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

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

CONTENTS

1. THE DEBATE ABOUT VITAMIN D DEFICIENCY AND SUPPLEMENTATION

1.1. VITAMIN D

Vitamin D is a group of fat soluble vitamins that are involved in absorption of calcium and phosphate in the intestines. They are two main forms - vitamin D (ergocalciferol) found in plants, and vitamin D (cholecalciferol) synthesised by the skin from sunlight or found in foods like fish. Approximately 3000 binding sites for the vitamin D receptor have been found throughout the human genome (ie: 3% of genome) suggesting regulation of many genes (Chowdhury et al 2014).

Vitamin D deficiency [1] has been linked to many diseases (eg: bone mineral disease, cancer [2]), and vitamin D supplements presented as a panacea for them (Welsh and Sattar 2014). The "vitamin D literature comprises a minefield of observational data and mixed quality evidence from predominately small trials" (Welsh and Sattar 2014 p1). Observational studies can show benefits with supplements, for example, while randomised controlled trials (RCTs) often do not (Theodoratou et al 2014) [3].

Theodoratou et al (2014) produced an umbrella review that include 107 systematic reviews and 74 meta-analyses of observational studies of plasma vitamin D concentrations, and 87 meta-analyses of RCTs of vitamin D supplements [4]. The authors could not reach definitive conclusions about deficiency or supplementation. All they could say was that "highly convincing evidence of a clear role of vitamin D does not exist for any outcome, but associations with a selection of outcomes are probable" (Theodoratou et al 2014 p1) [5].

On the other hand, Chowdhury et al's (2014) meta-

[1] Defined as circulating 25-hydroxyvitamin D concentration <30 nmol/L (Welsh and Sattar 2014).
[2] For example, two large scale studies in England in 2009 found a link between vitamin D levels and cognitive performance in over 65s (Welland 2009).
[3] The side effects of vitamin D supplements are often overlooked (eg: kidney-related) (Theodoratou et al 2014).
[4] A total of 137 health outcomes were reported.
[5] Probable associations between levels of vitamin D and birth weight, dental cavities in children, and maternal levels in pregnant women, for example (Kmietowicz 2014).

analysis of RCTs of vitamin D supplementation found 11% lower mortality among older adults than the placebo or no treatment [6]. But Welsh and Sattar (2014) felt that this finding "seems remarkable". They noted that six of fourteen studies in the meta-analysis [7] were classed as having a high risk of bias. Also, "indicative of inherent uncertainty, different authors have reached somewhat differing conclusions despite exhaustive analysis on apparently overlapping datasets" (Welsh and Sattar 2014 p1).

1.2. VITAMIN SUPPLEMENTS FOR PREGNANT MOTHERS

The effects of vitamin deficiency are seen as preventable in developed countries today (eg: re-emergence of rickets from vitamin D deficiency among sub-groups in the UK; Lockyer et al 2011). The health authorities in such countries usually have programmes to deal with such deficiencies, like the "Healthy Start" introduced in the UK in 2006 to give free vitamin supplements to pregnant and breastfeeding women, and children under five year (Lockyer et al 2011) [8].

There appears to a contradiction here. A programme to increase vitamin intake while an illness from vitamin deficiency is rising. Deficiency in vitamin D is a risk with certain diets, remaining indoors and/or covering the skin outdoors, living in the north of the UK, being obese, and over 65 years old (Lockyer et al 2011).

One possibility is that health professionals are not aware of vitamin D deficiency risks and how to combat it. This is what Lockyer et al (2011) investigated with a questionnaire sent to seventy-three health visitors and community midwives in northern England.

The majority of respondents (86%) knew sunlight was the main source of vitamin D, and that rickets was a common condition from deficiency (77%). But only half of them were aware of Department of Health guidelines for recommending vitamin supplements. The researchers felt that the health professionals had "forgotten the importance of promotion" (Lockyer et al 2011 p26).

Jain et al (2011) did a similar survey of seventy-seven health visitors, GPs and midwives in a south London borough. Less than half of the health visitors and midwives routinely recommended vitamin D supplements, and

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[6] Chowdhury et al (2014) included 73 cohort studies and 22 RCTs.

[7] Meta-analysis tends to use the fixed-effect (FE) model or the random-effects (RE) model. The FE model assumes that the effect is the same (fixed) in all studies included, and thus bigger studies are assigned larger weights. The RE model assumes that the effect varies across the studies included (Nikolakopoulou et al 2014).

[8] Vitamin supplements can be viewed as "alternative medicine" in some cases (appendix 1A).

hardly any GPs. Awareness of the Healthy Start scheme was high among health visitors, but non-existent among GPs asked in summer 2010.

The uptake of Healthy Start vitamins is low (eg: less than 30% of breastfeeding eligible mothers in certain areas; Jessiman et al 2013), and this is not entirely the fault of health professionals despite the above research.

Jessiman et al (2013) reported problems in the accessibility, awareness, and motivation of eligible families. Qualitative interviews were conducted with 65 relevant health professionals and 107 eligible parents in England. The researchers noted the multiple steps to access vitamins for parents, which act as barriers to uptake.

- Know about Healthy Start programme - eg: poor promotion by health professionals.
- Apply for free vitamin coupons - eg: midwife counter-signing of application form.
- Wait for coupons to arrive in the post.
- Take coupons to exchange point - eg: not available at high-street pharmacies.
- Sufficient vitamins available at exchange point.

Other barriers to uptake include professionals' scepticism about the need for vitamins as well as that of parents.

Jessiman et al (2013) recommended universal provision of vitamins to all pregnant women at first contact with antenatal services.

1.3. APPENDIX 1A - PREGNANT EMBODIMENT

Women use complementary and alternative medicine (CAM) more than men. "Feminism, and the drive to perform embodied femininity, has also been offered as (partial) explanations for the broader gendered consumption of CAM as a reaction against perceived biomedical patriarchy" (Meurk et al 2014 p160). There are other general explanations for CAM use, including individualism, agency and self-help (Meurk et al 2014).

Meurk et al (2014) found, what they called, "therapeutic dualism" among pregnant women. CAM was used by forty Australian women studied for themselves, but "biomedicine is used to ensure a safe and health baby" (Meurk et al 2014 p159).

Taking vitamin supplements was an interesting example of the interaction between biomedicine and CAM. Some women saw them as CAM, whereas others were advised by medical staff to take them. "Davina" stated: "My doctor did suggest taking folate, and I just took the multi-vitamin, particularly because I wasn't feeling that well because of my morning sickness and I was a bit selective about what I felt like eating".

Meurk et al (2014) commented: "The above representative excerpt is telling: while this woman described her doctor as advising her to take folate (in the interests of the foetus), it was of her own volition that she decided to take the multi-vitamin – to make up for any nutritional deficiencies that arose as a consequence of her morning sickness and changed eating habits. Both were acts of 'strengthening', yet biomedical expertise – supplementation as medication – was deployed in order to ensure the healthy development of the foetus while the woman relied on her own lay expertise in order that she maintain her physical wellness – her maternal body" (p165).

Lupton (2012) described "pregnant embodiment" as a "two-bodies-in-one-state", which can produce a feeling of loss of control for women. This was seen in the experiences of "morning sickness". Meurk et al's (2014) interviewees did not want to take pharmaceuticals during pregnancy (because of the thalidomide scandal in the 1960s), so one strategy was to "suck it up" (ie: stoicism). Some women reported finding CAM which alleviated the symptoms.

Pain was another aspect of pregnancy where CAM was popular. Both "Emily" and "Naomi", for example, enjoyed the benefits of acupuncture.

That was for the mother's health. "Monitoring the safe development of the foetus was exclusively, and without exception, considered the domain of biomedicine. For many of the participants, the ability to ensure the baby's health was one of the great benefits of biomedical care, providing reassurance to the new mother that the baby was 'normal' and would be delivered safely [...] However, the complete absence of CAM use in discourses of foetal care indicates a medical demarcation of maternal and foetal bodies; embodied practices could be, and were, individuated along the lines of medical traditions. CAM could be used to care for the mother, it was not employed to care for the foetus. And there is something paradoxical about this. Counter to numerous analyses in which CAM versus biomedicine are constructed in ways that are discursively oppositional – CAM is viewed positively because it is natural, gentle and holistic, whereas biomedicine is viewed negatively because it is artificial, toxic, potent and invasive... – here, in relation to the foetus, the reverse is evident. It is

biomedicine, not CAM, which is deemed to be protective and safe" (Meurk et al 2014 pp168, 169-170).

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2. RISK PERCEPTION IN A POST-MODERN WORLD [9]

2.1. RISK ASSESSMENT

A scientific assessment of risk can be quite different to the perception of it by individuals (or society). This may be due to the complexity of modern risks, how the media portrays them, or psychological processes [10].

Objective risk assessment gives a numerical value to an event based on the probability of adverse effects resulting from it [11]. The numerical value comes from epidemiological data usually (ie: large population samples). For example, the probability of death in the next year for a forty year-old man in the UK from smoking ten cigarettes per day is 1 in 200 compared to 1 in 850 from any natural cause (Dillon and Gill 2001).

Risk assessment of substances, for example, involves a number of aspects (Dillon and Gill 2001):

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[9] See appendix 2E.

[10] For example, a tendency to overestimate the risk of statistically low-risk events while underestimating the likelihood of statistically high-risk ones (Dillon and Gill 2001).

[11] Dillon and Gill (2001) noted three positions in relation to objective risk assessment. A logical positivist view that it is possible using scientific methods. The opposite is a cultural relativist view that sees all risk assessment as subjective (ie: not independent of its time, place, and method). The middle ground of "scientific proceduralism" combines both the other two positions - "Science is value-laden and that scientific experiments cannot be separated from the social context, but that nevertheless useful and reliable information can be obtained about specific risks" (Dillon and Gill 2001 p67).

Three theoretical sociological views on risk can be distinguished (Casiday 2007):

i) Cultural theory (Douglas and Wildavsky 1982) - risk is socially constructed around undesirable outcomes and perceived dangers leading to those outcomes in a particular time and place. For example, being ill from measles may be more "acceptable" risk than autism in relation to vaccination.

ii) Risk society (Beck 1992) - a growing awareness of risks, particularly new ones created by modern society. For example, the risk of side effects of a medication exist because modern society has developed such substances.

iii) Psychometric models - individual's subjective assessment of risks, including cognitive biases like the "illusion of invulnerability" (eg: "it won't happen to me").

- Hazard identification - is there a threat?
- Dose-response assessment - what is the relationship between the dose of the substance and the effect on health?
- Exposure assessment - how likely is exposure to the substance?
- Risk characterisation - what is the level of risk for a particular individual or group?

Risk perception takes account of the consequences of the event. So, a low likelihood risk with large consequences (eg: one occasional event where 100 people die) will be perceived as more dangerous than a high likelihood event with low consequences (eg: 100 regular events where one person dies).

Slovic et al (1980) summarised the perception of risk on two dimensions:

a) Known/observable/immediate effect (eg: car travel) - Not known/not observable/delayed effect (eg: DNA research).

b) Dread/not controllable/fatal consequences/risk not easily reduced (eg: nuclear power) - Not dread/controllable/not fatal consequences/risk easily reduced (eg: use of home appliances).

Thus (Dillon and Gill 2001):

- Unknown/dread (eg: nuclear power station accident).
- Known/dread (eg: terrorism).
- Known/not dread (eg: motor vehicle accident).
- Unknown/not dread (eg: water fluoridation).

The understanding of risk in modern society can be seen in the statement by the UK Government that "in theory at least, all accidents are preventable" (Department of Health 1992 quoted in Burrows et al 1995). Thus, accidents are viewed as calculable, controllable, as well as preventable (Prior 1995).

2.2. ACCIDENTS

Beck (1992) described society as not divided by access to wealth but by relative susceptibility to risk [12]. While Giddens (1991) argued that fate and destiny have been replaced by chance and risk in the world today. In such a situation accidents are problematic, particularly in the face of health promotion, as Green (1995) stated:

[12] This idea has been applied to the consequences of climate change (appendix 2A).

> Health promotion operates within a discourse of risk and its management in which the accident, as a random misfortune over which one can have no control, has no obvious place. The accident becomes something other than the unforeseen outcome of coincidence or fate. As epidemiology maps an ever-increasing range of risk factors for accidental injury and their social distribution becomes more exactly known, the accident becomes patterned and predictable. Having an accident results no longer from fate but from ignorance, miscalculation or the deliberate negligence of known risks. Accidents, in short, should no longer happen (p116).

This is the "professional orthodoxy", and the task is to educate the public who hold fatalistic views about such events (Green 1995). Yet the evidence is contradictory. For example, the "Children can't fly" campaign in New York reduced deaths of pre-school children from falls from windows by distributing free window guards in high-rise building (Green 1995). On the other hand, Carter and Jones (1993) found no difference in knowledge about safety or ownership of safety equipment between families where children had accidents and those who did not.

The failure to find benefits for educational programmes has led to a "victim blaming" ideology (Crawford 1986) rather than a structural critique (eg: the prohibitive cost of implementing recommended safety measures).

Green (1995) summed up: "In terms of accident prevention, we can certainly produce ever more sophisticated accounts of the risks for accidents: socio-demographic factors, psychological attributes, occupation, leisure pursuits, equipment design faults, etc. There is clearly a tension, though, between what we know to be risk factors at the population level and the logical impossibility of translating that population risk into an individual preventative action" (p130).

2.3. VACCINATION RESISTANCE

The World Health Organisation recommends 95% coverage for the MMR (measles, mumps, and rubella) vaccine to be fully effective in a population [13], but in Switzerland, for example, in recent years, the coverage has ranged from 50 to 93% in different cantons (Gross et al 2015).

[13] Casiday (2007) drew out three issues from the MMR and autism controversy:
i) Is there a real risk of autism?
ii) Who is responsible and trustworthy to assess that risk?
iii) What sort of evidence is appropriate to assess the risk?

The vaccine-sceptical group Australian Vaccination Network (1998) stated that "vaccines are extremely toxic and are suspected to cause more harm to more vaccinees than results when infection is naturally acquired" (quoted in Leask 2015). This is an example of anti-vaccine activists, who Leask (2015) argued "promote themselves as champions of transparency in public information and individual choice, and locate their rhetoric within latent themes of cover-up, manipulation for profit, threat of excessive government control and the back-to-nature idyll" (p2) [14].

Medical authorities lament the influence of such groups, and argue for adversarial public advocacy on behalf of vaccinations. Leask (2015), however, was cautious: "It is unrealistic to believe that it is possible to cease anti-vaccination efforts. As long as vaccination has existed, there have been such activists, just as there will always be a minority who stand outside the mainstream, reject orthodox medicine and its interventions, mistrust government and value natural health" (p3) [15].

Leask (2015) wanted efforts to help hesitant (rather than entrenched) non-vaccinators, and those who lack the opportunity to vaccinate because of practical, economic, social or geographical barriers. "With respect to media audiences, vaccine-hesitant parents [16] are the most important group. For them, trust in the source of information is a powerful moderator of message influence. Publicly adversarial debates are unlikely to convince them to vaccinate and may merely serve as catharsis for the converted. Advocates can employ empathic responses that focus on the issue, not the opponent, and appropriate the values underscoring vaccination – protection of children from serious diseases with an explicit acknowledgement of the importance of vaccine safety" (Leask 2015 p4).

The response of medical authorities to vaccine hesitancy, refusal or resistance is the "knowledge-deficit" approach that assumes that individuals need more proper information to change their minds. Dubé et al (2015) reviewed other reviews of studies to encourage vaccination acceptance. They found fifteen relevant

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[14] Such groups and views have a lot in common with "conspiracy theories", which French described as "scepticism without critical thinking" (speaking on "All in the Mind", BBC Radio 4, 26th May 2015) (appendix 2B).

[15] Yaqub et al (2014) described distrust of doctors, government sources, and pharmaceutical companies. Gross et al (2015) found that "vaccines per se were not mistrusted, but the institutions delivering the vaccines. In some cases the motivation of health system actors was perceived as being influenced by larger economic interests" (appendix 2C).

[16] "Vaccine hesitant" covers no immunisation, partial (only certain immunisations), and incomplete (immunisations but not following the recommended schedule) (Yaqub et al 2014).

reviews.

Most interventions to improve vaccination uptake were based around information or education, but "the data were very inconsistent and, in most cases, the evidence was low or moderate quality" (Dubé et al 2015). Another technique was incentive-based (eg: food vouchers, lottery prizes). The evidence of success in increasing uptake of pre-school vaccinations was limited. Multi-component interventions were best (eg: face-to-face education, information campaigns, and incentives in low- and middle-income countries). But the authors were saddened by the limited amount of good evidence, and they noted "the importance of understanding the specific concerns of various groups of vaccine-hesitant individuals, as an effective 'one size fits all' intervention is unlikely ever to exist" (Dubé et al 2015).

2.3.1. Trust

Hobson-West (2007) was among those who have argued that risk perception as in MMR vaccine uptake showed "the importance of trust and hence the close relationship between risk and trust. The broader implication is that social context is crucial and that this will be missed, or simplified, through a narrow focus on individual risk perception" (p199). Yet, at the same time, "risk is individualised or personalised" as "mothers stress the particularity of their child. Vulnerability to disease or to vaccine adverse reactions is seen as influenced by individual characteristics, including diet and hereditary factors" (Hobson-West 2007 p199).

Add to this the concept of risks as potentially catastrophic and unmanageable (Beck 1992), and a crisis of trust in professional experts (Hobson-West 2007) [17].

Hobson-West (2007) studied "vaccination resistance" in the UK (ie: organised resistance by "Vaccine Critical groups" [18]). Ten groups were identified, and interviews were made with their leaders. Hobson-West (2007) classified the groups into two categories:

a) Reformist (six groups - eg: Vaccine Victims Support Group) - Led by parents who believed that their child had been seriously injured by a vaccine, these groups tended to focus on compensation and highlighting

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[17] Brownlie and Howson (2005) described trust as "a complex relational practice that operates at a number of levels including the individual, interpersonal, institutional and socio-political" (quoted in Hobson-West 2007).

[18] Such pressure groups have been blamed for misinforming the public by, for example, Andre (2003) - "'a small group of the so-called educated in developed countries', who constitute an 'anti-vaccination movement' has been misclassifying health events after vaccination as vaccine reactions" (Poltorak et al 2005 p710).

the dangers of vaccination, but were generally supportive of vaccination theoretically.

b) Radical (four groups - eg: Informed Parents) - These groups challenged the use of vaccines generally as part of an interest in "alternative health".

Both groups did not directly challenge the risk statistics provided by medical authorities, but reframed risk in a number of ways. For example, emphasising the unknowns involved, like the effects of vaccination because of the lack of testing of them, or the limited knowledge about health generally. Thus the groups advocated helping parents develop their own expertise and to take responsibility for health. So, "by concentrating on unknowns and uncertainties, the Vaccine Critical groups undermine the value and relevance of official risk discourses" (Hobson-West 2007 p205).

The groups also criticised mass vaccination as ignoring the individual (ie: too concerned with the population level), and ignoring the social model of disease. Together this is "the construction of risk as essentially non-random" (Hobson-West 2007).

The Vaccine Critical groups reframed trust (in medical authorities) as negative. For example, one interviewee said: "I mean the majority of the population thinks vaccination is a good idea. To look into it, to question it. Who would? If you are a busy parent. It's so much easier. The doctors are telling you it's the right thing to do, TV adverts, friends and family... People are inherently lazy... If you don't have to research something then why do it? I feel privileged by the fact that I already had doubts because I'm just as lazy as anybody else" (Hobson-West 2007 p207).

Hobson-West (2007) noted: "Crucially, the Vaccine Critical groups do not present themselves as the alternative actors to be trusted. Whilst indirectly, of course, they depend on some kind of trust from their audience, the point is that discursively the leaders do not make their case by stressing their personal experience of parenting or their 'embodied knowledge'... in order to construct themselves as trustworthy sources of advice. Rather, the groups focus on the need for parents to engage in a process of personal education so that they can trust themselves to make the best decision" (p208). The Radical groups were more likely to use the language of empowerment.

Thus, "instead of good and bad parent categories being a function of compliance or non-compliance with vaccination advice..., the Vaccine Critical groups reframe these categories so that the good parent becomes one who spends the time to become informed and educated

about vaccination" (Hobson-West 2007 pp211-212) [19].

The Radical groups category describes "a trend particularly among well-educated parents in Europe and the USA to believe in keeping good health by maintaining bodily balances and gaining immunity in a natural way... [and] among parents who advocate holistic ideas about health, natural child birth and breast feeding" (Gross et al 2015) [20].

Gross et al (2015) explored the idea of "natural and healthy lifestyles" and childhood vaccination in thirty-two interviews with "vaccine hesitant" parents (mostly mothers) in Switzerland. A key theme to emerge from the interviews was faith in the immune system such that immunisation was not needed. This is summed up by one mother, who was an acupuncturist: "Our immune system is strong enough, and one should be able to overcome an illness with our own means". While another mother emphasised the evolution of the immune system: "I know it has worked for millions of years... I see this [vaccination] as antagonistic, because it [the vaccine] only exists for a few decades and it shall be much better than what has proved itself for millions of years; this does not make sense to me".

A third mother saw the benefits of illness: "Well, I think that it [illness] is like a necessary passage in order to grow. Often you see that children after overcoming a childhood disease make major steps in their development, acquisitions, and this again allows a good development to overcome these illnesses".

Healthy food and breastfeeding were also important to the interviewees as seen in these two extracts: "If one is really concerned with health, with food, with hygiene, with the whole life style, one has a natural immunity strong enough against so many things"; "I think with breast milk a baby has already sufficient antibodies. Why inject then something else at such an early stage?".

So, in this context, "immunisation was generally perceived as artificial and as an unnecessary intrusion into the development of a natural immune system and the healthy status of the child" (Gross et al 2015). The vaccine-acquired immunity was viewed as inferior to

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[19] Casiday (2007), based on data from sixteen focus groups and seventy-one individual interviews with parents, noted that "in addition to the risks of infectious disease and autism, parents balanced other risk concerns — both biological and social — in making their decisions. Such decisions, made on behalf of children unable to choose for themselves, and in the midst of contradictory information and uncertainty, symbolised what it means to be a 'good parent'. To cope with uncertainty, parents sought explanations for why some children seem to be more vulnerable to adverse outcomes than others" (p1059).

[20] What Petrie and Wessely (2002) described as part of "an increasing unease with modernity" (appendix), leading to "a Western modern dualism endowing positive qualities to anything 'natural' and holistic as opposed to anything scientific or technical" (Gross et al 2015).

natural immunity, and immunisation upset the natural bodily order of the child. For example, one mother said: "I think one weakens the person, I say... by inserting something into the body that is something synthetic... that is nothing natural, hence, our body does automatically fight that, it does need to get used to it... and then, if one does not accept it... if the body does not accept it... They are a bit like bombs... I say for the children they are like bombs that are sent into their blood, that's it (laughs)" [21].

Yaqub et al (2014) distinguished between trust (relying on someone else's knowledge) and legitimacy (the grounds on which the knowledge is based). Gross et al (2015) noted that, for their interviewees, "vaccine hesitancy seems to originate strongly in doubts about the legitimacy of an artificial intrusion into the 'natural' development of the immune system rather than merely reflecting a general distrust in the actors of the health care system".

2.3.2. Examples of Research

Poltorak et al (2005) used the ethnographic method to study attitudes towards MMR vaccination in Brighton and Hove in southern England [22]. This included interviews with doctors (general practitioners, GPs) and patients, and participant observation in carer and toddler groups during March-May 2003.

Overall, "when relating their engagement with the MMR, mothers' narratives ranged widely, frequently touching on personal histories, birth events, the social life of motherhood and engagements with health professionals, as much as on understandings of vaccination" (Poltorak et al 2005 p712).

1. Personal histories - Generally "mothers bring to parenthood" experiences and knowledge as well as expectations of and views about health professionals, which underlie the talk about MMR. This includes disease experiences in their family or others (eg: knowing unvaccinated child), as well as "increased awareness of iatrogenic disorders, medical mistakes and possibilities of error" (Poltorak et al 2005).

2. Birth events - There was a connection between the mothers' experience of decisions around pregnancy and birth, and vaccination. "The extent of active choice, and the kind of birth that a mother chooses emerged as a

[21] Martin (1994) referred to a change from concerns in health about "disinfection" to "detoxification".
[22] Uptake of the MMR vaccination was 71% in the area (below the UK average of 80%) at the time of the study (Poltorak et al 2005).

marker of the extent of her research and experience of dealing with often sceptical health professionals" (Poltorak et al 2005 p713). For example, mothers who wanted or had "natural" births may be more likely to reject MMR. While one young, single, mother who felt denied choice over her premature delivery wanted the MMR decision to be her choice. She stated: "Didn't have the choice of breastfeeding, she was so early she had to be droplet fed. Eye dropper thing because she didn't suck the bottle properly. So that choice was taken from her basically, didn't really want a caesarean, wanted to just have gas and air, didn't want an epidural, heard horror stories, didn't really have the choice for that, that kind of choice was taken away from me. So in a way it made it easier?" (p713).

3. Social life of motherhood - MMR talk was often part of discussion about other issues of concern related to the child as mothers shared information. "The narratives and participant observation suggest that parents rarely seek or give advice but rather learn from hearing and sharing experiences and tips, generally valuing forms of information sharing grounded in the unique relationship and responsibility that each has for their child" (Poltorak et al 2005 p714).

4. Engagement with health professionals - A relationship of trust between the mother and the health professional (GP, health visitor) was important.

