unsatisfactory for the patients. For example, one interviewee stated: "You go blindly on, you're not really satisfied, but then I thought well there's people a lot worse off than me. If that's what she [doctor] says it is, that's what it must be" (Interviewee 3) (p97). While another respondent said: "And I tried for two years, kept going to my doctors saying I got this pain in my legs and my arms and he [doctor] kept, oh it'll go off, it's your age, you know you're going through the crisis. And I believed all that" (Interviewee 9) (p97).

When objective medical tests were negative or normal, the individuals' confidence was shook - eg: "Like it was all in my head. Something's going wrong with my brain and I don't really know what's happening to it. Because nobody knew how much it hurt" (Interviewee 7) (p99). "However, negative tests did not exclusively produce feelings of self-doubt. They were also interpreted as evidence of a lack of understanding and the narrow view of illness adopted by medicine. Hence, some informants began to question the previously accepted superiority of medical knowledge to their own understanding" (Madden and Sim 2016 p100).

The upshot was referral to other medical professionals, and what Cox et al (2003) called a "medical merry-go-round", until "each informant received a diagnosis of FMS through a rheumatologist" (Madden and Sim 2016).

Receiving a diagnosis of FMS eventually is an example of "illnesses you have to fight to get" (Dumit 2006), and the sufferers are actively seeking a diagnosis "within the negotiated order" (Madden and Sim 2016).

6.4. APPENDIX 6B - BLOM ET AL (2012)

Blom et al (2012) recruited 54 individuals who recognised themselves as having BIID based on the following statement: "BIID is a term that covers several conditions in which people feel their body-image does not match with their body shape. When we use the term 'BIID' or 'BIID feelings' here we mean to indicate all these different forms of the condition. For example, some people would like to have their leg to be amputated under their knee, whereas others prefer to resemble someone who is paralysed". Recruitment occurred via advertisements on BIID websites mostly, but also referrals from participants (ie: snowball sampling) and from a Dutch psychiatric department medical centre.

They completed a questionnaire via the Internet that included 112 items. Thirty respondents wished for amputation of a limb or limbs, while the others preferred to be disabled in another way.

The key findings were:

- 80% of respondents were male;
- Mean age of onset 6-7 years old;
- 87% had thought of body modification, but less than 30% had tried it themselves;
- Just under half self-rated as homosexual or bisexual;
- One-third had a lifetime psychiatric co-morbidity.

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7. OBESITY

7.1. Cortisol and obesity
7.2. Childcare
7.3. Appendix 7A - Longitudinal studies
7.4. References

7.1. CORTISOL AND OBESITY

The development of obesity can be linked to exposure to long-term stress and the hyperactivation of the hypothalmaic-pituitary-adrenal (HPA) axis via cortisol levels. Cortisol is known to promote visceral fat (Jackson et al 2017).

There are different lines of evidence here, though the findings are not unequivocal (Jackson et al 2017):

i) Animal studies - eg: mild stressors (eg: tail pinch of mice) increased food intake (eg: Marti et al 1994) (or it remains unchanged), while severe stress (eg: noise) reduced food intake.

ii) Human self-reports - Eating more when feeling stressed (eg: Kandiah et al 2006), but also less (eg: Torres and Nowson 2007).

iii) Human laboratory studies - Increased caloric intake when food freely available in response to glucocortocoid infusion and artificially induced stress (eg: Epel et al 2001).

iv) Human neuroimaging studies - eg: the sensitivity of food reward areas in the brain altered during times of stress, and hence the craving for "comfort foods" (Born et al 2010).

v) Human endocrine studies - Cross-sectional studies compare cortisol levels in hair [60] between groups with different body mass index (BMI) (eg: Manenschijn et al 2011), while longitudinal studies follow a group over time (appendix 7A).

Jackson et al (2017) is an example of the latter using data from the English Longitudinal Study of Ageing

[60] Hair contains unbound cortisol and other lipophilic substances, and scalp hair grows at 1 cm per month giving an indicator of cortisol in that period. This is an advantage compared to traditional measures of cortisol - eg: saliva - "fluctuations in cortisol levels due to the circadian rhythm, pulsatile secretion, and daily variation arising from situational factors (eg: environmental stressors, diet, infection) mean they are not well suited for capturing long-term cortisol concentrations" (Jackson et al 2017 p540).

(ELSA) [61]. Hair samples were taken from over 2500 participants along with waist circumference and BMI measurements in 2008-9 and 2012-13. Hair cortisol was significantly positively correlated with body weight, BMI, and waist circumference measurements. The relationship was found to persist over a four-year period (ie: cortisol level in 2008-9 and weight in 2012-13).

The researchers concluded that "long-term exposure to elevated levels of cortisol over several months is associated with higher levels of adiposity", but accepted that the sample was "an older population, in which levels of cortisol may differ relative to younger adults, and the sample was almost exclusively white, so findings cannot be assumed to generalise" (Jackson et al 2017 p543).

7.2. CHILDCARE

A small number of studies have found an increased risk of obesity among children receiving non-parental pre-school childcare as compared to parental care (eg: Pearce et al 2010). Some studies have found no relationship or the opposite (eg: Lumeng et al 2005). Isong et al (2016) pointed out that "a major challenge is the fact that children in non-parental childcare and those in parental care may differ across many unmeasured variables not accounted for in existing studies" (p2).

The answer would be a "true" experiment, but, for instance, randomly placing some children in day nurseries, say, and others staying with their parent is impractical in real-life. The main alternative is the quasi-experimental method which tries to get as close to the true experiment.

One such of these, Isong et al (2016), reported the analysis of data from the Early Childhood Longitudinal Study Birth Cohort (ECLS-B) in the USA, which followed for six years 10 700 children born in 2001. Details of childcare arrangements were collected from parents, and dichotomised as parental care or non-parental childcare. Body mass index (BMI) was used for obesity.

Around 51% of the sample (n = 7200) was categorised as "parental care" at 24 months old, and the remainder as "non-parental childcare". These two groups were then assessed for level of obesity at 4 and 5 years old.

At five years old, 33.2% of the "parental care" group and 37.1% of the "non-parental childcare" group were classed as overweight or obese. This was a significant difference. But when confounding factors (eg:

[61] The ELSA began in 2002 with adults aged 50 years old or more living in England.

number of family members living in the area and care by relatives) were controlled for in the statistical analysis, this difference was not significant.

Non-parental childcare tends to cover centre-based care (eg: day nurseries), non-relative care (eg: paid childminder), and care by non-parent relatives. These are different forms of care which studies have combined (Isong et al 2016).

Isong et al (2016) made another observation: "parents who choose to take care of their children at home may also be more likely to cook healthier diets or emphasise healthy habits than parents who send their children to child care. This would imply that it is not childcare per se that increases the risk of obesity but other unmeasured behaviours that tend to cluster among parents who stay home with their children, and which are correlated with child weight" (p5).

7.3. APPENDIX 7A - LONGITUDINAL STUDIES

Panel or longitudinal studies follow the same individuals over time while cross-sectional studies compare groups at one point in time. Vaisey and Miles (2017) pointed out two key advantages of the former: "First, because each respondent appears in the data multiple times, he or she can in some sense serve as his or her own 'control group', allowing for more valid causal inferences... Second, because respondents are measured over time, it is sometimes possible to use temporal ordering to ask more complicated questions about social processes" (p45).

Participants are often asked the same questions at different times with the longitudinal design. The response to a question that is asked on three occasions, say, is "a function of five things: what's going on in the world at that time that affects everyone equally..., the values of any observed time-varying variables for the respondent, like age or income..., the values of any observed time-constant variables for the respondent, like gender or race..., some unobserved time-constant, person-specific 'stuff' (like personality) that affects the respondents answers equally at all three waves..., and some other idiosyncratic 'stuff' that varies from wave to wave for each respondent..." (Vaisey and Miles 2017 p46). The "person-specific 'stuff'" and "idiosyncratic 'stuff'" have the potential to bias answers if correlated with age or gender, say (Vaisey and Miles 2017).

Researchers try to combat this risk by controlling for personality in the statistical analysis, or by "subtracting out" observed and unobserved constant factors. This is done with statistical techniques like

the fixed-effects model (Vaisey and Miles 2017).

Taking as an example, the effect of church attendance on opposition to abortion, then time-constant variables might include gender, parents' education, and ethnicity (Vaisey and Miles 2017).

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8. CANCER: DIFFERENT RESEARCH PERSPECTIVES

8.1. Biological and environmental
8.2. Child abuse
8.3. Making sense of the experience
8.4. Internet use and health information
8.5. "Cures"
8.6. Pharmaceuticalisation
8.7. Appendix 8A - Genes and environment
8.8. References

8.1. BIOLOGICAL AND ENVIRONMENTAL

Most cancers originate in abnormalities in genes, either in the hereditary germ-line (ie: inherited from parents) or in somatic mutations (caused by environmental influences over the lifespan, like smoking). The latter are more common (Wapner 2016).

Murchison (2016) summed up cancer thus: "Cancer occurs when a single cell in the body acquires genetic changes that drive inappropriate cell proliferation. Once initiated, cancer evolves by natural selection, often producing cell lineages that spread through the host by a process called metastasis" (p628).

Cancers that are transmissible (ie: move between individuals) are exceptionally rare (eg: facial tumours in Tasmanian devils; Pearse and Swift 2006; or some molluscs; Metzger et al 2016), or during organ transplants very occasionally in humans (Murchison 2016).

Wu et al (2016) calculated that intrinsic processes (eg: random cell mutations) were of less importance than extrinsic factors (ie: environment) in cancers. Epidemiological studies have shown that the risk of many cancers is linked to environmental exposures (table 8.1).

There are large geographical variations in incidence rates. For example, breast cancer is five times higher in Western Europe than Eastern Asia and Middle Africa, while prostate cancer is twenty-five times higher in Australia than South-Central Asia (Wu et al 2016). But individuals moving from the lower incidence areas to the higher ones come to mirror the risk of their new area. "While several risk factors have been identified for these cancers, no single one can account for their substantial extrinsic risk proportions, suggesting complex mechanisms for their aetiologies" (Wu et al 2016 p44).

One factor could be diet, which accounts for three-quarters of colorectal cancer risk between areas, or similarly sun exposure for melanoma, and tobacco and alcohol for oesophageal cancer or head and neck cancer (Wu et al 2016).

The time trend of some cancers is increasing - eg: a fifteen-fold increase in lung cancer in the USA between 1930 and 2011, which suggests that "large risk proportions are attributable to changing environments" (eg: smoking, air pollution [62]) (Wu et al 2016).

- Melanocortin 1 receptor (MC1R) is a protein related to melanin, and to skin colouring. One version of the MC1R recessive gene is linked to freckles, red hair, and an inability to tan (when inherited from both parents - ie: R/R) (Robles-Espinoza et al 2016).

- MC1R has been linked to the risk of skin cancer [63]. Using data from the Cancer Genome Atlas skin cutaneous melanoma collection and the Yale Melanoma Genome Project, Robles-Espinoza et al (2016) found that the presence of one version of the MC1R gene (ie: R/R or R/0) gave a 42% higher risk of cell mutations (which are the basis of skin cancer) than not having that version of the gene (ie: 0/0) [64]. Sun exposure interacted with this risk to produce the actual skin cancer.

Table 8.1 - Skin cancer and red heads.

The growth of large datasets can help in the study of genes related to cancers. For example, the Collaborative Cancer Cloud has anonymised genetic sequences and imaging data from patients' health records, or the National Cancer Institute in the USA has the Cancer Genome Atlas based on over 11 000 cancer patients (Swartz 2016).

8.2. CHILD ABUSE

Individuals who report physical or sexual abuse are more likely to also report a cancer diagnosis than non-abused individuals (Alcala 2016). How to make sense of this relationship?

Alcala (2016) noted three problems with the research:

i) Defining abuse in an agreed manner - Definitions can focus on parents and children only or on wider

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[62] The WHO has estimated that three million people die worldwide from air pollution, with the worst countries being China, India, and Russia. Particulates are breathed in, and permeate the membrane of the lungs to enter the blood system (Vaughan 2016). Over 95% of inhabitants of large cities are exposed to pollutant levels above recommended amounts (Lewis and Edwards 2016).

[63] Red heads make up about 1-2% of the population, but 16% of melanoma (skin cancer) patients (Robles-Espinoza et al 2016).

[64] "This suggests that the majority of persons with one R allele, who do not have a red hair/sun sensitivity phenotype, may still be highly susceptible to the mutagenic effects of UV light" (Robles-Espinoza et al 2016 p4).

perpetrators and victims, or can concentrate only defining actions as abuse or neglect if the actions are not normative. Some studies distinguish different types of abuse, others abuse co-occurrence.

ii) Measurement and analysis of data - In order to have numerical data for analysis, scales are used where "child abuse types are lumped together and treated as interchangeable, ignoring the possibility that some experiences can be more damaging than others" (Alcala 2016 pp463-464). Furthermore, for convenience, analysis is based on dichotomous variables (eg: no vs any abuse).

iii) Theoretical basis to the relationship - For example, the Risky Families Model (Repetti et al 2002) focuses on the stressful environment of the dysfunctional/risky family, which produces a biological response that could lead to illness, or risky health behaviours which are responsible for diseases. But the model does not specifically explain the link between abuse and cancer (Alcala 2016).

Kelly-Irving et al (2013), however, proposed that physiological stress reactions from the abuse and risky health behaviours as coping mechanisms produce epigenetic changes that increase the vulnerability to cancer, as well as a compromised immune system to fight it. this work is based on animal studies (Alcala 2016).

Alcala (2016) proposed his own model (the six pathways model), which, though based on the other theories, treats each type of abuse differently, and has six pathways from abuse to cancer risk:

- Biological dysregulation
- Emotional processing deficits
- Exposure to viruses
- Social and cognitive deficits
- Risky health behaviours
- Lower socio-economic status.

This model combines the biological changes from abuse as well as the social ones (eg: "cumulative negative effects of abuse on academic achievement lead to lower adult socio-economic status"; Alcala 2016) [65].

Making generally, this could be a link between anxiety and cancer. Remes et al (2016) established the presence or absence of generalised anxiety disorder (GAD) in 1996-2000 among nearly 16 000 over 40 year-olds in the EPIC-Norfolk study in Britain, and the number of their

[65] There is always a lot of debate over genetic/biological and environmental/social causes of behaviour (appendix 8A).

deaths from any cancer between 2000 and 2015. Men with GAD were over twice as likely as those without it to die from cancer during the follow-up period. There was no association for women.

8.3. MAKING SENSE OF THE EXPERIENCE

Stewart and Rauch (2016) argued that "the excessive focus on cancer as an insidious living defect that needs to be destroyed has obscured the fact that cancer develops inside human beings" (p476). They used the ideas of Bourdieu, and of evolution in their argument.

Science can be seen as a "field", according to Bourdieu (1998), "a structured social space" with its own rules and practices. Individuals gain "status" within that field because of "scientific capital" ("a particular kind of symbolic capital, a capital based on knowledge and recognition"; Bourdieu 2004). "Scientific capital is embodied in the habitus of individual scientists so that their scientific practice is more of a practical mastery than a consciously formulated logical procedure" (Stewart and Rauch 2016 p478).

Bourdieu (2004) saw the "'scientific world as a universe of competition for the ''monopoly of the legitimate handling'' of scientific goods'. Those in possession of large volumes of scientific capital have power over others in the field and they are more likely to have the authority to set the rules of the game and maintain their pre-eminence in the face of competition from newcomers" (Stewart and Rauch 2016 p478).

The upshot is that a particular field has a dominant view ("the right way to do science"; Bourdieu 2004) called a "doxa" ("a set of inseparably cognitive and evaluative presuppositions whose acceptance is implied in membership itself") (Bourdieu 2000). In the case of cancer research, it is a "war on caner" approach (ie: the purpose of research is to find ways to destroy cancer cells) (Stewart and Rauch 2016).

This means that alternative views struggle to be heard, like viewing the tumour as a living entity under the influence of the principles of evolution. "Instead of asking how cancer develops we should be asking why it exists" (Stewart and Rauch 2016 p485).

Stewart and Rauch (2016) developed this argument: "we need to rethink cancer at a population level and not at a single cell level. This means that instead of merely tracing the journey from a single, normal cell (physiology) to when it becomes a 'diseased cell' by contraposition (pathophysiology), we can consider, at a macro-level, with a broader temporal approach, that anomalous cell developments are part of the wider

evolutionary process by which life develops" (p485).

Altogether, they stated: "Cancer is anomalous rather than abnormal; it develops in the specific environment that is the body, and tumours develop in a similar way to embryos: they construct a symbiotic space within an ecosystem that does not necessarily favour them" (Stewart and Rauch 2016 p489). In terms of treatment, Stewart and Rauch (2016) suggested that reprogramming cancer cells through bioengineering would be better than their destruction as in the "war on cancer".

8.4. INTERNET USE AND HEALTH INFORMATION

Among the millions of individuals who look up health information on the Internet each day, 70% of a US sample admitted that the information affected a health care decision (Helft et al 2003). That is fine when the information is good quality and beneficial to health, but what about when it is not?

This is a potential issue in relation to cancer. For example, Chen and Siu (2001) reported that, among 191 Canadian cancer patients, over half used the Internet to find cancer information, and over half of them were led to question their oncologist's advice or recommendation. This may not necessarily by bad, but there is a risk.

Helft et al (2003) looked at how oncologists viewed their patients' use of the Internet for cancer information with a survey of the American Society of Clinical Oncology members in 2001. Two hundred and sixty-six completed postal surveys were returned.

It was estimated that about one-third of patients obtained information via the Internet [66], and this added a median ten minutes to consultations discussing the material found.

In terms of the positive and negative effects of the material found, 57% of respondents felt it made patients more hopeful, but the information was perceived as increasing patients' confusion, anxiety, and understanding mildly to moderately.

Overall, 54% described the Internet's effect as negative here. Helft et al (2003) summarised: "Respondents commented that some patients developed unrealistic hopes and others suffered needless anxiety as a result of either inaccurate or inappropriate information. Some oncologists complained that the confusion some patients experienced added strain to the patient-physician relationship and caused some patients to question the treatment options offered by the

[66] Note that this study is over ten years old, so the numbers using the Internet for health information can be assumed to have increased.

physician. For example, many oncologists described patients who requested specific treatments that, although potentially in use as approved agents or as part of a clinical trial for specific disease states, were inappropriate for the described patient" (p945).

Just over one-third (36%) of the respondents saw the effect of the Internet as positive overall.

8.5. "CURES"

Fenton and Huang (2016) observed: "The general public is being encouraged by the lay press that to prevent cancer; they are persuaded to assess the acidity of their urine and/or saliva as an assessment of the acidity of their body and then to modify their diets accordingly" (p1). The solution offered is the alkaline diet (or acid-ash diet) (eg: Young 2002), which assumes that modern diets acidify the body and thus cause diseases like cancer [67], osteoporosis, and cardiovascular diseases. The origin of the idea is that the mineral compounds of foods cause the body to be acidic, alkaline or neutral (Sherman and Gettler 1912). Practically, individuals are encouraged to consume more fruit and vegetables and limited protein [68], as well as supplemented salts (eg: potassium bicarbonate) and using water alkaliniser machines (Fenton and Huang 2016).

Buclin et al's (2001) randomised controlled trial of such diet changes found that blood pH changed by 0.014 units and urine pH by 1.02 units. The alkaline diet could, thus, benefit in cancers of the urinary tract (Fenton and Huang 2016). But the effect of phosphorous on calcium metabolism was opposite to predicted by advocates (Fenton and Huang 2016).

Fenton et al (2011) found no evidence that the alkaline diet improved bone health.

Fenton and Huang (2016) performed a systematic review of studies of acid-base intakes of diet, supplemental salts to change blood pH, and consumption of alkaline water as related to cancer outcome. The researchers found one study that fitted inclusion criteria - Wright et al (2005). This study looked at diet

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[67] In laboratories, some cancer cells and tumours have been found to grow better in an acidic environment. "However, these in vitro examinations and animal studies of cancer cell behaviour are at the hypothesis-generating phase and should not be extrapolated to human health" (Fenton and Huang 2016 p4).

[68] Fenton and Huang (2016) noted: "The alkaline diet emphasises, to varying degrees, fresh fruits, vegetables, roots and tubers, and legumes with only a moderate protein intake. It is possible that some of these foods may have cancer-protective effects, not through their acidity/alkaline-promoting qualities but rather due to nutrient and non-nutritive compounds" (p4).

acid load and bladder cancer. Using a cohort of over 27 000 Finnish male smokers, who completed a food frequency questionnaire, it was found that the relative risk of cancer was 1.15 for the most acidic urine quintile versus the least acidic quintile. This was not statistically significant (Fenton and Huang 2016).

Of interest, Fenton and Huang (2016) noted a systematic review (Huebner et al 2014) that found no evidence for the alkaline diet benefiting cancer.

Thus, Fenton and Huang (2016) "did not find support for the acid-ash hypothesis which suggests that acid from the diet causes or contributes to cancer development" (p3).

8.6. PHARMACEUTICALISATION

In recent years, medicine use has rapidly increased, and pharmaceuticals now have a growing importance in everyday life (Davis 2015). Is this growth "adequately explained by 'progressive' accounts of techno-scientific progress meeting population health needs" (Davis 2015)? What Abraham (2010) called the "biomedicalism thesis". Or is the increase due to social processes like "pharmaceuticalisation"? This is the "transformation of human conditions, capacities or capabilities into opportunities for pharmaceutical intervention" (Williams et al 2011 quoted in Davis 2015).