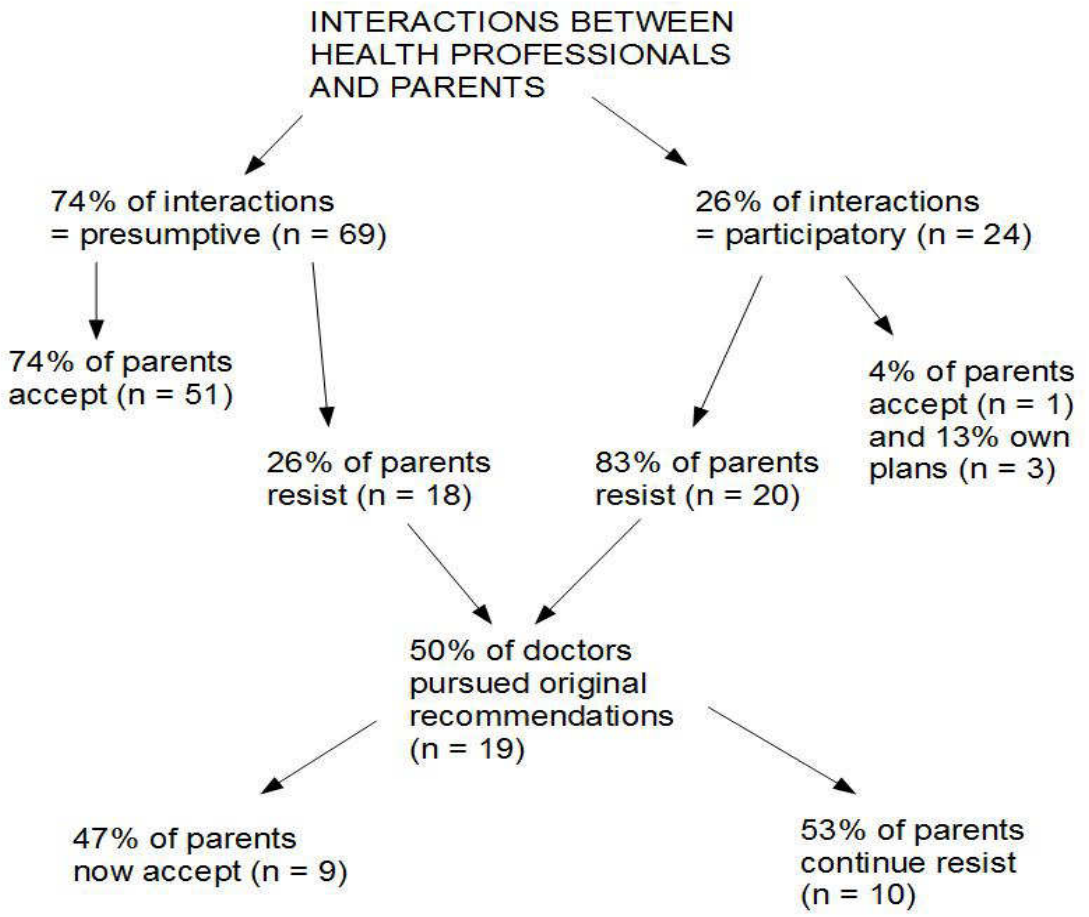
Poltorak et al (2005) summed up: "Mothers in this study tend to conceptualise their child's health and immune system as shaped by a specific pathway extending back into family health history, birth, illnesses and other events, and incorporating concerns about sleep, allergies, eczema, asthma, dietary tolerances, character and behaviour. This personalised framing extends into ideas about a child's particular vulnerabilities to disease or vaccination effects, so parents reflect on MMR 'risks' or 'safety' not in general, but 'for my child'" (p717).

In a recent US survey, 9% of respondents were convinced of the link between MMR and autism, and were thus definitely anti-vaccine, while 52% were unsure ("fence-sitters") (Editors 2015). The latter individuals can be moved towards vaccination by positive messages from doctors.

Opel et al (2013) found that parents resisted vaccination for their children significantly more often if health professionals used a participatory style of

communication [23] (eg: "What do you want to do about shots?") rather than a presumptive style [24] (eg: "Well, we have to do some shots") (83% vs 26% resistance). The health providers response to parents' resistance was important. A statement like "He/she really needs these shots" led to about half the initial resisters accepting vaccination for their child (figure 2.1). The researchers video-recorded vaccination discussions in the USA between doctors/nurses and parents of 1-19 month-olds at health supervision visits.

For anti-vaccine individuals, who usually distrust medical authorities, peer pressure and social norms could change attitudes (eg: Oraby et al 2014).



(Based on Opel et al 2013 figure 1 p1041 and figure 2 p1042)

Figure 2.1 - Responses of parents in ninety-three vaccination discussions where health professionals initiated vaccination recommendations.

[23] Described as "linguistically provided patients with relatively more decision-making latitude" (Opel et al 2013).

[24] Described as "linguistically presupposed that parents would vaccinate" (Opel et al 2013).

The Internet has been viewed as a "Pandora's box" of misinformation by some medical authorities. For example, Nasir (2000) analysed fifty-one websites that opposed childhood vaccination, and found that they presented themselves as unbiased, but were actually strongly against vaccination. Davies et al (2002) looked at one hundred such websites, finding that they "portrayed themselves as authorities on vaccination, appealed to viewers' emotions through personal testimonies of vaccine injury and calls for parental responsibility, and maintained a discourse of truth seeking often advancing evidence of medical conspiracies bolstered by their own privileged information" (Grant et al 2015 p3). But these studies related to Web 1.0 - characterised by static webpages displaying information, whereas Web 2.0 involves interactivity between users (as in social media).

Witteman and Zikmund-Fisher (2012) pointed out that "in this Web environment, effective communication about vaccinations is not about controlling what is available but rather, it is about responding and participating in an interactive, user-responsive environment" (quoted in Grant et al 2015). Studies of Web 2.0 have found that social media "is more of an echo chamber for circulating opinions among like minds that a means of randomly influencing less opinionated users" (Grant et al 2015 p4).

Grant et al (2015) compared two pro-vaccine and two vaccine-sceptical US-based websites. The former tended to present information in an authoritative style with little interactivity. The two vaccine-sceptical websites: "Rather than circulating deliberate misunderstandings of medical research, both websites strip evidence-based scientific information of its authority by questioning its primacy and call for alternative scientific studies that are sympathetic to its claims. The websites substantiate their calls for alternative research by fostering a community of individuals whose experiences with vaccines counter the information transmitted by medical and governmental websites. Through the community-building functions of Web 2.0, they curate interactive accounts of vaccine injury and scepticism, thus providing a corpus of medical texts that adhere to a different standard for scientific information; that is, the personal experience of vaccination" (Grant et al 2015 p16).

2.4. APPENDIX 2A - CLIMATE CHANGE

Beck (2015) argued that climate change has changed the world in terms of how individuals think about themselves: "our way of being in the world, our way of thinking about the world, and our way of imagining and doing politics" (p76). In particular: "The idea that we

are the masters of the universe has totally collapsed and has turned into its opposite. In the age of climate change, modernisation is not about progress, or about apocalypse – this is a false alternative. Rather, it is about something 'in-between'. We do not even have a word for this; we need a new public and scientific vocabulary. I propose the notion of 'Verwandlung' – 'metamorphosis of the world'" (Beck 2015 pp75-76).

Furthermore, Beck (2015) stated: "Climate change induces a basic sense of ethical and existential violation which creates all sorts of new developments – new norms, laws, markets, technologies, understandings of the nation and the state, and international and inter-urban co-operations" (p76). For example, inequality will become based around elevation above the ocean with rising sea levels rather than within traditional boundaries like nation-states.

Keck and Lakoff (2013) pointed out: "Many of the threats we now find most alarming — climate change, environmental radiation, emerging disease, endocrine disrupters, toxic chemicals—are not immediately perceptible to human senses. We rely on non-human indicators, whether animals or detection devices, to alert us to their possible onset. Such indicators can be thought of as sentinels, or heralds of an approaching danger". Analysis of statistical data can be part of this process.

Keck and Lakoff (2013) noted three issues with sentinels:

i) How to distinguish the signal (of danger) from the noise (the normal background)?

ii) The reliability and legitimacy of sentinel devices - eg: who interprets the signal?

iii) The credibility and validity of signals, particularly when faced with sceptics.

The concept of risk has changed to include "systemic risk". Collier and Lakoff (2011) observed: "Traditional insurance works because such individual risks do not co-vary. Life insurance, for example, is built on the proposition that the death of one policyholder in an insurance pool does not significantly change the risk of death of other policy-holders, and it is thus possible to 'spread' individual risks across a population. Catastrophe insurance, which has become increasingly important in the last two decades as insurance companies have dealt with 'superdisasters' such as 9/11 and the hurricanes of the early 1990s, presents a different problem. For an insurer in south Florida, a hurricane that caused losses for one insured property would also

cause losses for other policyholders in its portfolio. In other words, in contrast to the usual assumption of insurance, losses from a catastrophe are likely to display high levels of co-variation. Here, too, systemic risk is something more than an aggregation of individual risks. It is, rather, an emergent property of the insurance system itself".

This goes with Beck's (1992) talk of "modernisation risks" - these, "such as mass casualty terrorism, ecological crises, and global financial meltdowns – are generated by the success of modernisation processes. In other words, they are a product of the very systems – of finance, of insurance, of transportation and communication, of industrial production – that provide for the health and well-being of populations" (Collier and Lakoff 2011).

2.5. APPENDIX 2B - CONSPIRACY THEORIES

Brotherton and French (2015) noted that "conspiracy theories" "while not false by definition, are characteristically unverified, implausible, and epistemically unsound". A number of individual differences (eg: authoritarianism, agreeableness) and cognitive factors (eg: illusory pattern perception, confirmation bias) have been proposed to explain them, but Brotherton and French (2015) placed emphasis on attributions of intentionality (ie: "the ability to distinguish intentional actions and consequences from unintentional acts or outcomes, and to infer the specific intentions motivating people's actions"). Rosset (2008) referred to "intentionality bias" (ie: the automatic assumption that all actions are intentional/deliberate). "Only after the initial automatic attribution of intentionality has been made can higher-level cognitive processes evaluate and, if necessary, override this involuntary assumption" (Brotherton and French 2015).

"Intentionality bias" is strong in "conspiracy theories" where nothing happens by accident with the "postulated conspirators as preternaturally competent in their ability to plan and control events, and discounting the role of chance or unintended consequences" (Brotherton and French 2015).

Brotherton and French (2015) performed three studies to test the hypothesis that "individuals biased towards favouring intentional explanations for ambiguous actions in general may see conspiratorial explanations, which paint events as the product of powerful hidden agents' intentions, as being more plausible than non-conspiracist explanations".

Study 1

This correlational study aimed specifically to test the link between conspiracist ideation and anthropomorphism (the attribution to non-human animals or inanimate objects human-like intentionality). Eighty-four psychology undergraduates in London completed the Generic Conspiracist Beliefs (GCB) scale (Brotherton et al 2013) and the Individual Differences in Anthropomorphism Questionnaire (IDAQ) (Waytz et al 2010). The GCB has fifteen items, like "New and advanced technology which would harm current industry is being suppressed", each rated from "definitely not true" (1) to "definitely true" (5). This gives a range of total scores from 15 to 75, where a higher score is holding conspiracist beliefs.

The IDAQ also has fifteen items (eg: "To what extent does a television set experience emotions?"), each rated from 1 to 10. A higher total score (maximum 150) is greater anthropomorphism.

There was a significant positive correlation between the two scores ($r = +0.39$; $p<0.001$), which showed that "people who endorse generic conspiracist ideas more strongly tended also to endorse anthropomorphic statements more strongly" (Brotherton and French 2015).

Study 2

This correlational study looked at the relationship between conspiracist beliefs and intentionality bias. One hundred and two more psychology undergraduates completed the GCB scale. They also completed a measure of attribution of intentionality, partly designed specially by the researchers. Twelve sentences were presented (eg: "He set the house on fire"), and the task was to write "a brief description of the image that comes to mind when reading each sentence". The participants were then asked to categorise their description as "on purpose" or "by accident". Independent judges checked the categories, and scored "on purpose" as one point on each item (giving a maximum score of twelve). There was a small significant positive correlation between the GCB scores and "on purpose" scores ($r = +0.22$; $p<0.05$) - "that is, participants who endorsed generic conspiracist claims more strongly tended to offer slightly more intentional interpretations" (Brotherton and French 2015).

Study 3

This study investigated the relationship between conspiracist beliefs, anthropomorphism, and intentionality bias with eighty-six more students. The three measures previously used were completed by the

participants.

Surprisingly, there was no significant association between intentionality bias and anthropomorphism, but multiple regression analysis showed that both these variables significantly predicted conspiracist beliefs. Brotherton and French (2015) stated: "One potential explanation is that anthropomorphism reflects an individual's broad attitude towards the world and people's place in it, as opposed to reflecting a low-level bias towards overattributing intentionality. In other words, the intentionality bias measure may capture immediate, intuitive responses to a novel event, whereas anthropomorphism may reflect a more reasoned pre-existing attitude. The two appear to be distinct traits, which independently predict conspiracism".

2.6. APPENDIX 2C - WHAT KNOWLEDGE TO TRUST

Attitudes towards vaccination are part of a wider issue of how to know what is true. In relation to science, there will be knowledge claims that are outside the consensus - are these maverick or breakthroughs yet to be recognised?

Collins (2014) described how the boundaries of scientific knowledge are constructed through "technical judgments" - "technical judgments are the prerogative of experts and it is only the consequences of those judgments that are the prerogative of non-experts. But it is easy for the two kinds of judgment to become mixed up, with non-experts believing that it is possible for them to make technical judgments. One of the reasons that non-experts might, in good faith, think they can make technical judgments that differ from those of experts is that the scientific literature, including that version of it that can be readily found on the Internet, gives the impression of being technically empowering. Scientific journals operate with a convincing literary technology – the impersonal passive voice is used to convey objectivity and the reader is given the impression of being a 'virtual witness' of the experiments described (Shapin 1984). The Internet broadcasts the picture more widely. But the sense of empowerment provided by being a virtual witness, or something similar, is misleading" (p723).

Collins (2014) referred to the "tacit knowledge of the expert community" which is not available to non-experts, especially when faced with heterodox (contested) claims.

The "collective tacit knowledge" in any discipline comes from reading certain material (ie: particular journals and authors). This creates "knowledge of what 'you ought to have heard of'" (Collins 2014).

Expertise is established by credentials, experience, and track-record (Collins 2014). Collins (2014) used the case of a paper published in physics that challenged traditional held views. The response of ten experts in the field were used to show the "tacit knowledge of the expert community" in this situation. The author was unknown in terms of publications, the journal publishing the article was little known, and the topic was little discussed. The article also reportedly had errors, and displayed "markers of 'crankness'", as one expert said.

Critical approaches to knowledge may question the claim of experts to just know, and such questioning has partly opened the door such "that a scientific argument is much like any other argument so that the epistemological high point on which science once seemed to stand is, indeed, not much different from level ground" (Collins 2014 p729).

2.6.1. Pharmaceutical Harmonisation

The social construction of technical knowledge can be seen in the process of standard-setting for medications.

The development of medicines involves the positive side of progress, and the negative side of risk. Hence, innovation and regulation come face-to-face in a complex relationship (Abraham and Reed 2002). The innovation of pharmaceutical companies, which can be important in social progress, and the regulation of such innovation by government or relevant authorities to protect public health and welfare.

Abraham and Reed (2002) showed the complexity of the relationship in their study of the International Conference on Harmonisation of Technical Requirements for Regulation of Pharmaceuticals for Human Use (ICH) during the 1990s. The ICH set standards for the toxicity of pharmaceuticals, and involved the pharmaceutical industry and regulatory agencies.

Innovation in the pharmaceutical industry includes the discovery of the chemical compound, and the development of this discovery to the point of selling a product. The latter involves safety testing of the compound (usually its toxicity in non-human animals; appendix 2D), and the efficacy of the drug in humans. "The new discovery has been developed into a drug product innovation when, after completing their review of the manufacturer's drug-testing data on the compound, the regulators approve it for marketing" (Abraham and Reed 2002 p341). Innovation can also involve matching the chemical compound to a health need, or the discovery of a new process of assessing safety or efficacy. The latter is "process innovation" as opposed to "product innovation" (Freeman 1982).

Abraham and Reed (2002) observed: "Sociology and politics are particularly relevant to understanding process innovations in regulatory science, such as toxicology, because of the 'impure' nature of this type of science. Toxicological testing is characterised by a great deal of scientific uncertainty, and the validity of its traditional methodologies is contested. Consequently, the boundary between scientific and political judgments may become blurred and influence the definition of what is, and is not, 'technical'. Nevertheless, as we demonstrate in this paper, with careful and detailed empirical research, it is possible for sociological research to identify specific technical innovations and relate them to socio-political commitments and interests" (p341).

The cost of bringing a new chemical compound from discovery to market can be hundreds of millions of dollars/pounds for the pharmaceutical companies, and this has increased over recent decades. Costs can be reduced by lowering or changing regulatory requirements (eg: international standards rather than national standards).

Abraham and Reed (2002) pointed out: "According to representatives of the industry, the inconsistencies between national regulatory standards have produced wasteful duplication in drug testing, which has driven up drug development costs and created 'barriers to trade'" (p341). The ICH was created by the International Federation of Pharmaceutical Manufacturers' Associations (IFPMA) to aid standardisation of regulation ("pharmaceutical harmonisation") in the European Union, Japan, and the USA. Abraham and Reed (2002) quoted from IFPMA literature: "harmonisation through ICH brings important, life-saving treatments to patients faster, while releasing the pharmaceutical companies' development funds to projects that will produce the ground-breaking treatments of the future".

Abraham and Reed (2002) concentrated on the ICH's concern with the length of toxicity testing in non-human animals in their the first conference in 1991 [25]. In 1990 the length of this process with rats was a minimum of six months in the EU, and twelve months in Japan and the USA. The pharmaceutical industry argued that the standardisation to six months would save them over half a million dollars per compound (Abraham and Reed 2002). A six-month length was agreed at the 1991 meeting.

Though the debate was, on the surface, about "technical" details, it "was not 'technical' in the sense of being divorced from political judgments and social interests... A crucial part of this process for regulators has been the legitimising discourse of

[25] Non-human animals are given the compound, often in large doses, to establish the consequences (ie: "cumulative toxicity").

innovation and scientific/therapeutic 'progress'. Without this, one might readily conclude that ICH has reduced 'technical' standards for safety testing in the commercial interests of the pharmaceutical industry, but in the absence of any benefits for patients or public health. The involvement of regulatory agencies in such a scenario could lack public credibility. However, by also linking the lowering and loosening of 'technical' standards in ICH's regulatory science to innovation and 'progress' in the delivery of therapeutic benefits to patients, the regulatory agencies could legitimise their involvement in ICH as being consistent with their mission to protect and promote public health" (Abraham and Reed 2002 p360).

Similarly, the "technical" details on number of different species used in toxicity testing was reduced, and the size of dosage in such tests was "harmonised" (eg: twenty-five times human exposure rather than one hundred times) (Abraham and Reed 2002).

2.7. APPENDIX 2D - ATTITUDES TO ANIMAL TESTING

Animal testing in medical research is common, though public objection is evident. In a survey in 2010 in the EU, 22% objected while 67% supported it with mice, for example (quoted in Masterson et al 2014). But if the survey question referred to dogs or monkeys, the support in Europe drops below half (Masterson et al 2014).

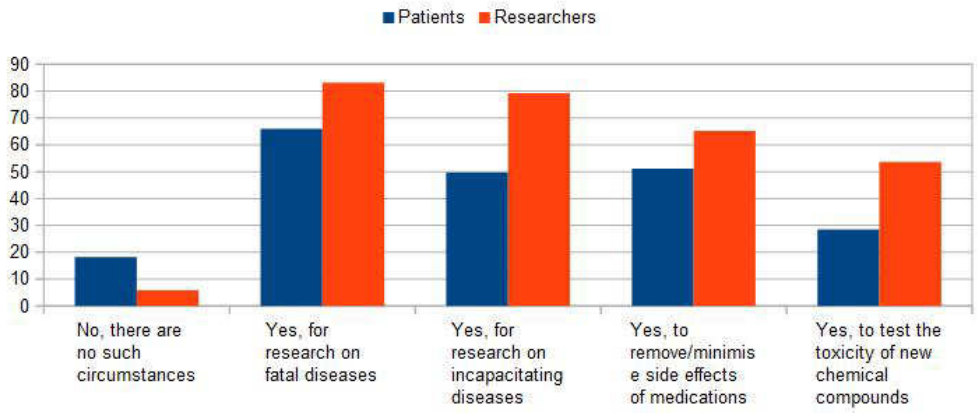
General surveys of attitudes do not necessarily include individuals directly involved or affected by animal testing. Consequently, Masterson et al (2014) surveyed 779 sufferers of chronic inflammatory diseases in the Swedish Rheumatism Association, and 217 scientific researchers in Sweden [26].

Less than one-fifth of patients and around 5% of researchers could see no circumstances to use animal testing. The majority were, thus, supportive in different situations (eg: "for research on fatal diseases"; "to remove/minimise side effects of medications") (figure 2.2). Women were significantly more likely to object in both groups (figure 2.3).

Support for the use of rats/mice was much higher than for cats/dogs and apes/monkeys in both groups (figure 2.4).

Along with the qualitative comments, the authors noted that "while a majority of patients support animal testing, they at the same time hold ambivalent feelings towards the moral justification of this practice" (Masterson et al 2014 p33). For example, one patient

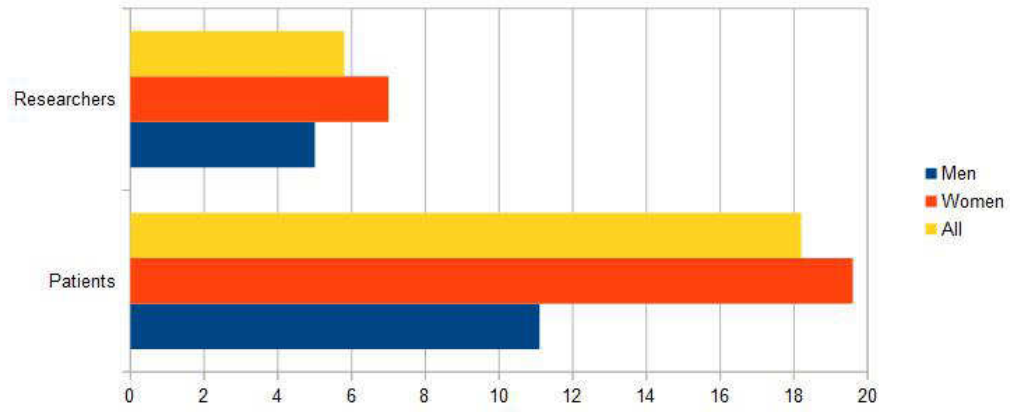
[26] Questionnaires were sent to 1200 patients and 364 researchers in early 2011.



(There were nine "yes" options, and multiple answers were allowed)

(Data from Masterson et al 2014 table 2 p31)

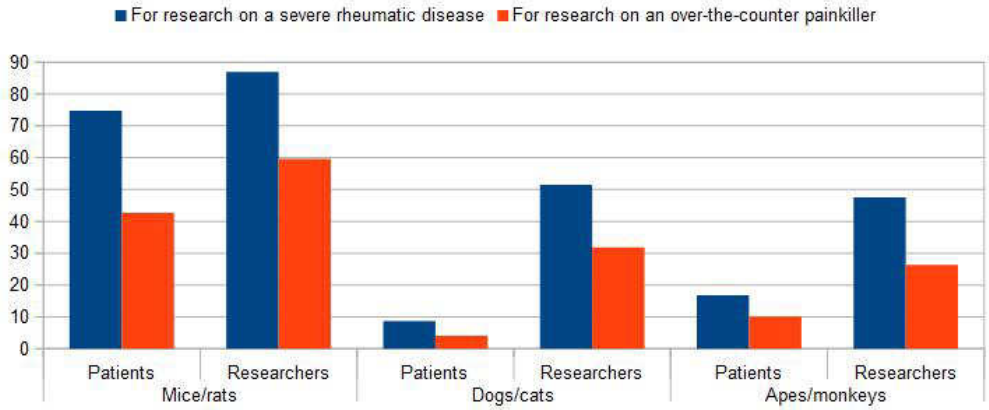
Figure 2.2 - Percentage agreeing with selective responses to question: "Do you believe that there are circumstances when it is acceptable to use animals in research?".



(Data from Masterson et al 2014 table 2 p31)

Figure 2.3 - Percentage of men and women answering, "No, there are no such circumstances" to the question: "Do you believe that there are circumstances when it is acceptable to use animals in research?".

said: "I'm against animal testing, actually, but animal testing must be done in some cases". One way to deal with the ambivalence was to use species lower on the phylogenetic tree (eg: mice/rats).



(Ten different groups of animals offered)

(Data from Masterson et al 2014 tables 3 and 4 p32)

Figure 2.4 - Percentage of respondents agreeing to use of selected groups of animals in testing in two different situations.

2.8. APPENDIX 2E - MODERNITY AND POST-MODERNITY

Modernity was characterised by "grand narratives" to understand the social world, which post-modernity rejected in favour of "micro-narratives" (Lyotard 1998) as it allows "liberated formerly silenced groups such as women and homosexuals to express their own realities in their own voices" (Parker 2015).

Hargreaves (1994) highlighted the following characteristics of post-modernity:

i) "Moving mosaic" - ie: power is dispersed rather than a traditional hierarchy.

ii) "Flexible accumulation" - "Essentially, traditional job demarcations are dismantled leading to overlaps and rotations, temporary contracts facilitate easy adjustments to the workforce and customised production is tailored to individual preferences and consumer demand. Ultimately, 'knowledge and information are its prime products' (Hargreaves 1994 p49) and flexibility is the key" (Parker 2015).

iii) Compression of time and space - eg: swifter communication with the development of the Internet, and consequently decision-making.

iv) Paradox of globalisation - As individuals find themselves in a global interconnected world, they focus more on "locally defined identities" (Parker 2015).

v) "Boundless self" - Individuals can be anything they want.