Abraham (2010) stated: "biomedicalism... cannot be an explanation for the growth in overall pharmaceutical markets or expanded pharmaceuticalisation in some therapeutic areas, because no such growth or expansion of drug innovation offering significant therapeutic advance has occurred in the last 15-20 years" (quoted in Davis 2015 p207). Davis (2015) challenged this argument: "increased rates of medicines prescribing can also be explained by increased utilisation of existing drugs to meet the established health needs of a growing patient population, despite declining rates of therapeutic innovation. Patient populations may expand due to demographic factors, higher incidence rates of disease, and/or improved diagnosis or access to healthcare. In such cases, biomedical explanations may provide a sufficient explanation for higher rates of medicines utilisation" (p207).

Davis (2015) concentrated on cancer to explore the arguments between biomedicalism and pharmaceuticalisation, including using interviews with US cancer patient advocates. Chemotherapy for cancer patients with solid tumours has increased in the 21st century in North America and Europe (eg: 67% increase between 2003-4 and 2009-10 in the UK; Davis 2015). This could be a response to "demand" as the global incidence

and prevalence of cancer are increasing, and pharmaceutical companies have invested in drugs related to oncology (ie: support for the "biomedicalism thesis").

On the other hand, drugs are developed for end-of-life cancer patients, which do not shrink or stabilise the tumour, but "the benefits offered by new drugs may not match patients' expectations or informed preferences and that aggressive use of chemotherapy towards the end-of-life is associated with poorer quality of life and death, regret, financial hardship and possibly shorter survival" (Davis 2015 p208). For example, Sobreno and Bruzzi (2009) reported a gain of an average of two months of life from new cancer drugs. For pharmaceutical companies any significant difference in survival rates in clinical trials is a reason for the drug to be approved by regulators and used.

From her interviews, Davis (2015) noted what she called "hype and hope" among patient advocates. For example, some advocates accepted and even partook in the "hype" of new drugs because of the belief that patients need "hope", "and this belief disinclines many advocates from publicly drawing attention to the gap that can exist between rhetoric and reality" (Davis 2015 p211. Also new drugs with limited benefits can be viewed as "stepping stones" "that may lead eventually to genuine breakthroughs" (Davis 2015). Add to this, that in surveys, the majority of people believe that a cure for cancer is within reach (eg: the next fifty years) (Davis 2015). All this supports the "pharmaceuticalisation" argument.

Davis (2015) ended with a middle position in the biomedicalism/pharmaceuticalisation argument for cancer drugs: "While some of... [the] growth [in medicine use] can undoubtedly be explained by an account of medicines consumption in which pharmacological progress and improved care meet expanding health needs - there is also evidence of inappropriate and overly aggressive use of drugs. This evidence demonstrates that although an increasing number of patients with advanced disease receive drug treatment, this treatment may not match their subjective expectations or informed preferences and that, irrespective of patient preferences, aggressive chemotherapeutic treatment towards the end-of-life is associated with poorer quality of life and death, shorter survival, regret, and in some cases severe financial hardship" (p212).

8.7. APPENDIX 8A - GENES AND ENVIRONMENT

Social genetic effects (SGE) (or indirect genetic effects) are "associations between genotypes of one individual and phenotype of another individual" (Baud et

al 2017). Studying mice, Baud et al (2017) found that genetic variation in one cage mate of a pair (cage mate A) influenced the variation in certain behaviours (eg: anxiety, wound healing, body weight) in the other cage mate (cage mate B).

So, cage mate A has a genotype that leads to them being aggressive, for example, and the consequent behaviour (phenotype) influences the behaviour of cage mate B (eg: more anxious). In relation to wound healing and body weight, it seems to be physiological responses to stress that influence cage mate B.

Baud et al (2017) noted the implications of SGE for heritability studies and the overestimation of inheritance.

Note that the study involved two inbred strains of mice.

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9. TWO STUDIES ON ROAD SAFETY

9.1. Cycling and accidents
9.2. Road crossing
9.3. References

9.1. CYCLING AND ACCIDENTS

Hess and Peterson (2015) began: "Many of the greatest challenges facing humanity globally can be addressed, in part, by bicycling. This statement may seem like exaggeration, but under scrutiny may be an understatement. For instance, obesity is tied to car dependency in the United States and linked to the first lifespan decline in 200 years for people living there. Cyclists are healthier and spend less time and money on medical care than other commuters. Bicycling can promote mobility, particularly for the poor and elderly who often live in landscapes with amenities too dispersed for pedestrian access and cannot afford personal motor vehicle travel. Replacing a car with a bicycle is, by a large margin, the single most important change a person can make to reduce their contributions to climate change. Finally, because average Americans spend 15.6% of their income on motor vehicle driving, riding bicycles could have a large, positive effect on economic welfare and overall quality of life" (p2).

One reason why bicycles have not solve these problems is safety concerns about their use. For example, around 70% of respondents in Texas saw cycling as "somewhat dangerous" or "very dangerous" in relation to traffic accidents (Sener et al 2009 quoted in Hess and Peterson 2015).

On the other side, cyclists upholding their legal right and riding in the middle of the lane "engenders resentment among motorists who must wait behind slow-moving bicycle traffic" (Hess and Peterson 2015).

Hess and Peterson (2015) investigated three different ways that could be used in the USA to communicate to motorists that cyclists have a legal right to use the road (as opposed to the pavement, cycle path, or special road lane) (figure 9.1):

- "Share the road" (sign) - Designed to warn motorists that slow-moving vehicles are possible.

- "Bicycles may use full lane" (sign) - Designed to remind motorists that cyclists have a legal right to occupy the full lane.

- Shared line markings.

(Source: Hess and Peterson 2015 figure 2)

Figure 9.1 - Three ways to communicate about cyclists.

In a web-based survey (figure 9.2) with over 1800 US respondents, "Bicycles may use full lane" was rated as most successful in communicating its message.

Cairns et al (2015) performed an overview of systematic reviews of the effects of 20 mph zones on health and found five reviews. Overall, such zones were effective in reducing accidents and injuries, as well as traffic speed and volume (Bambra and Gibson 2016).

9.2. ROAD CROSSING

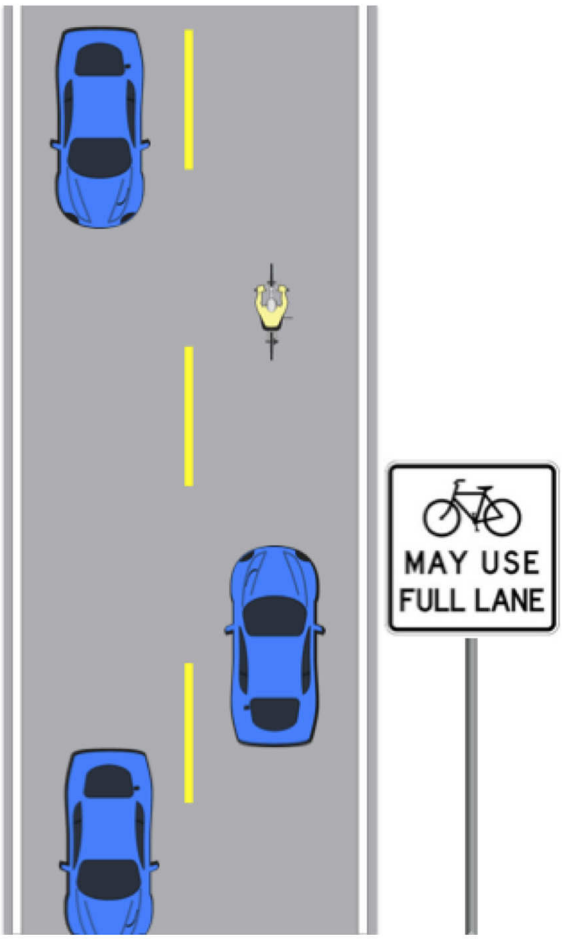
Children have a greater fatality risk when crossing the road because of poorer hazard perception than adults [69]. Hazard perception is "the ability to 'read the road' and anticipate forthcoming events or as situation awareness in the traffic environment" (Meir et al 2015 p101), and "the process of detecting, evaluating and responding to dangerous events on the road that have a high likelihood of leading to a collision" (Crundall et al 2012 quoted in Meir et al 2015).

Children under 9 or 10 years tend to have a greater risk. For example, Meir et al (2013) found that 7-9 year-olds, compared to 10-13 year-olds and adults, showed a lower awareness of potential hazards (eg: crossing even when view limited by parked vehicles).

[69] Under 14s are the highest group after the elderly for pedestrian mortalities in the European Union, while in the USA one-quarter of children killed by cars are on foot, and 20% of pedestrian deaths in Israel are children (Nuwer 2015).

Motorist - Bicyclist Interactions

* Required



Please examine the situation above and respond to each of the four statements. *

	Agree	Disagree
The bicyclist should move to the right and allow the following motorist to pass within the lane.	○	○
The motorist behind the bicyclist should slow and wait for a break in oncoming traffic before passing in the adjacent lane.	○	○
The bicyclist is permitted to ride in the center of the lane.	○	○
It is safe for the bicyclist to ride in the center of the lane.	○	○

Continue »

25% completed

(Source: Hess and Peterson 2015 figure 4)

Figure 9.2 - Example of survey format.

Meir et al (2015) focused on 7-9 year-olds with the Child-pedestrians Anticipate and Act Hazard Perception Training (CA^2HPT) intervention. This involves a 3-D virtual reality scenario.

Nine trainees in Israel were presented with eleven typical urban scenarios from a pedestrian's point of view (eg: road partially obscured by a curvature). Next these individuals were tested on eighteen similar scenarios along with fifteen controls. Altogether, "trainees were found to be more sensitive to potential hazards and to perform better in crossing tasks compared to control group members. That is, findings showed that 7–9-year-old child-trainees tended to decide to cross simulated roads significantly less in situations involving limited field of view partially obscured by parked vehicles than control group members. Indeed, trainees' performance (as opposed to controls') resembled more that of Meir et al's (2013) experienced-adult pedestrians" (Meir et al 2015 p108).

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10. ALCOHOL CONSUMPTION AND HEALTH PROBLEMS

10.1. Heart problems
10.2. Alcohol consumption in later life
10.3. Appendix A - Stress and immune system
10.4. References

10.1. HEART PROBLEMS

The trend of increasing population life expectancy is stagnating or declining in some parts of the world (eg: Russia; Nicholson et al 2005). Key to this is substance abuse, particularly alcohol use, which accounts for 6% of deaths globally (Zachariah 2017).

The cardiovascular consequences of alcohol use play an important role here. For example, arterial stiffness [70], which is exacerbated by alcohol use, predicts future stroke, heart problems, and hypertension (Zachariah 2017).

O'Neill et al (2017) used data from the Whitehall II cohort, which began in 1985 with over 10 000 UK civil servants. These participants were given health assessments every 4-5 years, with the most recent data available being 2012-13. Arterial stiffness was measured by a non-invasive pulse wave velocity (PWV) estimation, where pulses travel faster in less elastic blood vessels. Alcohol consumption was self-reported. Data were available for 3869 participants (74% male) (figure 10.1).

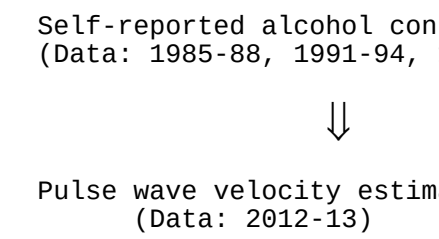


Figure 10.1 - Design of study.

Based on over 25 years of data, after controlling for demographic, lifestyle and clinical factors, stable heavy drinking (table 10.1) males had significantly higher PWV readings (ie: arterial stiffness) than moderate drinkers. There was no equivalent finding for women.

[70] Blood vessel walls that lack the required elasticity for blood flow changes.

- Stable non-drinker - no alcohol consumption at each data collection point (n = 167)
- Stable non-drinker - <14 units (112 g of ethanol) per week at each point (n = 569)
- Stable heavy drinker - >14 units (n = 541)
- Unstable moderate drinker - moderate and non-drinker at different data collection points (n = 1110)
- Unstable heavy drinker - moderate and heavy drinker at different times (n = 998)
- Former drinker - non-drinker at last data collection point, but previously drinker (n = 437)

Table 10.1 - Alcohol consumption groups.

Some studies (eg: Matsumoto et al 2009) have found a U-/J-shaped relationship between alcohol consumption and cardiovascular problems - ie: heavy drinkers and non-drinkers are worse off than moderate drinkers. This has been seen as a "protective effect" in moderate alcohol intake.

However, this finding could be the product of combining stable non-drinkers and recent non-drinkers as one category in analyses (Stockwell et al 2016). The latter are sometimes called "sick quitters" (individuals who reduce alcohol consumption because already ill). O'Neill et al (2017) confirmed that treating all current non-drinkers as one group hides the fact that it includes former drinkers who were "significantly more likely to report poorer health".

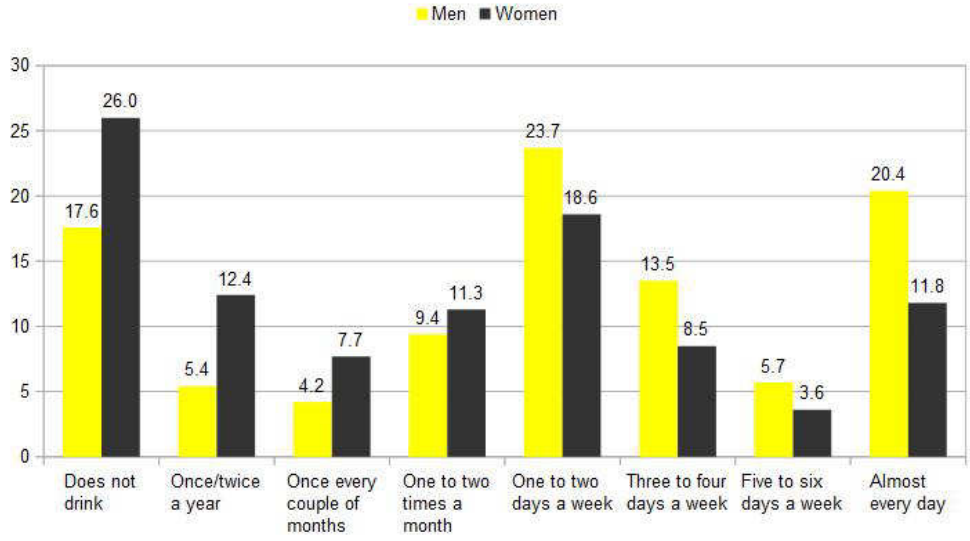
10.2. ALCOHOL CONSUMPTION IN LATER LIFE

Holdsworth et al (2017) stated: "Older people consume less alcohol than any other adult age group. However, in recent years survey data on alcohol consumption in the United Kingdom have shown that while younger age groups have experienced a decline in alcohol consumption, drinking behaviours among the elderly have not reduced in the same way" (p462).

To gain a more detailed picture, Holdsworth et al (2017) analysed data from the English Longitudinal Study of Ageing (ELSA), which began in 2002-3 with adults aged 45-65 years old, and the latest wave (data collection) was 2012-13. Self-reported information was available on frequency of drinking in the previous twelve months, and mean weekly units consumed.

In 2012-13, 18% of men and 26% of women reported not drinking any alcohol compared to 63% and 42% respectively who drank at least one to two days a week (figure 10.2).

The mean weekly units [71] consumed were 13.5 for men and 6.7 for women.



(Data from Holdsworth et al 2017 table 1 p473)

Figure 10.2 - Frequency of drinking in 2012-3 (%).

Analysis of demographic variables showed frequency of drinking in later life increased with wealth, education, and being a current or former smoker.

Holdsworth et al (2017) summed up: "The importance of both economic capital (as measured by wealth) and cultural capital (as indicated by education) confirm that drinking was mediated by individual's social status. In particular, resources were strongly associated with the frequency of drinking. This suggests that material resources are important in enabling older people to drink on a daily basis, but are less important in influencing how much older people drink when they do consume alcohol. It would appear that the influence of socio-economic characteristics on drinking is not just a question of affordability, but that more affluent social groups cultivate daily drinking practices, while those with fewer resources limit the number of days on which they drink" (p487).

Ageing has been found to be associated with "progressively higher level of circulating pro-inflammatory markers without apparent cause", and high inflammatory markers are, in turn, associated with a higher risk of age-related medical conditions (eg: low

[71] In the UK, one unit of alcohol is 10 millilitres (ml) or 8 g of pure alcohol (Holdsworth et al 2017).

muscle strength) (Bektas et al 2016).

Alcohol in moderate amounts (ie: between 5 - 14.9 g per day) has a positive impact on inflammation (and subsequently the risk of cardiovascular disease) as compared to heavy drinkers (obviously), and abstainers (less obviously). In other words, a J-shaped or U-shaped curve (Bektas et al 2016).

But is the benefit of a small amount of alcohol real? Those who answer "no", point to "sick quitters". These are individuals who showing the early signs of illness stop drinking. "If sick quitters are compared to 'moderate alcohol consumers' who continue to drink because they are and feel healthy and to 'heavy drinkers', who drink amounts of alcohol that are overtly toxic, it understandable how the 'j'- or 'u'-shaped association curves of risk can be generated. Hence, the association of moderate alcohol use with low biomarkers of inflammation may not be biologically causative" (Bektas et al 2016 p747).

On the other hand, Shah and Paulson (2016) showed that the benefits of moderate alcohol use are real in relation to the likelihood of frailty (via the reduction of an inflammatory protein) (appendix 10A).

Data from over 3200 over 65s were used from the 2008 wave of the Health and Retirement Study (HRS). Alcohol use was self-reported, with 1-14 drinks per week classed as moderate. Frailty was measured by the Paulson-Lichtenberg Frailty Index (PLFI) (Paulson and Lichtenberg 2015), which measures five behaviours - wasting, weakness, slowness, fatigue or exhaustion, and falls. Three or more symptoms is defined as frailty. C-reactive protein (CRP) was collected from dried blood spots.

Moderage drinking was significantly associated with lower levels of CRP and less frailty.

But not all alcohol is the same. Wine, for example, contains polyphenols, and these reduce inflammation (Bektas et al 2016).

10.3. APPENDIX 10A - STRESS AND IMMUNE SYSTEM

Long-term (chronic) stress can have negative effects on the immune system and health, but research is showing that it may not be the same for everyone. For example, early life stress/adversity (eg: maltreatment, poverty) can lead to an exaggerated immune reaction to stress in later life (Morey et al 2015).

In the short-term, a highly reactive immune system is beneficial, but in the longer term, high levels of

inflammation [72] increases the risk of chronic diseases, like atherosclerosis and frailty (eg: meta-analysis on early maltreatment; Coelho et al 2014).

In studies of older adults caring for an ill relative, prolonged stress produced longer wound healing times, for instance (Morey et al 2015).

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[72] "Local inflammation is a part of the healing process that includes accumulation of immune cells, anti-pathogen activity, and initiation of tissue repair. Chronic, systemic inflammation, in contrast, can promote tissue damage across a number of systems" (Morey et al 2015 p14).

11. MISUSE OF STEROIDS AND OPIOIDS - NOT TAKEN SERIOUSLY

11.1. Steroids
11.2. Prescription opioids for chronic pain
11.3. Appendix 11A - Reasons why AAS use not taken seriously
11.4. References

11.1. STEROIDS

Anabolic-androgenic steroids (AAS) are a group of drugs based around testosterone, and they are often taken by males to improve physique or help build muscles (ie: non-medical uses). AAS use, and the users who develop dependence, risk serious consequences, including cardiovascular effects and even premature death (Pope et al 2014).

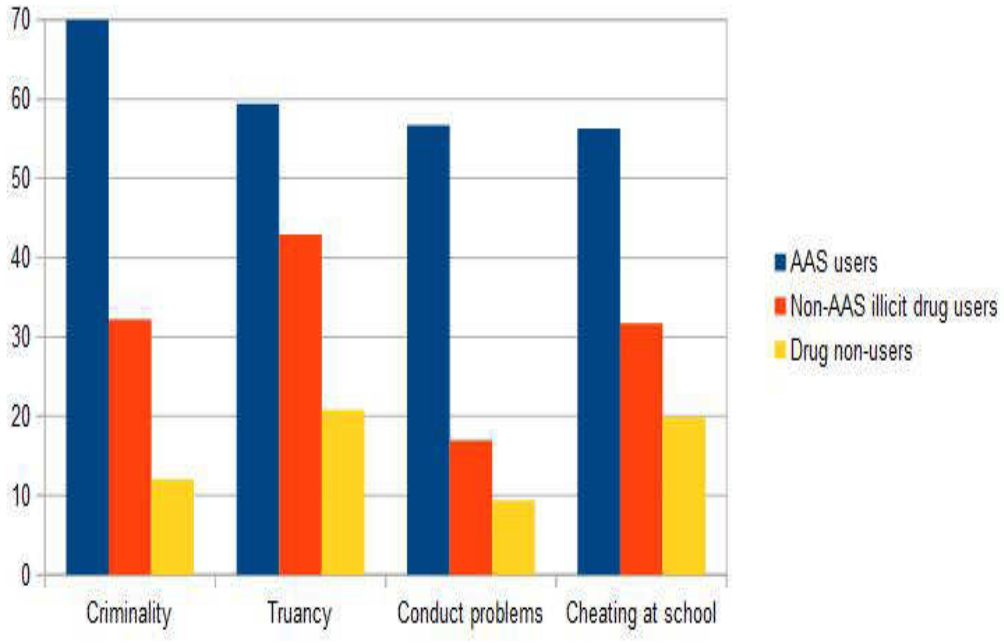
Pope et al (2014) attempted to calculate the prevalence rate for AAS use in the USA using data from four youth surveys and nine published studies since 2000. The lifetime prevalence among 17-18 year-olds was 2-5%, 1-2% among adults in their 20s, and about 1% for college students. Male users were between 8-50 times more than female users, depending on the study.