Watson (2005) criticised post-modernism as having "an unprincipled emphasis on personal and individual gratification at the expense of our responsibilities to others" (quoted in Parker 2015).

Sim (2005) suggested that modernity is "fighting back" with grand narratives like those of Islamic fundamentalism or "market fundamentalism" of neoliberalism. Both place faith in the grand narrative "at the expense of its impact on individuals" (quoted in Parker 2015).

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3. EVIDENCE-BASED MEDICINE OBVIOUSLY

3.1. EVIDENCE

It seems like commonsense that treatments should be evidence-based (ie: sound biomedical research evidence about the effectiveness of the treatment). Such evidence-based medicine offers a solution also to issues of rationing of healthcare. But, in practice, what is sound evidence can be contested in terms of the effectiveness of treatment and who has the authority to establish that (Harrison 1998) [27].

The contesting of evidence can be seen in the example of mammography screening for breast cancer. The idea is that such screening can detect the disease at an early stage, and then treatment can be offered to deal with it. The issue is whether screening leads to less deaths from breast cancer than not screening.

Independent UK Panel on Breast Cancer Screening (2012), for example, concluded from the evidence that there was a 20% relative reduction in mortality from breast cancer in women screened. But it was also found that UK screened women were three times more likely to be treated for a cancer that would not have harmed them as to have their lives saved (Wise 2013). Other studies have found no reduction in deaths after screening (eg: Mukhtar et al 2013).

These differences in findings between studies and reviews is probably due to differences in methodology, including the age group of women screened, and the length of the follow-up (table 3.1).

For example, in a Canadian study, Miller et al (2014) found no reduction in mortality from breast cancer in screened women aged 40-59 years old as compared to physical examination (ie: no screening) over twenty-five years. The researchers estimated that over 20% of screening detected breast cancers were over-diagnoses (ie: the cancer would not have been evident in the women's lifetime without screening).

This study had just under 90 000 participants from six Canadian provinces, of which half had been screened in 1980-1985. The fifteen screening centres involved had closed in 1988.

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[27] This is very important in relation to giving patient's information for them to make an informed decision about their treatment (appendix 3A).

- Healthier women receive screening vs random allocation.
- Volunteers vs random sampling.
- Frequency of screening (eg: annually).
- Timing of screening (in terms of progress of disease).
- Technique and sensitivity of screening.
- Measure of follow-up (eg: death certificates).
- Length of follow-up after screening.
- Age of women at screening.
- Comparability of control group to screened women.
- Nature of control group (eg: physical examination by physician or breast self-examination).
- Size of sample.
- Statistical analysis of data.
- Post-screening treatment.

Table 3.1 - Methodological differences between studies.

On the other hand, a Swedish study with a twenty-nine year follow-up reported a reduction in mortality of about one-third with mammography screening (Tabar et al 2011).

A recent study in Norway (Weedon-Fekjaer et al 2014) found a reduction in deaths of 28% in screened women aged 50-69 years old given biennial invitations to screen. The researchers analysed data from all older women in Norway after the introduction of mammography screening in 1995.

3.2. UNDEFINED ILLNESS

Biomedicine tends to view the body as healthy or unhealthy (ie: a dualism of the presence or absence of illness). "Haunting" (Gordon 1997) is a theoretical concept used to deal with situations and experiences that do not fit into dualisms like absent/present, or visible/invisible (Overend 2014).

Overend (2014) used the example of "undefined illness" [28] ("an illness with no objective pathological or empirical trace") in the form of "Candida ("a yeast-related disorder of vague symptomatology") [29]. She interviewed twenty-four individuals in Canada with self-identified/diagnosed Candida. "Aurora's" experience is typical: "I was going to my GP every week saying: 'please, please, please'. I was begging her to help me. And she'd say: 'I don't know what's wrong with you'.

[28] Other terms used include "chronic undefined disorders", "medically unexplained symptoms", "non" or "illegitimate illness", or "uncertain illnesses" (Overend 2014).

[29] Truss (1978) proposed that naturally-occurring Candida yeast exist in the gut which escape out and cause many and varied symptoms. The modern diet with high sugar content, for example, over-consumption of antibiotics, or environmental factors like air pollution can exacerbate it. Biomedicine practitioners generally are less convinced about the condition, and it is viewed as "speculative and unproven" (Overend 2014).

She'd take blood tests, and it wasn't Celiac Disease. Another GP suggested it was Giardia Lamblia [a type of parasite], but it wasn't that either. I think my GP was under the impression that it was psychosomatic in the end" (p69).

A variety of haunting-related words were used to describe the condition - "'parasitic', 'miasmic', 'a looming presence', 'living death', 'not of this world', and, as an 'overall sense' that 'things' were not 'quite right'. Many of them moreover repeat words such as 'creep', 'odd', 'bizarre', 'strange', and 'peculiar' to describe their symptoms of illness, and the haunting ways in which Candida lurks, without diagnosis, within the depths of the supposedly knowable body" (Overend 2014 p69).

Candida is like a "ghost" in that it cannot be clearly seen (by the biomedical gaze), it leaves traces of its presence, and there is a feeling of "possession" (eg: "Diana" said: "I just didn't feel like I was in control of my body"). Though Candida can only cause death in extreme circumstances, like with AIDS sufferers, there was a spectre of death for the sufferers (eg: "Phil": "I went from being a typical person in [my] twenties in good health to literally thinking I was dying").

Biomedicine has a dualism of "objective, visible sign of illness pathology" or not ("a manifestation of the mind"), but the experience of the individuals did not fit. Overend (2014) saw "the haunting descriptors common to undefined illness as a way to re-think these illness experiences beyond common (and arguably conveniently-simplistic) definitions of illness phenomena" (p70).

The experiences of "Sue" are a good example: "I had these perfectly formed circles [on my face], and I went to my doctor and she said it might be some kind of allergy. The circles itched, and burned, and were raised, so if I rubbed my hand against them I could feel them. And then within two to three hours, they were gone. They were really weird, but I only got them on my face. This is what I mean when I said that Candida is trying to out-fox me. It's constantly giving me different symptoms that I'm not quick enough to say: 'Ah, I bet that's Candida'. I go on for a couple of weeks thinking: 'what was that'? And then the penny drops. It's most peculiar. Some things that I had at the beginning are gone, and new ones keep popping up all the time" (p71).

Overend (2014) summarised the benefits of the concept of "haunting": "In an illness culture that heavily weights empirical modes of knowing (even when these modes of knowing continue to fray), we must learn to attend to, acknowledge, listen and care for, that which exists in the interstices of biomedical ways of knowing. To give credence to the ghostly matters of undefined illness is to respect (and perhaps even trust)

that which we do not know. Rather than rendering the ghost (and its ghostly matters) intelligible, the ghost teaches us 'to make a contact with what is without doubt... unsettling' (Gordon 1997), yet also vital, if we want to move beyond the empirical frames of bodily knowing that were so limiting to begin with" (p79).

3.3. APPENDIX 3A - PATIENT PREFERENCE

Western medicine is based on the patient's right to decide on their treatment. But what happens when patients cannot make a decision through sudden illness (eg: stroke) or gradual decline in cognitive function (eg: dementia) (ie: they become incapacitated). One answer is to encourage patients to have discussed their wishes beforehand (instructional advance directives; ADs). If this has not occurred, a surrogate decision maker (eg: family member) is asked, and/or clinicians choose the best course of action. ADs are not common, and, where they do exist, they can be difficult to interpret for decision makers (Rid 2014).

An alternative approach is the use of a "Patient Preference Predictor" (PPP) (Rid 2014). This predicts the course of treatment for incapacitated patients based on data about similar individuals' treatment preferences in similar situations.

Concerns have been raised about PPPs as patients can change their minds over treatment preferences in short periods of time. Other concerns relate to the collection of data, and the classifying of individuals as similar (Rid 2014).

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4. HIV AND POVERTY

4.1. INTRODUCTION

Researchers have distinguished HIV-1 and HIV-2 based on their origins. HIV-1 originated from apes, and has four groups, again based on origin (labelled as M, N, O and P). Group M is common worldwide, and has nine sub-types (A-D, F-H, J and K) with sub-type B dominant in Western Europe and the Americas. HIV-2 is less transmissible, and like the other types of HIV-1 is mainly restricted to West Africa. HIV-2 originated from sooty mangabey monkeys (Maartens et al 2014).

It is estimated that 35 million people are living with HIV worldwide, and this is an increase in recent years (eg: 31 million in 2002), but as much because of sufferers living longer with anti-retroviral therapy (Maartens et al 2014).

Globally in 2012, there were over two million new cases of HIV infection (ie: an incidence of 2.3 million) down from 3.3 million in 2002 (Maartens et al 2014). But sixteen of twenty-six sub-Saharan African countries had over a 50% reduction in new infections between 2001 and 2012 (Jones et al 2014).

There reduction in new cases is due to the decline in heterosexual transmission, in the main. However, transmission of HIV via men who had sex with men remains stable, and is related to issues like stigma, access to care, and risk-taking behaviours (Maartens et al 2014).

HIV-1 sexual transmission is increased by multiple sexual partners, including concurrent relationships, and alcohol and drug use which can encourage risky sexual behaviour (eg: no condom) (Maartens et al 2014).

HIV infection is still a risk across the world, but there are population-level successes due to a combination of biomedical, behavioural, and structural policies (Jones et al 2014):

a) Biomedical - eg: use of anti-retroviral therapy (ART); pre-exposure prophylaxis for HIV-negative individuals; voluntary male medical circumcision.

b) Behavioural - eg: condom use; reduce needle sharing by injecting drug users.

c) Structural - more resources for higher risk

populations and geographical regions ("transmission hotspots") (eg: men with have sex with men in Nairobi, Kenya).

4.2. POVERTY AND HIV/AIDS IN AFRICA

In Africa, countries with high rates of HIV/AIDS tend to be poorer, but this is not always the case. This begs the question as to what is the relationship between poverty and HIV/AIDS in Africa.

For example, Gilles et al (1996) correlated AIDS prevalence per 100 000 people with gross national product (GNP) (using 1991 data). There was a positive correlation for Europe and the Americas (ie: higher AIDS prevalence in richer countries), but a negative correlation for Sub-Saharan Africa (ie: higher AIDS in poorer countries). Note that the positive correlations were statistically significant, but the negative one was not (Mufune 2015).

But Fox's (2012) analysis of data for sixteen Sub-Saharan African countries found that "in poorer countries/regions wealthier individuals were more likely to be HIV positive, whereas in wealthier countries/regions it was poorer individuals who had a higher probability of being infected with HIV. He concluded that inequality trumps wealth, that is, living in a region with greater inequality in wealth was significantly associated with increased individual risk of HIV infection, net of absolute wealth" (Mupune 2015 p20).

Studies often produce correlations, which are not causation. Gillies et al (1996), for example, suggested that aspects of poverty like homelessness, migration, and the breakdown of social networks could be the causes of the transmission of HIV. While Stillwaggon (2000) drew a parallel with other infectious diseases. Poverty leads to low calorie and/or protein consumption, which weakens the immune system, and makes the individual vulnerable to infection.

However, there are poorer countries in Africa that have lower HIV infection rates than richer ones. For example, Chad and Mali (poor countries) have infection rates of 5% or less of the population compared to 20% in South Africa (rich country) (Mufune 2015).

Also there are examples of countries that have lowered the HIV infection rate without a reduction in poverty (eg: eastern Zimbabwe between 1998 and 2003) (Mufune 2015).

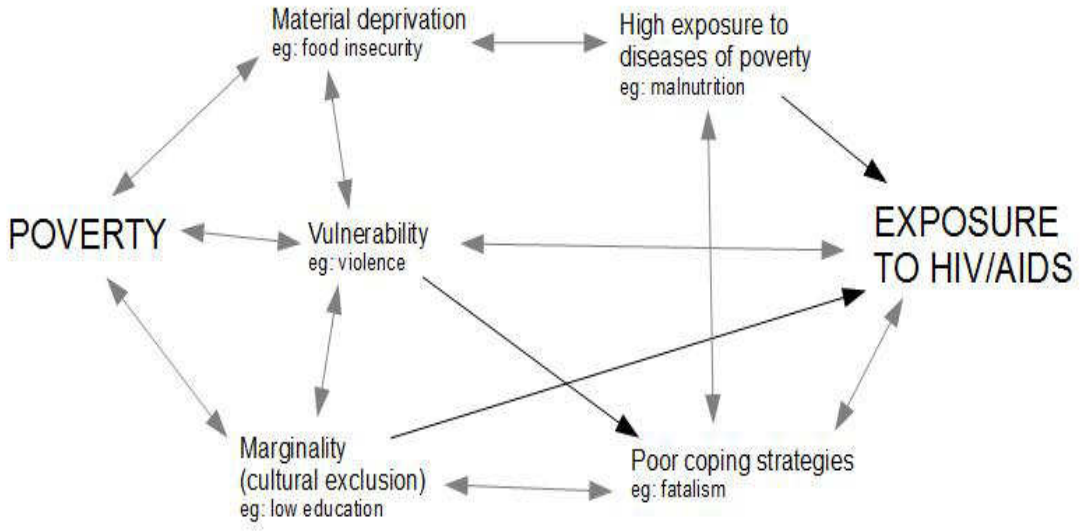
Macro-based studies that compare overall poverty and HIV/AIDS levels have a number of methodological problems, including defining poverty (absolute or relative), and what measure of poverty/wealth to use (eg: GNP, gross

domestic product per person, living on US $1 per day).

Mufune (2015) summed up: "Disentangling the pattern of causation between poverty and HIV/AIDS may be fruitless, if not impossible. It is just possible that both poverty and wealth provide conditions for HIV infection, that is, the relationship is not mutually exclusive. It is also important to point out that macro-level analyses of income risk ecological fallacies in particular – just because poor countries have more HIV, this does not mean that the poor within those countries have higher levels of HIV at all times. Macro-level studies that simply correlate poverty rates with HIV often fall down in their conclusions because there is an assumed constant and context-independent direction of causal effect, which may not always be the case. In addition, poverty itself does not have a specific outcome in terms of sexual practices" (p10).

The alternative is micro-based studies which focus on specific factors in HIV transmission (eg: shared needles among injecting drug users; "trading sex for survival needs"). So, poverty could lead to more HIV risk-taking behaviours.

Mufune (2015) preferred a more complex model of the link between poverty and HIV/AIDS, which includes both macro- and micro-based studies (figure 4.1). Three aspects of poverty are important:



(Based on Mufune 2015 figure 1 p14)

Figure 4.1. - Links between poverty and HIV/AIDS.

i) Material deprivation - eg: an individual hungry today may exchange sex for food having full awareness of the risk.

ii) Vulnerability - eg: commercial sex workers; individuals experiencing partner violence

iii) Exclusion - eg: through lack of education.

Mufune (2015) stated: "In the literature the 'poverty HIV/AIDS relationship' is usually expressed in a singular, decontextualised and unchanging way (the way that, say, exposure to ultra-violet radiation affects skin cancer rates). The literature is not particularly good at recognising that poor people are not poor in the same way and do not have the same living circumstances or similar incomes or skills... Poverty is therefore a complex, multi-dimensional concept that relates to inequalities, material deprivation, and exclusion. All these must be taken into account in relation to HIV/AIDS. Consequently, there are multiple ways that the situation of poverty manifests in HIV exposure" (p24).

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5. EVALUATING HEALTH PROMOTION PROGRAMMES - SOME EXAMPLES

5.1. OBESITY

The concern about rising obesity in the West, particularly among the young, has led to school-based programmes to deal with it. There has been a decade of such programmes in the USA, and the rates of obesity among the young have not changed (Nanney et al 2014). There have been a variety of different programmes, but evaluating them is a problem.

The School Obesity-Related Policy Evaluation (ScOPE) was designed for administrators to evaluate school programmes. It makes use of multiple sources of data on school food and physical activity policies. For example, questionnaires are used to assess mean daily fruit and vegetable intake, mean soda consumption, and physical activity levels. There are also criteria by which to evaluate school practice - eg: "fruit/vegetables available at school events", "vending machine or school store is available for students to purchase snacks/bars" (Nanney et al 2014).

5.1.1. Health Promoting Schools

The World Health Organisation (WHO) was behind the Health Promoting Schools (HPS) scheme (table 5.1) started in 1995 to encourage "healthy structures" and develop the link between health and education (Fathi et al 2014).

- Fosters health and learning.
- Engages with health and education officials, teachers, teachers' unions, students, parents, health providers and community leaders in efforts to make the school a healthy place.
- Strives to provide a healthy environment, school health education, and school health services along with school/community projects and outreach, health promotion programmes for staff, nutrition and food safety programmes, opportunities for physical education and recreation, and programmes for counselling, social support and mental health

promotion.

- Implements policies and practices that respect an individual's well being and dignity, provide multiple opportunities for success, and acknowledge good efforts and intentions as well as personal achievements.

- Strives to improve the health of school personnel, families and community members as well as pupils; and works with community leaders to help them understand how the community contributes to, or undermines, health and education.

(Source: http://www.who.int/school_youth_health/gshi/hps/en/; accessed 17/12/2014)

Table 5.1 - Characteristics of a health promoting school.

The success of the HPS scheme around the world depends upon overcoming a number of obstacles, including insufficient preparedness of schools, and lack of resources (St Leger 2001).

Specifically, in Iran, Fathi et al (2014) found five sets of barriers in their evaluation of the HPS scheme from interviews with fourteen participants (eg: school health experts). These barriers were:

i) Lack of collaboration between different levels of administration and bodies involved (eg: local government, Ministries of Education, and Health).

ii) General policy aims of HPS not adapted to specific cultural situations.

iii) Unprepared infrastructure - eg: the designing of the school environment to encourage physical exercise including green spaces can be costly.

iv) Problems in human resources - eg: lack of specialist staff.

v) Limited public participation - eg: lack of collaboration of parents.

5.2. "SWINE FLU"

Recommended behaviour change in response to pubic health advice about pandemic influenza, for example, is varied. Older, female, more educated, or non-White individuals are more likely to respond to preventive messages (eg: hand hygiene). Greater perceived susceptibility to and perceived severity of the disease are also relevant (Bish and Michie 2010; appendix 5A) along with greater national level anxiety, and greater trust in the authorities (Crosier et al 2015).

Crosier et al (2015) reported on the Effective

Communication in Outbreak Management (E.Com) project, which looked for lessons from the 2009 H1N1 "swine flu" pandemic. Interviews with involved communication specialists, policy advisors, and social scientists in England, Italy and Hungary in 2013 were analysed. Four main themes emerged:

1. Understanding of audiences - There was no research about the best content, design, tone, emotional appeal, or targeting of communications to the general public or health professionals, mostly because of "an emergency mindset". "None of the respondents considered the lack of audience research to inform the content of their campaigns, or to target messages at different groups, an important omission. They reasoned that the key prevention messages applied to all groups in society, and that as a result there was no need to segment the audience for the purpose of communications" (Crosier et al 2015 p136).

2. Message content and tone - The tone was serious about the risks, but with the reassurance about the appropriate measures.

3. Communication channels and social media - Social media and the Internet were viewed as an obstacle to communication by the respondents. Speaking about the Internet, one expert said: you don't know if the information is trustworthy or not", and alternative views proposed by celebrities, who are more famous than doctors, has greater influence.

4. A failure to evaluate - Only in England was there a government-funded evaluation of public attitudes and behaviours during and after the pandemic.

Crosier et al (2015) viewed the response of the governments in terms of communication as poor: "the growing scientific literature on behaviour change demonstrates that tailored messages focusing on known motivators for specific groups are more likely to produce desired behavioural outcomes than a uniform information giving or instructional campaign. Evidence from public health areas other than pandemic influenza, indicates that well-planned and sustained health promotion programmes that are informed by – and respond to – the various needs and motivations of different audiences, can make a significant impact on disease prevention, management, early diagnosis and compliance with treatment" (p138).

5.3. FOOD LABELS

The belief of policy-makers that there is a link between food choice and disease has produced strategies to influence the eating habits of the population, including "fat tax" (on high-fat foods; eg: in Denmark), and subsides for fresh fruit and vegetables. This has come from the "market success" of cheap processed food which is producing a "public health disaster". But the strategies used are not necessarily effective - for example, in Denmark the "fat tax" was abolished in 2012 for having a negative economic effect (Mayers 2014).

One strategy that has been used widely is the nutritional information food label. Though there is disagreement about what should be included on them between the food industry and public health advocates, say, "there is near universal agreement that more information is a good thing" (Mayers 2014).

Mayers (2014) argued that food labels can be seen as a means by which neoliberal governments "normalise subjects as responsible for health via consumer choice, while eliding the social determinants of health antecedent to choice. So, individuals "that make 'healthy' choices are recognised as responsible and good citizens, while those that fail can be stigmatised as irresponsible and culpable for any disease that may result" (Mayers 2014 p385).

It is not that Mayers (2014) is critical of food labels, but that the information given about food "is imbued with relations of power that shape behaviours towards specific norms" (as power and knowledge go together according to Foucault).

Bauman (2000) stated that in "the land of the individual freedom of choice the option to escape normalisation and to refuse participation in the normalising game is emphatically not on the agenda" (quoted in Mayers 2014).

If food labels and healthy choices construct the "healthy consumer", this can be challenged by "critique" ("the art of not being governed quite so much") (Foucault 1997). Put simply, a questioning of the underlying norms, which in this case is the responsibility of the individual for their health.

Mayers (2014) presented "alternative food systems" (eg: farmers' markets) as a possible "critique": "Farmers' markets, community-supported agriculture or the slow food movement are not free from the impulses of the food industry or immune from neoliberal governmental strategies... My intention is simply to indicate that certain practices within these systems can be used in the formulation of an ethics of the self that critique and resists the conducting strategies of neoliberal

governmentality" (pp388-389) [30].

5.4. APPENDIX 5A - PROTECTIVE BEHAVIOURS

There are three types of protective behaviours in response to an influenza pandemic (Bish and Michie 2010):

i) Preventive - eg: hand washing, cleaning surfaces.

ii) Avoidant - eg: avoiding crowds, quarantine restrictions.

iii) Management - eg: taking medication, seeking help from health professionals.

Bish and Michie (2010) carried out a literature search for pandemics since 2002 in order to understand the factors that influence the performance of the protective behaviours. Twenty-six relevant papers (covering twenty studies) were found. The following demographic variables were extracted from the studies:

i) Age - Older adults are more likely to carry out preventive behaviours (like mask wearing, hand washing) (eg: cross-sectional studies in Singapore and Hong Kong during SARS outbreak in 2002-3), but not all studies had this finding.

ii) Gender - Most studies found that women are more likely than men to carry out behaviours (eg: an Australian study about intentions to comply with home quarantine restrictions in a future pandemic).

iii) Ethnicity - Few studies have looked at this variable, but a UK study did find that non-White individuals were more likely to take avoidant behaviours than Whites.

iv) Education level - Generally clear pattern that

[30] "Governmentality" is a concept used by Foucault (eg: 2007). In modern Western democracies, governments govern in ways beyond imposing laws. "To conduct the conduct of individuals, communities or populations ‘is not a matter of imposing a law’ but employing tactics to arrange ‘things so that this or that end may be achieved through a certain number of means’ (Foucault 2007)" (Mayers 2014 p379). There is a "governing through choice and freedom" (Mayers 2014). Put simply, individuals are constructed in terms of their behaviour through norms and the environment. "By reconceiving the subject as an entrepreneur of his or herself, all choices and activities of life, not just labour, are transformed into investments and incomes that ‘may or may not improve human capital’... In rethinking the subject as an entrepreneur who is free to choose to invest in their self, neoliberal homo oeconomicus becomes governable through systematic ‘modifications in the variables of the environment’" (Mayers 2014 p380). In one sense, the individual is governing themselves in an "artificially arranged" environment (Mayers 2014).

more educated people take protective behaviours.

v) Marital status - Inconclusive, particularly as few studies.

Bish and Michie (2010) summarised the psychological variables that were associated with carrying out the protective behaviours:

1. Perceived susceptibility to the disease - Concern or worry about developing the disease, and estimates of risk or likelihood of getting the disease all clearly associated with protective behaviours.

2. Perceived severity of disease - eg: association between this variable for "swine flu" in the UK and hand washing.

3. Perceived efficacy of behaviours - Belief that the protective behaviours would work was linked to their performance (eg: mask wearing to protect against SARS).

4. Perceived costs of behaviours - Only covered by a few studies, but perceived costs reduced the performance of the behaviours (eg: nowhere to dispose of tissues reduced their use).

5. Perceived self-efficacy - This is the individual's perceived ability to carry out the protective behaviours or avoid infection - eg: an Internet survey found that high perceived self-efficacy associated with avoidant behaviours.

6. Social norms - Social pressure to perform protective behaviours can encourage their use.

7. Cues to action - Perceived symptoms of the disease prompted precautionary behaviours.

8. State anxiety - This is an individual's level of general anxiety, and more of it is associated with precautionary behaviours.

9. Perceptions about communications from authority - Perceptions of clear and consistent communication from authorities leads to precautionary behaviours.

10. Knowledge - Generally more knowledge about the subject was associated with more protective behaviours.

5.4.1. Doing the Opposite - Seeking Risk

Robinson (2014) proposed that the dominance of

HIV/AIDS and public health discourse in relation to gay men's sexuality and sexual practices has created the "'proper', healthy gay citizen" - ie: "one who is HIV-negative and follows 'safe sex' practices, preferably through monogamy, is the ideal gay man who every male sexual minority should strive to be" (p236).