The mean for AAS dependence was 32.5% of users (using DSM-III-R or DSM-IV criteria for dependence).

Hallgren et al (2015) pointed out that "some media reports and other publications in the United States and elsewhere suggest a perception that AAS use is less harmful than traditional' non-AAS illicit drug use because it is not thought to be associated with significant social problems, such as violence and anti-social behaviour. Such beliefs may perpetuate the notion that AAS use is relatively benign with few serious social consequences" (p321) (appendix 11A).

This is not the case. Hallgren et al (2015) showed that Swedish male adolescents taking AAS had significantly higher anti-social behaviours than non-AAS illicit drug users and drug non-users. The researchers analysed data from the Stockholm Student Survey, which is completed each year between fifteen and seventeen years old. Three years were chosen - 2004, 2008, and 2012 - and only males were used as females "very rarely reported AAS use". AAS use covered "anabolic steroids", "testosterone", and "growth hormone". Anti-social behaviours included bullying others, criminal behaviour, truancy, cheating at school, and conduct problems. All responses were self-reported with no independent verification because of anonymity.

The prevalence of AAS use was 0.7 - 0.9% at seventeen years old (which compares to over 3% in another Swedish study; Nilsson et al 2001) [73]. The AAS users had 4.4 - 6.9 times greater anti-social behaviours than drug non-users ($p<0.001$), and 1.7 - 3.4 times higher than non-AAS illicit drug users ($p<0.03$) (figure 11.1). "Of particular concern is the high proportion of adolescent AAS users who engaged in serious criminal activities, including rape, burglary, and the use of weapons" (Hallgren et al 2015 p323) [74].



(Data from Hallgren et al 2015 table 1 p324)

Figure 11.1 - Percentage of seventeen year-olds in 2012 reporting selected anti-social behaviours.

Table 11.1 summarises the main strengths and weaknesses with the Hallgren et al (2015) study.

[73] Among Swedish adult males, Lundholm et al (2015) found a strong association between use of AAS at any time in their lives and a conviction for violent crime.

[74] Looking at the situation differently, Pope et al (2012) found that conduct problems among 233 male adolescent weightlifters predicted AAS use.

STRENGTHS	WEAKNESSES
1. Large sample size - over 9000 in total. 2. Comprehensive survey, which the participants were used to completing. 3. Use of three different years to assess the stability of the data. 4. The survey "specifically mentioned 'doping' and 'anabolic steroids', which helped to minimise possible confusion with corticosteroid products or nutritional supplements - a potential problem with anonymous surveys asking about 'steroids'" (Hallgren et al 2015 p325).	1. Honesty of responses - "some participants may have misrepresented their actual use of illicit substances, or provided false-positive or false-negative responses because they misinterpreted certain questions" (Hallgren et al 2015 pp325-326). 2. A cross-sectional design, which compares the groups at one point in time, and so causal relationships cannot be established. 3. Only males, of a particular age, and in one city in the country, which limits generalisability of findings. 4. Limited information about the environment and family, which may have influenced AAS use and/or anti-social behaviours.

Table 11.1 - Main strengths and weaknesses of Hallgren et al (2015).

11.2. PRESCRIPTION OPIOIDS FOR CHRONIC PAIN

Chronic pain (ie: longer than six months) is estimated to afflict one in ten individuals, and its experience is influenced by psychological factors (eg: many sufferers have a history of physical or sexual abuse) (Jurcik et al 2015).

Opioid analgesics can be effective, but there is the risk of misuse, abuse, addiction, and diversion. Such behaviours include selling prescription drugs, forging prescriptions, stealing drugs from others, obtaining drugs from non-medical sources, and re-using prescriptions (Jurcik et al 2015). Trescot et al (2006) reported an over 500% increase in the non-medical use of prescription opioids in the last twenty years. "Concerns for misuse often leave clinicians feeling unwilling to treat chronic non-cancer pain patients, particularly those with co-existing substance abuse issues..." (Jurcik et al 2015 p43).

Depression can exacerbate chronic pain, limit the effectiveness of treatment for the pain, and increase the risk of opioid misuse (Jurcik et al 2015). Wasan et al (2012), for example, found that increased craving for prescription opioids was associated with anxiety and depressive symptoms.

The risk factors for opioid misuse are summarised in table 11.2 (Jurcik et al 2015).

Lower risk	Higher risk
• Older • Compliant • No history of misuse • Stable mood and emotions • Thoughtful (as opposed to impulsive/risk-taker)	• Family or personal history of substance abuse/rehabilitation • Younger • History of criminal/illegal activity • Frequent contact with high-risk individuals and/or environments • History of risk-taking • History of interpersonal problems • Cigarette smoking • History of severe depression and/or anxiety • Childhood abuse • Multiple psychosocial stressors

Table 11.2 - Summary of main risk factors for opioid misuse.

Screening measures have been developed to identify high risk individuals. For example, the Screener and Opioid Assessment for Patients with Pain-Revised (SOAPP-R) (Butler et al 2004) is completed by the patient, while the Opioid Compliance Checklist (OCC) (Jamison et al 2014) lists the acceptable behaviours for patients, which are monitored through urine samples or behavioural observations, for instance, including taking prescriptions to the same dispensary, not borrowing opioids from others, and taking care not to lose medications. Violation of the agreement could ultimately mean discontinuation of prescriptions (Jurcik et al 2015).

11.3. APPENDIX 11A - REASONS WHY AAS USE NOT TAKEN SERIOUSLY

Pope et al (2014) offered some reasons why AAS use and dependence is often overlooked, including:

i) AAS use starts more often in the 20s [75] when individuals are generally not observed closely by their parents at home and by teachers at school [76].

ii) Public attention focuses on AAS use by competitive and elite sportspeople.

iii) AAS users are secretive. For example, Pope et al (2004) found that over half of users had never told a doctor that they were seeing, while doctors rarely ask (Pope et al 2014).

iv) AAS use rarely leads to emergency hospital admission, so doctors do not encounter it here.

v) General AAS use did not begin until the 1980s and 1990s, so there are few ageing users at this point when the consequences of use may be seen by doctors.

vi) Surveys and the general public can confuse illicit AAS with medically prescribed corticosteroids, and over-the-counter supplements (mistakenly called "steroids").

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Nilsson, S et al (2001) The prevalence of the use of androgenic anabolic steroids by adolescents in a county of Sweden European Journal of Public Health 11, 195-197

[75] 80% of users (Pope et al 2014).

[76] Miech et al (2015) reported that adolescents who had no experience of illicit drugs were at the highest risk of misuse of opioids as an adult after prescription use of the drugs as an adolescent. This was based on the "Monitoring the Future" project in the USA where 6000 16-17 year-olds were followed up between 19 and 23 years old (Cunningham 2016).

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12. ALCOHOL CONSUMPTION AND "DRINKING STORIES"

12.1. Introduction
12.2. "Drinking stories"
12.3. Appendix 12A - Populism
12.4. Appendix 12B - Emerging adulthood
12.5. Appendix 12C - Gender and alcohol
12.6. References

12.1. INTRODUCTION

Alcohol consumption in Britain has risen by about one-third since the end of the twentieth century, and it has a market worth of £25 billion per year as 150 000 outlets (including pubs, clubs, and shops) are licensed to sell alcohol (Szmigin et al 2008) [77].

"Binge drinking" is used in the popular media in particular, but there is no agreed definition other than consumption of a large amount of alcohol in one sitting (Szmigin et al 2008).

"Binge drinking", as opposed to moderate or responsible drinking, particularly among young adults is seen as a concern. Government-backed health messages emphasise "normal" drinking, though Murgraff et al (1998) noted that "while heavy drinkers may contribute disproportionately to harm it is those who drink 'normally' who are responsible for the majority of damage" (Szmigin et al 2008 p360).

There are also contradictory messages in UK government policy. "The environment encourages alcohol consumption through a huge range of marketing communication techniques, growth in clubs and pubs targeted at young people and liberalisation of licensing laws to potentially allow up to 24 hour drinking, while at the same time requiring restraint in terms of how much alcohol is consumed. Measham and Brain (2005) refer to this as the 'simultaneous processes of economic deregulation and social regulation' which they see as emblematic of a consumer society which both seduces and represses" (Szmigin et al 2008 p360).

Alcohol consumption is associated with pleasure, escape from daily pressures, and bonding, according to interviews with 18-25 year-olds in the UK reported by Szmigin et al (2008). It has been called a "calculated

[77] Home Office after the introduction of 24-hour opening hours for pubs in Britain showed the movement of drink-related disorder to 3-6 am with later closing times, but no change in such disorders over 6 pm to 6 am period (Travis and Watt 2008).

hedonism", though the longer term consequences for physical health were rarely considered (Szmigin et al 2008).

12.2. "DRINKING STORIES"

Tutenges and Sandberg (2013) argued that part of the motivation of young people's drinking behaviour [78] was "the desire to accumulate drinking stories as a form of social or cultural capital" (O'Neill 2014) [79] [80]. Individuals "purposively engage in activities with narrative potential" (Tutenges and Sandberg 2013), like the man who publicly groped a woman in order to get a physical retaliation and "a great story".

The "good stories" usually involve personal experiences of heavy drinking [81] and subsequent behaviour/events that occurred. Tutenges and Sandberg (2013) conducted forty-five semi-structured interviews in 2007 and 2008 with over one hundred young Danes on holiday at a "nightlife resort" in Bulgaria [82].

It was found that "episodes of drinking could turn into stories if they involved one or several acts of transgression, defined as the crossing of boundaries set by an authority or convention" (Tutenges and Sandberg 2013 p540). For example, violating self-control and hygiene:

- Karen: Mette has a thing about sleeping on the floor when she gets sufficiently drunk.

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[78] Cooper (1994) suggested four motives for alcohol consumption:
i) Social - eg: to improve social interactions;
ii) Coping - eg: to deal with negative emotions;
iii) Enhancement - eg: to increase positive emotions;
iv) Conformity - eg: to fit in with others.

[79] "Drinking stories" have been found to have different purposes - eg: to recall happy moments and forge closer relationships (women in Australia; Sheehan and Ridge 2001); to gain masculine recognition (US male college students; Workman 2001); as resistance to government messages of responsible drinking and self-control (British youth; Griffin et al 2009). This latter case could be seen as an example of "compartmentalised rebellion", where individuals conform in the main except for specific events or areas of their lives. This mixture of conformity and individualism has been called terms like "conforming individualism", and can be seen in the political attitudes of young people (appendix 12A).

[80] This may be part of a stage of life called "emerging adulthood" (appendix 12B).

[81] There are many negative consequences to young people's hazard drinking behaviour. Barry and Piazza-Gardner (2012) emphasised the number of deaths and injuries where alcohol was a contributing factor for that age group - eg: 1700 deaths and 599 000 injuries per year among 18-25 year-olds in the USA.

[82] This holiday site had meaning: "what is special about place is not some romance of a pre-given collective identity or of the eternity of the hills. Rather, what is special about place is precisely that throwntogetherness, the unavoidable challenge of negotiating a here-and-now" (Massey 2005 quoted in Hinchcliffe 2009).

- Mette: No. It was because I had gone out to throw up. And then I couldn't deal with getting back to bed again, and so I just took my duvet and pillow with me [to the toilet]. I was lying there sleeping like a baby, and then Karen came and threw up all over me.

- Interviewer: Really?

- Karen: She was lying with her head right next to the bowl [...]. So apparently, I threw up right in her face. I'm so sorry [laughs] (Tutenges and Sandberg 2013 p540).

"Master narratives", "canonical claims" or "formula stories" (Loseke 2012) involved "individuals who hurt themselves, passed out, wrecked hotel rooms, shocked or annoyed strangers, climbed or jumped from balconies, got into fights, stripped, had public sex or encountered exotic individuals such as drug dealers or prostitutes" (Tutenges and Sandberg 2013 p540).

The interviewees themselves were aware of engaging in heavy drinking to get good stories:

- Birgitte: You've got to get out there and try stuff before you get old and grey. We don't want to find ourselves thinking back to an eventless life.

- Kathrine: When I turn 30, I want to be able to think to myself, 'I don't regret anything I did. I tried out all the things that had to be tried out' [...]. Also, to be able to tell your children, 'listen, I was part of it, and I've tried it'. Then they will think, 'damn, my mother was really cool when she was young' [laughter].

- Birgitte: Yeah, that could be totally awesome (Tutenges and Sandberg 2013 p542).

Tutenges and Sandberg (2013) summed up: "As we interpret them, the stories were used for a number of reasons, including for entertainment, to overcome distressing experiences, to put ethical dilemmas up for debate, to present 'moral selves', to explore taboos and to strengthen friendship ties. Although based on chaotic situations, the stories bore many resemblances to one another, touching upon the same themes (eg: vomiting, falling down, stripping, fighting) and sequencing events according to the same basic scheme (alcohol was consumed, transgressions ensued)" (p542).

O'Neill (2014) was critical of Tutenges and Sandberg (2013), asking: "Why then are the authors not more concerned by the preponderance of stories in which male participants describe subjecting women to various forms of sexual humiliation and harassment"? She argued that the drinking stories reflected and reproduced gendered

power relations. "In exalting drinking stories as 'graphic expositions of the imperfectability of human nature' (Tutenges and Sandberg 2014 p2), the authors effectively excuse themselves from having to attend to the social and political implications of such narratives" (O'Neill 2014 p356) (ie: the role of alcohol use and sexual harassment and violence).

Radcliffe and Measham (2014) felt that the young women's drinking experiences and freedoms were "insecure and contested", and were different to the men's, because of the "sexualisation of the NTE [night-time economy] and drinking culture" and "the taken for granted heteronormativity".

Radcliffe and Measham (2014) explained the under-exploring of gender by Tutenges and Sandberg (2013) thus: "In part this may be that the research interviews were conducted by a male interviewer, sometimes alongside male peers/respondents in group interviews and sometimes, out of doors, which together may have resulted in a less conducive atmosphere for young women to reflect on the relationship between gender and their own drinking experiences" (p346) (appendix 12C).

Tutenges and Sandberg (2014) defended themselves: "it is important not to interpret the discriminatory elements in drinking stories as a straightforward indication of a general tendency towards discrimination on the part of the story-tellers, or a sign that the milieus where the stories circulate most intensively (nightlife venues, fraternities, sororities etc) are fraught with inequality and intolerance. Rather, drinking stories are part of an age old expressive culture which purposively, playfully and provocatively goes against established views of right and wrong. These stories are meant to disturb, and are therefore filled with 'anti-structural' episodes (Turner 1997) and 'grotesque imagery' in 'a world turned upside down' (Bakhtin 1968), where the politically correct is ridiculed and depravation celebrated. Hence the frequent reference in the stories to easy women, dumb blondes, brainless machos, über gay men and drooling, incontinent, out-of-control bodies" (p348).

Furthermore, they said: "The performance of drinking stories can be poorly executed, badly timed and so forth, but it is never simply a mechanical parroting of the dominating discourses of a sexist, racist and capitalist society. Some level of originality and personal touch always goes into the performance, which may be considered a creative remixing of fragments drawn from existing stories and communicative resources" (Tutenges and Sandberg 2014 p349). Tutenges and Sandberg (2014) wanted to be sympathetic to the "real depth and substance in drinking stories".

Measham and Brain (2005) referred to a "new culture of intoxication" to describe how alcoholic drinks have been re-branded as intoxicating drugs, and this links to the "carnivalesque" (Bakhtin 1968) ("the idea of fun and drunkenness"; Haydock 2016). "Carnivalesque also reflects the "overthrow of everyday norms": "Features include free and familiar contact, profane speech and grotesque realism, with an emphasis on the body, and attention drawn to its natural features and functions, such as sex, excretion" (Haydock 2016 p1057).

Haydock (2016) performed an ethnographic study of drinking in a town in the south of England in 2007-8. On the one side, certain drinking venues presented themselves as a place "you can let your hair down and go crazy" (ie: encouraged the carnivalesque), as well as certain drinks (like "alcopops") advertised around "being wicked" (Haydock 2016).

On the consumer's side, the carnivalesque was about "outrageous" stories. Haydock (2016) gave this example: "Noel told me how Phil (who was standing next to him at the time) had 'got his cock out' at the end of a night out when they had gone back to someone's room, and started hitting it against a wardrobe. This was considered amongst the group to be hilarious, and Phil's reaction seemed to be one of a mixture of shame and pride" (p1060).

12.3. APPENDIX 12A - POPULISM

"Populist" political parties are associated with "forms of anti-elitism and a cynicism towards those who are responsible for government", and "populism" can be seen as ways that individuals express their unfulfilled political demands collectively in the face of established structures of power and authority and dominant ideas and cultural values" (Pollock et al 2015 p142).

"Populism" is used by some to refer to "anti-modern" thinking, but this pejorative use of the term can belittle it. Ranciere (2006) noted that populism is "often used as a rhetorical strategy that silences dissent in relation to the prevailing consensus; the 'oligarch', as he calls it, of social and political science, works to govern without people, that is, 'without any dividing of the people; to govern without politics'. The implication of this, for Ranciere is that if science cannot impress its vision of progress upon the people, then those people are dismissed as 'ignorant', 'backward' and attached to a past that is no longer in keeping with what the experts consider to be legitimate" (Pollock et al 2015 p143).

Keane (2009) has talked of "pluriversality" (ie: to "empower people everywhere, so that they can get on with living their diverse lives on earth freed from the pride

and prejudice of moguls, magnates, tyrants and tycoons"; Keane 2009 quoted in Pollock et al 2015).

Pollock et al (2015) explored populism in the political attitudes of nearly 17 000 16-25 year-olds in fourteen European countries from the MYPLACE survey in 2012-13. It was found that "young people take up a mixture of political positions, some of which are strongly associated with indices of 'populism' - cynicism, authoritarianism, nativism and xenophobia" (p158). But there was also "ideological inconsistency", and the populism could not be equated with left- or right-wing ideology. There were local variations in the populist views, and the plurality of beliefs.

The media may or may not have an influence on political attitudes (and voting behaviour), depending on the study. The problem is how to measure the effect.

Experiments are difficult to perform. In one field experiment in the USA, Gerber et al (2009) randomly assigned free subscriptions of a left-leaning newspaper or a right-leaning one to participants. The only significant effect was that recipients of the left-leaning newspaper were more likely to vote for a left-leaning party. "Recipient's political attitudes remained unchanged across all groups" (Reeves et al 2016).

Quasi-natural experiments involve making use of naturally occurring events - eg: the availability of a satellite news channel with a particular political leaning in an area and subsequent voting choices.

Reeves et al (2016) made use of the right-leaning "The Sun" tabloid newspaper in the UK switching its support from the Conservative to the Labour Party in 1997, and then back in 2010. Data from the British Household Panel Survey before and after the changes were analysed. This survey not only asked about voting preference, but about the newspaper read.

It was calculated that each switch of support produced a change of about half a million votes, though there was no change in underlying political preferences. "The magnitude of these changes, about 2% of the popular vote, would have been unable to alter the outcome of the 1997 General Election, but may have affected the 2010 Election" (Reeves et al 2016 p44).

12.4. APPENDIX 12B - EMERGING ADULTHOOD

Arnett (2000) proposed the term "emerging adulthood" to cover the period of 18 to 25 years old (ie: late teens to mid- to late twenties). The term was designed to cover a period of life that is different in industrial societies in the 21st century as, for instance, individuals marry/settle down later, and lack of job

security, while some individuals are still in education. "Most young people now spent the period from their late teens to their mid-20s not settling into long-term adult roles but trying out different experiences and gradually making their way toward enduring choices in love and work" (Arnett 2007 p69).

Arnett (2004) outlined five features of emerging adulthood as:

- Age of identity exploration
- Age of instability
- Self-focused age
- Age of feeling in-between
- Age of possibility.

Arnett (2007) argued that emerging adulthood had advantages over other terms for the same age group, like:

- Late adolescence - "Unlike adolescents, 18-to-25-year-olds are not going through puberty, are not in secondary school, are not legally defined as children or juveniles, and often have moved out of their parents' household" (Arnett 2007 p69).

- Young adulthood - This can refer to diverse periods up to age 40.

- Transition to adulthood - Arnett (2007) asked: "why call this period merely a 'transition' rather than a period of development in its own right?" (p70).

- "Quarter-life crisis" (Robbins and Wilner 2001) - But not a crisis for everyone.