Sexual health promotion sends the message of personal risk reduction, through, for example, condom use. Individuals are portrayed as rational actors who choose to avoid HIV infection. This fits with Max Weber's (eg: 1930) idea of rationalisation, which "involves systematic rules that each individual should methodically follow in order to achieve a certain (rational) end, and the means used to achieve this end does not involve emotions, irrationality or regard for others" (Robinson 2014 p239).

But how to make sense of gay men who choose not to use a condom ("barebacking")? [31] These are "irrational" actors, who become seen as "Other" (Robinson 2014). Some men who bareback responded against the norms and "oughts" of rational health promotion, showing that they "refused to go quietly into the ghetto of desexualised quarantine" (Gonzalez 2010 quoted in Robinson 2014). Gauthier and Forsyth's (1999) analysis of websites and chat rooms found that "resistance" as well as "that fear of infection inhibited their behaviour... that their perceived quality of life had diminished to unacceptable low levels" (quoted in Robinson 2014).

As Robinson (2014) emphasised: "There could be a 'relief' in contracting HIV, as the fear of infection that inhibited one's behaviour is gone, and depending upon one's socioeconomic status, one's HIV could be medically manageable... In having nothing to lose in engaging in condomless sex anymore, some gay men who bareback, and especially those who have a positive serostatus, feel that they have re-gained control over their sex lives and from HIV, which has dominated their sexual relations for so long" (p244). Even a form of eroticisation of the risky, and "new modes of being" (Robinson 2014).

Rationalisation, according to Weber, can become an "iron cage", where all is routinised and without "mystery" (a "disenchantment of the world"). Robinson (2014) stated: "some gay men who bareback may be seeking re-enchantment in this disenchanted sexual universe.

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[31] Based on a literature review of twenty-one quantitative studies of barebacking, Gallen and Tomas (2015) found several risk factors, including:

i) Internet - to meet like-minded partners.

ii) Age - younger men more likely.

iii) Substance use - eg: alcohol and reduction of inhibitions.

iii) Sexual role identity - eg: self-identification with receptive/passive role as riskier.

Overall, perception of risk was low.

Barebacking may allow a breaking from the mundane, unspontaneous 'safe sex' discourse, and a finding of new ways to experience love, intimacy, pleasure and the erotic. In escaping the disciplining of contracting HIV, some gay men who bareback begin to focus on what society has constructed as the spontaneity of the erotic, and these men may privilege this form of intimacy over the disciplining sexual health discourse. Even more so, I suggest that HIV-negative men, who may want to contract HIV, completely move outside of the sexual health discourse and the spectre of HIV. These men try not to live in fear of contracting the disease anymore. In seeking to experience this 'unlimited intimacy', these men who bareback may engender a new life - a life that is not completely mundane and routinised" (p246).

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6. ALCOHOL IMAGERY ON TELEVISION AND ALCOHOL CONSUMPTION IN THE UK

- How much?
- Effects
- Appendix 6A - Energy drink consumption
- References

Understanding the relationship between seeing alcohol imagery on television [32] and alcohol consumption requires two types of study. Firstly, descriptive studies of the quantity of imagery, and then studies of the effect of seeing that imagery.

How Much?

Alcohol imagery is common in popular television programmes. For example, in the UK in 2005, Cumberbatch and Gauntlett (2005) counted an average of twelve alcohol-related scenes per hour in ten programmes watched by 10-15 year-olds, with over one-third of their major characters identified as drinkers.

More recently, Lyons et al (2014) reported alcohol imagery in over 40% of programmes between 6-10 pm on the five national free-to-air channels in the UK in 2010 [33]. Three different weeks in this year were analysed in one-minute intervals using five categories (table 6.1).

1. Alcohol use - actual use of alcohol on-screen by any character.

2. Implied alcohol use - the presence of any implied but not actual use, categorised as a visible appearance of an alcoholic drink but without consumption, or a verbal reference to alcohol use (eg: ordering a drink).

3. Other reference to alcohol - reference to alcohol without actual or implied use (eg: beer pumps behind a bar in the background of a scene) or a verbal or written reference to alcohol that was unrelated to actual or implied current use.

4. Alcohol brand appearance - clear, unambiguous alcohol branding on-screen.

5. Any alcohol - the presence of any of the above.

(Source: Lyons et al 2014 p427)

Table 6.1 - Categories of coding.

[32] Marketing strategies play a role in energy drink consumption (Striley and Khan 2014) (appendix 6A).

[33] BBC1 and 2, and commercial channels, ITV1, Channel 4 and Channel 5.

There were 420 hours of broadcasting, 613 programmes, 1121 advertisement breaks, and 25 210 one-minute intervals in the sample. Alcohol appeared on average once every nine minutes of broadcasting [34].

Lyons et al (2014) concluded: "Our findings thus demonstrate that prime-time television is a major source of exposure to alcohol imagery among children, and as such is likely to be contributing to uptake and consumption of alcohol among young people in the UK. Tighter regulation of advertising and promotion of alcoholic drinks, including promotion through sporting events, has been proposed as a means to reduce consumption among children and young people; our findings suggest that such measures should include television programme content as well as advertising, particularly before the 9 p.m. watershed" (p432) [35].

Effects

Alcohol advertising and marketing increase alcohol consumption among young people, as well as a younger initiation of alcohol use, and consuming alcohol without parental knowledge by children and adolescents (Lyons et al 2014) [36]. Cross-sectional studies, which compare groups at one point in time (eg: exposure to alcohol advertising vs not), support this conclusion (eg: Hanewinkel et al 2007; exposure to alcohol use in contemporary movies and adolescent alcohol use without parental knowledge and binge drinking in Germany).

There are a few dissenting voices to the effect of alcohol advertising (usually supported by the alcohol industry). The problem is establishing a causal link between advertising and behaviour.

The method to use here is the prospective cohort (longitudinal) study, which controls for confounding variables like family and peer drinking. This method measures exposure to alcohol advertising at baseline, and subsequent alcohol consumption. The nature of time in this situation means that the relationship has to be in one direction (rather than the two-way relationship of correlations).

Smith and Foxcroft (2009) performed a systematic review of seven cohort studies on the subject up to October 2006. Three criteria for inclusion of a study

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[34] This compares to every six minutes in 1988 (Smith et al 1988), and every 3.2 minutes on popular soap operas in 1997 (Furnham et al 1997) in the UK.

[35] It was calculated that a ban on alcohol advertising in the USA, for example, could reduce youth drinking by about a quarter and their binge drinking by nearly a half (Smith and Foxcroft 2009).

[36] For example, over 90% of 15-16 year-olds have drunk alcohol at least once, while one in eight of them have been drunk more than twenty times in their lives (Anderson et al 2009).

were used - young people (10-26 year-olds), alcohol advertising in broadcast and print media, and actual alcohol consumption (as opposed to intention to drink) (usually self-reported) [37]. All the studies showed significant associations between prior exposure to alcohol advertising and marketing and subsequent alcohol drinking behaviour, including earlier age of onset and increased consumption.

But the studies were unable to explain how advertising led to drinking, and "what aspects of advertising and marketing are the active components" (Smith and Foxcroft 2009). Anderson et al (2009) pointed out that "the duration of advertising effects need to be taken into account: a powerful campaign may continue to have an effect years after it was first deployed. Indeed, advertisers deliberately try to enhance these long-term effects as part of their effort to build brands" (p230).

The studies also had a high drop-out rate (Smith and Foxcroft 2009).

A similar systematic review was performed by Anderson et al (2009). They included thirteen longitudinal studies up to September 2008 that covered 10-21 year-olds [38]. Twelve of the studies supported the link between advertising and alcohol drinking, and the other study found an effect on intention to drink.

Anderson et al (2009) observed that "both cross-sectional and longitudinal studies are likely to underestimate any effects, because they focus principally on advertising, which is only a part of the promotional effort that is put behind alcohol products... While some of the selected studies looked at promotion (eg: merchandising) as well as advertising, none looked at the cumulative impact that a coherent and fully fledged 'marketing communications mix'... may have. This communication effort is, in turn, only part of a company's marketing strategy that also includes price promotions, packaging, distribution and product design" (pp241-242). For example, around £200 m was spent in the UK in 2003 on alcohol mass media advertising, but this is nearer £800 m when including promotions like point of sale, and electronic communication (Anderson et al 2009) [39].

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[37] The studies varied in methodology - eg: follow-up at 1 year vs 14 years; exposure to advertising (eg: self-reported); drinking (past month vs year); advertisements, music videos or contemporary movies. Five of the studies were from the USA.

[38] Including the same seven studies as Smith and Foxcroft (2009).

[39] Advertising and marketing does not necessarily tell the truth. For example, Pitts et al (2014) found that foods high in fat and/or sugar were more likely to be marketed as low in another ingredient (eg: low calorie). This made use of the "halo effect" - "that consumers tend to generalise nutritional claims, interpreting a low fat or low calorie claim as indicating that the food is healthier overall" (Pitts et al

APPENDIX 6A - ENERGY DRINK CONSUMPTION

Caffeine is consumed by the majority of adults in coffee, tea, and chocolate, but also, in recent years, in energy drinks and carbonated beverages. DSM5 recognises caffeine intoxication at high doses, caffeine withdrawal, and caffeine use disorder (CUD) [40], while ICD-10 refers to caffeine dependence (Striley and Khan 2014).

The consumption of caffeine in energy drinks is particularly problematic - eg: increased visits to emergency departments for adolescents with adverse effects (between 2007 and 2011). The mixing of energy drinks with alcohol (AmED) is a further risk (Striley and Khan 2014).

In terms of the frequency of energy drink consumption generally, an Italian study found that 1.3% of 11-13 year-olds consumed them daily [41] and 5.5% weekly (Gallimberti et al 2013). In studies of older students, up to half of respondents have "current consumption". But this term can vary between studies - eg: one or two drinks in last thirty days (Striley and Khan 2014).

In New Zealand, Bunting et al (2013) used focus groups with 16-35 year-olds. The older respondents (29-35 year-olds) were more likely to consume energy drinks with alcohol, though they admitted to health concerns about it.

Jackson et al (2013) studied a random sample of 169 13-25 year-olds at a US emergency department. Just over half had consumed energy drinks in the last month, and these individuals were significantly more likely to report a shortage of money, getting into trouble, mind

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2014). Furthermore, they stated: "Whilst it is quite possible that a food can be high in one particular less healthy nutrient and low in another, consumers do not necessarily recognize these nuances. Our results suggest that manufacturers and marketers may be exploiting these nuances and the 'halo effect' to their own, rather than consumers', advantage. This is particularly worrying given the greater tendency we found for 'foods high in fat and/or sugar' to be marketed using 'light' and 'reduced' marketing messages. Such messages may encourage consumers to believe that these products are healthier, despite them falling in to a food group that current UK recommendations suggest should only be consumed in 'small amounts'" (Pitts et al 2014 p423). Pitts et al (2014) performed a content analysis of 726 advertisements for food and alcohol in 108 issues of popular UK monthly women's magazines in 2008.

[40] Key symptoms - efforts (unsuccessful) to cut down; continued use despite problems from caffeine; withdrawal (Striley and Khan 2014).

[41] This compared to 40% of adult men in a US study (Wimer and Levant 2013).

racing, and restlessness/jitteriness than non-drinkers. This study was self-reports.

But Kurtz et al (2013) performed an experiment to isolate the physiological effects of caffeine in energy drinks. Volunteers were given a caffeinated or decaffeinated energy drink in a double blind condition, and later the opposite as this was a crossover study. They were monitored for three hours after consumption. Blood pressure significantly increased after the caffeinated drink. The two types of drinks contained the same other ingredients.

Concerning the combination of energy drinks and alcohol, a Brazilian study of over 12000 students (Eckschmidt et al 2013) found that AmED consumers were more likely to be male, single, and participate in high-risk drinking behaviour (eg: high frequency of drinking; binge drinking). These individuals were also over twice as likely to drive at high speeds (ie: high-risk traffic behaviours) as well as having a greater risk of "being taken advantage of sexually" or "taking advantage of someone else sexually".

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7. PHYSICAL ACTIVITY: TWO DIFFERENT ASPECTS

7.1. NEIGHBOURHOOD

The characteristics of a neighbourhood or local environment can influence level of physical activity (PA) and exercise. These characteristics include "pedestrian infrastructure" (eg: presence or absence of pavements; their quality or condition), and amount of traffic, as well as personal safety (Kwarteng et al 2014).

Using data from over 900 individuals in The Healthy Environments Partnership (HEP) in low-to-moderate income areas of Detroit, USA, in 2002-3, Kwarteng et al (2014) examined the perception of the neighbourhood, sidewalk condition and PA. Four main measures were taken:

i) PA - number of minutes of PA, self-reported, based on level of energy expended (eg: vigorous, moderate).

ii) Perceptions of neighbourhood physical environment - seven items (eg: "there is heavy car or truck traffic in my neighbourhood").

iii) Perceptions of neighbourhood social environment - six items (eg: frequency of gang activity).

iv) Condition of sidewalk (pavement) and street (road [42]) as rated by observers.

The researchers found that the condition of the sidewalk (but not the street) was positively associated with PA. In other words, more PA in neighbourhoods with sidewalks in good condition, and less PA in areas with poor quality sidewalks. This relationship was stronger for younger participants (25-37 years old) than older ones, but did not vary with perceptions of neighbourhood physical or social environment. The perception of neighbourhood social environment (ie: level of social disorder) was negative associated with PA for White participants and older residents only.

This study has the following limitations in relation to the measurement of PA:

- It was self-reported. Objective measures of PA would be

[42] Area used by traffic.

better (eg: wearing GPS device).

- The type of PA was not distinguished (eg: walking to shops; jogging).

- No account was taken of location of PA. It is possible that individuals were active outside their residential neighbourhoods.

The findings were correlational (ie: not causal), so it was not possible to say "whether sidewalk condition is actually an antecedent of PA, or whether neighbourhoods with more sedentary populations are less likely to invest in sidewalk maintenance" (Kwarteng et al 2014 p365).

7.2. OBESITY

The information available about health and obesity is "part of an array of obesity-related messages so vast that any adult female living in North America would be hard-pressed to miss the alarm about the obesity epidemic or the common health prescription for women at 'risk' of overweight or obesity: weight loss through lifestyle change (diet and exercise)" (Dumas et al 2014 p140).

Three challenges to "obesity science" by scholars and activists can be distinguished - questioning the idea that obesity causes ill health, positive "fat" messages (ie: "fat acceptance"), and the neoliberal emphasis on individual responsibility (sometimes called "healthism"; Crawford 1980; which ends up blaming the victim) (Dumas et al 2014).

Health promotion programmes for obesity tend to encourage a healthy lifestyle, and to place responsibility upon the individual. But there are problems with this approach for individuals from socio-economically deprived groups. For example, such individuals have strong present-time orientation (or short-termism), and respond to needs immediately. "In other words, conditions of necessity underline concerns for health improvement 'when there are so many things that come first' (Bourdieu 1984)" (Dumas et al 2014 p142) [43] [44].

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[43] Bourdieu (1984) talked of the "choice of the necessary".

[44] There are three key concepts in Bourdieu's (1984) theory - "field", "habitus", and "capital". "Field" is the term for a social setting in which individuals have social positions (eg: family or employment setting), while "habitus" is "a socially regulated (structured), largely unconscious set of attitudes and habits of thought and feeling that guide the social actor in their actions within specific fields" (Robinson and Robertson 2014 p341). "Habitus" can be gendered, and is quite determined by socialisation. But it can change as in "'women entering the workforce after child-rearing' encountering incompatibilities between habitus of the domestic field and the 'objective requirements of the workplace' (McNay 1999)" (Robinson and Robertson 2014 p343).

Dumas et al's (2014) interviews with fifteen young underprivileged women in Quebec, Canada, showed "the manner in which the participants' health and weight management practices were influenced by their immediate needs and responsibilities, as well as their embodied social knowledge for how to cope with stress and responsibilities – despite their awareness of normative health guidelines" (p139).

Living "day by day" or "within the moment" was dominant. This can be seen in what "Dominique" (mother of three with partner) said: "I don't have the will nor the guts to do exercise or anything. Our budget doesn't allow us to exercise or do any sort of activity, you know? If I wanted to sign up at Curves [an exercise facility for women] or a gym, well it costs a lot of money! And I have three kids, so their activities come first. As for food, healthy foods are the most expensive. We are a family of five, so I have to take my budget into consideration; we must have enough food for the month. I have to keep track of these things. But I find I have no will, no energy..." (Dumas et al 2014 p145).

Single mother, "Jacqueline" reported similar issues: "At the moment, I'm taking care of my three kids by myself and I'm always running around for them. But we still walk sometimes; we play outside and in the snow. I don't play any sports or do any sort of formal physical activity right now, but it's because I don't really have the time either. I have to manage my time and finish my education. If I did have the time, I'd like to train or to hit a punching bag. But as I said, I don't have the time, so I take care of my kids, and I do a lot of cleaning!" (Dumas et al 2014 p146) [45].

Dumas et al (2014) summed up: "Several women face barriers and pressing concerns, compelling them to fulfil imminent needs and respond to social norms rather than engaging in health practices or weight control strategies in order to avoid future and intangible health complications" (p151).

"Capital" can take different forms - economic, cultural ("the ability to negotiate cultural rules of good taste in order to obtain and sustain social distinction"), social ("social connections or networks that enable the actor to make use of, gain access to or profit from other forms of capital"), and symbolic ("power that comes with social position, conferring on the bearer prestige, honour and recognition granted by diverse social groups") (Robinson and Robertson 2014 p341).

[45] In relation to class, Dumas et al (2014) described how "underprivileged and working class conditions bring about a conception of the body as a tool or a means to an end in order to fulfil imminent necessities (for example, acquiring food and shelter, taking care of their children). As such, the tastes and preferences in food, physical activity and bodily appearances of underprivileged groups have a tendency to differ from upper class women who, in turn, hold a reflexive relation to the body and who perceive the body as a project and an end in itself" (p142).

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8. HEALTH WORKERS AND ALTRUISM AS A MOTIVATION

- Appendix 8A - Emotional labour and care workers
- Appendix 8B - Care as gift
- References

In low- and middle-income countries, there is concern over the movement of health workers from rural to urban areas, and leaving to go to higher-income countries. A number of factors have been proposed to explain the movements, including working conditions, and financial incentives (Smith et al 2013).

However, financial incentives to stay may not be as powerful as altruistic motivations (eg: helping others in community) [46]. Smith et al (2013) showed this in an experimental game study with over 1000 student nurses in Kenya, South Africa, and Thailand. The "dictator game", commonly used in economics, was adapted for the study. It involves giving one player of a pair a sum of money, which they can share as they wish. The amount given to the partner is taken as the measure of altruism of the player. The average in studies with economics and business students in the USA and Europe is less than 10% (eg: Eckel and Grossman 1996).

The pair of players are usually unseen and anonymous. In fact, there is not a second player. It is the creation of a scenario to measure the willingness of the individual to share a gift/endowment.

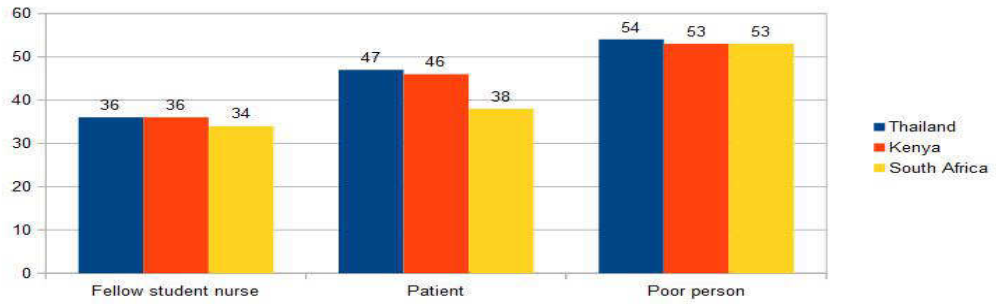
Smith et al (2013) got the student nurses to play three times, and told them only that the partner was a fellow student nurse, a patient, or a poor person. The sum of money was the equivalent to the daily starting wage of a nurse in their country. After the game, the participants completed a questionnaire about attitudes, values and motivations.

The student nurses gave about one-third of the money away to the other player. Smith et al (2013) noted that this finding "would fit with the more qualitative and anecdotal evidence concerning the importance of altruism for those who enter the medical professions" (p168). The amount varied depending on the other player (eg: around half given to a poor person), and the country (eg: slightly higher in Thailand) (figure 8.1). The number of nurses who gave nothing was small (figure 8.2).

Giving money away was found to be associated with certain characteristics of the student nurses - older

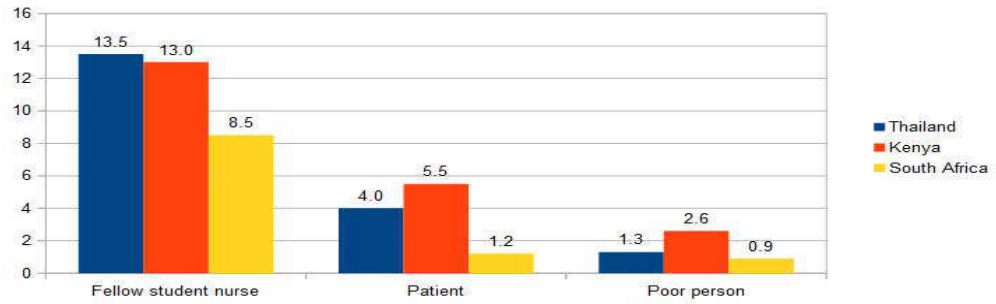
[46] There is interest in the emotional life and aspects of work of health and care workers (appendix 8A).

(generally, but strongest in fellow student nurse condition), and being female, and having children in the poor person condition. Individuals who reported financial motivations tended to give less to the partner.



(Data from Smith et al 2013 table 1 p167)

Figure 8.1 - Mean percentage donated to partner.



(Data from Smith et al 2013 table 1 p167)

Figure 8.2 - Percentage of student nurses who donated nothing.

APPENDIX 8A - EMOTIONAL LABOUR AND CARE WORKERS

Nursing in the West today has undergone the "processes of professionalisation, medicalisation and technicisation... - high level of professional accountability, rigid structural and regulatory control and increasing technological and medical specialisation" (Johnson 2015 p112) [47]. This has meant that non-technical, emotional tasks have been transferred down the workplace hierarchy to, for example, care workers. This involves "emotional labour" (Hochschild 1983).

Originally described in relation to flight attendants, it is the process of managing emotions to fit the workplace demands (eg: smiling at each customer

[47] Stacey (2011) argued that self-interest becomes the way to find meaning if care work is devalued.

whatever happens). "Surface acting" is displaying the correct emotions demanded by the employers, while "deep acting" is producing the "real feeling".

"Hochschild's research led her to express concern about the emotional costs for workers when these, formerly private, acts of emotion management come to be bought and sold as a form of labour (emotional labour) and, in turn, instrumentalised and standardised by company prescribed feeling rules and rules of display... Hochschild's focus was on the manner in which the commercialisation of emotional exchanges has subordinated a private emotional system to commercial logic and, in doing so, has transformed it, eliminating the worker's right to command what is given in social interaction and to whom... For Hochschild, when a profit motive is placed beneath these aspects of emotional life they are transmuted and it becomes necessary for the worker to relinquish control over how her work is to be carried out, leaving her role deskilled and devalued" (Johnson 2015 p113), and a feeling of estrangement between the self and feelings.

Johnson (2015) explored this work in a study of care workers in a private residential home for the elderly in southern England. The company ("Oakwood") that owned the home explicitly encouraged "emotional labour" with the concept of "the good worker". Johnson (2015) looked at publicly available documents and the company training material, and undertook participant observation at an induction training week for new employees as well as interviews with six new recruits after the training and one year later.

Johnson (2015) highlighted the following themes from her analysis:

1. The naturalisation of emotional labour - The company used phrases like "real happiness and joy come from serving others", and "born to care", while the recruits referred to themselves as "naturally" caring. Thus the low wages paid (as is common in this job sector) were not questioned. "It appeared that, because the carers had naturalised a key aspect of their role – emotional labour – they undervalued their work and felt that, without emphasising the technical and learnt aspects of their role, they would have weak grounds for expecting higher wages" (Johnson 2015 p117) [48].

2. Motivations to care: altruism as a resource - Because the workers were "born carers", then care work

[48] This can be seen more generally in the financial undervaluing of work seen as "natural" and/or "feminine" (as in caring and nurturing) (Ehrenreich and Hochschild 2002).

was the obvious profession - "Five of the six new recruits described their motivations to become carers in terms of how the role would allow them to express their philanthropic nature and realise their true self. 'Wendy', for example, who had previously cared for her mother, stated: 'I need to pass that care I have on to somebody else' and suggested that care-work would allow her to do this, providing 'that double whammy... a career and job satisfaction as well'" (Johnson 2015 p117).

Again this limited the employees' ability to challenge the low pay. "By defining the carers' work not only as natural but as naturally remunerated in the same moral currency of hugs and thank-yous (in what Oakwood's CEO unashamedly refers to as a 'second paycheque' in a video shown to new recruits) the company further undermined its employees' capacity to dispute their pay packets by causing them to evaluate their work in terms of sentiment" (Johnson 2015 p117).

3. Deep acting: the management of feeling rules - When a caring relationship is commercialised as in the care worker and resident, there is a risk of "surface acting" (ie: smiling without meaning it) [49], but the company encouraged "deep acting" by telling the workers "to behave towards residents 'as if' they were family or close friends" (Johnson 2015). This could lead to confusion between the self and the role (ie: over the carer's "real" family) (Johnson 2015).

4. Voluntarism - Taking the idea of treating the residents as "family" further, the workers came to evaluate their job in terms of doing extra for the clients - eg: "Sarah" said: "I came in, in my own time. I didn't get paid for it... and she [the resident] was really thankful for it and that made me happy" (Johnson 2015 p119).