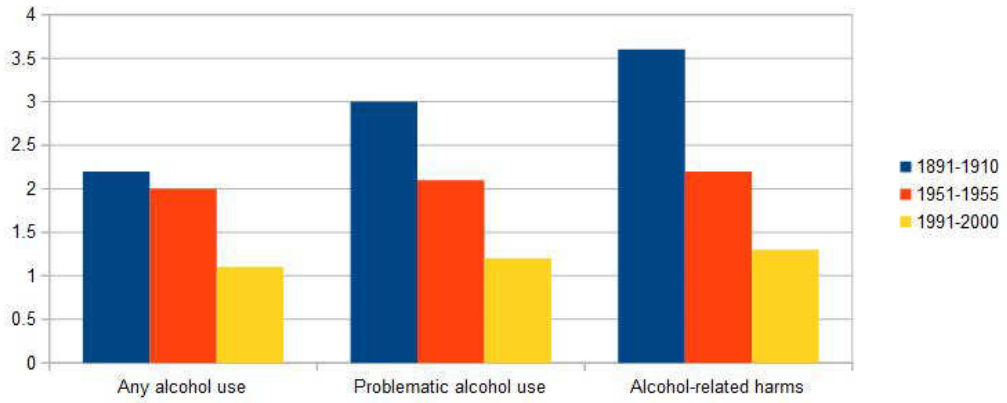
12.5. APPENDIX 12C - GENDER AND ALCOHOL

Historically, alcohol use and alcohol-related harms have been much higher for men than women, but this is changing. For example, the Finnish Drinking Habits Survey (Harkonen and Makela 2011) found no gender differences in frequency of heavy episodic drinking (ie: 6+ drinks on one occasion for men and 4+ drinks for women).

Slade et al (2016) found the male-female gap closing particularly among young adults in their review and meta-analysis. Sixty-eight studies published between 1980 and 2014 were found. Three categories were distinguished for comparison - any alcohol use, problematic alcohol use, and alcohol-related harms.

The data were stratified into five-year birth cohorts covering 1891 to 2000. Generally, there was a male excess in alcohol use across the age groups until those born from 1976 onwards where there is "a narrowing

of the male-female gap" (Slade et al 2016). For example, among those born between 1891 and 1910, males were twice as likely to report alcohol use than females, while the sex ratio was only 1.1 for those born between 1991 and 2000. For problematic alcohol use, the sex ratio decreased from three-fold at the beginning of the study period to 1.2 most recently, and alcohol-related harms fell from 3.6 to 1.3 respectively (figure 12.1).



(Data from Slade et al 2016 tables 5-7)

Figure 12.1 - Sex ratio for selected birth cohorts (where a higher number is more men than women).

It should be noted that the data do not "empirically determine whether observed changes in the sex ratio are being driven by increases or decreases in male or female prevalence or whether, in fact, there is a more complex indicator-specific and/or birth cohort-dependent relationship between male and female alcohol use and/or harms that is driving the change in sex ratios over time" (Slade et al 2016). However, forty-two studies that reported sex convergence suggested that the reason was an increase among females compared to males in younger age groups.

There are a number of possible explanations that have been proposed for this increase, including:

a) Changes in traditional female gender role - Seedat et al (2009), for example, found that countries where traditional gender roles were declining (eg: more women in the labour force) had smaller gender gaps in alcohol use.

b) Broader social changes - Alati et al (2014), for instance, found that daughters were five times more likely to report heavy drinking than their mothers in over 1000 mother-daughter pairs, which the authors saw as

partly due to the later age of childbearing.

Other recent changes include cheapness and ease of availability of alcohol, and alcohol advertising and sponsorship (Boseley 2016).

Renold and Ringrose (2008) talked of the "schizoid" discourse of femininity for women today: "Respectability and the importance of maintaining a 'good' sexual reputation remain as normative elements of contemporary femininity, this rests uneasily alongside a post-feminist discourse in which young women are also exhorted to be always 'up for it' and agentically (hetero-)sexual" (Griffin et al 2013 p185-186). The latter involves enacting an "excessive" or "hyper-sexual" femininity for young women in the urban night-time economy (ie: "characterised by high heels, short skirts, low-cut tops, fake tan, long, straight and (bottle) blonde hair, smooth bare legs in all climates, lots of make-up and a buxom slimness"; Griffin et al 2013 p186).

Griffin et al (2013) explored "hyper-sexual femininity", alcohol consumption, and the "culture of intoxication". Once more young women are faced with contradictions: "They are exhorted to be sassy and independent – but not feminist...; to be 'up for it' and to drink and get drunk alongside young men – but not to 'drink like men'... Hyper-sexual femininity calls on young women to look and act as agentically sexy within a pornified night-time economy pervaded by 'cheap deals' on alcohol, but to somehow distance themselves from the troubling figure of the 'drunken slut'... All this is happening in the context of a pervasive media discourse of anxiety about drunken young women..., and intense voyeuristic speculation in the activities of 'drunken (female) celebs'" (Griffin et al 2013 p187).

Griffin et al (2013) used data from the "Young People and Alcohol" study, which included analysis of alcohol advertising, video and print media, and group and individual interviews with 18-25 year-olds in three areas of England. Key themes from the analysis of the interviews included:

i) The pleasure of getting drunk and losing all inhibitions - eg: "Laura" reported: "It's just great, it's just fantastically fun to do that sometimes... you know fun sometimes just to lose all your inhibitions... you just lose your inhibitions... you're confident... it's fun... you just have fun and you're not bothered what anyone else thinks of you" (p190) [83].

[83] The rational addiction model (Becker and Murphy 1988) argued that "the consumption of addictive goods like tobacco and alcohol was a cogent choice made by utility-maximising individuals on the basis of factors like income, pleasure and price" (Reubi 2016 p483). Such a view allows the possibility of "sin taxes" (Reubi 2016) or "social taxes" (Becker 1997) to reduce the demand for such products.

ii) Risks for women in the culture of intoxication - eg: sexual assault and drunken men. For example, "Laura" stated: "you get lots of random guys coming over to see you... you say no and they don't actually understand the word no" (p192).

iii) The sexualisation of the night-time economy - eg: some bars and clubs have poles that customers (young women) can dance around.

"Outside the night-time economy, pole-dancing has become a widely available and popular activity for women in many affluent post-industrial societies, constructed as a form of 'sexercise; in all-female classes... Post-feminist discourse constitutes such practices as a reflection of assertive female (hetero)sexual 'empowerment' (Donaghue et al 2011). Evans and colleagues (2010) refer to young women's involvement in pole-dancing classes in the UK as part of the 'technology of sexiness'. Characterised by the 'doubled' quality of post-feminism, pole dancing 'produces a consumer practice that is constructed as liberating [for women], and yet it is tied into a culturally historical context that situates it as sexist and objectifying (Evans et al 2010)" (Griffin et al 2013 p194).

iv) Walking a tightrope between respectability and the "drunken slut" - Some of the interviewees distanced themselves from the latter by emphasising their responsible drinking and criticising others.

Griffin et al (2013) summed up: "Young women are called on to 'have fun' as if they are 'free' and 'liberated' subjects, and as if pervasive sexual double standards have faded away. They are exhorted to enjoy the pleasures of the post-feminist masquerade [McRobbie 2009] within the culture of intoxication as if the risks and dangers associated with being visibly drunk (and dancing round a pole in a night club) can be dealt with without recourse to feminist critique – or the presence of a boyfriend. More than this, young women are called on to operate as if they were unaware of the illusory and unstable nature of the promise of freedom, fun and empowered sexuality offered by hyper-sexual femininity and the culture of intoxication. Our work indicates that young women are aware of the illusory nature of this promise, as well as the unstable character of respectable femininity and the continued existence of the sexual double standard. They do manage to inhabit this impossible space in which pleasure and danger are locked in a dangerous and alluring embrace" (p198).

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13. TWO STUDIES OF THE HEALTH CONSEQUENCES OF IMMIGRATION POLICIES IN THE USA

In recent years, the US Government has tightened its policies on undocumented immigrants and increased deportations (eg: 2.7 million deportations while Obama was President; Reardon 2017).

There are health consequences of the stress and fear of deportation that undocumented immigrants and their families and community live with in the USA [84].

For example, Novak et al (2017) concentrated on a US Immigration and Customs Enforcement (ICE) raid of a meat-processing plant in Postville, Iowa, on 12th May 2008 ("largest single-site raid yet seen in the USA"), which resulted in 300 Latino deportations [85]. The researchers examined the birth certificates of over 200 000 Iowa children born from 2006 to 2010 [86], concentrating on those born in 37 weeks after the raid (12th May 2008 - 26th January 2009) compared to those born in the same period one year earlier (12th May 2007 - 26th January 2008) (n = 52 344) [87]. Low birth weight was defined as less than 2500 g at birth, and the category "Latina" was used based on any self-report of Hispanic ethnicity.

Latino mothers were 24% more likely to give birth to undersized babies in the year after the raid than before, while non-Latino White mothers were unaffected (figure 13.1), "suggesting that Latino populations were uniquely stressed by the incident" (Reardon 2017 p148) [88] [89].

But it was not possible to know how many of the Latino mothers were undocumented immigrants.

Research on undocumented immigrants is difficult. "For ethical reasons, most researchers do not ask study participants about their citizenship status, and many immigrants hesitate to seek medical care or register with the government, which limits relevant public data" (Reardon 2017 p149).

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[84] Novak et al (2017) pointed out: "Although USA-born Latinos are not subject to immigration deportation, many are embedded in communities targeted by immigration enforcement and may experience discrimination, 'othering' or chronic identity-related vigilance in response to racialised exclusion" (p2).

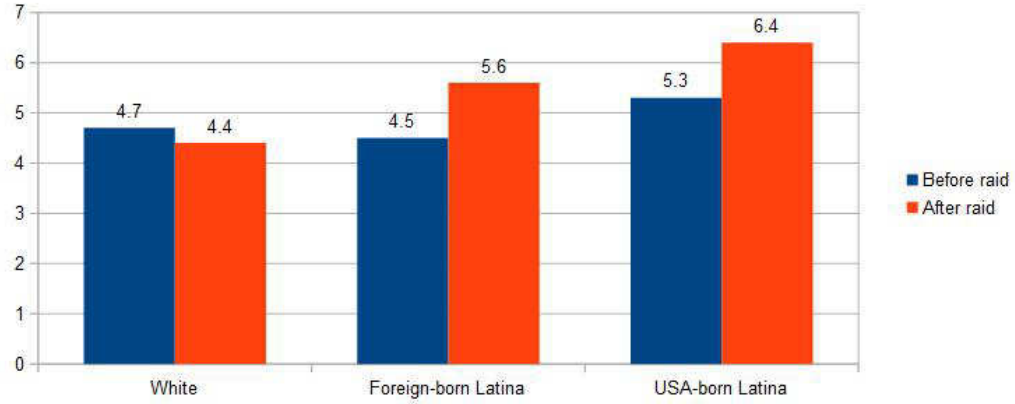
[85] "Reports from throughout Iowa after the Postville raid include evidence of individuals and families preparing for the possibility of further immigration enforcement, avoiding public space, restricting spending, losing income or economic security due to changing employment practices and experiencing increased discrimination, stereotype threat or racialised exclusion as public discourse frequently conflated Latino/Hispanic phenotype with undocumented status" (Novak et al 2017 pp6-7).

[86] The whole of Iowa was used as specific geographical information not released by Iowa Department of Public Health (Novak et al 2017).

[87] Birth certificates did not include certain relevant information to low birth weight (eg: pre-natal smoking; pre-natal care).

[88] Low birth weight is associated with developmental problems and health risks (Reardon 2017).

[89] Lauderdale (2006) found increased low birth weight babies among Arabic-named mothers in California after 11th September 2001.



(Data from Novak et al 2017 table 1)

Figure 13.1 - Percentage of babies born with low birth weight.

However, Lopez et al (2017) reported a health study that was running in Washtenaw County, Michigan, when there was a raid by immigration agents in 2013. The "Encuesta Buenos Vecinos" (EBV) ("Good Neighbours Survey"), in Spanish and English involving online and face-to-face interviews, ran from September 2013 to January 2014 (and the ICE raid was on 7th November 2013).

Individuals who completed the survey after the raid (n = 151) reported poorer health than those who completed before (n = 325) (mean 3.6 vs 3.4 out of 5; p = 0.06). Self-rated health (SRH) was negatively correlated with fear of deportation (r = -0.27; p<0.001), for example. Many of the former said "they were too afraid to leave their homes for food or medical care, and displayed symptoms of post-traumatic stress disorder" (Reardon et al 2017).

Overall, Lopez et al (2017 stated, "participants who completed the EBV survey after the raid reported higher levels of immigration enforcement stress and lower SRH scores, despite a lower percentage of foreign-born participants completing the survey after the raid. Our analyses present strong evidence of the negative influence of immigration raids both directly and indirectly on the lives and health of Latinos in the communities in which raids occur" (p705). The researchers continued: "This raid was an extreme example of an immigration law enforcement effort that was unpredictable to the community in which it occurred, incorporated overt militarised displays of power, and included an invasion of personal space" (Lopez et al 2017 p707).

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14. "NEEDLE FIXATION" AND THEORETICAL IDEAS

"Needle fixation" is a contested term describing "the behaviour of repetitive needle injection from the drug users perspective" (Vitellone 2015) [90] [91].

Pates et al (2001) emphasised habit, when they stated that it "was probably the final common pathway of a number of multi-factorially determined and variously motivated reasons for injecting which then become maintained as a habit by conditioning" (quoted in Vitellone 2015) [92]. The association of the "rush" (positive effect), and the removal of the negative effects of the withdrawal are key, as well as secondary gains (or external motivations) like "ritualisation and the use of common objects, the skill of injecting and social status, and the displacement of masochistic sexual desires, intimacy and sexual pleasure onto the needle" (Vitellone 2015 p374) [93]. The upshot for policy intervention was to "move injectors away from injecting" (Pates et al 2001).

Fraser et al (2004, 2005) challenged the concept of "needle fixation":

- "What are the health and social implications of the creation of such a category?" (2004);
- "What good will this category do?" (2005).

Fraser et al (2004) were drawing on the ideas of Foucault that "injecting drug users are the products of discourse". McBride and Pates (2005) responded that Foucault's ideas had "little bearing on most peoples injecting".

Vitellone (2015) offered other theoretical interpretations of injecting behaviour [94]:

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[90] Theories are "machineries of knowing" (Knorr Cetina 1999).

[91] "To understand the activity of subjects, their emotions their passions, we must turn our attention to that which attaches and activates them – an obvious proposition but one normally overlooked" (Latour 2010 quoted in Vitellone 2015)..

[92] "Reward processing" describes the motivation towards a desired goal, and includes reward expectancy and the subjective experience of the reward. Dysfunctional reward processing and anticipation is evident in addiction and impulsivity (Jin et al 2016).

Jin et al (2016) investigated the pattern of brain activation during reward anticipation with functional magnetic resonance scans of 1544 14 year-olds while playing a gambling game. Three main sets of brain connections or nodes were identified, which showed that areas of the brain related to perception, cognition, and motor control were all involved in reward processing. But different pattern of nodes were associated with addiction to impulsivity.

[93] Recently, from a biological perspective, Zhu et al (2016) identified the role of part of the thalamus in the physical and emotional feelings of withdrawal from opiate dependence using mouse models.

[94] These explanations were in opposition to biomedicalisation, which Clarke et al (2010) defined as "technoscientific interventions in biomedical diagnostics, treatments, practices and health to exert more and faster transformations of bodies, selves, and lives" (quoted in Lowy and Sanabria 2016 p14).

1. Howard Becker and symbolic interactionism - "What matters is not the conditioning effects of the object on individual injecting behaviour but the social meanings attached to the object by social actors and its impact on future injecting" (Vitellone 2015 p376).

Specifically, Fitzgerald et al (1999) emphasised the importance of "the way others define a drug for that person". The process of injecting for the first time challenges how the individual sees themselves. "The drug users' feelings of being different and thoughts of being judged negatively by others suggest the initiation to injecting behaviour involves the subject's internalisation of the objects meaning as deviant. Here, the symbolism of the needle separates the individual from the outside world. Here, the representation of the syringe challenges social roles and social identities" (Vitellone 2015 p377). The first injection is "a separation rite" which causes "the social death of the individual" (Fitzgerald et al 1999). This describes the emergence of a "deviant behaviour", however, and not necessarily the experience of the individual (Vitellone 2015).

2. Pierre Bourdieu and habitus - From an ethnographic study of homeless heroin addicts in a US inner city area, Bourgois (2007) observed that "African Americans and whites administer their heroin injections differently" - ie: "macro power relations become 'routinised' in injecting behaviour patterns" (Vitellone 2015).

Bourgois (2007) explained that habitus in this context "links social structural power relations to intimate ways of being at the level of individual interactions to show how everyday practices and preconscious patterns of thought generate and reproduce social inequality" (quoted in Vitellone 2015).

Garcia's (2010) ethnographic study of Hispano addicts in New Mexico suggested that this type of social analysis ignored the personal experience, and the "structures of feeling". She described the relapse of "John" as "mourning a lost sense of place" rather than as habit or as social structure and forces played out, and linked to Sigmund Freud's concept of melancholia. There was an "unfinished grief" or "mourning without end" related to the individual as well as the "regions historical scars of a lost past" (Vitellone 2015).

Vitellone (2015) questioned both Bourgois's and Garcia's approaches as "silent on the question of the material reality of injecting".

3. Gomart and Hennion (1999) and the sociology of attachment - This approach concentrated on "the objects, techniques and constraints entangled with the addicted subject" - ie: "to shift the focus from a subject 'who acts' to the 'devices by which amateurs put their passion into practice' (Gomart and Hennion 1999)" (Vitellone 2015). Put simply, the individual becomes attached to the needle - ie: "the syringe is an object of passion" (Vitellone 2015).

This approach also wanted to get away from addiction as a passive or active action. It is both: "the user passes between active and passive. That is, between 'I am manipulated' (because I agree to it) and 'I manipulate' (an object which is stronger than myself). This 'passing' is at the heart of a theory of attachment. It emphasises the force of things as the locus of an event, of an emergence" (Gomart and Hennion 1999 quoted in Vitellone 2015).

Vitellone (2015) preferred this approach, particularly when the drug user is treated as "a co-experimenter" (Gomart and Hennion 1999) with the academic researcher.

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15. FOOD ADDICTION

15.1. Introduction
15.2. Craving
15.3. Reward-based eating
15.4. Sense of loss of control
15.5. Appendix 15A - Impulsivity
    15.5.1. Resisting desires
15.6. References

15.1. INTRODUCTION

Food addiction is where "individuals become physically and psychologically dependent on high fat, high sugar (HFHS) foods" (Pivarunas and Conner 2015 p9).

The same areas of the brain (including the amygdala and orbitofrontal cortex) are activated by food and drug cues, and dopamine is a key neurotransmitter in relation to both. Also repeated excessive consumption leads to tolerance, withdrawal, and continued use despite the negative consequences (Pivarunas and Conner 2015) [95].

Key behaviours in common are impulsivity (appendix 15A), and emotion regulation. Whiteside et al (2005) distinguished four aspects of impulsivity:

i) Urgency - acting quickly when experiencing negative emotions. Other researchers have talked of "negative urgency" (impulsivity when distressed) and "positive urgency" (impulsivity when elated) (Pivarunas and Conner 2015). Research has found that "negative urgency triggers alcohol and drug use and more frequent binge eating and purging. Of course, at the core of negative urgency is negative affect – the individual acts impulsively while experiencing or because of negative affect. Thus, the impulsive actions become an attempt to regulate affect" (Pivarunas and Conner 2015 p11).

ii) Lack of pre-meditation (eg: consequences).

iii) Lack of perseverance - inability to focus on a task.

iv) Sensation-seeking.

Emotion regulation is "the extent to which individuals influence, experience and express their emotions... Dysregulation occurs when an individual

[95] For example, rats show behaviours similar to those of addiction in response to sugar (Joyner et al 2015).

does not possess the skills necessary to regulate negative affect or emotional distress" (Pivarunas and Conner 2015 p10).

The Yale Food Addiction Scale (YFAS) (Gearhardt et al 2009) is used to measure food addiction. It has twenty-five items related to the past year (eg: "I want to cut down or stop eating certain kinds of food"), and uses the diagnostic criteria associated with substance dependence [96].

Based on its use, food addiction has been diagnosed in around half of individuals with Binge Eating Disorder [97], up to a quarter of obese individuals [98], and up to 10% of general population samples (Pivarunas and Conner 2015) [99] [100].

Pivarunas and Conner (2015) asked just under 900 undergraduates at Colorado State University, USA, to complete the YFAS, and measures of impulsivity and emotion regulation. High YFAS scores were associated with negative urgency, and emotion regulation (or more correctly, emotion dysregulation), but unexpectedly not other aspects of impulsivity.

15.2. CRAVING

Craving is another aspect of addictive substances. Joyner et al (2015) found that food craving was involved in problematic eating outcomes (eg: obesity).

Around 300 adult volunteers in north-eastern USA were recruited via an advertisement about a study on eating behaviour and health. They completed the YFAS, an eating questionnaire, and the Food Craving Inventory (FCI) (White et al 2002). The FCI has 28 items that cover the cravings for high fats (eg: bacon), carbohydrates/starches (eg: bread), sweets (eg: biscuits), and fast-food fats (eg: hamburger).

Addictive-like eating was significantly associated with overall food craving (as well as body mass index; BMI), and overall food craving was significantly

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[96] Food addiction is operationalised by such questionnaires. Grant and Kinney (1991) described an operational definition thus: it "assigns to a concept by specifying the activities or procedures necessary for measurement. In essence, operational definitions describe what is measured and how it is measured" (quoted in Parahoo 1997).