This is "philanthropic emotion management" (Bolton and Boyd 2003): ie: "workers' activities that are motivated by a choice to surpass organisational prescriptions, displaying additional emotion to what a company requires in the form of a gift" (Johnson 2015 p119) (appendix 8B).

5. Maintaining a smile: surface acting - At the same time, it was recognised that the care workers may have to pretend sometimes - eg: "if you've got problems you put a front on" ("Josie"). Johnson (2015) noted that "while

[49] Also called "soulless convivality" (Gorz 1989) or "cold modern solution" (Hochschild 2003).

acknowledging that being positive at work would entail the maintenance of a front – surface acting – the carers sincerely defined the assumption of this front as a reflection of self; an offshoot of their ready-made capacity to care" (p121).

6. Carer vulnerability - Johnson (2015) stated: "the carer–resident relationship is one-way: it requires that the carer gives of herself without expecting anything from the resident in return... [So] there is a danger that the one-way nature of the carer–client relationship can be extended or taken advantage of. In the case of Oakwood, the vulnerability of the clients was, quite rightly, considered as a legitimate basis for the carers to manage their own emotional displays" (p121).

7. Emotional distress - The carers suffered a cost for their deep emotional attachment to the residents. "Sarah" said: "At the end of the day, if you don't feel emotional you don't care, and then you're not a carer. It's like when residents die and you get some people who are like 'Oh you'll get used to it' and I think 'Well... I'm showing my emotion because I care'... you do get emotionally attached to everyone" (p122).

8. Moral advocates: being critical of the company - At one level it seems that the workers by becoming emotionally involved with the residents were vulnerable to economic exploitation by the company [50]. But this was not the case. "Of the six experienced carers, those who appeared to most personalise their relationships with the residents (Sarah, Rachel and Jess) were also more likely to express scepticism over the moral integrity of the company. The sincerity with which they undertook their caring role; the heartfelt use of sentiment which they brought to it, was, ironically, what seemed to have led them to adopt a more critical attitude towards the corporate strategy of Oakwood" (Johnson 2015 p123).

However, ironically, "by making the residents the sole subjects of their moral concern, the carers had effectively suppressed their own moral interests, even refusing to complain about their own ill-treatment at the hands of difficult residents. Furthermore, as the carers' altruistic reasoning had caused them to disregard their

[50] Fevre (2000) described this as "demoralisation", where sentiments/emotions dominate in a social interaction which is about common sense/economics - "a category mistake which acts to persuade employees that the commercial transaction in which they are engaged is one in which moral rules of behaviour apply – one which must be interpreted in terms of sentiment" (Johnson 2015 p114).

economic interests, they also stood in danger of inviting the company to address their concerns by shifting the burden of care back to the already overworked carers – that is, by urging them to work harder in order to ensure that their virtuous aspirations of providing good quality care were realised" (Johnson 2015 pp123-124).

APPENDIX 8B - CARE AS GIFT

Fox (1995) distinguished "care-as-discipline" and "care-as-gift". "Care-as-gift refers to the idea that care may be 'based on relations which value giving, concern and enabling the person who is cared for' (Fox 1995 p111). Recognising that care may be exercised as love, trust and generosity, this account emphasises the altruistic rewards and satisfactions for care that may benefit individuals as well as society... Care-as-discipline emphasises care as an institutionalised set of practices that gives professionals the authority to care and to determine what it means to care" (MacBride-Stewart 2014 p88).

Furthermore, "when care is given as gift, it contains something of the giver. To accept a gift-of-care is to acknowledge that a gift may be a form of exchange not just by a person, but of the person. It is the relationship between the gift (whether a practice of respect or an object), the giver and the recipient, which suggests that gifts are unlikely to be given in a disinterested manner" (MacBride-Stewart 2014 p89).

MacBride-Stewart (2014) explored these ideas in interviews with thirty-two primary care doctors in Wales. Organisational changes in the National Health Service have meant that "care-as-discipline" can dominate, but MacBride-Stewart (2014) argued that "care-as-gift" "is not necessarily absent". Two key themes emerged from the interviews on "care-as-gift":

i) Doctors' satisfaction and rewards for "caring well".

ii) Medicine "is a good job" - eg: shorter working hours for doctors ultimately leads to better patient care ("Doctor 06" said: "you feel better able to deal with the requirements of the day"; p98).

The first theme is summed up by this quote from "Doctor 24": "Assisting patients to find solutions is one of the key factors of the job where one gets significant personal reward when you see that has actually worked out. Satisfaction actually comes from providing a good service with a good group of people. We have got changes to make and things to do and that's what interests me.

There is lots of satisfaction to be gained. It's not always a bed of rose petals... It's a difficult job... But it's a good job" (p94). Acknowledgements by patients of their care was important. As "Doctor 23" said: "when they say thank you... when they seem better. One dear little old chap comes in and says 'oh, you know, since I've seen you, I've never felt better, doctor'... It's when people say that you've made a difference and when people say 'I like coming to see you because you listen to me'" (p95).

MacBride-Stewart (2014) summed up: "From the data, 'caring well' does appear to represent an emotional connection that forms part of a holistic approach to care favoured by primary care doctors. That is, doctors' accounts of receiving positive feedback from patients served to reiterate their professional skill. It reflects the ways in which primary care doctors are doing professionally what they are expected to do. These accounts also support the view that patients welcome care that is generous and giving. 'Caring well' appears to confirm the quality of care only where it is taken as a measure of patient satisfaction. As we can see from the doctors' accounts, the satisfactions of patients and doctors were mutually rewarding" (p97).

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9. SOCIAL MARKETING

9.1. OUTLINE OF SOCIAL MARKETING

Around one hundred years ago ill health was due to infectious diseases, whereas today it is the high incidence of chronic degenerative diseases (eg: cancers). Also with changes in health related behaviours has emerged the term "health promotion", "virtually unknown until the late 1970s" (Parish 1995).

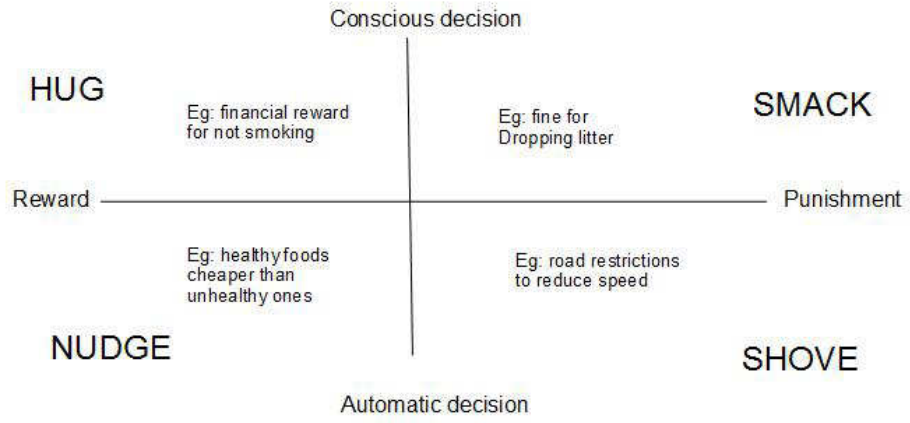
Paul Corrigan (a former government advisor on health in the UK) argued that public health has to be understood today in relation to "consumption experiences" or choices: "People enjoy consumption and the sense of being in control that it brings them. In these circumstances determining factors make a less powerful impact and the concept of external determining factors is less acceptable to people" (quoted in French 2010 p3).

Le Grand (2007) stated four criteria of modern public services and its professionals - trust (to deliver high-quality services), targets (for achieving these services), voice (of users), and the "other invisible hand" (ie: choice and competition) (appendix 9A).

"In this situation, state approaches to behaviour change that emphasise telling people what to do, or restricting behaviour by the force of law, can be doomed to failure unless they have the popular support of the vast majority of citizens" (French 2010 p4). From this situation has emerged a "new paternalism" which places responsibility on individuals, providers of public services, and private organisations to create the environment in which healthy choices can be made (French 2010). For example, in recent surveys in the UK, the vast majority of respondents agree that they are responsible for their own health (eg: 90%) as compared to the government (eg: 30%) (French 2010).

Out of this context has developed techniques like social marketing, and "nudging" to tackle health issues and unhealthy behaviours. Social marketing covers information, incentives and penalties, and changes to the environment to encourage positive health behaviours [51] (figure 9.1).

[51] French (2009) argued that "there is a close ideological match between social marketing and liberal democratic imperatives. [with] Social marketing's focus on outcome, return on investment and its emphasis on developing interventions that can respond to diverse needs..." (p262).



(Based on French et al 2011 figure 1.2 p17)

Figure 9.1 - Different aspects of changing behaviour.

The term "social marketing" was first coined by Kotler and Zaltman (1971) to refer to the application of marketing techniques to health and social issues. French and Blair-Stevens (2005) used the definition of "the systematic application of marketing, alongside other concepts and techniques, to achieve specific behavioural goals, for a social good".

Kotler and Zaltman (1971) distinguished sales which convinces customers to buy, and marketing that finds the wants of the target audiences and then creates the goods or services to fulfil them (Truss 2010).

Social marketing has a number of core principles (French 2009):

i) People at the centre - ie: "all interventions are based around and directly respond to the needs and wants of the person, rather than the person having to fit around the needs of the service or intervention" (pp262-263).

ii) Clear and measurable "behavioural goals".

iii) Developing "actionable insight" about behaviour.

iv) "Exchange" - change in behaviour (eg: smoking cessation) in exchange for valued gain (eg: better health).

v) "Competition" - ie: competing against marketing of unhealthy products.

vi) "Segmentation" - focusing on particular groups

that would benefit from behaviour change.

vii) "Intervention mix" and "marketing mix" - a combination of interventions.

"Social marketing's primary purpose is to achieve a particular 'social or public good' (ie: there is some benefit to individual, groups, communities, or society)" (French and Blair-Stevens 2010 p32).

Social marketing is also partly a response to the success of marketing by companies which produced unhealthy behaviours - eg: tobacco promotion influences young people to smoke; alcohol marketing and adolescent drinking (Hastings 2010). Examples of interventions include "Truth" [52] (a youth anti-tobacco campaign that highlights the tactics used by the tobacco industry to get young people to smoke), and "Food Dudes" [53] (a healthy eating programme for young children (4-11 years old) using cartoon "superheroes" [54]) (French 2009).

There is evidence to support the benefits of social marketing interventions in areas of health like (Stead and Gordon 2010):

- Nutrition - eg: increased fruit consumption; reduced fat intake.
- Substance misuse - eg: "Project SixTeen" (smoking prevention in adolescents); "Project Northland" (alcoholism prevention).
- Physical activity - eg: increased exercise.

9.2. NATURE OF MESSAGE

Public health campaigns attempt to persuade people to change their behaviours. Sometimes they succeed, sometimes they have no effect, and other times they can produce the opposite behaviour to desired. The nature of the message is important.

One aspect of this is the "message sensation value" (MSV). This describes features of a message that gain the attention of the target audience (eg: edit of visual message; emotionally arousing elements). Messages with a high MSV have greater processing than with low MSV generally (Xu 2015).

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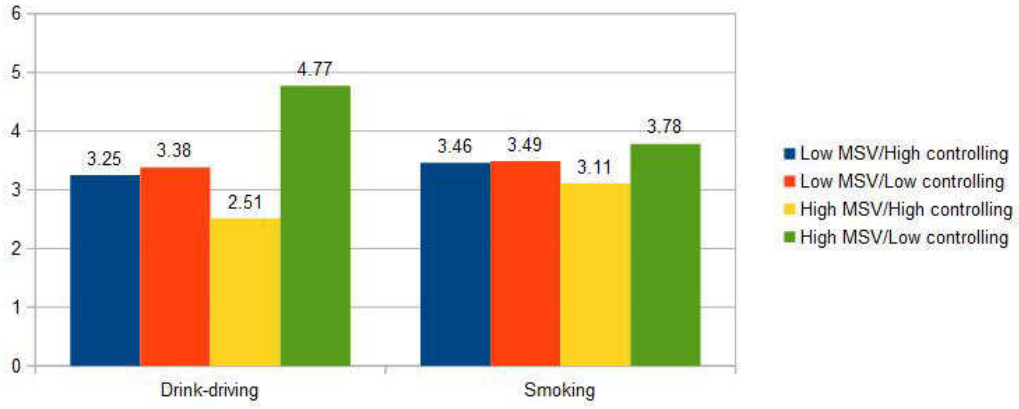
[52] http://www.protectthetruth.org/.

[53] http://www.fooddudes.co.uk/.

[54] The programme uses role modelling with "Food Dudes" defeating "General Junk" and "Junk Punks" in short cartoon films, and rewards (eg: stickers) for eating fruit and vegetables. In the Wolverhampton programme 61% of children increased their fruit and vegetable consumption (French et al 2011).

But graphic and arousing messages could backfire if the individual feels that restrictions are being placed on their valued behaviours. "A worst-case scenario would be to produce powerful health message campaigns successfully engaging the attention of... individuals, only to provoke them into frenzied efforts to take up the contra-advocated behaviours in anxious attempts at restoring newly threatened freedoms" (Miller and Quick 2010 quoted in Xu 2015 p426). A perceived threat to freedom can produce reactance (ie: reaction in the opposite direction to desired). "High controlling" messages, which use forceful language and explicit direction, can produce reactance (Xu 2015).

Xu (2015) varied the level of MSV (high/low) and controlling language (high/low) in experimental messages discouraging drink-driving, and smoking with undergraduates at a university in south-eastern USA. High controlling language messages used words like "must" and "should", while low messages had "can" and "possibly". After viewing one of four set of messages, the participants completed questionnaires, which included measures of perceived threat to freedom, and perceived effectiveness. The low controlling language/high MSV messages were rated as most effective for both behaviours (figure 9.2). This was stronger for individuals rated as low sensation-seekers than high [55]. The high controlling language/high MSV messages produced the highest anger score (taken as a measure of reactance) (figure 9.3).

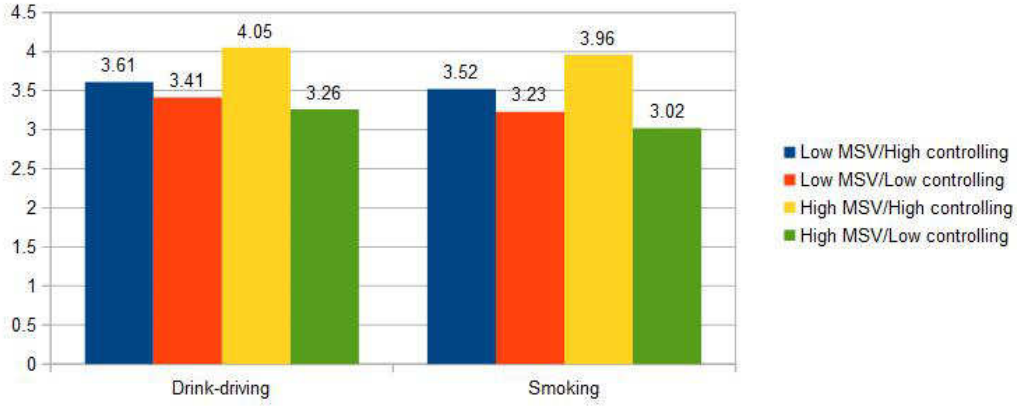


(Data from Xu 2015 figure 1 p431)

(Higher score = more effective)

Figure 9.2 - Mean perceived effectiveness of messages (out of 7).

[55] High sensation-seekers are often the target of health campaigns.



(Data from Xu 2015 figure 2 p432)

(Higher score = more anger)

Figure 9.3 - Mean rating of anger in response to messages (out of 7).

Overall, the participants responded well to high MSV/low controlling language messages - "high sensation may garner better perceived effectiveness when the ad tones down the controlling language without threatening the viewer's freedom. When individuals are confronted with their undesirable behaviour (smoking, drinking, etc) or told that they 'must, should, or cannot' do something, they are likely to become argumentative, deny the accuracy of the charge and assert their personal freedom" (Xu 2015 p436).

Nestler and Egloff (2010) found that an individual's level of cognitive avoidance influenced their response to a scary health message. Cognitive avoidance is the degree to which a individual thinks about threatening information, with high scorers coping by avoiding thinking about it. Nestler and Egloff (2010) scored cognitive avoidance with the Mainz Coping Inventory - Physical Threat (MCI-P) (Krohne et al 2000), which describes different situations (eg: visit to dentist) and offers cognitive avoidance reactions (eg: denial, attention diversion) as true or false for self.

The researchers presented 297 German students with an article about a new fictitious health risk from caffeine leading to gastrointestinal cancer [56]. The

[56] "It was described as an article from a professional medical journal and was entitled 'Caffeine Consumption and Xyelinenteritis (XE), a New Health Risk?'. Briefly, the article began by describing XE as a gastrointestinal disease. The article then described a (fictitious) study in the New England Journal of Medicine that had found a causal connection between XE and caffeine consumption. According to this report, caffeine inhibits an enzyme, esteroziamine, which controls the level of a toxic

participants read one of two versions, which varied on level of threat from health risk (ie: common or not). Low cognitive avoiders responded more favourably towards the high threat message, and high avoiders to the low threat message. This included the intention to reduce caffeine consumption.

9.3. APPENDIX 9A - PUBLIC SECTOR DECISION-MAKING

Phillips and Bana e Costa (2014) listed five factors that lead to poor decision-making in the public sector, and Bartlett et al (2014) applied them to the placing of women in secure hospitals:

i) Multiple and conflicting objectives - eg: courts vs clinicians.

ii) Insufficient detail about options - eg: limited experience of specialist health commissioners of female forensic patients' needs.

iii) Decision-making devolved in lower levels - eg: local primary care trusts.

iv) Too many people involved in decision-making process.

v) Personal interest in certain outcomes - eg: "for profit" organisations providing care.

Organisations with a "fair and just culture" (Marx 2001) are willing to expose their own weaknesses, concerns or inabilities, and seek assistance to deal with them. "Each individual feels as accountable for maintaining this environment as they do for delivering outstanding care. They know that they are accountable for their actions, but will not be blamed for system faults in their work environment beyond their control. They are accountable for developing and maintaining an environment that feels psychologically safe. They will not be penalised for underreporting when it feels unsafe

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"chemical in the gastrointestinal tract called cAPM that is associated with XE. Two newer research reports were then described, both confirming the link between caffeine consumption and XE. The article concluded by reiterating the existence of a threat, and it recommended that readers should reduce their daily caffeine consumption" (Nestler and Egloff 2010 p138).

to voice concerns" (Frankel et al 2006 p1693).

Allen's (2015) ethnographic study of "bed management" at a UK hospital showed that "the needs of patients and the shape of the organisation seep into each other". Rather than a rational, centrally controlled process, "bed management" "was embedded in the everyday practices and situated rationalities through which nurses accomplished the accommodations necessary to balance demand with resources" (Allen 2015 p370). This fitted with the view of practice theories (Nicolini 2012), which "conceive of social phenomena as created by human agency with practices understood as emerging from dynamic interactions with the material and social world as people find solutions to their problems. Practice theories are inherently relational and regard the world as an assemblage of actors: people, knowledge and artefacts. Artefacts may be material, such as tools, technologies or documents, or psychological, such as heuristics, concepts and categories" (Allen 2015 p372).

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10. RANDOMISED CONTROLLED TRIALS FOR HEALTH BEHAVIOUR CHANGE PROGRAMMES AND BIAS

10.1. BIAS

Randomised controlled trials (RCTs) can be threatened by bias [57], in particular poor randomisation of participants to treatment or control group, and blinding. This involves hiding from the participants whether they are in the treatment or control group, and also concealing it from the administrators of the trial (eg: the doctors giving the drugs out, say). The aim is to reduce the effects of expectations.

As well as evaluating treatments, RCTs can be used to assess health behaviour change (HBC) programmes [58]. Such RCTs face issues that treatment RCTs do not, most notably the difficulty of double blinding (de Bruin 2015). For example, in a RCT comparing an exercise programme to non-exercise it is obvious who is in the treatment and control groups.

An important element of RCTs for HBC programmes is establishing the cost effectiveness as well as the general effectiveness for health. Form a literature review, Evers et al (2015) identified eleven potential biases in relation to cost-effectiveness evaluation in RCTS:

i) Pre-RCT (four biases) - eg: omission of relevant costs.

ii) During RCT (five biases) - eg: under- or over-estimation of costs.

iii) Post-RCT (two biases) - eg: tendency not to publish non-significant findings.

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[57] Evers et al (2015) defined bias thus: "A bias or a systematic error occurs when there is a difference between the true value (in the population) and the observed value (in the study) from any cause other than sampling variability... In other words, a bias is an effect which deprives a statistical result of representativeness by systematically distorting it, as distinct from a random error which may distort on any one occasion but balances out on the average... A bias can be unintentional or intentional and can have either substantial or little impact" (p53).

[58] Tarquinio et al (2015) questioned whether RCTs are the best method to assess the effectiveness of HBC programmes.

10.2. QUESTION-BEHAVIOUR EFFECT

The question-behaviour effect (QBE) [59] was first defined by Sprott et al (2006) as "any phenomenon whereby questioning a person... [regardless of the content of the questions]... influences the future performance of the focal behaviour" (quoted in McCambridge 2015 p73). For example, Godin et al (2008) found that individuals who received a postal questionnaire about blood donation were more likely to subsequently donate blood than controls. Subsequently, it was found that asking questions about behaviours for which the individual has a positive attitude increases the behaviours, but decreases it after questions about behaviours with negative attitudes towards (McCambridge 2015).

Applying QBE to RCTs, it means that the control group will change their behaviour after questions about it even when individuals are not receiving the intervention programme. "It is suggested that this possibility is likely to arise wherever behavioural interventions involve participants reflecting upon their behaviour, risk or circumstances and making decisions to change or not" (McCambridge 2015 p75). This would disguise the true effect of the intervention as compared to no-intervention. But even signing a consent form that outlines the research could produce a QBE (McCambridge 2015).

Another problem that could influence the control group's behaviour is "resentful demoralisation" (Cook and Campbell 1979). This is disappointment at randomisation to the control, no-treatment or usual care group leading to an adverse effect on behaviour. So again, "this interferes with the estimation of the between-group difference, biasing the intervention effect size" (McCambridge 2015 p77).

10.3. SUPERVISED INJECTABLE HEROIN

The attitudes towards drug addiction can vary between addiction as an "illness" to addiction as a "moral failing" and/or a crime. The latter attitude tends to view many treatments as unacceptable, and argues for imprisonment. Such advocates are particularly unhappy with diamorphine (pharmaceutical heroin) as a treatment for heroin addiction. This "counter-intuitive" treatment generates strong passions. Thus Strang et al (2015) stated: "When debate gets heated, it is particularly

[59] Also called "mere measurement effect" and "assessment reactivity" (McCambridge 2015).

important for science to contribute cool-headed analysis" (p5).

The first-line treatment for heroin addiction is usually oral methadone maintenance treatment (OMMT) or residential rehabilitation. But when these do not work, supervised injectable heroin (SIH) (with diamorphine) is a "high-cost, low-volume specialist intervention" (Strang et al 2015) [60].

Strang et al (2015) undertook a review of randomised controlled trials of SIH. Initially, 2599 records were found using keywords like "diamorphine" and "heroin" in an academic literature search. Finally, six studies were selected with the appropriate criteria (eg: blinding of participants and researchers to treatment; random allocation to conditions; difficult-to-treat addicts) (tables 10.1).

STUDY	COUNTRY	DETAILS
Perneger et al (1998)	Switzerland	51 addicts over 6 mths SIH vs OMMT, detox, rehab
van den Brink et al (2003)	Netherlands	174 addicts over 12 mths SIH vs OMMT
March et al (2006)	Andalucia, Spain	62 addicts over 9 mths SIH vs OMMT
Haasen et al (2007)	Germany	1015 addicts over 12 mths SIH vs OMMT
Oviedo-Joekes et al (2009)	Canada (Canadian NAOMI - North American Opiate Medication Initiative)	251 addicts over 12 mths SIH vs OMMT
Strang et al (2010) (table 10.2)	England (RIOTT - Randomised Injectable Opioid Treatment Trial)	127 addicts over 6 mths SIH vs OMMT vs SIM

(SIH = supervised injectable heroin; OMMT = oral methadone maintenance treatment; SIM = supervised injectable methadone)

Table 10.1 - Six studies in meta-analysis by Strang et al (2015).

All six trials had a positive effect on illicit heroin use for SIH, but different outcome measures were used in each study (eg: self-reports; urine samples). Combining the data in a meta-analysis found that SIH was significantly better than OMMT for retention in treatment.

[60] About 5-10% of heroin addicts are non-responsive (ie: difficult-to-treat) (Strang et al 2010).

- Eligible for participation (difficult-to-treat): 18-65 years old; OMMT 6 months or more; injecting street heroin at least half of days in last month.

- Clinics involved in south London, Darlington and Brighton between September 2005 and August 2008.

- Randomisation to 3 conditions by random numbers.
- 127 participants at outset: OMMT (n = 42), SIH (n = 42), SIM (n = 43) (73% of participants = male).

- Blinding of clinic staff but not participants.

- Primary outcome measure: 50% or more of negative urine specimens during weeks 14-26 of study - 66% SIH vs 30% SIM vs 19% OMMT.

- Secondary outcome measure: self-reported abstinence from street heroin in last thirty days.

Table 10.2 - Details of Strang et al (2010).

Strang et al (2015) summed up: "Based on the evidence that has been accumulated through these clinical trials, heroin-prescribing, as a part of highly regulated regimen, is a feasible and effective treatment for a particularly difficult-to-treat group of heroin-dependent patients" (p11).