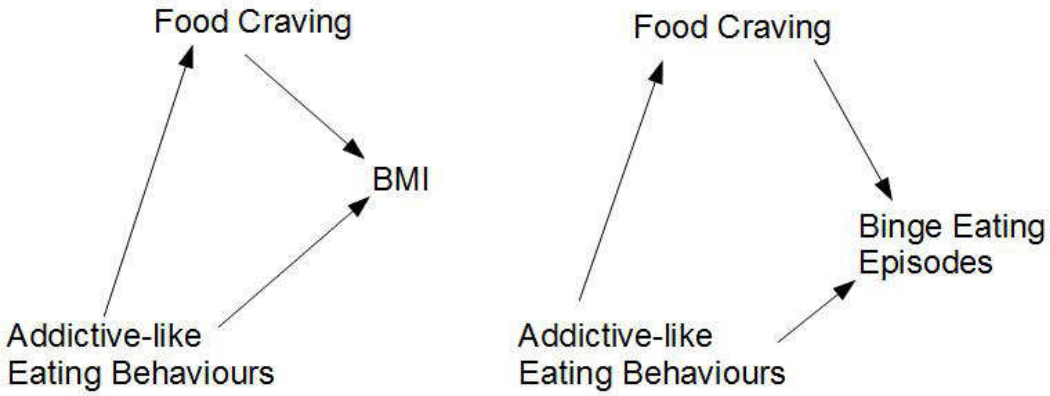
[97] 40-60% (depending on study) (Chen et al 2015).

[98] 15-25% (depending on study) (Chen et al 2015).

[99] Gearhardt et al (2009) diagnosed 11.4% of the non-clinical sample with food addiction in their original study with YFAS.

[100] The YFAS has been translated into a number of languages for use worldwide, including China, where 9.2% of 14-19 year-old females were diagnosed as being food addicted (Chen et al 2015), French (8.7% of non-clinical sample; Brunault et al 2014), and German (8.8%; Meule et al 2012).

associated with BMI. The same relationships were also found for binge eating episodes (figure 15.1).



(Based on Joyner et al 2015 figure 1 p99 and figure 2 p100)

Figure 15.1 - Significant associations found by Joyner et al (2015).

Cravings for fats was related to BMI, but not binge eating, while cravings for fast-food fats had no relationship with BMI or binge eating. Cravings for sweets and carbohydrates/starches were associated with binge eating episodes, but not BMI.

Joyner et al (2015) concluded: "cravings for sugar or non-sugar carbohydrates appear to be more closely associated with addictive-like eating and bingeing, while carvings for fat appear to be more closely related to elevated BMI" (p100).

There were three key limitations to the study:

i) Over 80% of the volunteers were female.

ii) Measures of height and weight (for BMI calculation) were self-reported.

iii) A cross-sectional study does not allow for establishing causation.

Food cravings can be defined as "hunger-reducing, mood-improving experiences" (Malika et al 2015). The State and Trait Food Cravings Questionnaire (FCQ) (Cepeda-Benito et al 2000) is used to measure them with items derived from drug cravings questionnaires. The FCQ measures food cravings as a state (FCQ-S) or a trait (FCQ-T). The latter does not specify a particular food, but focuses on the characteristics of the general craving experience.

The FCQ-T has thirty-nine items, which makes it

time-consuming to administer. A reduced version with fifteen items has been developed (FCQ-T-r) (Hormes and Meule 2016) (table 15.1).

- When I crave something, I know I won't be able to stop eating once I start.
- If I give in to a food craving, all control is lost.
- My emotions often make me want to eat.
- I find myself preoccupied with food.

(Source: Hormes and Meule 2016 table 1 p35)

Table 15.1 - Items from FCQ-T-r.

Such questionnaires are often validated with college students or treatment-seeking overweight and obese individuals (Malika et al 2015).

Malika et al (2015) felt that qualitative research is a better way to understand the experience of food cravings (and food addiction). They recruited women in Michigan, USA, with young children to talk about their own and their children's eating behaviours in forty-three individual semi-structured interviews and nine focus groups with thirty-one participants. The women were receiving government assistance for low-income families.

All sessions were audio-recorded and then transcribed. From the subsequent analysis, five themes emerged:

i) "Food craving is a strong want or desire for food and is an acceptable behaviour".

a) Craving was described as an intense desire or longing - eg: "If I didn't have carrots at that moment, I craved it and craved it until I had it and it was like, (sighs) 'It's good. It's yummy. It's satisfying'" (p26).

b) It was seen as acceptable - eg: "A craving might also be your body telling you you're not getting enough of this nutrient – you need to eat this kind of food. If I'm craving steak or hamburger or just beef in general I know that I probably need the iron in my body" (p26).

ii) "Food addiction exists and is characterised by specific behavioural features" - Most of the women "felt that food addiction exists. They felt that they had seen it and they knew what it looked and felt like" (Malika et al 2015) - eg: "When I was a heavy soda drinker I didn't even taste it; I just drank it just to drink it. Then it wouldn't be until I say 'That's a lot of calories, I should quit' that I start getting the headaches and so I would maybe drink some just to kind of curve the headache" (p27).

iii) Food cravings and food addictions are similar, but the former is less serious, but more common - "A food craving is different than an addiction is, because an addiction is something that you think you can't live without. A craving is more of, 'Oh I haven't had whatever restaurant in a while I really want their main dish' ...[an addiction is if] I go back to that restaurant every single day and get that same dish over and over and over again" (p27).

iv) Food cravings were described in a humorous tone, but food addictions were described in a serious tone - In most cases, "cravings were seen as an everyday, ordinary issue that everyone experienced and had funny stories to tell as a result of it. Food addiction was not perceived as immoral, reflecting a lack of will, or a character failing. Instead, addiction was seen as simply a behavioural phenomenon; it was not viewed as reflective of amoral failing" (Malika et al 2015 p27).

v) Food cravings are common in children, but "they can only become addicted to foods if their parents 'let' them" - eg: one woman said: "Honestly I think the only way a child can – any child – can have an addiction, to something is if the parent gives them an overabundance of it. 'Cause there's no way they can get it themselves in preschool" (p27).

Malika et al (2015) noted the implication of their study: "Current interventions aimed at reducing food craving... have operated under the assumption that people are attempting to suppress the urge to eat craved foods, the same way a person may attempt to suppress the urge to use drugs or alcohol, yet fail... The results of our qualitative work, however suggest that these intervention approaches may not be effective for obesity prevention in some demographic groups such as the low-income women we interviewed. In our cohort, food craving was not associated with feeling the need to suppress the behaviour and was not described as aversive or as an experience to be avoided or fought against. Instead, food craving was described as acceptable, with little attempt to change, avoid or control it" (p28).

Malika et al (2015) went on: "The framing of food craving as a behaviour to be guarded against, as in most commonly used questionnaires, may represent a middle- or upper-income conceptualisation of food craving. Middle to upper income populations tend to view health as the absence of disease and a battle to be fought, while lower income populations view health as 'feeling good' and having an overall sense of well-being... In summary, questionnaires that frame food craving as a behaviour to be resisted or guarded against may not resonate with populations who do not view

food craving in this manner" (p28).

15.3. REWARD-BASED EATING

Reward-based eating may be due to alterations in the brain, particularly in endogenous opioid system, after consumption of high levels of "highly processed, palatable, and arguably addictive foods", which "may increase susceptibility to, and bias experiences of, opioid-mediated food cravings, which are often for those highly palatable foods" (Mason et al 2015 p53) [101]. So, opioid antagonists (blockers) can suppress this process, as reported with rats (Mason et al 2015).

Mason et al (2015) performed a small-scale study of the use of naltrexone [102] with thirty-nine obese volunteers in the USA. Over four weeks, participants were given three pills of naltrexone and two placebo pills in a double-blind, randomised order. The Reward-Based Eating Drive (RED) Scale (Epel et al 2014) [103] was completed beforehand, and a food-craving intensity diary was kept throughout the study.

Craving intensity did not vary between naltrexone or placebo, but the positive association between reward-based eating and craving intensity was reduced after the drug.

15.4. SENSE OF LOSS OF CONTROL

The sense of loss of control in Binge Eating Disorder can be explained by Action Control Theory (Kuhl 1992). Self-regulatory behaviour (ie: the ability to plan, initiate, and complete intended actions) is a continuum from "action-oriented" to "state-oriented". The former individuals are "highly successful at initiating goal-directed action (decision-related action orientation: AOD), which requires the up-regulation, or effortful increase, of positive affect in order to initiate goal-directed behaviour. Action oriented individuals are also adept at carrying out intended actions even after experiencing failure (failure-related action orientation: AOF), requiring successful down-

[101] "Chronic over-consumption of palatable food can dampen endogenous opioid action. Rodents chronically consuming a highly palatable diet that are either removed from the diet or administered an opioid antagonist demonstrate opioid-withdrawal behaviour.... Similarly, women reporting more emotional or binge eating also report symptomology consistent with opioid withdrawal when under opioidergic blockade" (Mason et al 2015 p54).

[102] An opioid antagonist commonly used with alcohol and drug dependence.

[103] The RED Scale measures lack of control over eating, lack of fullness, and preoccupation with food. The nine items include "When I start eating, I just can't seem to stop" and "I don't get full easily" (Mason et al 2015).

regulation, or effortful decrease, of negative affect associated with previously adverse experiences" (Reese et al 2016 p64). "State-oriented" individuals have low AOD (ie: unable to translate intention into action), and low AOF (ie: distracted by previous failures) leading to less ability to self-regulate behaviour to achieve goals (Reese et al 2016).

Low AOD has been found to predict negative alcohol-related consequences among binge-drinking students, for example (Palfai et al 2002), and greater disordered eating among female undergraduates (Palfai 2002).

Baumeister and Heatherton (1996) presented self-control (willpower) as a resource that gets used up, and so consequently "ego-depletion" leads to a loss of self-control. However, Job et al (2010) found that belief about willpower mattered more. In other words, if an individual believed that it was a resource that got used up, they showed ego-depletion more than individuals who did not hold that belief. "Thus, even in highly demanding everyday situations, beliefs about the nature of willpower seem to play an important role in self-regulatory ability, a notion with significant implications for addictive behavioural outcomes and binge eating behaviour" (Reese et al 2016 p65).

Reese et al (2016) investigated AOD and AOF, and belief about willpower in relation to binge-eating behaviours with 1128 US online volunteers.

AOD and AOF were measured by the Action-Control Scale (ACS) (Kuhl 1994), which has 36 items, including "when I have to take care of something important but which is also unpleasant" (AOD stem): "I can do it and get it over with" (action-oriented response) or "it can take a while before I can bring myself to do it" (state-oriented response). While an example of an AOF stem is "when I am in a competition and have lost every time": "I can soon put losing out of my mind" (action-oriented response) or "the thought that I lost keeps running through my mind" (state-oriented response).

The Implicit Beliefs in Willpower (Job et al 2010) has ten items, including "after a strenuous mental exercise, your energy is depleted and you must rest to get it refuelled again" (which is scored 1 to 6). Higher scores indicate belief in willpower as a limited resource.

Separately, lower scores on this questionnaire predicted less binge-eating behaviours, as did high AOD and high AOF scores on the ACS. In terms of the interaction between the two questionnaire scores, low AOD, high AOF, and belief in willpower as limited predicted more binge-eating behaviours, but not with high AOD, or belief in unlimited willpower. "Thus, an ability to regulate negative affective states (ie: high failure-

related action orientation) seems to be a particularly important protective factor for eating outcomes, but may not be as protective if an individual is low in decision-related action orientation (ie: less skilled at up-regulating positive affect) and believes in the limited theory of willpower" (Reese et al 2016 p66).

15.5. APPENDIX 15A - IMPULSIVITY

Self-reports of impulsivity by abstinent substance-dependent individuals (AbD) may be more accurate than behavioural measures or scans (Taylor et al 2016). The problem is that these different methods measure "distinct attributes, often conceptualised in very different ways" (Taylor et al 2016).

The Barratt Impulsivity Scale (BIS-11) (Patton et al 1995) is a commonly used self-report measure [104], which like all such measures has high ecological validity, but are "reliant on individual insight and are susceptible to bias" (Taylor et al 2016).

The Go/NoGo Task (GNG) is a popular behavioural measure that quantifies the ability to inhibit a response before it is started [105], and the Stop Signal Task (SST) which involves inhibiting a response after it has been started [106]. Less inhibitory control has been found in drug and alcohol dependent individuals (Taylor et al 2016).

Does impulsivity change when an individual abstains from their substance of dependence? The studies are divided, and this is, in part, due to the method for measuring impulsivity, which led to the research by Taylor et al (2016).

One hundred and forty-three volunteers were recruited across England, of which 57 had no history of substance dependence (controls), twenty-seven alcohol AbD, and the remainder poly-drug AbD. Participants completed four self-report questionnaires on impulsivity, including BIS-11, and three behavioural measures. One of these tasks was delay discounting (ie: the willingness to put off a reward). Different immediate rewards are offered with greater rewards later, varying the time to wait (eg: £10 today or £25 in one week). A GNG was performed during a functional magnetic resonance imaging

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[104] Items like "I am restless at the theatre or lecture", "I plan tasks carefully", and "I act 'on impulse'" are rated from "rarely" to "always".

[105] A sequence of Xs and Ys, say, are presented on a computer screen, and the task is to press a button as quickly as possible when the letter appears (Go), except if the same letter appears twice in a row (NoGo).

[106] For example, individuals push a button in response to a visual cue on the computer screen, but must stop when a particular noise (eg: beep) is played. The reaction time to stop is recorded ("stop-signal reaction time").

(fMRI) scan.

Taylor et al (2016) found that both groups of AbD participants scored significantly higher than the controls on the self-report measures, but there was no difference between the AbD individuals and controls on the other measures.

15.5.1. Resisting Desires

Acting upon a desire can be risky. "Social norms, morals, and the contingencies of physical health dictate that many desires should be resisted" (Hofmann et al 2012 p582). For example, it is estimated that 40% of deaths in Western societies are the long-term consequences of acting on desires for tobacco, sex, alcohol, recreational drugs, or certain foods (Schroeder 2007). So, the importance of self-regulation and self-control. Self-regulation produces conflict with desires.

Hofmann et al (2012) investigated desires, resistance, and conflict using an experience-sampling methodology. Two hundred and eight participants in a city in Germany carried a smartphone for seven days, which randomly beeped. At the signal, the participants reported if they had a desire currently or recently, and whether they were fulfilling or resisting it (table 15.2).

- Experience a desire (ie: craving, urge or longing to do a certain thing) now or in last 30 minutes (up to 3 desires maximum).
- If yes, list of 15 categories (eg: eat, work, spend).
- Strength of desire (0-7).
- Conflict of desire with other goals: 0-4.
- Nature of conflict from list of 20 options.
- Resisted desire: yes/no.

Table 15.2 - Experience-sampling measures.

In total, there were 10 558 responses, and 7827 "desire episodes", and 7573 conflicts. The most frequent desires related to eating, drinking, and sleep, followed by leisure, social contact, and media use. Resistance was above average for sleep, sex, leisure, spending, and eating, and below average for social contact, alcohol, media use, and work.

Conflicts were grouped into six categories:

i) Health-related (eg: how much alcohol to consume);

ii) Abstinence-related (eg: saving vs spending money);

iii) Achievement-related (eg: studying vs doing something else);

iv) Social-related (eg: socialising or not);

v) Time-use- related (eg: doing something now or later);

vi) Other.

Hofmann et al (2012) summed up:

> Desire, conflict, and resistance are frequent and pervasive features of daily life. Although modern civilization may involve advanced and sophisticated forms of behaviour, we found that the desires felt most frequently pertained to basic bodily needs, such as eating, drinking, and sleeping. The desire for social contact was also prominent, reflecting the need to belong... These desires were not only the most commonly felt but also some of the most strongly felt.
> In contrast, acquired tastes, including even those for supposedly addictive substances such as tobacco, alcohol, and coffee, were below average in subjective strength. These findings challenge the stereotype of addiction as driven by irresistibly strong desires. Given the range of desires we sampled, it was surprising that those for sleep and leisure emerged as the most problematic (ie: conflicted) desires. These results suggest a pervasive tension between natural inclinations to rest and relax and the multitude of other obligations, including work [...]
>
> Extrapolating from the data, it was calculated that the average adult spends eight hours per day feeling desires, three hours resisting them, and half an hour succumbing to previously resisted ones (p587).

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16. SMOKING CESSATION

16.1. Smoking cessation treatments
16.2. Tuberculosis and smoking
16.3. E-cigarettes
16.3.1. Health
16.4. Smoking and stigma
16.5. Appendix 11A - Social context of smoking
16.6. References

16.1. SMOKING CESSATION TREATMENTS

Smoking cessation treatments face the challenge of a high relapse rate. A number of different factors have been identified that help or hinder cessation, including gender (male, better), age of smoking onset (later initiation, better), previous history of depression (yes, worse), and prior attempts to quit (previous failures, worse) (Lopez-Nunez et al 2016).

The type of treatment is also important. For example, contingency management (CM), based on operant conditioning, rewards desirable behaviour, and has been shown to improve smoking reduction (Lopez-Nunez et al 2016).

Lopez-Nunez et al (2016) reported a randomised controlled trial that compared cognitive-behavioural therapy (CBT) to CBT and CM among 154 outpatients at an addictive behaviours clinic in Spain. THe CBT focused on the thoughts related to smoking (eg: triggers) and quitting (eg: dealing with nicotine withdrawal symptoms). Rewards in the form of points to be exchanged in local shops, for instance, was the CM. These were given for full smoking abstinence or reduced smoking (based on urine samples [107]). The treatment lasted six weeks and follow-up was made at six months.

Both CM groups improved smoking cessation and abstinence during treatment compared to CBT alone, as well as treatment retention, and in-treatment abstinence (ie: total number of days without smoking during the treatment) was the best predictor of long-term abstinence (ie: at six months).

Fear of or actual weight gain may encourage smoking relapse, particularly for women [108]. The health risks of smoking are greater for post-menopausal women because smoking has anti-oestrogenic effects, and there is more

[107] This measured cotinine, which is an excreted metabolite of nicotine.

[108] Less than 10% of men gained one-fifth body weight post-smoking cessation compared to 20% of women (O'Hara et al 1998).

weight gain post-cessation (1 kg extra for every ten years older) (Copeland et al 2015). Thus the need for individually tailored smoking cessation and weight gain prevention programmes for such women.

Copeland et al (2015) designed and evaluation such a programme. Ninety-two post-menopausal women smokers who used smoking to control weight were recruited in Baton Rouge, Louisiana, for a two-week cessation group. Then they received eight weeks of individually-tailored or group follow-up, which included weight gain prevention. The group follow-up led to more smoking abstinence at two months, which was "contrary to prediction and inconsistent with the growing literature regarding the benefits of tailored interventions for smokers" (Copeland et al 2015 p112).

The authors offered this explanation: "Although the individual sessions were intended to benefit participants with one-on-one provision of tailored materials, the group setting also allowed for provision of tailored information by therapists who had access to group participants' high risk information and had worked with these participants over the course of the study. It could therefore be that the amount of individualised information provided in the group format was sufficient, and that the group format itself was preferred by participants. Anecdotally, participants assigned to the individual sessions expressed discontent in being separated from group members with whom they initially quit smoking" (p112).

In terms of weight gain, it was similar for both types of follow-up (5-6 lbs at eight weeks). Pre-treatment weight concern predicted post-treatment weight gain irrelevant of individual or group format.

Public health interventions as in reducing smoking are examples of "governmentality" (Foucault 2000) - "a liberal version of governance in which the freedom of individuals is incontrovertible and attempts to regulate conduct take the form of encouraging people to make one free choice rather than another... By highlighting individual freedom this form of regulation is often – and deliberately – inconspicuous. As Foucault explains, modern 'power is tolerable only on condition that it mask a substantial part of itself. Its success is proportional to its ability to hide its own mechanisms' (Foucault 1979)" (Crammond and Carey 2017 p91). Regulation is, thus, presented as in the population's best interests. Increased tax on cigarettes, for example, is designed to encourage individuals to exercise their freedom in another way (ie: to stop buying the product).

It is sometimes assumed that individuals who do not stop smoking have not listened to the health messages, but such individuals are aware of risk discourses. So,

"whether a person accepts that a risk is significant enough to warrant behaviour change, or simply one other in a risky world, the discourse of risk itself is inescapable" (Crammond and Carey 2017 pp92-93). This idea can be seen in the response of an Australian female smoker interviewed by Gilbert (2005): "Well, all the health risks,... I'm aware of all of it, but I think with my lifestyle I shouldn't really worry. I mean, I should worry about it, but I work out everyday, I eat healthy, apart from smoking, that's probably the unhealthiest thing" (quoted in Crammond and Carey 2017).

16.2. TUBERCULOSIS AND SMOKING

Nichter et al (2016) lamented the dearth of information "about the smoking habits of individuals who have been or are currently being treated for pulmonary tuberculosis (TB) in low- and middle-income countries" (p70). These researchers concentrated on Indonesia, which ranks third in the world for number of current smokers, and fourth for total cigarette consumption (behind China, Russia, and the USA), according to World Health Organisation data. Furthermore, smoking is increasing - from 54% of males over fifteen years old in 1995 to 67% in 2011 (Nichter et al 2016).

The health risks of smoking and second hand smoke exposure are not well known in Indonesia, even among health professionals. For example, Ng et al (2007) reported that over 80% of doctors in one area of the country saw no real harm with 5-10 cigarettes a day. The same number of cigarettes was viewed by many laypeople as good for well-being, and not harmful if a "suitable" cigarette for one's body is used (eg: clove or menthol cigarette) (Nichter et al 2008).

Smoking contributes to TB incidence and TB-related deaths as well as "renders one more susceptible to TB, hastens conversion from latent TB infection to active TB disease and increases the chances of both developing severe TB and experiencing TB relapse after the successful completion of TB treatment... Formerly treated TB patients who resume smoking are three times more likely to experience TB" (Nichter et al 2016 p71).

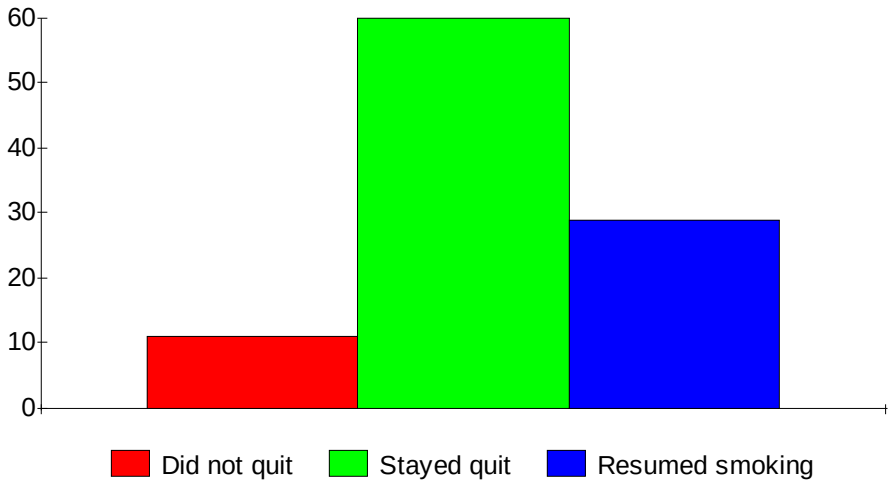
Ng et al (2008) found that two-thirds of 239 male patients with TB smoked daily before the diagnosis of TB, and the vast majority of these (90%) quit during TB treatment. But nearly half of the quitters had resumed smoking within six months post-TB treatment (three-quarters daily smoking - around fifty individuals). Those who thought it was not harmful to smoke after TB treatment were sixteen times more likely to resume.

Nichter et al (2016) designed a programme to make

individuals with TB aware of the health risks of resuming smoking post-treatment. They recruited 101 men with newly diagnosed TB who smoked in Yogyakarta Province, Java. Half of these received TB-specific quit smoking messages from a doctor, and an educational booklet and cessation guide, while the other participants received the same information from a trained family member. Smoking was assessed at baseline, 3 and 6 months during TB treatment, and three and six months post-treatment. Fifty-five individuals completed the study (ie: complete data at one year).

At three months of TB treatment, 78% of participants reported quitting smoking, and 18% of them has resumed by six months of treatment. At six months post-treatment, 30% of patients had resumed smoking (8% >6 cigarettes per day).

At six months post-treatment, 55% of the family message group were still quit and 67% of the doctor message group (figure 16.1). This is not a significant difference.



(Data from Nichter et al 2016 table 1 p75)

Figure 16.1 - Percentage of patients at six months after TB treatment.

The two groups had two differences:

i) More recalcitrant smokers (including heavy) (ie: never quitted) in the family message group;

ii) Non-significantly more individuals in the doctor message group resumed heavy smoking after quitting.

Fifteen participants were interviewed indepth about their attitudes to smoking and quitting. The researchers

picked out some key findings from these interviews:

a) Smoking is a social behaviour (appendix 16A), and quitters used various strategies to refuse offers of cigarettes (eg: "my doctor has told me not to smoke"; "I have smoked already"). But the "patients do not turn down cigarettes in social contexts by explicitly noting that smoking is harmful for health. If health is mentioned, most former patients state that their doctor has advised them against smoking or that smoking is counter indicated while taking medicine. This makes it appear that the individual is still too weak or sick to smoke at present, not that smoking is a health hazard. One reason former patients resumed smoking at low-moderate levels was to signal to others that they were no longer too sick to smoke" (Nichter et al 2016 p76).

b) Those who smoked did so, more often, alone than in social situations, and after meals as "a form of enjoyment associated with completing a meal and a way of removing the sour aftertaste... from one's mouth after consuming food" (Nichter et al 2016 pp76-77).

c) Resumers often took a few puffs to remember the taste rather than smoke a whole cigarette - eg: one man said: "Before cigarettes were as important as rice [staple food], but now they are like a dessert. I can enjoy a small amount and feel satisfied" (p77).

d) During TB treatment, the cigarettes often had a bitter taste, and so after treatment when cigarettes tasted good again, it was taken as a sign of being healthy. For example, one informant said: "Smoking checks my health. If I feel good and the cigarette tastes delicious, that means my health is good" (p77).

e) "Notably, all the fifteen informants believed that the benefits of low-moderate level smoking outweighed the risks as long as one was attentive to bodily warning signs. Some informants voiced the opinion that just as smoking too much was harmful for the body, so too was shocking a body accustomed to smoking for many years by quitting. Low-moderate level smoking was a form of harm reduction that maximised the benefits of smoking and minimised the risks of both heavy smoking and the shock of quitting" (Nichter et al 2016 p77).

16.3. E-CIGARETTES

Electronic cigarettes (E-cigs) are a relatively recent arrival (eg: 2007 in the USA; Barrington-Trimis et al 2016), and there is much controversy about them, including whether they are harmful to health, their

effectiveness in helping tobacco smoking cessation, and if the encourage cigarette and E-cigarette use in the young.

In relation to the latter issue, the National Youth Tobacco Survey (NYTS) in the USA reported an increased use of E-cigarettes in the past month from just over 1% of adolescents in 2011 to 16% in 2015. At the same time, the NYTS found that cigarette use fell from 16% in 2011 to 9% in 2014 (Barrington-Trimis et al 2016).

How to interpret these data?

a) E-cigarettes are being used instead of cigarettes; or

b) E-cigarettes are "recruiting new users who otherwise would not have initiated cigarette use (or perhaps any other tobacco product) if E-cigarettes were not available" (Barrington-Trimis et al 2016 p2).

Barrington-Trimis et al (2016) presented evidence from the Southern California Children's Health Study (CHS) to suggest the latter. The CHS began in 1993 to follow five cohorts to 17-18 years old, who were 15-16, 12-13, 9-10, or 5-6 years old at the beginning. The data from 2004 for cigarette use was compared to cigarette and E-cigarette use in 2014. E-cigarettes were not available in 2004, but the researchers "hypothesised that an increase from this benchmark may indicate that E-cigarettes are currently being used by adolescents who would not otherwise have smoked if E-cigarettes were not available" (Barrington-Trimis et al 2016 p2). Data were available for around 500 adolescents.

The combined prevalence of current cigarette and E-cigarette use [109] in 2014 was 14% of 17-18 year-olds, which was significantly greater than 9% for cigarette use by that age group in 2004 (benchmark) [110]. The researchers saw these figures as supporting their hypothesis.

Barrington-Trimis et al (2016) concluded:

> E-cigarettes have gained popularity in recent years, in part because of availability in a wide variety of flavourings that may be appealing to adolescents and young adults, the perception that E-cigarettes are less harmful than smoking, absence or poor enforcement of regulations on indoor use, and the recent popularity of product-specific venues that encourage use of these products in social situations, such as vape shops. Such characteristics of E-cigarettes may be recruiting

[109] "Current use" means in past 24 hours, past week, or past month, as opposed to past year or ever in lifetime.

[110] All data were self-reports with no independent verification.

> new users who are deterred from initiating cigarettes because of concerns about the health hazards of smoking and social stigmatisation of cigarette use. There is concern that the increasing prevalence of E-cigarette use could even lead to initiation of smoking among previously non-smoking adolescent E-cigarette users in what has been described as a 'gateway effect', either as a result of social normalisation of alternative product use and smoking behaviours more generally, leading to renormalisation of smoking or by directly increasing use of cigarettes through establishment of reward seeking behaviours (eg: nicotine dependence) (p8).

Similar findings come from Miech et al's (2017) analysis of data from the US annual Monitoring the Future (MTF) study in 2014 and 2015, which involved a nationally representative sample of 16-17 year-olds. Small sub-samples were followed up one year later. The incidence of cigarette smoking in never previously smoked was over four times higher for individuals who had previously vaped (31% vs 7% for never vaped) [111]. Miech et al (2017) explained: "Desensitisation to the dangers of smoking may play a role in explaining how vaping can progress to smoking among youth who have no history of cigarette use. Youth who begin to vape primarily to experiment and because vaping tastes good (the most common reasons for vaping) may detect no immediate health consequences and conclude that the dangers of smoking are exaggerated" (p3).

This study did not collect data on the substances vaped or the motivations for cigarette smoking (Miech et al 2017).

Among sub-groups, Unger et al (2016) found that the likelihood of cigarette smoking in their 20s was three times greater for a US Hispanic sample who had vaped in their teens.

Soule et al (2016) explored the reasons for using e-cigs with online responses from over one hundred delegates at three conferences in Washington DC and Las Vegas. The online surveys were based around 125 statements which were elicited from indepth interviews with thirty e-cig users.

Eleven clusters of reasons emerged from the analysis:

- As a cessation method;
- Perceived health benefits compared to tobacco smoking;
- "Private regard" (eg: not harming others with second-hand smoke);
- Convenience;

[111] The risk of continued cigarette smoking was twice as high with e-cigarette use.

- "Conscientiousness" (eg: no longer supporting the tobacco industry);
- "Pleasurable effects";
- "Unanticipated benefits" (eg: regaining sense of taste and smell);
- "Perceived agency" (eg: wanting to try something new);
- "Therapeutic" (eg: promoting relaxation);
- "Hobby interests" (eg: mixing one's own liquid with different flavourings);
- "Networking/social impacts" (eg: not associated with stigma of tobacco smoking).

16.3.1. Health

Animal or cell studies of the toxins in e-liquid (ie: the aerosol of e-cigarettes from heating a solvent) may not be relevant to humans because of e-cigarette user characteristics, device characteristics, and the interaction between the two (Shahab et al 2017).

Studies of humans and e-cigarettes tend to short-term (eg: 2-4 weeks), and lacking in real-world controls (eg: nicotine replacement therapy; NRT) to reduce the risk of confounding variables (Shahab et al 2017).

In their study, Shahab et al (2017) attempted to rectify these problems. They studied 181 volunteers in London over a six-month period. Five groups were recruited:

i) Tobacco/combustible cigarette smokers;

ii) Former smokers with long-term use (ie: >six months) of e-cigarettes;

iii) Former smokers with long-term use of NRT;

iv) Long-term combustible and e-cigarette use;

v) Long-term combustible cigarette and NRT use.

Nicotine levels as measured in saliva and urine was similar in all five groups. This finding supported "the view that users seek a particular level of nicotine intake, regardless of the delivery system, and adjust product use accordingly" (Shahab et al 2017 p395).

Former smokers using e-cigarettes or NRT, not surprisingly, had significantly lower levels of carcinogens and toxins in their urine than the other groups. This finding suggested that "complete substitution of combustible cigarettes with e-cigarettes may reduce disease risk and support the assertion that e-cigarette use may be less harmful than smoking" (Shahab et al 2017 p397).

16.4. SMOKING AND STIGMA

The decline in tobacco smoking, particularly in the West, has meant that it is denormalised, and smokers are stigmatised, especially in the case of those individuals smoking outside public buildings (Evans and Furst 2016).

Evans and Furst (2016) explored how 156 individuals taking smoke breaks in front of Manhattan office buildings felt about the stigmatisation of smokers. Three-quarters of them admitted that they felt passersby viewed them differently to non-smokers, but over half said they did not feel stigmatised in response to a direct question about it.

Detailed analysis of the responses found three reactions to the question about stigma:

i) "Admission of a stigmatised status" - eg: "The [strangers] that don't smoke they look at you like you're disgusting. I guess they look at you like you are lower than them just because you smoke. [Strangers] look at me like I'm gross, like I'm the most disgusting human being, and they walk past me and they hold their nose and everything" (p283).

ii) "Denial of a stigmatised status" - eg: "No, [I am] absolutely not [stigmatised]. We live in the United States, people are gonna do whatever they want to do, because I believe if you pay rent there you should be able to smoke outside wherever and whenever you want to" (p285).

iii) "Justification for minimising stigmatisation" - eg: "I am a smoker. I have been addicted to cigarettes for many years. For this I am not proud. However, I am tired of being told that my second hand smoke will kill. How about the people who are on their phones while driving? I will die a lot sooner from their careless driving than any of my second hand smoke will reach anyone" (p287).

These three reactions "do not represent discrete categories; rather, they fall along a continuum from acceptance to denial of stigmatisation, with justification falling somewhere in between the two" (Evans and Furst 2016 p287).

Evans and Furst (2016) ended with a warning: "The problem with stigmatisation as a weapon of public health is that it can lead to an increase in governmental intrusion into the lives of citizens and enacted stigma can create a channel towards further social control... There are consequences to the stigmatisation of smokers. Currently, the stigmatisation of smokers is so pronounced and severe that even those with lung cancer who have

never smoked tobacco or who had quit years before they were diagnosed with lung cancer are perceived as objects of stigma and blamed for their condition" (p289).

Concentrating on the "smoking ban" in Ireland, which was introduced on the 29th March 2004 [112], Fernandez (2016) explored how policy "help produce and reproduce individuals' identification as 'responsible' and 'irresponsible' citizens" (p256). This fits with Foucault's (eg: 2000) work on "governmentality", where the State does not enforce rules as much as construct individuals to enforce the rules themselves (eg: self-surveillance rather than surveillance). "From a governmentality perspective, the rise of neo-liberal political projects are understood not as a decline of state sovereignty, but as a promotion of forms of government that foster and enforce individual responsibility and the play of market forces and entrepreneurial models in a variety of social domains" (Fernandez 2016 p258).

So, as applied to health promotion: "Every citizen must now become an active partner in seeking health, accepting their responsibility for securing their well-being. The underlying expectation is that coercion is unnecessary and that rational and responsible citizens will 'freely' govern themselves in ways consistent with expert knowledge... Furthermore, increasingly, ideal 'healthy' citizens not only take steps to protect their own health, they are also concerned about the health of others. This dimension of the obligations of the 'healthy citizen' is highly apparent in discourses about second-hand smoke" (Fernandez 2016 p258). In other words, the policing of a policy is left to individuals for themselves or among themselves.

Fernandez (2016) drew on newspaper articles and

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[112] The World Health Organisation's "Framework Convention on Tobacco Control" (FCTC), adopted in 2003, was key in international anti-smoking efforts, but Reubi and Berridge (2016) described a longer history to tobacco control. These authors distinguished three periods - (i) initial conferences of individual experts in the 1960s and 1970s with the growing public awareness of the dangers of tobacco; (ii) the consolidation of efforts and development of strategies in 1980s and 1990s; and (iii) globalisation, successful lawsuits, and the FCTC in the 21st century. "From the 1990s onwards, a growing number of public health experts began talking about ‘global health’ rather than ‘international health’ or ‘health and development’. Drawing on the then pervasive theories on globalisation, these commentators believed that the world was undergoing a process of economic, political and social integration. For them, trade liberalisation and a revolution in communication and transportation technologies were leading to ever growing flows of information, goods, capital and people across political and geographical boundaries. Inherent to these processes of globalisation, they warned, were new types of threats to human health, from the rapid propagation of infections enabled by the development of air travel to the global spread of fatty foods, alcoholic beverages and cigarettes made possible by the abolition of trade barriers. For these commentators, the existing international health architecture centred on the nation-state was not equipped to deal with these new problems" (Reubi and Berridge 2016 p468).

letters, official speeches and policies for the period January 2003 (from the announcement of the ban) to 2014 (the ten-year anniversary). Different identities were presented in the discourses, including "irresponsible smokers", "irresponsible parents", "smokers as a burden/spongers", and "responsible smokers". The latter supported the ban, unlike "smokers were seen as passively irresponsible (they should know about the damage they do to others), or indeed, as actively irresponsible and selfish (if they do realise of the damage they do and continue to do so)" (Fernandez 2016 p262).

Fernandez (2016) summed up: "A key strategy to enlist people to the rationale of the ban was to construct smoking in the presence of others as an act of irresponsibility and selfishness. This was achieved by deploying the language of risk, the use of statistics and the force of facts, and further reinforced by rhetorical devices such as the metaphor of contagion. In revealing the irresponsible smoker identity, this analysis also helps highlight how the regulation of smoking is interlinked with social and moral processes" (p270).

16.5. APPENDIX 16A - SOCIAL CONTEXT OF SMOKING

Ecological momentary assessment (EMA) involves individuals reporting their behaviour at a point when they receive a random prompt (eg: text message). It is a good method to use to understand smoking behaviour.

EMA was used in a study of Korean Americans emerging adults (KAEAs) between November 2013 and May 2014 [113]. The participants were aged 18-25 years old, and smoked at least four cigarettes per day. Seventy-eight volunteers used the EMA smartphone app for a seven-day period. Each day there were five random prompts to complete a short questionnaire, and the participants were instructed to click the "I'm about to smoke" icon on screen when relevant. The short questionnaire covered mood, cigarette craving, and social context (Huh et al 2016).

Craving was found to be associated with negative mood, and when with Korean friend(s) (Huh et al 2016). This confirmed what Huh et al (2014) had found in a previous KAEA EMA study.

Huh et al's (2016) further analysis of the EMA data found that being around Korean friends, who were likely to smoke, was associated with increased momentary craving to smoke.

Huh et al (2016) stated: "One possible mechanistic explanation for the current findings is that the specific

[113] Emerging adulthood is a key time for the development of smoking, particularly from "light", "intermittent", or "social" smokers to established smokers (Huh et al 2016).

social context of being in the presence of Korean friends may act as a particularly salient smoking cue (ie: sights, smells or environmental contexts associated with smoking that evoke learned, or conditioned, drug-seeking responses such as craving...). It is possible that throughout their smoking history, participants may have had more smoking occasions with their Korean friends compared to other non-Korean friends. Indeed, our post hoc analyses showed a greater likelihood of smoking (vs. non-smoking random prompts) in the presence of Korean friends... compared to other social contexts. Thus, the repeated pairings of smoking with their Korean friends may have created a conditioned response, such that this specific social context directly elicits craving and subsequent smoking. Of course this is speculative as we did not directly measure cue reactivity to the various social contexts" (p28).

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17. ADULT-ONSET ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (ADHD)

Two recent longitudinal studies (Cage et al 2016 and Agnew-Blais et al 2016) suggested "a paradigmatic shift" in the understanding of attention-deficit/hyperactivity disorder (ADHD) with two key findings: (i) the onset of ADHD in adulthood, and (ii) that this type of ADHD is distinct from the childhood-onset type (Faraone and Biederman 2016).

Previous studies had suggested a decline in ADHD symptoms with age. For example, Moffitt et al (2015) found that only 5% of childhood-diagnosed ADHD sufferers were classed as still having the full diagnosis at 38 years old.

1. Cage et al (2016)

This study used data from the 1993 Pelotas Birth Cohort Study of 5249 individuals born in Pelotas, Brazil, in 1993, who were followed up at age 18-19 years old.

At 11 years old, 9% of children received a diagnosis of ADHD, and 12% at follow-up. The group diagnosed at 11 years old contained 393 children, of which 12% were lost to follow-up at 18-19 years old, 73% had no symptoms then, and 15% were still diagnosed with ADHD.

There were 492 individuals diagnosed with ADHD at 18-19 years old, 12% had had ADHD diagnosed previously, but the remainder (except for 3% not assessed at 11 years old) had not. Thus, "the existence of two syndromes that have distinct developmental trajectories, with a late-onset far more prevalent among adults than a childhood onset" (Cage et al 2016 p711).

Key methodological issues:

i) Trained interviewers used at 11 and 18-19 years old, but different screening instruments used for diagnosis at each age. Also no formal diagnosis of ADHD by psychiatrists at either age.

ii) Self-reports of current behaviour/problems used to avoid recall bias, but parents' reports used for childhood (when required). Studies often face recall bias. For example, an adult with ADHD is asked if they had the condition as a child (Faraone and Biederman 2016).

iii) Community sample for the longitudinal study with a retention rate of 81% by 18-19 years old.

2. Agnew-Blais et al (2016)

This study used data from the Environmental Risk (E-Risk) Longitudinal Twin Study of 2332 twins born in England and Wales in 1994-5 [114], with the latest follow-up at 18 years old.

Assessments of ADHD were made at 5, 7, 10 and 12 years old, and 247 participants were diagnosed at least at one point (12% of sample). Fifty-four of them were diagnosed with ADHD at 18 years old (persistent group), and the remainder had remitted (no diagnosis group). One hundred and twelve individuals were diagnosed at 18 years old for the first time (late-onset group) (5.5% of sample).

The authors concluded: "We identified heterogeneity in the DSM-5 young adult ADHD population such that this group consisted of a large, late-onset ADHD group with no childhood diagnosis, and a smaller group with persistent ADHD. The extent to which childhood-onset and late-onset adult ADHD may reflect different causes has implications for genetic studies and treatment of ADHD" (pp713).

Key methodological issues:

i) Information for diagnosis at 18 years old was based on self-reports, but co-informants (eg: parents) were asked to confirm details. Faraone and Biederman (2016) pointed out that "self-reports of ADHD in adults are less reliable than informants reports" (pE1), and they warned: "Be cautious about self-reports of adult-onset ADHD unless convinced that the patients can introspect and have insight into the nature of their problems" (p656).

ii) No formal diagnosis of psychiatric disorders.

iii) Twin study.