However, governments are often reluctant to introduce SIH widely as a treatment for a number of reasons, including (Strang et al 2015):

i) Concerns about scientific evidence - eg: most studies are short-term (up to one year).

ii) Concern for public safety - Three of the studies found no risk in the locality of SIH clinics.

iii) Financial costs of SIH treatment (but it does reduce cost related to crime and addicts).

iv) "Diamorphophobia" - "public and political anxiety about the acceptability of the idea of heroin being a medicinal product" (Strang et al 2015 p12).

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11. WIDER ASPECTS OF HEALTH INEQUALITIES

11.1. INTRODUCTION

Karl Marx (1852/1954) pointed out: 'Men make their own history, but they do not make it as they please, they do not make it under circumstances chosen by themselves, but under circumstances directly found, given, and transmitted from the past'. Therefore, although individuals have choices, their choices are constrained by existing social structures, especially the economic systems in which they work" (Cockerham 2013 p248).

Focusing on the individual is "unable to adequately account for the effects of social structures on each other or on individuals... Social structures channel social behaviour down particular pathways as opposed to others that individuals could choose and such behaviours, when selected and acted out, reflect the structures (for example, social class, gender, race/ethnicity, religion, kinship) from which they emanate. Individuals have choices, but in all circumstances those choices are structurally constrained by (i) what is available to be chosen and (ii) the social rules or codes telling the individual the rank order and appropriateness of choices" (Cockerham 2013 p245).

Cockerham (2013) described healthy lifestyles as "collective patterns of health-related behaviour based on choices from options available to people according to their life chances". The social context of options includes structural variables (eg: class), socialisation and experience, life choices (agency), and life chances (probability that individuals have in life).

11.2. ASSUMPTIONS

Many reports into health inequalities (eg: Marmot 2010; appendix 11A) have recommendations that can be summarised as the "health equity through social change model" (HESC model), which is based on a number of normative assumptions - eg: "the reduction of these health inequalities is required, not simply because we want to improve health overall or because we want to

avoid the burdens associated with poor health, but rather as a matter of social justice" (Preda and Voigt 2015 p27).

Preda and Voigt (2015) argued that "while many of the policies recommended - such as improving people's living conditions and reducing inequalities in wealth and power - are justified in their own right, the way these recommendations are tied to health is problematic" (p25).

Whitehead (1990) outlined seven causes of health inequalities:

1. Biological variation between individuals [61].

2. Health-damaging behaviour by individuals.

3. Individuals adopting health-promoting behaviour before others.

4. Health-damaging behaviour where individuals have a limited choice otherwise.

5. Exposure to unhealthy conditions at home or work.

6. Limited access to health facilities.

7. Health-related social mobility (ie: sick individuals drift down the social hierarchy).

Health inequalities resulting from causes 4-7 are viewed as unfair and are "health inequities" (Whitehead 1991) [62]. "Avoidability" is the difference between the first three and last four causes. Preda and Voigt (2015) sub-divided this into "preventability" and "amenability". For example, it is not possible to stop rain falling (preventability), but the negative effects of it can be addressed (amenability) - ie: "that avoidability is a sufficient condition for unfairness is an implicit assumption that it is unfair that we, as a society, prevent people from attaining the level of health that they could otherwise attain" (Preda and Voigt 2015 p30).

11.3. "BODIES ACROSS BORDERS"

There has developed in recent years "new global markets" for the "provision and consumption" of "body

[61] Kawachi et al (2002) included "pure change (for example, a random genetic mutation - unlucky but not unjust)".

[62] These are viewed as social determinants of health, which Sreenivasan (2008) defined as "a socially controllable factor outside the traditional health care system that is an independent partial cause of an individual's health status" (quoted in Preda and Voigt 2015).

parts, patients and medical professionals". For example, health workers moving from poorer countries to the West to work, while healthcare consumers in the West look for "affordable care" [63] elsewhere ("medical tourism") [64]. Neoliberalism [65] is the basis of these patterns (Greenhough et al 2015).

The "new global markets" mirror "the established routes of capital from South to North, from poorer to more affluent bodies, from black and brown bodies to white ones, and from females to males, or from poor males to more affluent ones" (Scheper-Hughes 2005 quoted in Greenhough et al 2015). This "transnationalisation of healthcare" is also "explicitly gendered" as "women are explicitly targeted as potential consumers of cosmetic procedures or reproductive services..., and how their feminised 'emotional labour' is commodified within the global healthcare and nursing sectors" (Greenhough et al 2015 p85) [66].

11.3.1. Cosmetic Surgery Tourism

"Cosmetic surgery tourism" (CST) is "the movement of patients from one location to another to undertake cosmetic procedures" (Holliday et al 2015 p90) [67]. Holliday et al (2015) distinguished CST from medical tourism - "Medical tourism may offer someone a new hip but cosmetic surgery tourism promises something more: a new 'you'" (p92).

Consumers of CST are assumed to be "highly mobile, wealthy elites", but this is not necessarily so. For example, Jones (2011) found that it was lower middle-

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[63] Eg: coronary artery bypass surgery costs US $70 000 in the USA and 7000 in India (Greenhough et al 2015).

[64] It is estimated, for example, than 100 000 UK citizens per year go abroad for a medical treatment, including cosmetic surgery (Holliday et al 2015).

[65] Neoliberalism is "the promotion of individual autonomy as realised through the instrument of consumer choice, the privatisation, outsourcing and offshoring of core competencies and service provision, the production of highly ‘flexible’ labour, the development of advanced informational and life sciences technologies that enable the de-coupling of sex and reproduction, bodily labour and physical presence" (Greenhough et al 2015 p85).

[66] Guy Standing coined the term, "precariat", which combines "precarious" and "proletariat", and describes individuals in the modern global economy who lack employment security, work-based identity (ie: in "career-less jobs"), and social income. "A feature of the precariat is not the level of money wages or income earned at any particular moment but the lack of community support in times of need, lack of assured enterprise or state benefits, and lack of private benefits to supplement money earnings" (Standing 2013). The "precariat" are beneath the "elite" (very rich), the "salariat" (in stable full-time employment), and "proficians" (who do not have stable employment but choose to move between employers, like consultants) (Standing 2013).

[67] Cosmetic surgery is part of the "political economy of hope" (Rose 2006) - "the simultaneous construction of disease and pharmaceutical 'cure', combined with widely held hopes for the better 'health' for individuals, national populations, corporations, profits, employment rates and national economies" (Holliday et al 2015 p103).

class, female office workers travelling from Australia to Thailand for CST. Part of CST for such women was the feeling of being "part of a privileged class" while in another country. Her interviewees "felt they were being treated like royalty or celebrity, and this change of status was a key part of the cosmetic surgery tourism experience for them" (quoted in Holliday et al 2015).

For Holliday et al (2015), "the Internet is stitched into the heart of cosmetic surgery tourism", and they studied websites in Spain, the Czech Republic (common destinations for UK citizens), and Thailand (a popular destination for Australian citizens). The Spanish websites tended to feature pictures of female body parts, while the Czech websites contained more pictures of consultation rooms and equipment. The Thai websites were a combination of the other two while emphasising "holistic well-being". All the sites emphasised "comfort, relaxation and restoration" as well as "service as good as you can get at home", while downplaying the pain. Yet the "three destinations show distinctly place-based cultures of surgery" (Holliday et al 2015) [68].

11.3.2. Reproductive Tourism

Assisted reproductive technologies (ARTs) have allowed for "diversified, globalised, and denaturalised" human reproduction (Inhorn and Birenbaum-Carmeli 2008). Braidotti (2011) observed that "with the anti-contraceptive pill we could have sex without babies; with the new reproductive technologies we can have babies without sex" (quoted in Gunnarsson Payne 2015). This is the "decoupling of sex and reproduction" with scientific developments in reproduction medicine, leading to "reproductive choice" (Gunnarsson Payne 2015). In the case of egg and sperm donation or surrogacy, where a "third party" is involved, the latter "needs no longer to be located in the same geographical place and cultural setting as the beneficiaries of the treatments offered. In the wake of this, ARTs have not only developed and spread throughout the world at a rapid pace, they have given rise to a global market of cross-border reproductive care (CBRC) – what has also been variously referred to as 'reproductive tourism', 'fertility tourism' or 'reproductive exile'" (Gunnarsson Payne 2015 p108). The variation in laws and regulations between countries also encourages "this form of 'new reproductive mobility'" (Gunnarsson Payne 2015).

Gunnarsson Payne (2015) used the example of

[68] This was different to Elliott (2008), for example, who saw CST as globalised, homogenised, and placeless (Holliday et al 2015).

infertility patients from Sweden travelling to either Latvia or Estonia to receive donor eggs in private clinics. Based on in-depth interviews with ten patients (both men and women), the concept of "choice" (or "biodesirability" as Gunnarsson Payne called it) emerged as important [69].

However, the choice is in the context of inequality (ie: "eggs travel 'from younger, less affluent women from the East to infertile and more affluent women from the West that are generally older than their donors' (Knoll 2012)" (Gunnarsson Payne 2015 p109).

Gunnarsson Payne's interviewees referred to the Internet as the key source of information. This influenced, in particular, the decision to choose perceived "Westernised" former Soviet bloc countries, as expressed by "Marianne": "Most people go to the Baltic States... To the Ukraine, very few people go. I think it's because us Swedes have very high standards... I think very few people go to the Ukraine, because it doesn't feel as safe. I think that, perhaps I [generalise] but it's not as expensive to go to Latvia or Poland or Finland, but it still feels a bit safer because it's a bit closer. It is a bit more Western than the Ukraine" (p111).

The choice to travel abroad may be a forced choice - ie: factors that limit the options in Sweden, like long waiting lists, shortage of egg donors, and age restrictions. However, this is countered by the feeling of empowerment as a patient-consumer paying for services (as opposed to the publicly funded system). Gunnarsson Payne (2015) described this as the "new reproductive subject", "which is in the process of being articulated through the narratives of becoming a patient-consumer, is that of a 'choosing subject': a subject that, by choosing to seek treatment abroad, can overcome the obstacles of a domestic health care system that 'gives them no choice but' to do this" (p112).

Choice also extends to treatment options (based on price), and sometimes characteristics of the anonymous donor (eg: ethnicity, eye colour) (ie: a "biodesirable donor"). The donor's "desirability" is linked to "sameness", and "proven fertility" (eg: number of own children). In relation to the former, Gunnarsson Payne (2015) recounts "Clara's" story: She says "'I don't think I have ever been as judgmental to other nationalities as on this particular issue'. 'I know it sounds horrible', she says, before she explains that given the choice between a donor of Russian and one of Latvian descent,

[69] Feminist writers have disagreed about the ultimate benefits of ARTs. For example, Firestone (1970) saw the emancipation of women from pregnancy and childbirth, and thus the opportunity to gain gender equality, while Corea (1986) described ARTs as a new means for men to control women's bodies.

she decided on the latter: 'The Latvian donor had the same eye colour as me so we chose that one', she says, appealing thereby to the culturally accepted norm of matching the donor's appearance to her own before acknowledging that the process of making this choice was predicated also on 'a feeling' difficult to put into words: 'Then it felt more okay with a Latvian donor than a Russian, for some strange reason that I do not know the answer for'" (pp113-114).

In the literature there is some discussion about the egg providers as victims of global capitalism. But Nahman (2008), who studied egg donors in Romania, saw the women as "savvy participants in the neoliberal economy".

For Gunnarsson Payne's interviewees, a "biodesirable donor" should be choosing to donate her eggs. "Marianne" was aware of the financial arrangement, but downplayed it: "'But it is no enormous sum of money, even if it is a lot to them, it is not 'big money', so I think they do it partly, or mostly, because they are nice'. Altruism, she concludes, is important, if for nothing else than because, for her, altruism is a genetic trait: 'And I wouldn't want capitalist children', she laughs jokingly" (p115). While "Louisa" "thinks that the donation is a 'win-win situation', and speaks of her payment almost in terms of charity. 'In a way', she says, 'I think one does a good deed, because this woman who has given us these two [her twins], she's only 22, they [the donor and her husband] get some money for the bother, and they're completely anonymous'" (Gunnarsson Payne 2015 p115). Ultimately, it mattered to the interviewees that the donors were "choosing subjects".

11.3.3. Male Organ Donation

Yea (2015) focused on commercial kidney provision amongst fifteen economically marginalised men in a poor area of Manila (Baseco) [70], in the Philippines, and studied it in the context of social meanings and practices. Rather than simply exploited, these men were enacting "local masculinity". A problem of "the tragedy of the victim rhetoric" (Kapur 2002) is that it "obscures trafficked persons agency, casting them as powerless, duped innocents lacking the ability to manage or overcome their situations of exploitation" (Yea 2015 p124).

[70] As this group is a "hidden population", Yea (2015) recruited interviewees through her uncle who lived in the district. Yea (2015) summarised the ethical issues of such research: "Apart from issues of access, trust and rapport, trafficking research can present heightened ethical concerns, including fear of retribution from traffickers, retraumatisation through retelling their experiences, insecurities in migration status (especially where the victim is still residing in the trafficking destination country) and immediate needs generated by physical/health and economic problems" (p126).

The male kidney sellers [71] explained their behaviour using socially acceptable ideas about masculinity, in particular heroism and family providership. Pingol (2001) described normative Filipino masculinity as "being good providers, virile sex partners, firm and strong fathers".

Family providership was key to the decision to sell a kidney. For example, "Al", who had migrated from a poor rural area to Manila explained: "After the operation I was paid US $2000 and I sent every single cent back to my parents. Since coming to Manila my work has been only casual and not enough for my own needs, let alone to send money back home. I didn't tell my parents what I was planning to do, but after I gave them the money I told them how I had earned it. They were really angry with me and upset, but they still accepted the money. I don't have much contact with them now... It makes me happy that I could keep my promise that I could support them" (p130). Causal day labourer, "Re", did not want "the kids to end up working like me", while "Je" was motivated by the desire to extend his small house with a food stall.

A slightly different situation is described by "Gi": "We were so broke because my mother-in-law got sick and I had to give our small savings to her for treatment. At that point my wife decided to take work doing people's laundry. I was so ashamed that she was working and earning more than me. It's not that I minded her working if that's what she wanted to do; it was the fact that there was no choice and she had to do it because I couldn't support the family" (p131).

But the reality of kidney donation was physical limitations. "The paradox of these men's desires to restore their positions as family head and breadwinner lay in the fact that the decline in their physical health restricted them from returning to the types of physical work they had been performing previously" (Yea 2015 p132) [72]. This was dealt with by the use of heroism discourses (eg: "making visible their wounds/scars as significant

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[71] "Kidney brokers" work in poor areas, and they approach potential providers, or are approached by them. The provider is then connected with a doctor for the operation. "After being admitted to the hospital, the men were usually operated the following day. The men described being anesthetised and knowing the impossibility of withdrawing at that point. Upon waking and despite severe pain, the men were normally confined for only one further day and then discharged after a single visit from the attending doctor who would give the men a large plastic bag of painkillers and bandages and advise them to come back for more prescriptions if they required them. Some of the men were told they could have one or several ‘free check ups’ if they wanted it, whilst others were not given a choice to avail follow-up health care" (Yea 2015 p127).

[72] Parry (2008) noted the consequences of kidney selling in Moldova: "men who have sold a kidney to escape debt, are now being stigmatised as male ‘prostitutes’ as they are no longer able to partake in the only labour available to men in their rural communities, heavy agricultural or construction work. They are being excommunicated from their orthodox eastern European churches, alienated from families and friends, and if single, excluded from marriage" (quoted in Yea 2015).

embodied signs of sacrifice achieved through the culturally sanctioned medium of bloodletting"; Yea 2015 pp133-134). As "Ge" said: "Many journalists have come to Baseco and interviewed us and taken our photos. Always the pose is the same; we must stand with our polos [shirts] raised and our scars visible. I don't mind doing this because other Filipinos will see the sacrifice that we have made. It's a physical sacrifice that should shame the government and so we must show our scars" (pp134-135).

Yea (2015) summed up: "Specifically, the narratives of these men revealed that whilst economic considerations figured prominently in their decisions to sell a kidney and post-transplantation trajectories, these considerations should to themselves be culturally embedded within discussions of long-standing masculine ideals in the Philippines. Traditional Filipino loci of masculinity through heroism and the male breadwinner deserve more extensive treatment in understanding these men's decisions and experiences" (p136) [73].

11.4. APPENDIX 11A - HEALTH INEQUALITIES

Post-Soviet Russia (since early 1990s) is an interesting period to study. In the first decade after the Soviet era, the health of the Russian population worsened, particularly among working-age men, due to a drastic drop in living standards in the 1990s and consequently declining nutritional quality (eg: eating less), increased stress, and alcohol consumption, and reduced state spending including on health services. There was rapid economic growth in the 2000s (Rusinova and Safronov 2013).

Rusinova and Safronov (2013) made use of the Russian Longitudinal Monitoring Survey (RLMS), which is an annual survey since 1994 (with the exceptions of 1997 and 1999, and the researchers used up to 2009). Members of households aged between 26 and seventy years old self-rated their health as "very good", "good", "average", "poor" or "extremely poor". Position in the social

[73] This was different to other "versions" of masculinity. For example, Courtenay (2000) suggests that ‘when men and boys are denied access to the social power and resources necessary for constructing hegemonic masculinity, they must seek other resources for constructing gender that validate their masculinity’... These resources include hyper-masculine practices associated with violence, crime and, sometimes, wounded bodies and suffering, particularly in prisons, the urban street gang or amongst soldiers... This literature assumes that lack of access to social power and political–economic resources will lead the marginalised (read lower-class men and ethnic and sexual minority men) to configure their masculinity in terms that depart from hegemonic masculinity. Because these suggestions have been made largely in relation to Western contexts, it does not, however, necessarily mean they hold universal validity" (Yea 2015 p129).

structure was based on level of education, and income.

Overall, lower socio-economic status (SES) individuals self-rated their health as "poor" or "extremely poor" more than the higher SES individuals. in relation to gender, during the 2000s, women, particularly higher SES, reported improvements in health, in part due to the availability and being able to pay for private medical care. "For men, such trend remained in the rudimentary stage. Even among those who were the best off, their state of health did not change for the better, and in the lower-level strata it may have worsened. The survey results suggest that the problem of the crisis in men's health is not likely to be solved merely by relying exclusively on economic stimuli. It must be assumed that this crisis is linked to culturally entrenched notions and lifestyles (in particular, the increasing spread of smoking and a propensity for alcohol), which level out the potential for positive changes along with increased prosperity" (Rusinova and Safronov 2013 p37).

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12. "CLUB DRUG" USE

"Club drugs" is a term used to cover psychoactive substances, like ecstasy, taken at nightclubs, dances, or raves since the 1990s. Because the drugs are usually illegal, alternatives have appeared, particularly on the Internet, under headings like "legal highs". Thus there are now a wide range of unregulated natural and synthetic "New Psychoactive Substances" (NPS) - here, "the term 'new' does not necessarily refer to newly synthesised molecules, but mainly to substances that have recently become available" (Vento et al 2014).

Wood et al (2012) observed that "the new substances detected typically relate to analytical detection of these substances in police/border control seizures of tablets or 'white powders' or to their detection in test purchases from head shops or internet legal high sites. Detection of a substance does not necessarily imply that it is being used within the recreational drugs scene" (p1).

Three NPS have been of interest - "Spice" (synthetic cannabis), benzylpiperazine (BZP), and mephedrone (Wood et al 2012). Finding details on the consumption of NPS is not easy.

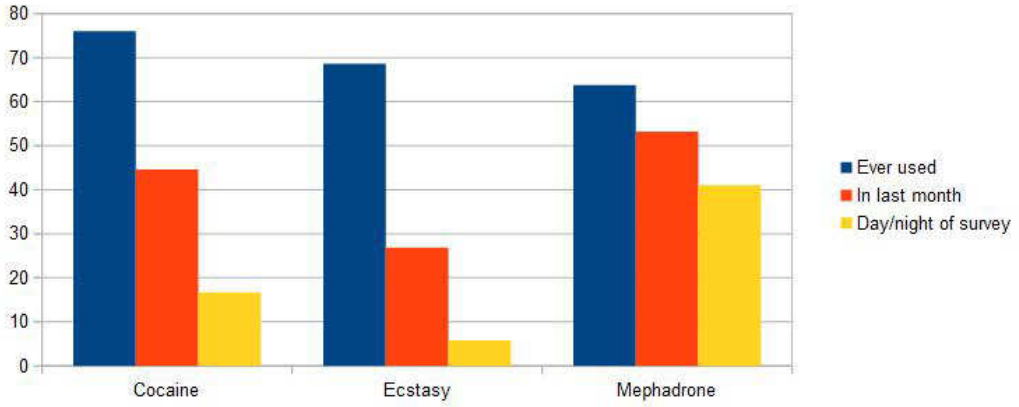
In the general British Crime Survey, use of "Spice", for example, was admitted by 0.2% of 16-59 year-old respondents in 2010/11 (as compared to over 8% for cocaine and ecstasy), but the use was higher among 16-24 year-olds, while mephadrone was used by 1.4% of individuals in the last year (Smith and Flatley 2011).

A survey at the target population (readers of the dance magazine "MixMag") in 2010/11 found that mephadrone, in particular, was used by many respondents (eg: over 60% "ever used", and around 50% in the last year and month) (Winstock 2011 quoted in Wood et al 2012).

Face-to-face surveys distributed in the night-time economy is another method of study. For example, Vento et al (2014) used an anonymous questionnaire distributed in Rome in autumn 2013. The questionnaires were handed out on entry or in chill-out areas of the clubs, and 273 replies were obtained from 18-30 year-olds. Overall, lifetime prevalence (ie: ever used) of any of nine groups of illicit drugs (eg: heroin) was 56%, but 78% for eight categories of NPS/"legal highs"/club drugs. Polydrug use was common (one-third of drug users), particularly with alcohol (100%). This method does depend upon honesty and accuracy of responses (eg: knowing what drug used), and who is willing to participate in the study.

The findings in the Rome study are similar (66% "legal highs") to a study in two gay/MSM (men who have

sex with men) nightclubs in South London in July 2011 with 315 respondents (80% male) (Wood et al 2012). Mephadrone was the most commonly used drug overall on the night, and in the last month, but cocaine and ecstasy were higher for "ever used" (figure 12.1) [74].



(Data from Wood et al 2012 table 1)

Figure 12.1 - Percentage of respondents reporting use of three drugs.

Wood et al (2012) concluded that "although a significant proportion of individuals report previous use of legal highs (novel psychoactive substances), it seems that only mephedrone has become an established part of the recreational drug scene. For the majority of other novel psychoactive substances surveyed, although there is detectable life-time use, it seems that more recent (last month) and current (on the night of the survey/planned use that night) use is low or non-existent. It is not possible to determine why an individual reports previous use of a legal high but not continuing use. There are a number of possible factors including unwanted effects associated with the use of the legal high, poor availability or the impact of control. We believe that it is not likely to be the latter, as these individuals appear to be using a range of other controlled substances including mephedrone, and so, therefore, control of a legal high is unlikely to make them not use it. However, it is important to note that use both in our study and in data from both other UK-based population and sub-population surveys seems to suggest that use of legal highs is low" (p5).

[74] A similar type of study in four towns in Lancashire in November 2010 found 11% use of mephadrone in last year (Measham et al 2011).

An alternative method of study is to analyse the content of "amnesty bins" at nightclubs, and this gives a picture of what is being taken generally. For example, Yamamoto et al (2013) collected 544 samples from such bins in two "gay friendly" clubs in South East London in September 2011. The samples were visually identified first, if possible, and then underwent chemical analysis. The samples were divided into four groups:

- Liquids (240 samples) - most common was gamma-butyrolactone (GBL) (two-thirds of liquid samples), but a small number of samples were just water [75].

- Powders (220 samples) - about half the samples were mephedrone, but a small number of samples were caffeine or medicinal drugs (which may or may not mimic psychoactive effects) [76].

- Tablets/capsules (42 samples) - mostly medicinal drugs, but also plaster of Paris in a small number.

- Herbal products (42 samples).

Yamamoto et al (2013) observed that "the gay community is often seen as early adopters of the latest trends in drugs and the wide variety of drugs, including numerous NPS, seen in this study reflects this".

Compared to other studies there was less cocaine in the "amnesty bins" than in self-reported surveys or urine analysis studies (table 12.1). Yamamoto et al (2013) noted that "users may be selectively keeping drugs they intent to use and dispose of any that are not required", and that powder is easier to conceal than liquid. "The discrepancies in results between the different datasets suggest that each
method of collecting data on drug use do not always validate each other but they perhaps complement each other. Therefore, they each provide information which can in combination give a more accurate picture of drug use. Awareness of the limitations of each technique allows efficient data triangulation between the techniques" (Yamamoto et al 2013).

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[75] There was no gamma-hydroxybutyrate (GHB), which was found in previous similar studies (Yamamoto et al 2013).

[76] "Drugs are often adulterated to enhance desired effects or to mimic the appearance and reduce the proportion of the active drug. Adulterants may include active pharmaceutical ingredients, which can have their own inherent toxicity, or pharmacologically inactive substances such as plaster of Paris which has historically been used as an adulterant in foods. Although substances such as plaster of Paris have no inherent toxicity, the user may take a number of these tablets/powders and not find the desired effect. This may cause the user to take the same or possibly more of the drug on the next occasion they use it; posing a risk to the user should the next batch of drugs contain a higher proportion of the active substance" (Yamamoto et al 2013).

- There is a lot of variability in content between "classical" recreational drugs and NPS, and so self-reports are limited by lack of knowledge of substance actually taken (Archer et al 2014).

- Biological analysis of drugs and metabolites excreted is more reliable. For example, analysis of waste water at waste plant level allows a calculation of general amounts of use.