General issues - Faraone and Biederman's (2016) challenges:

a) Sibley et al (2012) found that "current symptoms of ADHD were under-reported by adults who had had ADHD in childhood and over-reported by adults who did not have ADHD in childhood" and so studies "may have under-

[114] There are a number of long-running general longitudinal studies running in the UK, including the National Study of Health and Development (NSHD) (5362 individuals born in England, Scotland and Wales in 1946), National Child Development Study (NCDS) (17 000 individuals born in 1958), British Cohort Study (BCS 70) (17 000 individuals born in 1970), Millennium Cohort Study (MCS) (19 000 individuals born in 2000-2), and Avon Longitudinal Study of Parents and Children (ALSPAC) (14 000 pregnant women in 1991-2 and their children in south-west England) (Steptoe 2016).

estimated the persistence of ADHD and over-estimated the prevalence of adult-onset ADHD" (Faraone and Biederman 2016 p655).

b) Faraone and Biederman (2016) were confident that the adult-onset ADHD found in the two studies was not a misdiagnosis of another disorder because other studies have found support for the diagnostic category.

c) Faraone and Biederman (2016) felt that the claims of the two studies as "a paradigmatic shift" "seem premature". The adult-onset cases did not have a prior diagnosis of ADHD, but the individuals had childhood problems (eg: conduct disorders in both studies).

d) Faraone and Biederman (2016) noted the existence of a sub-threshold category of adulthood ADHD from the data of the studies which the authors themselves did not discuss. "In sub-threshold cases, the onset of symptoms and impairment could be separated by many years, particularly among individuals with strong intellectual abilities and those living in supportive, well-structured childhood environments. Such intellectual and social scaffolding would help youth with ADHD to compensate in early life, only to decompensate into a full ADHD syndrome when the scaffolding is removed" (Faraone and Biederman 2016 p656).

Faraone and Biederman (2016) concluded that "these new data are a 'call to arms' to study adult-onset ADHD, determine whether and how to incorporate age at onset into future diagnostic criteria, and clarify how it emerges from sub-threshold ADHD and other neurodevelopmental anomalies in childhood" (p656).

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18. ILLICIT DRUGS AS TREATMENT FOR MENTAL DISORDERS

18.1. Introduction
18.2. Psilocybin
18.3. LSD
18.4. Ecstasy/MDMA
18.5. References

18.1. INTRODUCTION

Nosengo (2016) noted that "taking drugs that have been developed for one disorder and 'repositioning' them to tackle another is an increasingly important strategy for researchers in industry and academia alike" (p314). The best known example is sildenafil, developed for angina, which became marketed as "Viagra", or more recently, ebselen, developed for stroke patients, being used with bipolar disorder (Nosengo 2016).

Drugs that have been approved for one condition can skip Phase I safety trials for the second condition, and that reduces the cost to the pharmaceutical companies. It is reported that it takes up to fifteen years from drug discovery to sales to the "consumer", and $2-3 billion on average [115]. "Repositioned" drugs may only cost $300 million, and take 6-7 years to come to market (Nosengo 2016).

Another approach is to "reposition" illicit or recreational drugs to help with mental disorders.

18.2. PSILOCYBIN

The challenge of treat-resistant depression has encouraged the search for new medications, or substances not usually thought of as treatments, like psilocybin. This substance from certain types of mushrooms has been known as "magic mushrooms" among users wanting a hallucinogenic experience. The underlying chemical is psilocin, which interacts with serotonin (Carhart-Harris et al 2016b).

It has been observed that lifetime users of psychedelic drugs have less psychological distress and suicidality than users of other recreational/illicit substances (Hendricks et al 2015).

In controlled studies, two doses of psilocybin have been linked to abstinence by long-term heavy tobacco

[115] The expense of new drug development is heightened because Phase II trials eliminate 68% of compounds, and Phase III trials 40% (Nosengo 2016).

smokers at six months, reduced drinking at eight months by alcohol-dependent individuals, and decreased anxiety and depression among dying cancer patients six months after doses (Carhart-Harris et al 2016b).

But there are few controlled studies of psilocybin and depression. Carhart-Harris et al (2016b) performed an open-label feasibility trial with twelve sufferers of moderate-to-severe, unipolar, treatment-resistant major depression. Open-label means that participants and researchers knew the drug that was being taken (ie: no blinding and no control group). As a feasibility study, it was small-scale and less methodologically rigorous than a randomised controlled trial. The participants were recruited in north-west London, and they received two doses of psilocybin one week apart. As the drug is illegal in the UK, special permission was gained from the Home Office, and the participants were observed in hospital for six hours after dosing. Follow-up measures of depression were taken up to three months after.

Relative to baseline scores, depression was significantly reduced at one week and three months after. The authors concluded: "This study provides preliminary support for the safety and efficacy of psilocybin for treatment-resistant depression and motivates further trials, with more rigorous designs, to better examine the therapeutic potential of this approach" (Carhart-Harris et al 2016b p619).

18.3. LSD

Carhart-Harris et al (2016a) reported the study of lysergic acid diethylamide (LSD) using three neuroimaging techniques - arterial spin labelling (ASL) [116], blood oxygen level-dependent (BOLD) measures, and magnetoencephalography (MEG) [117]. There was increased blood flow to the visual cortex after taking LSD along with a decrease in alpha waves (type of electrical activity), and change in the connectivity of neurons in that area, all related to the visual hallucinations. Other changes in the brain were linked to other effects of the drug (eg: feeling of "altered meaning" and the "decoupling" of connections between the parahippocampus and part of the cortex).

Carhart-Harris et al (2016a) summed up: "It seems increasingly evident that psychedelics reduce the stability and integrity of well-established brain

[116] A "magnetic resonance imaging technique for measuring tissue perfusion using a freely diffusible intrinsic tracer" (Petcharunpaisan et al 2010).

[117] The study used twenty healthy volunteers who were scanned at two different times after a placebo or LSD.

networks... and simultaneously reduce the degree of separateness or segregation between them... that is, they induce network disintegration and desegregation. Importantly, these effects are consistent with the more general principle that cortical brain activity becomes more 'entropic' under psychedelics" (p4857). This "entropic" effect, argued the authors, could mean that LSD has therapeutic potential with mental disorders (ie: to breakdown the automatic and rigid behaviours in some psychiatric disorders).

18.4. ECSTASY/MDMA

Attempts to study the neurotoxic effects of MDMA/"Ecstasy" in humans faces a number of challenges. For observational studies, users are asked retrospectively about their use and behaviour, for example, but "retrospective memory loss is a well-documented occurrence in ecstasy users, potentially impairing their ability to recall how many times they have consumed ecstasy and thereby influencing the results of the study" (Amoroso 2016 p1101). Also such studies tend not to have baseline measures of cognitive ability for users. Furthermore, there is little way of knowing the strength/dose of the drug that was purchased illicitly. "Ecstasy" bought "on the street" does not always contain MDMA (Amoroso 2016).

Regular users of the drug may have impaired cognitive functioning from a lifestyle that disrupts circadian rhythms (eg: late-night parties), or from the use of other recreational drugs. So recruiting such individuals for clinical (ie: laboratory-based and controlled) studies may be problematic (Amoroso 2016).

Despite these methodological issues, there have been many studies of the effects of "Ecstasy". For example, Rogers et al's (2009) review of observational studies found over 4000 articles, of which 422 studies were deemed relevant. Most of these studies found small, and not significant, differences in cognitive functioning between "Ecstasy" users and controls. Three other meta-analyses have subsequently found the same size of difference for short-term and working memory, visuo-spatial memory, and executive functioning (Amoroso 2016).

Amoroso (2016) pointed out that the "literature becomes less convincing when the inconsistencies across studies are considered". For example, smaller differences between users and non-users have been reported over time, and larger cognitive impairments for users in US than European studies (Taylor et al 2011), as well as evidence of publication bias (ie: non-publication of studies finding no difference) (Amoroso 2016).

Amoroso (2016) concluded that "observational

research on ecstasy users has reached a point of diminishing returns. Unfortunately, although millions of dollars have been spent on observational studies, far less has been spent on the 25 completed clinical studies... that use rigorous methodology and actual MDMA. Research is showing that MDMA might be an effective treatment for PTSD, a finding that could certainly have great value to public health. To use funding most efficiently, money should be diverted away from poorly controlled observational research and towards clinical research, including but not limited to MDMA-assisted psychotherapy, which would have the biggest impact on improving public health" (p1102).

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19. TWO DIFFERENT STUDIES ON INTENSIVE CARE UNITS (ICUs)

19.1. ICU psychosis
19.2. Inter-professional working
19.3. References

19.1. ICU PSYCHOSIS

Patients in the Intensive Care Unit (ICU) of a hospital can experience delirium, in the form of increased agitation, paranoid thoughts, hallucinations, or becoming withdrawn. Estimates vary between 30-75% of patients experiencing at least one episode (Darbyshire et al 2016).

Darbyshire et al (2016) analysed qualitative data on individuals' experiences of ICU collected between 1994 and 2005 in the Healthtalk project. This database covered forty patients and 37 relatives. Four themes were drawn out on the patients' sense-making of the experiences of ICU.

1. Making sense of the environment - The ICU environment with machines, lights, noises, and busyness could trigger confusion. "Many patients were unable to recognise contemporaneously that they were ill, or in hospital, which is consistent with difficulties in interpreting the (often unpleasant) treatments that patients receive whilst on the ICU. Many patients describe feelings of bewilderment and abandonment. This often manifests in the meaning they attribute to their time on the ICU. Some patients describe going through a process of 'trying to piece together what was happening' [Patient 06] by attempting to make sense of their unfamiliar surroundings" (Darbyshire et al 2016 p6). Johansson et al (2012) described the ICU as a "brutal and ruthless uncontrollable barrage".

One patient described their feelings as restraint and imprisonment - "I couldn't move, couldn't move at all, I felt my throat, and I knew that I had a pipe into my throat, a thick pipe. I could feel the wires, I could see all the wires in my arms and my legs, I just didn't know what had happened, I was just, I just didn't know. I just didn't have a clue. And I thought, I thought aright I've been kidnapped, and I'm in a clinic, and I'm somewhere like Dubai or somewhere like that, but I know my family will be looking for me" (Patient 05) (p6).

Another patient went further in their "vivid dreams" - "Part of the nightmares that I'd had... was that I had been kidnapped by triads, don't ask me where they came

from. I dreamt that they cut off my little finger, when I woke up no matter how many times I counted them there was only four... so I was convinced that had truly happened" (Patient 05) (pp6-7).

2. Isolation - Problems communicating made the patients feel isolated and vulnerable. This is seen in the vivid imagery of two patients - "I felt like a lump of meat on a butcher's table with the real me inside but not able to get out -... I was part of this and yet I wasn't part of it" (Patient 27). "I was out, as this fish, in a boat, a glass-bottomed boat. But I was in the boat and people were looking through the glass bottom at me, as opposed to the other way round" (Patient 26) (p8).

3. Paranoia - For example, one patient reported, what would be called "persecutory delusions" and "delusions of reference", in relation to the ICU staff - "they were looking at something in the magazine together and they were laughing, and I thought they were laughing, that I was in the magazine and they were laughing at me. And I thought that I had a cat's nose painted on and whiskers and that I was in the magazine like that that and they were laughing at me... I imagined that they were talking about me all the time, saying that I was a drug addict and I shouldn't even be in there" (Patient 05) (p8) [118].

4. Blurred reality - Difficulties distinguishing fact and fiction at the time - "kind of like being in a Twilight Zone it's, 'Have I dreamt that or did it happen? Or is this real? Or have I imagined it?' So you need telling not once but several times" (Patient 01) (p9).

Another patient described it thus: "I can remember sort of vivid people... but to me they were plasticine. They weren't real. But obviously they were real because they were obviously talking to me. So the words registered but the mind didn't take in that they were actually real people. They were like Wallace and Gromit type characters" (Patient 23) (p9).

Darbyshire et al (2016) summed up the experiences of the individuals: "Even when patients recognised they were seriously ill, they did not necessarily associate this with being in hospital. The general public is unlikely to have a great deal of exposure to a real ICU environment. Media portrayals seldom closely depict the reality of day-to-day clinical practice. For many patients, their

[118] "ICU psychosis" (Page and Ely 2015).

admission to ICU is often unexpected and far removed from even a routine hospital admission, where patients tend to be fully aware of their circumstances. Participants therefore sought alternative explanations which, when fused with the dreamlike, part-sedated state, became very powerful" (p10).

Lack of control was disturbing to many patients: ie: "their restriction of movement and inability to perform basic activities that are taken for granted as a healthy functioning adult shocking and intolerable. Unable to sit up, eat and drink unaided, or move about at will, they describe an unsettling window to the edges of life. The indignities and shock that they experience seem to trigger a sense that they are somehow no longer civilised beings" (Darbyshire et al 2016 p11). This produced a consequent dissociation. "Patients are therefore making sense of their extraordinary circumstances by creating personal explanations that may seem irrational to others" (Darbyshire et al 2016 p11).

19.2. INTER-PROFESSIONAL WORKING

Xyrichis et al (2017) undertook an ethnographic study of three ICUs in two hospitals in England between 2008 and 2009. In total, there were 240 hours of non-participant observation, and interviews with twenty-seven health professionals. The focus was upon the "boundaries" between different types of health professionals working in the ICUs.

Concentrating on doctor-nurse boundaries, the researchers distinguished three thematic headings:

i) "Boundaries reproduced" - the "expected" professional boundaries and hierarchy between doctors and nurses;

ii) "Boundaries obscured" - eg: consultants drawing on the knowledge of patients of experienced ICU nurses;

iii) "Boundaries suspended" - in urgent situations the focus was upon what "needs doing" and roles were allocated on this basis.

Xyrichis et al (2017) summed up: "While previous research [119] suggested that ICU doctors tended to exclude nurses from clinical decision-making... our data include instances of doctors both including and excluding nurses from the decision-making process. They included nurses by inviting them to comment on their patients' progress,

[119] For example, a literature review of twenty-three ethnographic studies in ICUs found little evidence of collaborative working between doctors and nurses (Paradis et al 2014).

responses to treatment and readiness to be extubated; and they excluded nurses by rejecting their concerns over patients' medication regimes. Doctors solicited nurses' views on matters they perceived to be within nursing jurisdiction and expertise, but excluded them on matters they believed to be outside of nurses' legitimate claim. Therefore, contrary to previous assumptions, exclusion and inclusion of nurses in ICU decision-making was not a de facto position but related to perceived areas of professional jurisdiction" (p110).

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20. EATING DISORDERS IN MIDDLE AGE

Studies vary in their estimates of lifetime prevalence of eating disorders because of differences in sample used and its size, diagnostic criteria used (eg: DSM-IV and DSM-5), and study design (eg: self-reported questionnaire or clinician-diagnosed measure). In terms of the sample age group, almost all studies concentrate on adolescents and young adults, which is the peak age of onset of anorexia and bulimia. Micali et al (2017) were interested in women in their 40s and 50s with such conditions.

Data from the Avon Longitudinal Study of Parents and Children (ALSPAC) were used. This study covers 14 500 pregnant women in Avon (south-west England) who gave birth in 1991-2. By 2009 9233 women were still in the study, and they were sent a questionnaire about eating disorders (of which 5655 completed) [120]. Of these women, 826 were categorised as suffering from an eating disorder, and invited to a interview (and 524 attended) [121]. A control sample of 698 women were invited for interview, and 518 attended [122].

Lifetime prevalence for any eating disorder was 15%, and 3.6% for current (ie: last year) prevalence (figure 20.1). The most common disorders for these mid-life women was other specified feeding and eating disorder (OSFED), which covers purging, and sub-threshold anorexia or bulimia, followed by binge eating disorder. Only around one-quarter of women had sought treatment for an eating disorder at any time in their life.

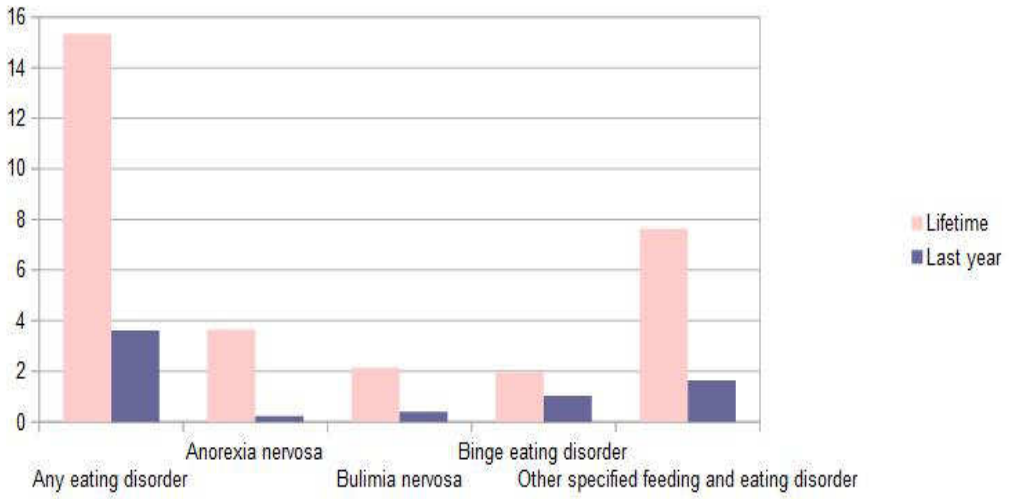
Negative experiences in childhood were found to be risk factors for eating disorders, including death of a carer, parental separation/divorce, childhood sexual abuse, and childhood unhappiness. Here are some examples of significant odds ratios, where one is not suffering from an eating disorder:

- Death of carer in childhood - seven times more likely to report purging disorder;
- Parental separation/divorce - over twice more likely to report anorexia or bulimia;
- Childhood sexual abuse - bulimia nearly five times more likely;

[120] Eating Disorders Diagnostic Schedule (EDDS) (Stice et al 2000). It has a sensitivity of 98% (ie: distinguishing cases from non-cases) and specificity (ie: non-cases) of 75% (ie: false positives more common than false negatives) (Micali et al 2017).

[121] Structured Clinical Interview for DSM-IV-TR disorders (SCID-I) (First et al 2002). Three trained interviewers used, and a selection of interviews were recorded for inter-rater reliability.

[122] The average age of all the women involved was 48 years old.



(Data from Micali et al 2017 table 1)

Figure 20.1 - Percentage of respondents with selected eating disorders.

- Childhood happiness - bulimia nearly five times more likely.

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21. BIOLOGICAL AGEING AND HEALTH

21.1. Extended lifespan
21.2. Biological age
21.3. Centenarians
21.4. References

21.1. EXTENDED LIFESPAN

Partridge (2010) summed up the situation today: "For a given age, health now is better than it was 150 years ago, but this welcome change is also producing great challenges. Many of these are socio-economic, concerning issues such as work force participation and affordability of pension schemes. Paradoxically, there is also a major medical problem. The improvement in individual health means that larger numbers of individuals reach older ages, and hence live long enough to suffer from ageing-related disease and loss of function" (p147) [123] [124] [125].

Key developments that have occurred in the understanding of the biology of ageing include the discovery of single-gene mutations in nematode worms that doubled their lifespan (eg: Kenyon et al 1993), and the use of dietary restriction (DR) to increase lifespan in laboratory rats and mice (eg: McCay et al 1935). These are examples of slowing down ageing [126] [127].

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[123] Dong et al (2016) analysed data for the UK, USA, France and Japan on the average lifespan and the number of people living to 110 years old and beyond. Through the average lifespan has increased over the 20th century, which was initially down to fewer child deaths, but then mostly due to people dying later, the "maximum lifespan" (ie: oldest individuals) has not been rising in step. It is possible that "115 is like a borderline - you can't cross that unless you're an exceptional individual" (Jan Vijg in Wilson 2016). The idea of a "maximum lifespan" is disputed by other researchers (Wilson 2016).

[124] Talking about living for much longer (ie: thousands of years), bioethicist James Hughes stated: "A big problem... is you live long enough and you'll go through so many changes that there's no longer any meaning to you having lived longer" (quoted in Rosner 2016).

[125] If treatments that prolong life become available, because of their high cost, Monbiot (2014) imagined an increase in inequality between "the treated" (living longer) and "the untreated" (dying younger as society is more unequal).

[126] The search for ageing mechanisms and means of controlling it include the enzyme mTOR and the drug rapamycin which blocks it (Gifford 2016).

A recent "potential life-prolonger" is metformin (prescribed for type 2 diabetes), which increases cells' sensitivity to insulin (Gifford 2016). Bannister et al (2014) reported that older British diabetics talking this drug were living 18% longer than non-diabetics.

[127] DNA damage in cells is common, and if this cannot be repaired by the body, cells are killed (apoptosis), except for those that remain (senescent cells). These cells are not "working" fully, and can "promote disease development and accelerate ageing", while "genetic clearance of senescent cells can delay features of ageing" (Baar et al 2017). Baar et al (2017) investigated how damaged cells avoid apoptosis and become senescent cells, finding a certain cell penetrating peptide (FOX04-DRI) that is key. The researchers were able to reverse the senescent cells in mice, and counteract physical ageing changes (eg: hair loss). Not surprisingly, this research gained a lot of media interest with the possibility of reversing ageing. But this research was only with mice (of a particular genetic make-up - ie: fast-ageing) and short-term.

But humans want more than an extended lifespan, rather a healthy extended lifespan. In other words, slowing down the rate of ageing and decline in physical functions. For example, fruit flies kept at lowered temperatures have a slowing in the rate of ageing (eg: Mair et al 2003). DR reduces the impact of ageing-related diseases (Partridge 2010) [128].

But, ultimately, how applicable are the findings with laboratory animals to humans? Furthermore, "Translating these discoveries into medical treatments poses new challenges, including changing clinical thinking towards broad-spectrum, preventative medicine and finding novel routes to drug development" (Partridge 2010 p147).

21.2. BIOLOGICAL AGE

"From the fifth decade of life, advancing age is associated with an exponential increase in burden in many different chronic conditions" (Belsky et al 2015 pE4104) [129]. But the "pace of ageing" (PoA) means that the individual experience will vary here.

Belsky et al (2015) found that before midlife, "individuals who were ageing more rapidly were less physically able, showed cognitive decline and brain aging, self-reported worse health, and looked older" (pE4104). This was based on data from the Dunedin Study birth cohort of 1972-73 in New Zealand (ie: when 1073 individuals were 38 years old).

"Physiological age" or "biological age" (BA) and PoA involved eighteen biomarkers including measures of the integrity of cardiovascular, metabolic and immune systems [130].

The BA of the participants ranged from 28 to 61 years [131]. PoA was calculated with data from the cohort at 26 and 32 years old as well, and varied from 0 years of physiological change per chronological year to 3 years per chronological year.

Individuals with an advanced BA (ie: BA older than chronological age) had experienced more rapid PoA in the past twelve years. "Thus, a 38 year-old with a Biological Age of 40 years was estimated to have aged 1.2 years faster over the course of the 12-year follow-up period

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[128] Work by Sakura Minawi involved injecting blood plasma from young mice into older ones, who were rejuvenated (eg: improving memory) (Hamzelou 2016).

[129] This is the distinction between lifespan and "health span" (ie: the length of healthy life) (Gifford 2016).

[130] In the US National Health and Nutrition Survey (NHANES), BA was a better predictor of death than chronological age.

[131] The BA was calculated by the Klemera-Doubal equation (Klemera and Doubal 2006). Simply, for each physiological measure, the individual's score is compared to norm data for different ages.

compared with a peer whose chronological age and Biological Age were 38. This estimate suggests that a substantial component of individual differences in Biological Age at midlife emerges during adulthood" (Belsky et al 2015 pE4106).

The biologically older individuals were found (compared to individuals BA equals chronological age) to:

- Perform worse on tests of balance and motor skills [132].
- Have more self-rated physical limitations.
- Have poorer cognitive functioning.
- Have poorer self-rated health
- Look older from photographs judged by independent observers.

The researchers concluded: "Early identification of accelerated ageing before chronic disease becomes established may offer opportunities for prevention" (Belsky et al 2015 pE4109).

This study has the following limitations:

i) The measurement of BA was "a biomarker scoring algorithm previously calibrated on a large, mixed-age sample", but it "remains controversial" (Belsky et al 2015).

ii) The Dunedin Study cohort was predominantly White (93% self-rated). The "weathering hypothesis" (eg: Levine and Crimmins 2014) argued that "the stresses of ethnic minority status accelerate ageing" (Belsky et al 2015).

iii) The follow-up was at 38 years old (rather than older) ("right-censored" data), and physiological measures were taken first at 26 years old (rather than younger) ("left-censored" data) (Belsky et al 2015).

iv) Measurements were taken every six years, which may have missed some changes.

v) An overall PoA score was calculated, whereas "ageing is likely to affect different bodily systems to different degrees at different points in the lifespan" (Belsky et al 2015 pE4109).

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[132] Eg: Unipedel Stance Test - maximum time to maintain balance standing on one leg with eyes closed.

vi) The independent judges of appearance were undergraduate students.

Newman (2015) argued that the data used for PoA was "fundamentally flawed". She said: "Looking at the changes over time in the individual measures, it is quite clear that the cohort was gaining weight between ages 26 and 38 y. Many of the measures used, such as waist-to-hip ratio, blood pressure, cholesterol, triglycerides, and HgbA1C, are markers of declining physical activity and obesity. Weight gain would explain the increases in cardiovascular risk that are occurring at the same time" (pE7163). In other words, decline in physical functioning could be the product of weight gain as much as ageing.

Belsky (2015) countered that "individual differences in ageing are already established years before age-related disease onset" (pE7164). The weight gain only accounted for a small change in the other biomarkers of ageing. Belsky (2015) reported reanalysing the data, while statistically controlling for weight gain, and the original findings did not change. Therefore the study was "not 'fundamentally flawed'", he argued.

21.3. CENTENARIANS

The "old-old" are those individuals above 80 years old, but this category fails to distinguish those aged 100 years and above as "a separate cohort even though their longevity is remarkable" (Evans et al 20014) [133].

This is particularly important, Evans et al (2014) argued, in relation to end of life care (EoLC) and death. These researchers analysed the official statistics for England for 2001 to 2010 for details of death.

Over 35 000 centenarians were found for the study period (ranging from 100 to 115 years at death), with 88% being female. Most died in hospital or in residential care or nursing home.

The main cause of death on the death certificate was "old age", followed by pneumonia. "Centenarians' dying forms a picture of frailty exacerbated by the presence of a common stressor amongst older people of acute lung infection" (Evans et al 2014). Around 5% of 70-84 year-olds had pneumonia as the cause of death (versus 18% of centenarians), for example. On the positive side, centenarians have outlined the common causes of death of younger elderly (eg: heart disease) (figure 21.1).

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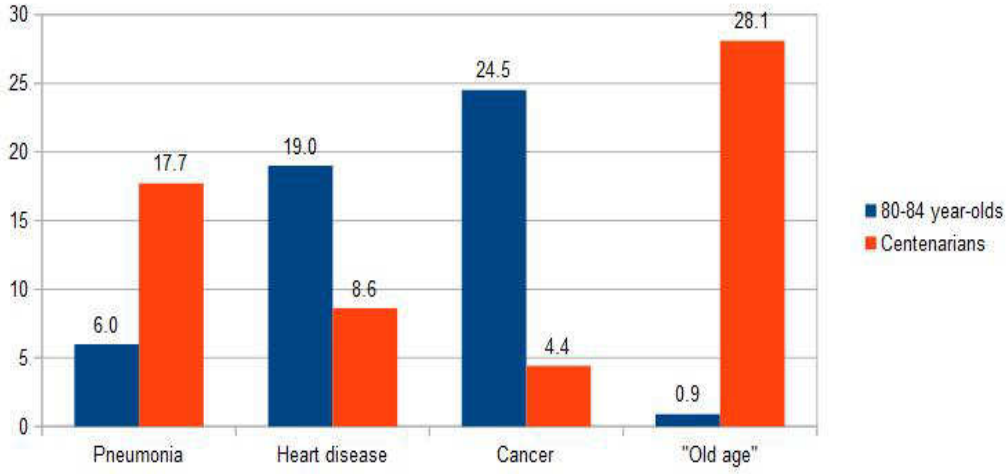
[133] In the study of centenarians, the adage "the older you get, the healthier you have been" is used (eg: such individuals have fewer genes linked to major diseases) (Marsa 2016).

Research by Horvath et al (2015) found the cerebellum of a 112 year-old woman had aged slower than the rest of the body (Masra 2016).



(Data from Evans et al 2014 table 3)

Figure 21.1 - Main causes of death (%) among 80-80 year-olds and centenarians.

Evans et al (2014) concluded that "dying in hospital from an 'acute' cause or stressor event is common for centenarians in England. A policy imperative is the recognition of centenarians' seemingly 'hidden needs' of increased likelihood of 'acute' decline and wider provision of anticipatory care to enable people to remain in their usual residence and reduce reliance on hospital care at the EoL".

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22. MASS AND SOCIAL MEDIA AND ALCOHOL USE

22.1. Mass media advertisements
22.2. Social media
22.2.1. Smartphone apps
22.3. References

22.1. MASS MEDIA ADVERTISEMENTS

Mass and social media influence alcohol consumption, particularly among adolescents and young adults.

Mass media alcohol harm reduction advertising is one way to try and reduce alcohol consumption. But should the advertisements target high-risk individuals and groups, or the population as a whole? "While targeting campaigns to sub-groups holds logical appeal, others have noted that this approach also carries risks. A focus on particular high-risk population sub-groups (such as young adults) can exempt people outside those groups (such as older adults) from heeding the message even though they may also be at risk, promoting a culture in which 'our' drinking is acceptable and 'their' drinking is problematic" (Wakefield et al 2017 p2). A "common denominator" approach (Hornik and Ramirez 2006) uses a single campaign to address commonly shared beliefs of many sub-groups.

Any health campaign needs to promote behaviour change to succeed, and this is related to the perceived effectiveness of the message. This is "the extent to which a message recipient believes that a health message will affect him or her personally in terms of the particular message objectives" (Yzer et al 2015 quoted in Wakefield et al 2017).

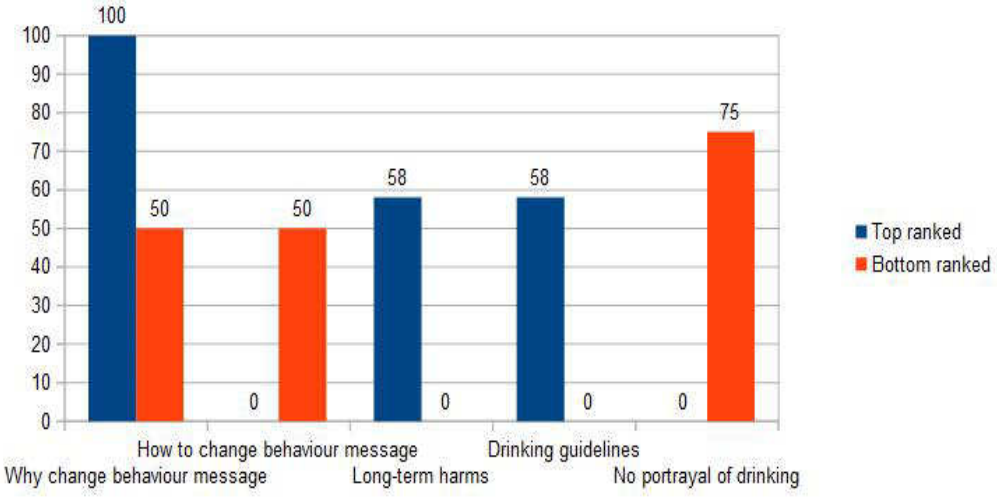
Wakefield et al (2017) investigated the perceptions of 83 alcohol harm reduction television advertisements with 2174 adult drinkers in Australia. In an online study, each participant viewed three advertisements, and then completed a questionnaire about cognitive and emotional responses (eg: "felt motivated to reduce the amount of alcohol I drink"). The participants were divided into high or low risk of alcohol-related harm in the short- and long-term based on their responses to questions about the amount of alcohol consumed - ie: four groups:

- Low risk of harm - neither of below (51% of sample);
- High risk of short-term harm - >4 drinks on any occasion at least once a month (18%);
- High risk of long-term harm - >2 drinks per day on average (3%);
- High risk of harm - both of above (28%).

Overall, the top ranked advertisements, in terms of motivation to change behaviour, were related to alcohol and cancer/"what you can't see" from Australia, New Zealand, and the UK. These advertisements were also top ranked by various sub-groups (eg: younger drinkers; high risk of harm). This fits with the "common denominator" approach.

The key characteristic of the top ranked advertisements compared to the bottom ranked was a "why change behaviour" message - ie: a reason was given to change behaviour (figure 22.1).

This study only measured self-reported motivation to change, not actual reduction in drinking.



(Data from Wakefield et al 2017 table 4)

Figure 22.1 - Selected significant differences between top 15 and bottom 15 ranked advertisements (%).

22.2. SOCIAL MEDIA

Alcohol-related content is common on social media (eg: postings about wild parties), and Facebook pictures and messages convey positive attitudes towards alcohol (Westgate and Holliday 2016). Specifically, Egan and Moreno (2011) found that 85% of male undergraduates in their sample displayed alcohol in their profiles.

Westgate and Holliday (2016) asked the following key questions:

a) Does social media use generally correlate with alcohol consumption?

There is mixed evidence here. For example, a longitudinal study of 1563 adolescents (Huang et al

2014a) found no association, while in another study, having more Facebook "friends" was found to correlate with more hazardous drinking (Westgate et al 2014).

b) Does alcohol-related content on social media reflect offline behaviour?

The answer here is yes. Individuals who post more alcohol-related content on Facebook consume more alcohol (eg: female students; Miller et al 2014). While a longitudinal study (Pumper and Moreno 2013) found that undergraduates who met the criteria for dependent alcohol use on arriving at university posted more content featuring intoxication in their first year than undergraduates not showing dependent alcohol use.

It seems that online identities reflect actual behaviour and identity. For example, Back et al (2010) asked strangers to rate the personalities presented in Facebook profiles, and these correlated with actual personality ratings by real-life friends and by the profile owners themselves. "By contrast, impression management, or trying to 'appear cool' by posting alcohol-related content that does not reflect one's actual behaviour, appears to play a relatively minor role in social media. Indeed, in focus groups, adolescents reported that they typically interpreted alcohol-related content displays as reflecting actual use rather than mere posturing" (Westgate and Holliday 2016 p28).

c) Does alcohol-related content on social media influence alcohol consumption?

This could be the case. For example, exposure to drinking on Facebook significantly predicted later increased drinking in Huang et al's (2014a) longitudinal study.

Litt and Stock (2011) found that adolescents presented with fake Facebook profiles with references to alcohol were more willing to try alcohol than after fake profiles without references to alcohol.

One mechanism of influence could be "drinking norms", "or how much people believe that similar others are drinking, powerfully influence actual drinking behaviour. Perceptions of drinking norms are often inflated: people generally overestimate how much members of their group are actually drinking. Social media may contribute to this effect by making alcohol-related content particularly prominent, frequent, and personally salient" (Westgate and Holliday 2016 p29).

Add to this advertising and marketing of alcohol brands on social media (Westgate and Holliday 2016).

On the other hand, there is the "selection effect", where individuals seek out like-minded people. For example, heavy drinking adolescents sought out "friends" on Facebook who were similar (Huang et al 2014b).

Social media's influence may be via (Moreno and Whitehill 2016):

a) Observational/social learning and imitation;

b) Individuals explore content about experiences and behaviours they are considering doing, and see these reinforced with "likes", say, and so are motivated to do the behaviour (Media Practice Model; Brown 2000);

c) The Facebook Information Model (Lee et al 2006) describes the influence of social media around thirteen clusters (eg: influence on identity; social norms).

22.2.1. Smartphone Apps

In a survey of smartphone apps in the "iTunes" and the "Google Play" stores, using the search terms "alcohol" and "drink", Crane et al (2015) found that over half of 662 apps encouraged drinking (eg: drinking games; bar finders), one-fifth related to blood alcohol measurement, and half of the remainder (14% of total) to reducing alcohol.

Moreno and Whitehall (2016) considered apps related to substance use generally along two dimensions - risk-promoting/risk-protective and high/low connectedness - producing four quadrants:

- Risk-promoting/high connectedness - eg: "Let's get WASTED! Drinking Game", which keeps score of number of drinks consumed by multiple players with the aim of intoxication;

- Risk-protective/high connectedness - eg: "A-CHESS" (Alcohol-Comprehensive Health Enhancement Support System), which was developed to help individuals recovering from alcohol dependence. Two individuals are nominated to be contacted if an individual is in a risky situation;

- Risk-promoting/low connectedness - eg: "Marijuana Recipes and Cooking" (edible marijuana recipes);

- Risk-protective/low connectedness - eg: "D-ARIANNA" (Digital-Alcohol Risk Alertness Notifying Network for Adolescents and young Adults) (an app-based

questionnaire about binge drinking risks).

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23. ACADEMIC ABILITY AND SUBSTANCE USE

Regular surveys of adolescents in England by the Health and Social Care Information Centre have found that smoking, drinking, and cannabis use among fourteen year-olds, for example, has declined in the 21st century. In 2004, 12% were smoking cigarettes regularly compared to 4% in 2014, 23% were drinking alcohol at least weekly down to 6%, and 17% and 9% respectively had tried cannabis (Williams and Hagger-Johnson 2017). "Despite the downward trend in use over the last decade, these risky health behaviours present a large problem in terms of public health as substance use is a risk factor for immediate and long-term health problems, as well as negative non-health outcomes such as poor educational and employment outcomes" (Williams and Hagger-Johnson 2017 p1).

One interesting variable here is academic ability (which is a proxy for intelligence). Higher academic ability is associated with more likely not to smoke, or if started smoking, greater cessation (Williams and Hagger-Johnson 2017). The studies are clear here, but less in agreement for alcohol and cannabis use. All three possible relationships have been found - eg: higher ability and less drinking, more drinking, or no link (Williams and Hagger-Johnson 2017).

In terms of longitudinal studies, for example, Batty et al (2008) found that higher academic ability at age eleven was associated with higher alcohol consumption as an adult in the "1970 British cohort".

Williams and Hagger-Johnson (2017) also used academic ability at age 11 in another British cohort study. They used data from the Longitudinal Study of Young People in England (LYSPE), which began in 2004 with 15 770 English 13-14 year-olds. Annual follow-ups were made until 2010, when the participants were 19-20 years old (n = 6059). Academic ability at age 11 was categorised into three groups (low, medium, and high) based on standard school examinations in English, Mathematics and Science (Key Stage 2 of the National Curriculum Test).

Smoking, alcohol and cannabis use were self-reported as ever tried at 13-14 years old, and subsequently the quantities involved (eg: six cigarettes a week; alcohol on most days). No data were collected on regularity of cannabis use nor the amount of alcohol consumed. Analysis was made for 13-17 years and 18-20 years old.

At both ages, the high academic ability group was less likely to smoke regularly than the low-ability group, but more likely to drink occasionally and persistently, and to use cannabis. This is a similar pattern to adults (Williams and Hagger-Johnson 2017).

The reasons for the findings in this study are not clear. Several explanations have been proposed, including (Williams and Hagger-Johnson 2017):

a) Higher academic ability individuals may be more willing to experiment with substances;

b) Higher academic ability individuals may mix with older adolescents/adults who provide the substances;

c) Greater honesty in self-reported substance use by higher ability group;

d) Lower ability individuals found the questionnaire more difficult (eg: unable to recognise that cannabis is a drug);

e) High ability individuals more responsive to health messages (eg: for smoking).

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24. EATING FRUIT AND VEGETABLES AND PSYCHOLOGICAL DISTRESS

A diet low in fruit and vegetables has been linked to physical and mental health problems (Nguyen et al 2017). A recent meta-analysis (Liu et al 2016) found that increased consumption of these foods was significantly associated with a lower risk of depression.

In a study in Australia, Nguyen et al (2017) showed the benefits of fruit and vegetable consumption in relation to psychological distress for middle-aged and older adults. Data came from the "45 and Up Study" (Banks et al 2008) of adults over 45 years old in New South Wales, which began in 2006-8. A follow-up questionnaire was completed by over 50 000 individuals in 2010.

Psychological distress was self-reported using the Kessler Psychological Distress Scale (K10), which includes ten questions about anxiety and depressive symptoms in the last month. Total scores range from 10-50, and thirty and above is defined as high psychological distress. Fruit and vegetable consumption was scored in response to "how many serves" per day, and divided into ten groups for analysis. Details of other relevant variables were also collected (eg: demographic characteristics; lifestyle risk factors).

After statistical adjustment for other variables, consumption of fruit and vegetables (separate or combined) was significantly associated with less psychological distress (figure), and the relationship was stronger for women. Men with medium levels of consumption had the greatest benefits.

The researchers offered a possible explanation for the findings: "Fruit and vegetables are rich in micro-nutrients and phytochemicals that may help reduce oxidative stress and inflammation, processes that can have detrimental effects on mental health. For example, anti-oxidants such as vitamins C, E and polyphenols may help reduce oxidative stress while the mineral magnesium has been associated with lower levels of C reactive protein, a marker of low-grade inflammation. Deficiencies in B vitamins such as folic acid (vitamin B9) have been associated with depression. Low levels of these vitamins can cause high homocysteine levels which in turn can impair methylation processes involved in the synthesis and metabolism of neurotransmitters that may affect mood" (Nguyen et al 2017 p8).

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25. EXPRESSIVE WRITING AND WOUND HEALING

Wound healing speed is negatively impacted by stress, but this can be countered by written emotional disclosure or "expressive writing" (EW) (Pennebaker 1997). This involves writing emotionally about past traumatic events.

EW "causes a short term increase in distress, negative mood and physical symptoms... However, often participants report they feel better and they have physiological improvements in the long term after expressing their problems rather than keeping them bottled up" (Robinson et al 2017 p218). For example, individuals with rheumatoid arthritis had poorer functioning immediately after writing, but significantly better than the control group three months later (Kelley et al 1997).

Experimental studies of EW and wound healing (eg: Weinman et al 2008) have tended to involve EW before the standardised wound is given. But in real-life individuals cannot predict when a wound will occur. Robinson et al's (2017) study investigated EW after a wound. One hundred and twenty-two adult volunteers in New Zealand were randomly allocated to receive a standard 4 mm wound on the arm before or after EW [134]. The prompt for writing was the "deepest thoughts and feelings about a traumatic, upsetting experience of your life" (or a life-changing one, if not). Writing was instructed for twenty minutes per day for three consecutive days. The state of the wound was assessed at Days 10 and 14.

At Day 10, over half of the EW-before group's wounds had healed, which was significantly more than the other three groups. Robinson et al (2017) stated that "participants who performed expressive writing prior to wounding experienced improvements in positive and negative affect, whereas those who performed expressive writing after wounding experienced deteriorations in positive affect and increases in negative affect, which may have influenced healing. Previous research has linked optimism to better healing (which could be likened to positive affective states), and linked depression with worse healing (which could be likened to negative affective states" (p225).

However, individuals in the post-wound EW group who wrote sooner after the wound (in first 6 days) had better healing at Day 14 than individuals in that group who started writing later.

[134] There were two control groups who wrote about how their spent their time before or after the wound.

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