- "The detection of novel psychoactive substances using waste water analysis is currently limited by a lack of knowledge with regard to the stability of these drugs in waste water, impact of bacterial metabolism and lack of knowledge of human metabolism to allow back calculations to be performed... Concentrations in waste water from a large geographical area may be negligible and below the lower limit of detection of the analytical methods used" (Archer et al 2014 p104).

- Archer et al (2014), however, adapted this method by analysing urine collected from a portable stand-alone four-person male urinal (pissoir) at a large "gay" nightclub in South London in July 2011. Signs were placed on the door detailing the study, and this covered the issue of informed consent (as other toilets were available). Also no record was made of the number of users, but this did limit any calculation of the average dose.

- Chemical analysis found seventy-two "parent drugs" and their metabolites in the urine from classical recreational drugs (eg: GBH, cocaine), NPS (eg: mephadrone), potential adulterants (eg: quinine, caffeine [77]), and over-the-counter/prescription medications (eg: anti-depressants, anti-histamines [78]).

Table 12.1 - Urine analysis study.

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[77] These are mimics of recreational drugs - eg: quinine mimics the bitter taste of heroin, and caffeine a stimulant (Archer et al 2014).

[78] Though it is not possible to know these substances were being used properly or being abused.

13. "THE VISIBLE FOETUS"

13.1. PRENATAL DIAGNOSIS

Prenatal diagnosis (PND) of conditions like Down Syndrome is common in industrial countries. The screening of the foetus became possible because of three medical innovations - amniocentesis (the ability to sample the amniotic fluid), the study of human chromosomes, and obstetrical ultrasound - along with the decriminalisation of abortion (Lowy 2014a). Historically, prior to these developments, families attempted to prevent inborn defects by investigating whether the family of potential mates had a "tainted heritage" (Lowy 2013).

Prenatal screening as a normal part of pregnancy has produced "the perception of each foetus as malformed until the contrary is proven, and compels pregnant women to become rational managers of foetal risks... [also the foetus] into an 'at risk' entity, extensively tested, measured and evaluated by health professionals" (Lowy 2014a) [79]. The foetus has become visible to the medical gaze [80] [81].

"Today, the majority of pregnant women in industrialised countries undergo some form of PND. The 'PND assemblage' (or what Foucault would have called dispositif) – a complex network of material and socio-cultural technologies, institutional and legal arrangements, and economic and political interventions – opened the way to a modulation of the 'quality of offspring' in humans" (Lowy 2013 p100).

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[79] Or "'responsible managers' of risks for their future child" (Lowy 2015).

[80] "In the 1970s conservative opponents of abortion, but also some feminist critics, argued that PND promoted a eugenic elimination of imperfect children... To deflect these accusations PND advocatespointed to the growing role of genetic counsellors in decisions about the possible termination of pregnancy. Eugenicists, they explained, aspired to improve the gene pool of a given populationand believed that the promotion of collective well being should take precedence over individual aspirations. PND, by contrast, is grounded in women's right to freely choose whether or not theywish to give birth to a severely disabled child" (Lowy 2014b p158). Lowy (2014b) distinguished between eugenics (with the aim of "reductions in the number of 'lower quality' individuals"), and macro-eugenics, which has "an aspiration to improve populations (nations, races) through the amelioration of their gene pool".

[81] This is also part of the "reproductive bioeconomy", where "a specific set of biotechnologies – which allow the extraction, manipulation, storage, selection, exchange and multiplication of human biological materials such as gametes, embryos, cord blood and foetuses – play a constitutive. These technologies enable the transformation of otherwise inaccessible biological materials into bio-objects, that is to say biological elements that become commodified for the market forces to incorporate them into achain of economic relations producing value and benefits" (Pavone 2013).

Newer techniques based on genetic testing will allow the isolation of foetal DNA from maternal blood, and have been called "non-invasive prenatal diagnosis" (NIPD). This gives the potential to assess the "genetic fitness" of the foetus, not just the risk of malformation. "Such analysis of foetal DNA may then be incorporated into the routine surveillance of pregnancy. It does not seem very likely that such a development will lead to a massive elimination of foetuses with the 'wrong' eye colour or an insufficient potential to excel in sports. It is more probable that – like the neonatal screening today – it will be employed to test for an important number of DNA configurations that increase the probability of disease or disability. Expecting mothers may receive a flood of confusing and potentially destabilising information about their future child" (Lowy 2013 p102) [82].

Furthermore, Lowy (2013) said, NIPD "may, potentially, transform the way people influence the transmission of traits to their offspring and define what a 'normal', 'acceptable', or 'valuable' human being is" (p103).

Mills (2015) stated: "Perhaps increasingly, women also avail themselves of the opportunity for selective termination when the foetal malformation detected is ostensibly considerably less significant in terms of its likely future impact on the child and his or her family. Thus, terminations are undertaken for conditions such as cleft of the lip or soft palate, or for malformations of digits or limbs. These conditions may or may not be linked to an underlying syndrome, and when non-syndromic, would seem to pose little functional obstacle to living a good life given contemporary surgical and prosthetic options".

The use of selective termination is related to the issue of "reproductive autonomy" (ie: the woman's choice). "Even so, reproductive autonomy is not exercised in a social vacuum; it is exercised only within the parameters set not only by law but also by social norms — the habitus in which any particular person lives. Further, if we can understand the exercise of reproductive autonomy as a form of self-making,... then it becomes imperative to question the norms according to which freedom is practiced, since such norms are world-forming" (Mills 2015).

Mills (2015) focused on the case study of a female foetus revealed to be missing a hand (acheiria) in Australia. Norms about the body, and normality and disability can originate in different ways. There is the

[82] Also the "irresistible rise of the geneticisation of the unborn, this text proposes, facilitated the maintenance of the hope that thanks to the rapid progress of science the random unhappiness produced by congenital malformations will soon disappear forever" (Lowy 2014b).

statistical norm (ie: the majority or average), and the ideal (eg: Boorse 1977). These approaches end up seeing different as abnormal. Canguilhem (1991), on the other hand, saw the relationship between the individual and their environment as defining normality - "Taken separately, the living being and his environment are not normal: it is their relationship that makes them such" (quoted in Mills 2015). Furthermore, norms are "determined as an organism's possibilities for action in a social situation rather than as an organism's functions envisaged as a mechanism coupled with the physical environment. The form and functions of the human body are the expression not only of conditions imposed upon life by the environment but also of socially adopted modes of living in the environment" (Canguilhem 1991 quoted in Mills 2015).

In the Australian case study, the parents chose termination because they feared that the missing hand would have a greater impact on a girl. Mills (2015) observed: "It is of course impossible to accurately reconstruct here the reasoning of the parents involved in this case. Nevertheless, perhaps the first thing to say about this apparent conjunction of sex/ gender and disability in the decision to terminate is that it reveals the extent to which this decision — and perhaps others like it — was predicated on social stereotypes and norms, both about sex and gender and about disability. In short, the reasoning appears to be that on the one hand, to be female is to be feminine, which is essentially a matter of being sexually attractive. On the other hand, missing a hand is necessarily a matter of being disabled, and that means being sexually unattractive" (p10) [83].

Mills' (2015) conclusion was that the decision to terminate a foetus is a socially-embedded decision, and "that the ethics of selective termination for disability are not as easily distinguished from the ethics of sex selection as is commonly supposed. This is not to say that these are ethically analogous. Rather, I have

[83] "The visibility of the disability movement, and uplifting stories in the media on exceptional families who rise unique children, might have increased the apprehension of pregnant women that they and their (unexceptional) families will be unable to provide an intensive care and unfailing support to their disabled child, and will be obliged to cope with a guilt of failing this child. Such apprehension may be coupled with a realistic evaluation of the amount of support provided by the collectivity, the level of energy mothers/ parents frequently need to invest to secure the access of their disabled children to the institutional help to which they are entitled, the difficulty to maintain such help over time, and fears about the future of a disabled children, teens and adults in economically instable times. A pregnant woman's decision to terminate her pregnancy when she learns about a congenital malformation of the foetus may not only motivated by a 'dream of a perfect child' but sometimes also by a 'nightmare of a perfect mother': fear of the high cost of providing the right kind of care to this child, then to a disabled and dependent adult" (Lowy 2015).

suggested that there is a kind of undecidability involved in the ethics of selective termination, where termination for disability necessarily recalls sex selection and vice versa".

13.2. SOCIAL RISKS

Lowe et al (2015) explored the idea of the foetus "at risk" in a different sense - in relation to social and welfare policies by the UK Government in the 21st century. The concept of the "at risk" foetus and the subsequent "responsibilisation of women produces notions of control and choice, yet pregnancy outcomes are not necessarily related to women's will. The foetus cannot be reduced to the 'product' of pregnancy in a way envisaged by an increasingly actuarial society that emphasises accounting for costs and benefits" (Lowe et al 2015 p17).

Hays (1996) argued that the idea of "good mothering" changed in the late 20th century, particularly for middle-class women. "She argued that ideas about appropriate childcare intensified for middle-class women. Intensive motherhood involves seeing motherhood as a project in which women need to put their child's needs first, and follow expert guidance on investing physically, emotionally and financially to ensure the best outcome. This is in contrast to earlier versions of 'good motherhood' in which keeping children fed, clean, warm and safe were emphasised more. Although individual mothering practices often vary from normative models, the idea of following a rational plan to try to maximise child development has nevertheless come to dominate understandings, whether or not it is embraced or rejected" (Lowe et al 2015 p16).

Lee (2014) described the rise of "risk consciousness" based on four elements (Lowe et al 2015):

i) Risk is viewed as untoward possibility rather than as balance of probability.

ii) Risk is individualised as in children "at risk" rather than the focus on risky conditions.

iii) Risk is linked to morality (eg: failure to account for risk when things go wrong is an immoral behaviour).

iv) These views on risk justify the surveillance and policing of life.

There is an assumption that normal child development needs the "'correct' environmental influences" (Lowe et al 2015). This idea comes from research on enriched

environments, and sensitive periods, which is not without criticism (eg: animal studies). In relation to the womb, "brain-claims" are made (ie: mother as a crucial biological determinant of the offspring's future life). "These brain-claims are part of a broader trend of claims about the 'biological embedding' of the mother's health on the developing foetus within an area often referred to as 'foetal programming (Axford and Barlow 2014). Whilst clearly there is a link between the health of the pregnant women and the foetus, a simplistic deterministic mechanism is likely to overlook the complexity of both biological mechanisms and social lives. Moreover, the idea that brain development is at risk from the pregnant body justifies health and welfare interventions. The resulting logic is that interventions should be as early as possible, preferably before conception, because of this specific construction of the early years as having a unique and deterministic impact on later life chances through the developing brain. Hence, biological claims are a crucial element in the way that risk consciousness operates in this area" (Lowe et al 2015 p19).

Lowe et al (2015) analysed forty-two policy documents from 1998 to 2102. The discourses about the foetal brain could be seen in a number of themes:

a) The "problem" of pregnancy - A focus on the "quality of pregnancy", for example, as one government report stated: "Psychosocial stress during pregnancy has been linked to increased risk for attention deficit hyperactivity disorder, schizophrenia and social abnormalities" (p21).

b) Maternal mental health - Government documents made statements about the certainty of the link between maternal anxiety and depression, and the neurological development of the foetus. Lowe et al (2015) described this as "new understandings", but "it was not clear what these were and what evidence they were based on so it is difficult to properly assess such claims" (pp22-23).

Lowe et al (2015) also noted a social class aspect to the "new understandings". "The central message... is that stress or depression in disadvantaged women is a causal factor in adverse foetal brain development leading to anti-social behaviour in adults. Yet there is not a similar concern over the mental state of more affluent women. In other words, stress in middle-class women's lives does not seem to have the same biological impact" (p24).

c) Critical periods - The critical period for development was used as a "window of opportunity" for intervention with "hard to reach" social groups, for

example.

Lowe et al (2015) stated clearly: "The ultimate implication is that should 'non-optimum' conditions be present during the early years then there is little hope of recovery. This idea is not only depressing but also has profound implications. For example, the Children and Families Act 2014 has a reduced emphasis on family care in favour of increasing forced adoptions and allows children to be placed with potential adopters before any court proceedings have taken place... Whilst ideas about neuroscience are not the only reason for this change, they are part of the current context of child protection... These developments are a clear indication of the shift in understandings of risk as untoward possibilities rather than balance of probabilities" (p26).

Lowe et al (2015) argued that "the emphasis on women living in disadvantage undermines the claims to biology through its selective application and re-individualises the risk" (p27).

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14. MENTAL ILLNESS AND PHYSICAL ILLNESS

- Appendix 14A - Recovery and hope
- Appendix 14B - Socio-economic factors and mental and physical health
- Subjective social status
- Health promotion
- References

Individuals with serious mental illness (SMI) die approximately twenty-years earlier than the general population, in part because of a greater medical illness burden (ie: more physical illnesses) [84] (Forty et al 2014).

Leaving aside suicide or violent death, one traditional explanation for the premature deaths is unhealthy lifestyle, including smoking and alcohol misuse, and another is the consequences of psychotropic medications. In the case of schizophrenia with a life expectancy of 20% lower than the average, risk factors for physical health problems include smoking and alcohol misuse, unemployment, obesity, lack of exercise, and changes in glucose metabolism from anti-psychotic medication (Crawford et al 2014).

However, the relationship between mental and physical health could be bidirectional - the mental disorder leading to the medical condition or the medical condition increasing the risk of a mental disorder (eg: via stress) (Forty et al 2014) [85].

Recent studies of the human genome have suggested a common origin to some mental and physical illnesses (eg: bipolar disease and coronary artery disease and type 2 diabetes; Torkamani et al 2008).

Forty et al (2014) found significantly more physical illness among a sample of 1720 individuals with bipolar disorder in the UK. The participants were recruited in three areas - Birmingham, Cardiff, and London - and met the DSM-IV and ICD-10 criteria for bipolar disorder. They were of White European ethnicity, at least eighteen years old, and had no history of drug or alcohol abuse. The participants reported their lifetime experience of twenty health problems, including asthma, hypertension, and heart disease [86].

There were two comparison groups - 1737 individuals with recurrent major depression from the same three areas

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[84] A co-morbidity of mental and physical disorders.

[85] Would recovery from the mental disorder change this relationship (appendix 14A)?

[86] This is a self-report measure. Farmer et al (2008) compared a sample of sixty-one self-reports with their medical records and found 93% agreement.

of the country, and 1340 healthy volunteers from London.

Significant differences were found between the bipolar group and the comparison groups on nineteen of the physical illnesses (the exception being type I diabetes) Eleven conditions were higher, and the three most prevalent illnesses were migraine, asthma, and elevated lipids.

There was no difference in rates of smoking and alcohol misuse between individuals in the bipolar group with or without a history of physical illness. This is a challenge to the unhealthy lifestyle explanation of co-morbidity.

Another explanation for the early death of individuals with SMI could be poor healthcare for physical illnesses. For example, Sullivan et al (2006) found that individuals with diabetes and schizophrenia received less specialist treatment for the former condition than individuals with diabetes alone.

Using the National Audit of Schizophrenia (NAS) data in the UK, Crawford et al (2014) found that assessment and treatment of common physical health problems fell "well below acceptable standards" for individuals with schizophrenia. For example, less than a quarter of the sample had had nine aspects of physical health monitored by health professionals in the previous twelve months (eg: body mass index, blood pressure, alcohol use) (ie: risk factors for premature death). The NAS retrospectively examined clinical records of a sample of over 5000 individuals with schizophrenia from August-November 2011.

There may be reasons for this finding including that mental health case workers do not see physical needs as important as the mental health needs, nor do the individuals themselves (eg: "a 'troubling acceptance' of patients' poor physical health") (Crawford et al 2014).

Another aspect of healthcare is the use of services available. For example, women with a mental disorder have lower rates of mammography screening for breast cancer than the general population (Mitchell et al 2014). Mitchell et al (2014) found twenty-nine published studies up to February 2014 on the subject for their meta-analysis. Combining the studies gave over 700 000 women (the majority from North America).

The overall odds ratio was 0.71. If the odds ratio of screening for the general population is 1.00, then women with mental disorders were significantly less likely to be screened. The odds ratio for women with mood disorders was 0.83 (slightly better, but still significantly lower than the general population), and 0.54 for SMI (ie: almost 50% less likely than the general

population) [87].

These findings could, in part, explain why cancer is detected later on average in people with mental illness. But why are women with mental disorders less likely to be screened? Mitchell et al (2014) offered one "plausible hypothesis" - "the low uptake in those with mental illness is explained by current distress. Stress, distress and anxiety have been linked to short-term risk-averse behaviours resulting in avoidance of screening invitations" (p432). Though the meta-analysis did not support this idea, contact with medical professionals is lower. For example, only two-thirds of individuals with SMI attended an invited physical health check-up compared to over four-fifths of individuals with diabetes (Hardy and Gray 2012).

Add to this that "the low screening rates may be partly ascribed to a failure of primary healthcare providers to take the physical healthcare complaints of people with mental illness seriously. For instance, healthcare providers may fail to screen people with mental illness for cancer owing to a preoccupation with other co-morbidities and confusion around symptom attributes. One author stated that providers attributed many of the patients' physical complaints to their psychiatric symptoms, which resulted in an underestimation of the post-test probability of other medical conditions" (Mitchell et al 2014 p433).

APPENDIX 14A - RECOVERY AND HOPE

Recovery is seen as a meaningful goal for individuals with mental disorders, particularly when psychiatry has historically been negative about it. "Over the course of 50 years, people with lived experience who were frustrated with the status quo in psychiatry told their stories of recovery... Rather than stealing hope from patients in our clinic, mental health providers learned to instil optimism and promote a sense of future" (Corrigan 2014 p423).

So, hope of recovery is key. It encourages well-being, and motivates participation in treatment. But what of "false hope"? Corrigan (2014) asked: "Is it false hope to suggest to a person with formal thought disorder and delusions of reference that she might be able to go to medical school" (p423)?

In relation to positive behaviour change, Polivy and Herman (2002) described a "false hope syndrome" with unrealistic expectations about the ease of changing, but little success in reducing smoking or increasing

[87] Risk factors related to social deprivation, for example, were not isolated in the analysis (Mitchell et al 2014) (appendix 14B).

exercise, for instance. Corrigan (2014) stated: "False hope results in continued attempts to pursue avenues of behaviour change that are ineffective for the individual. False hope prevents people from objectively assessing their status and goals. Applied to psychiatric disabilities, false hope might suggest that people pursue work goals that exceed true abilities. For example, someone seeks a full-time job as a paralegal when a more realistic job may be a part-time janitorial assistant" (p424).

But if we are not careful, we end up at the hopelessness of the past. Behaviour change is not necessarily success or failure, and small improvements can continue to foster hope, which is a positive force. "Hope, however, is not blind. It does not mean individuals forego careful self-assessment and critical thinking. Life's decisions are more effective when the individual has knowledge about the full range of personal challenges and response options" (Corrigan 2014 p424).

APPENDIX 14B - SOCIO-ECONOMIC FACTORS AND MENTAL AND PHYSICAL HEALTH

Mental health problems are common (eg: 1 in 4 Americans; Kessler et al 2005), but they also vary with demographic and socio-economic variables (eg: higher among women, ethnic minorities, single individuals, younger people, and lower SES) (Businelle et al 2014).

The link between lower SES and mental health problems is mediated by greater number of stressors (eg: finances, relationships, and employment), or by fewer stressors of greater severity, or less ability to cope than individuals of higher SES (Businelle et al 2014).

Businelle et al (2014) produced evidence for this statement using data from the National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) in the USA. Wave 1 of NESARC interviewed a nationally representative sample of over 43 000 individuals in 2001-2, and then re-interviewed over 34 000 of them in 2004-5 (Wave 2). SES was measured by number of years of education, total household income in the last year, and presence or absence of health insurance. Respondents were asked about twelve types of stressful events (eg: death of a family member or close friend; being fired or laid off) in the twelve months prior to Wave 1. A self-report measure of mental health was used.

The number of stressful life events experienced in 2000-1 were found to mediate the relationship between SES and mental health in 2004-5. Put another way, "exposure to life stressors helps to explain commonly reported socio-economic and demographic disparities in mental health" (Businelle et al 2014 p205).

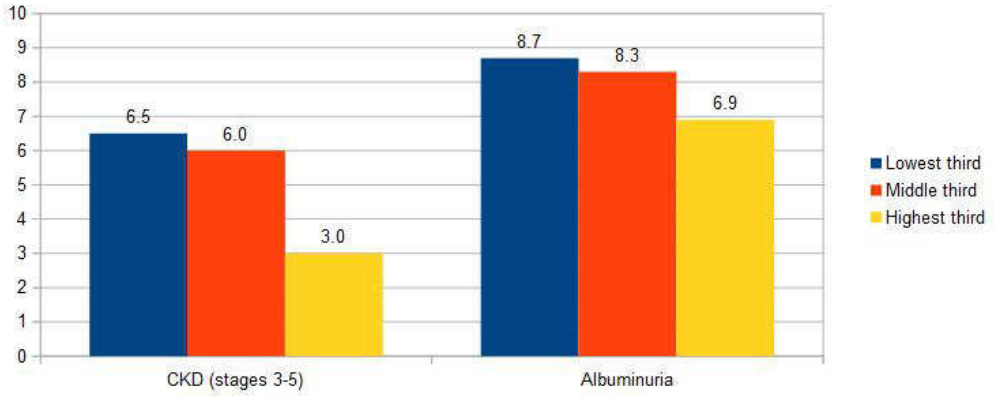
Socio-economic factors and status affect physical and mental health in many and diverse ways. Here are a selection of recent examples of studies.

There is an inverse relationship between kidney problems (eg: chronic kidney disease, CKD; renal replacement therapy) and socio-economic status (SES) in the UK (Fraser et al 2014). The basis of this statement is the Health Surveys for England (HSEs) which are yearly, national, representative studies.

Fraser et al (2014) focused on the 2009 and 2010 HSEs, which covered over 13 000 individuals aged sixteen years and over. As well as individual interviews, nurses collected urine and blood samples from approximately half of the respondents. CKD [88] was determined from these samples by estimated glomerular filtration rate (eGFR) [89], and the presence of albuminuria [90].

Six different measures were used for SES - occupation grouping (high, middle, low), education level, household income, household tenure (owned or rented), access to motor vehicle, and area-level deprivation.

Overall, CKD (stages 3-5) was calculated as 5.2% and albuminuria 8.0%. The rates were higher for lower SES individuals however SES was measured (figure 14.1).



(Data from Fraser et al 2014 table 2 p581)

Figure 14.1 - Prevalence of kidney problems based on household income.

This compares to a study in Sweden where CKD was twice as high in families of unskilled workers than of

[88] CKD is divided into five stages, of which 3-5 were viewed as kidney problems in this study.
[89] Volume of fluid filtered in the kidneys in a certain time.
[90] Albuminuria describes the presence of albumin in the urine which is a symptom of kidney damage.

professionals (even adjusting for age, sex, body mass index, smoking, alcohol, and aspirin and paracetamol use (Fored et al 2003). But a study in Australia found no association between CKD and SES (as measured by education and income) (White et al 2008).

Does an economic crisis lead to increased suicide? This is not an easy question to answer, particularly in terms of establishing causation.

Fountoulakis et al (2014) confirmed a general relationship between the economic environment and suicide rates for twenty-nine European countries since the 2008 global economic crisis, but not "a clear causal relationship". "The temporal sequence and correlation of events (suicide rise first, economic recession follows, synchronisation of suicide rate changes across the continent) suggests there is a close relationship between the economic environment and suicide rates; however this relationship is not that of a direct cause and effect" (Fountoulakis et al 2014 p491).

Data were gathered for number of deaths by suicide, unemployment rate, gross domestic product (GDP) per capita, annual economic growth rate, and inflation (table 14.1) for each country for 2000 to 2011.

- Suicide rate - number of suicides per 100 000 inhabitants.
- Unemployment rate - share of the labour force that is without work but available for and seeking it.
- GDP per capita - "the sum of gross value added by all resident producers in the economy plus any product taxes and minus any subsidies not included in the value of the product" divided by the population size.
- Annual economic growth rate - annual percentage growth rate of GDP at market prices.
- Inflation - annual percentage change in consumer price index.

(Fountoulakis et al 2014 pp486-487)

Table 14.1 - Definitions of variables.

Altogether there was a correlation between suicide rates and economic measures (except GDP per capita) for men, and only unemployment for women. But increases in the suicide rate appeared a few months before the 2008 economic crisis.

The researchers identified three patterns in suicide rates than covered all but two of the twenty-nine countries:

- Pattern A (13 countries; eg: UK) - declining since 2000

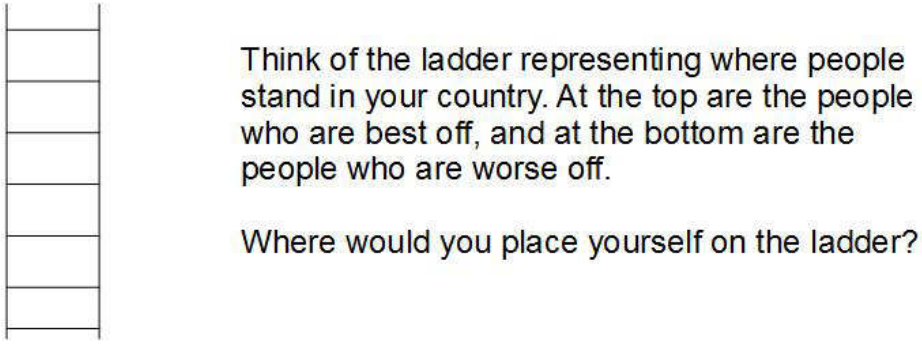
with a temporary increase after 2007 and then stabilises.

- Pattern B (3 countries; eg: Sweden) - declining since 2000 with a temporary increase after 2007 and then declines again.

- Pattern C (11 countries; eg: Norway) - declining since 2000 and then increasing after 2007.

Subjective Social Status

Social status is related to health, both in the objective sense (objective social status; OSS) and in the subjective perception of social position (subjective social status; SSS). The latter is measured by the MacArthur Scale of Subjective Social Status (Adler et al 2000), which uses a ladder for the individual to place themselves in relation to the national or local population (figure 14.2). The former tends to concentrate on money, education and occupation (national SSS) [91], while the latter is perceived standing at work or in relevant aspects of the local community (community SSS). SSS is influenced by income, life satisfaction, education, job control, and everyday discrimination, for example (Euteneuer 2014).



(Based on Euteneuer 2014 figure 1 p338)

Figure 14.2 - A ladder for measuring SSS.

SSS may be more strongly related to health than OSS,

[91] Low national SSS has been found to significantly relate to reduced immune response (eg: John-Henderson et al 2013), and this could be one of the mechanisms by which low SSS leads to health problems.

particularly through self-rated health (SRH), which itself is a predictor of illness and mortality (Burstrom and Fredlund 2001). The link between SRH and SSS was shown, for example, in a cross-sectional study of over 15 000 civil servants in Brazil (Carmelo et al 2014). While in a seven-month longitudinal study of US healthcare workers (Thompson et al 2014) a decline in SSS was associated with significantly poorer weekly SRH, especially for those placing themselves on the bottom half of the SSS ladder.

SSS is also related to mental health. For example, among US adolescents lower school SSS was associated with depression, and SSS generally with alcohol and drug abuse (Euteneuer 2014).

Health Promotion

Interventions to change unhealthy behaviour can improve long-term health (eg: increased leisure-time physical activity to reduce heart disease). But such interventions often have a lower uptake among lower SES groups, who may benefit most (eg: less leisure time after working long hours). More uptake by higher SES groups can increase inequalities in health further (Gulliford et al 2014).

Gulliford et al (2014) showed in an analysis of data from the HSEs 2006 and 2008 that interventions to increase physical activity would benefit lower SES groups more than higher ones. The HSEs categorise physical activity based on thirty minutes exercise per day (minimum) - inactive (one day per week), insufficient (1-4 days), and active (5 days). SES in the HSEs was based on measures of deprivation (eg: low income, unemployment).

It was calculated that a programme to increase physical activity over five years would lead to approximately twice as many incremental quality adjusted life-years (QUALYS) in the most deprived 20% compared to the least deprived 20%. However, this was a statistical modelling exercise, and it made a number of assumptions, including that the exercise programme would be followed. The authors concluded: "In spite of these limitations, we believe our results are important in drawing attention to the potentially greater cost-effectiveness of intervention at lower socio-economic levels" (Gulliford et al 2014 p681).

Lifestyle-related risk factors for health (eg: smoking, obesity) can be challenged by health promotion (HP), defined as "the process of enabling people to increase control over their health and its determinants, and thereby their health" (World Health Organisation 2005 quoted in Lee et al 2014). These risk factors are greater

among lower SES groups, who tend to have less contact with health professionals other than in emergencies. So, an opportunity for hospitals to address these factors.

The National Health Promotion in Hospital Audit was developed in England to evaluate HP by hospitals. Lee et al (2014) reported the data from around fifty hospitals in 2009 and 2011. Evidence of HP was verbal or written advice or referral to a specialist service for smoking, alcohol misuse, obesity, or physical inactivity from one hundred in-patients sampled in each hospital.

It was found that assessment and HP were less than the recommended standard. For example, the standard was assess all patients for smoking and HP to one-third of smokers, but three-quarters of smokers did not receive HP. The researchers stated: "It appears that the overall acknowledgement of lifestyle risk factors through assessment in hospital is improving, but the practice of actually acting upon the identification of a risk factor through HP remains low" (Lee et al 2014 p655).

Other studies have shown the barriers to nurse HP, including heavy workloads, lack of training, and "a ward culture lacking HP", and "nurses reporting a lack of support and being torn between disease-oriented tasks, routine work and promoting health" (Lee et al 2014). On the other side, hospitalised patients view the hospital as an appropriate place to give them HP.

However, one-off brief interventions in hospital may be of limited use in smoking cessation, say (Lee et al 2014).

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15. SIGNS OF OVULATION?

Female primates have fertility cycles, and in many species the ovulatory status is clearly advertised to males (eg: anogenital swellings). Hominids do not have such obvious signs, but differences in females have been found in studies (Burriss et al 2015).

The loss of overt signals could be to confuse males about paternity of their offspring and encourage support rather than desertion (eg: Sillen-Tullberg and Moller 1993). "Women may stand to benefit by concealing all remaining cues to ovulation, such as body odour or face shape, but have not yet concealed these sufficiently to avoid their being detected by men, who are (or were) under selection pressure to acquire information about female fertility. Alternatively, women may have suppressed cues to ovulation that are widely perceptible, and retained those that can be directed at preferred men" (Burriss et al 2015).

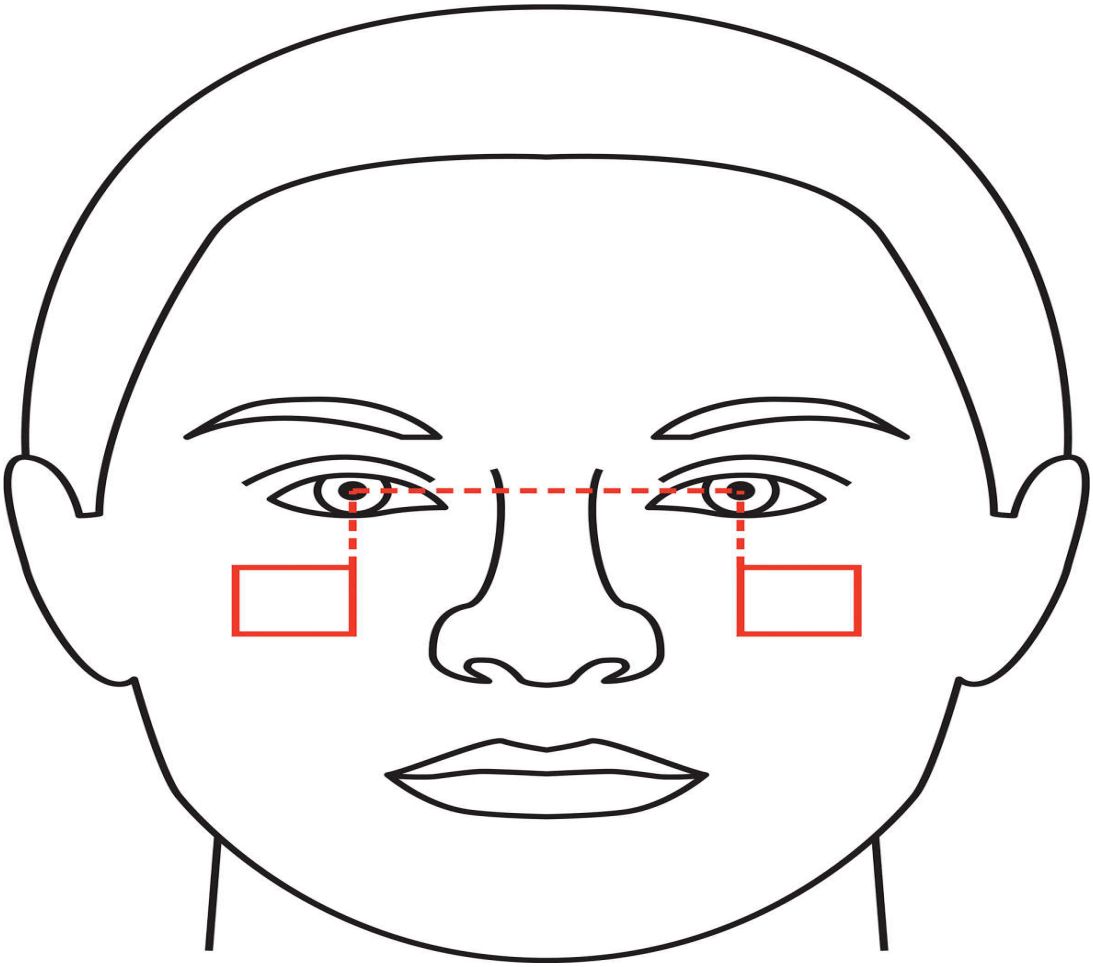
For example, women's behaviour changes near ovulation (ie: peak fertility - peri-ovulation) - they are more attracted to masculine men, flirt more with attractive men, and wear more revealing clothing. Campbell (1974) described this as "voluntary signalling by the female replacing the involuntary physiological signals of oestrus" (quoted in Burriss et al 2015).

In terms of "involuntary signals", men rate women's voices at peri-ovulation as more attractive, for instance (Burriss et al 2015). Also men rate facial photographs of unfamiliar women taken during peri-ovulation as more attractive (eg: Roberts et al 2004). This is part of the interest in facial changes as a subtle sign of fertility status, particularly skin colour. Changes in the level of the hormones oestrogen and progesterone will probably be the cause of facial skin colour changes, but the studies are contradictory (Burriss et al 2015).

Part of the problem is the methodology used, including self-reports by women, and photographs. The closeness and sex of the photographer, for example, can influence skin colouring.

Thus, in their study, Burriss et al (2015) had females photographing twenty-two UK female undergraduates without make-up at the same time each weekday (2-3 pm or 6-7 pm) for a month. Red, green and blue colour values were calculated from cheek patches (figure 15.1). Menstrual cycle was determined by urine measure of luteinising hormone.

Redness was found to rise around ovulation and decline at menstruation, but the changes were felt to be too subtle for the human visual system to detect. Burriss et al (2015) stated: "When we modelled how skin would be perceived by the human visual system, we found that,

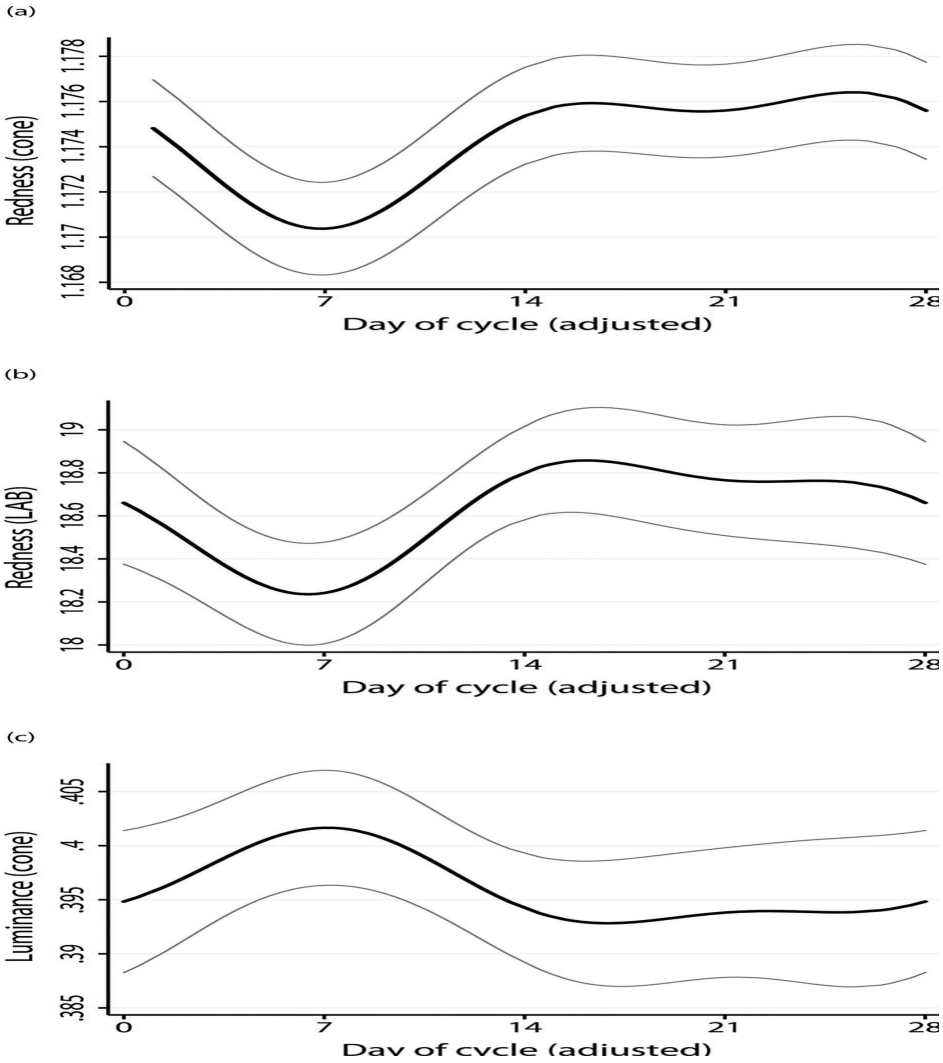


(Source: Burriss et al 2015 figure 1)

Figure 15.1 - Location of cheek patches.

although significant changes in redness were detected, the differences in skin colour were below the level detectable by the human visual system. Even if redness comparisons were made by persons with maximally sensitive cones of individuals displayed side-by-side under ideal lighting conditions, the differences would not be noticeable. It is therefore unlikely that these genuine colour differences act as a cue or signal of female fertility status, or are responsible for effects of cycle on female attractiveness". Skin luminance did not vary significantly (figure 15.2).

So, the rating of female faces as more attractive at peri-ovulation may be due to other factors including face shape, lip colour and size, pupillary dilation (Burriss et al 2015).



(LAB = L (luminance - achromatic brightness), A (red-green ratio), B (blue-yellow ratio); Day 0 = 1st day of menstruation; Day 14 = ovulation)

(Source: Burriss et al 2015 figure 2)

Figure 15.2 - Facial skin colour over month.

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16. EPIGENETICS, BIOPREDICTION AND BIOTECHNOLOGY

16.1. INTRODUCTION

"Bioprediction" describes "how scientific evidence from brain scans, genetics, and other biological assays is likely to be used to diagnose and predict 'bad' behaviour" (Singh and Sinnott-Armstrong 2014 p2).

Singh and Sinnoot-Armstrong (2014) referred to "categories of persons and the application of bioprediction science":

1. The innocent - eg: prodormal categories.

2. The guilty - "bioprediction in criminal law could be useful if accurate and properly applied but also could become disastrous if abused" (Singh and Sinnott-Armstrong 2014 p9).

3. The marked - ie: carriers of bio-markers.

4. The patients - eg: implications of biomarkers.

But "diagnosis of mental illness interacts in complicated ways with assessment and management of bad behaviour" (Singh and Sinnott-Armstrong 2014 p10).

Wolpe (2014) observed: "Being labelled a biological criminal can stigmatise differently from other forms of criminal labelling. Such labelling can impede the possibility of rehabilitation or reform" (p126).

Bioprediction can also be applied to other areas of life, like health, and is grounded in developments in epigenetics and biotechnology, for instance.

16.2. EPIGENETICS

"Epigenetics is one of the most rapidly expanding fields in the life sciences. Its rise is frequently framed as a revolutionary turn that heralds a new epoch both for gene-based epistemology and for the wider

discourse on life that pervades knowledge-intensive societies of the molecular age" (Meloni and Testa 2014 p431).

Epigenetics is the "next big thing" in bioscience (Ebrahim 2012) [92]. In the academic world, the number of publications with the word "epigenetics" in the title has risen over ten-fold in the 21st century (Meloni and Testa 2014), and it has gone "pop" (Davey Smith 2012) with features in the popular media and uses in advertising.

But epigenetics "seems to flourish in the remarkable ambiguity of its defining term, with its apparent ability to accommodate - and productively align - a rather diverse range of biological questions and epistemic stances" (Meloni and Testa 2014 pp432-433). Meloni and Testa (2014) distinguished two overlapping meanings of molecular epigenetics in the literature - (i) "all levels of cellular function that overlay genes" (Meloni and Testa 2014), or (ii) "any long-term change in gene function that persists even when the initial trigger is long gone that does not involve a change in gene sequence or structure" (McGowan and Szyf 2010 quoted in Meloni and Testa 2014). The former meaning is more shallow and widespread, and leads to the blurred boundary that covers the influence of "environmental signals" on genes (Meloni and Testa 2014).

Meloni and Testa (2014) wanted to explore "the way in which epigenetic knowledge is becoming 'a social phenomenon in itself' (Landecker and Panofsky, 2013), including the imaginaries and visions that are catalysing this transition, and that we will refer to here as epigenetic imagination" (p437). There is, of course, a voice of caution - "much more work is therefore needed before we will know the extent to which epigenetic mechanisms represent a third factor - beyond nature and nurture - in controlling an individual's traits in health and disease" (Nestler 2013 quoted in Meloni and Testa 2014). This stands against Sweatt (2013), for example, who stated: "it is now clear that there is a dynamic interplay between genes and experience, a clearly delineated and biochemically driven mechanistic interface between nature and nurture. That mechanistic interface is epigenetics" (quoted in Meloni and Testa 2014).

As well as contradictory views on epigenetics, there is also tension, summed up in a "Time" magazine article as "both good and bad news" - "the bad news being the vulnerability of the epigenome to wrong lifestyles ('eating too much can change the epigenetic marks atop

[92] Other phrases used include the "decade of the epigenome" (Martens et al 2011), and the "era of epigenetics" (Hurd 2010).

your DNA in ways that cause the genes for obesity to express themselves too strongly and the genes for longevity to express themselves too weakly' (Cloud, 2010) and the good news being the newly recognised capacity 'to manipulate epigenetic marks in the lab', which means that scientists 'are developing drugs that treat illness simply by silencing bad genes and jump-starting good ones'" (Meloni and Testa 2014 p444).

The "bad news" aspect reinforces the individual's responsibility for their health, but also the responsibility of grandparents for future generations through "transgenerational resilience of epigenetic states" (Meloni and Testa 2014) [93].

Meloni and Testa (2014) also highlighted "a reconfiguration of social disparities in epigenetic terms", even to the point of the "molecular biology of the social position" (Niewohner 2011). Biological determinism to the max. For Meloni and Testa (2014) this is different to "gene-centred twentieth century biology" because of the open boundaries in defining epigenetics. So rather than the simple nature or nurture debate being collapsed by epigenetics (eg: environmental influences at the gene level), there is the possibility of turning the relationship around to suggest that genes influence social aspects of the individual. Thus, "epigenetics' materialisation of novel links between the genetic and the social, its making the body porous and permeable to the world is exactly the channel by which the capture of the body in molecular terms is made possible. The openness of the genome to the social is thus always on the verge of collapsing the social onto a mere source of differential genetic expression" (Meloni and Testa 2014 p449).

16.3. OWNERSHIP

New medical technologies have meant that human organs and tissues are available in different ways, including cryogenically stored tissue samples, genetically modified cell-lines (eg: "Mo" and "HeLa" cell lines), isolated sequences of DNA, scans and digitalised images. But how to classify these "new biotechnological artefacts", particularly in relation to "ownership" (Parry and Gere 2006)?

For example, genetically modified human cell-lines, "while initially derived from (and fully reliant upon) donated human tissues, they also owe their existence as

[93] This is a controversial concept where, for example, the diet of a boy at puberty could influence their sperm and the future risk that way or of pregnant women not only affecting their own offspring, but if found, the eggs for their offspring.

highly engineered artefacts to the constituencies responsible for bringing them into the world, as such. These new artefacts are simultaneously corporeal [94] and informational, biological and technological, natural and artificial and may thus be viewed as being more or less 'essentially' related to one's 'self'" (Parry and Gere 2006 pp139-140).

One way to look at an "engineered body part", say, is with the idea of "collective": "These artefacts do not suddenly arrive in the world as discreet, fully formed objects, rather, they are negotiated into being. Their identities are not fixed, but made and re-made in response to new technologies, new scientific expertise, public consultation, funding crises, institutional expansion and reform" (Parry and Gere 2006 p141). In other words, the engineered body part is a combination of the donated tissue, the technology, and the expertise, for instance.

Another example is tissue/organ donation after death. Who owns the donated body part? One answer could be the relatives of the donor, who could maintain some control over the use and biotechnological artefacts produced from it. This is described as a "property-in-the-self model" (Parry and Gere 2006). An alternative is the organisation that holds the donation is the owner, particularly if the organisation has "added to" the tissue/organ (eg: method of storage; finding from analysis).

The concept of "collectives" (or "collective custodianship") is a middle point - "While donors may be considered the rightful owners of their embodied and unprocessed biological or genetic materials, it can be argued that they have considerably less claim to be considered as the exclusive owners of any of the many engineered artefacts that are generated out of those materials. The task of realising biotechnological artefacts — of enabling them to exist in the world, is, as we hope to have illustrated here, an immensely lengthy and complex one. The artefact itself is, in fact, best understood as an embodiment of all the intricate Gordian relations — between donors, technologies, research scientists, funding bodies, technicians, institutions and charities that allow them to be in the world as they are now — and indeed as they might be...[] no one person can own a collection, and neither perhaps can they be said to own the multiply constructed assemblages that are contemporary biotechnological artefacts. They are simply held in trust for use by present and forthcoming generations" (Parry and Gere 2006 pp153, 156).

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[94] Corporeal = "of the body".

16.4. SPORT

Direct-to-consumers (DTC) genetic tests are growing in popularity, particularly in the USA, and specifically for sports performance. In this case, genome sequencing of the child is used to measure athletic potential, though "it is not clear exactly how many parents and coaches are using these tests" (Camporesi 2013) [95]. The companies selling these tests claim to be looking for "performance enhancing polymorphisms". For example, elite sprinters were found to have a significantly higher frequency of a particular version of the ACTN3 gene (Camporesi 2013) [96]. But Camporesi (2013) was cautious about what Caulfield (2011) called "sciencepoloitation" [97]. Also the ACTN3 gene only accounts for 2% of variance in muscle performance, for instance (Camporesi 2013).

Furthermore, Camporesi (2013) noted the issue of correlation not causation (ie: the presence of the version of the gene in elite sprinters is a correlation not an established causation of their performance), and of false negatives, "as the parents will act upon the results of these tests and the claims made by the companies and actively discourage their children from a particular kind of sports for which they allegedly do not have a genetic predisposition" (p177).

Camporesi (2013) described the DTC genetic tests as "the latest tool available to parents to steer their children's future". This has an impact on the children's right to an open future (ROF) [98] - as "some parents are constantly projecting into the future of their children, and do not give a proper value to the present child that they have in front of them" (p179). However, the ROF can never be entirely open as parenting narrows the possible futures: "Simply by ling their own lives as they choose, the parents will be forming an environment around the child that will tend to shape his budding loyalties and habits" (Feinberg 1980 quoted in Camporesi 2013) [99].

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[95] Caulfield (2011) divided such tests into "the clearly preposterous", "the marginally pertinent", and "the vaguely predictive".

[96] "Although many genes and gene sequence variants have been tentatively associated with performance-related traits, few if any have risen to a level that would be called conclusive.... Not only is the field of genetics of sports performance in its infancy, but the DTC genetic tests take data obtained in one pool of subjects (i.e. elite athletes) and apply them to a substantially different one (ie: children, teenagers) in what... refers to as the problem of ‘externality’" (Camporesi 2013 pp176-177).

[97] This is "the exploitation of legitimate fields of science and, too often, patients and the general public, for profit and personal gain" (Caulfield 2011 quoted in Camporesi 2013).

[98] "The violation means that when the child is an autonomous adult, certain key options will be already closed to her, undermining her capacity for self-determination" (Camporesi 2013 p179).

[99] Camporesi (2013) admitted that talented children are a difficult balance between nurturing the special ability/skill and the self-determination of the children.

Camporesi and McNamee (2014) likened professional sportspeople to "guinea pigs" [100] with their use of performance enhancing technologies (PETs), including for treatment of injury, and health optimisation. "Innovative interventions" like gene transfer or pre-emptive surgery have been tried, but some of them may be "snake oil" (Franklyn-Miller et al 2011).

Making use of Calvano's (2009) "six memos for the next millennium", Camporesi and McNamee (2014) applied three of them to this situation [101]:

i) Visibility - This refers to the level of information and transparency that the "patient" has. Sportspeople using PETs tend not to have this as "the data on safety and efficacy does not see the light of day in scientific journals, or does so in - one suspects - anodyne form and only after competitive advantage is not compromised" (Camporesi and McNamee 2014 p2).

ii) Multiplicity - The use of multiple drugs, for example, where the consequences of one substance are little known, let alone high dosage polypharmacy doping. Such consequences have been linked to the death at 38 years old of the US sprinter Florence Griffith Joyner, and at 27 years old of German heptathlete Birgit Dressel (Camporesi and McNamee 2014).

iii) Consistency - This covers the integrity or fairness of sport.

Camporesi and McNamee (2014) proposed "the legitimisation of a research enterprise to measure the enhancement effects of agents within a systematic governance framework. This would promote greater visibility and consistency in the context of professional sport currently lacking both, and where athletes may be subjected to an unregulated research system, which poses high risks to their health" (p8).

16.5. SLEEP

Wolf-Meyer (2009) explored the scientific pursuit to limit or eradicate human sleep. "These scientific, sports-based and military projects are all experiments

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[100] King and Robeson (2007) described them as "unwitting or unwilling research subjects" as "well understood problems in research ethics (ie: vulnerability, voluntariness, undue influence, full disclosure, equitable subject selections, conflict of interest) become particularly problematic in the professional sports context, as opposed to the more typical health, medical and scientific contexts in and through which research is already governed" (Camporesi and McNamee 2014 p2).

[101] The other three are lightness, quietness, and exactitude.

with the extremes. The extremes bring together science fictions and normative everyday regimes through technics (Stiegler 1994). This is to say that the extremes begin with assumptions about normalcy, extend these assumptions to their ends, and then insinuate these new models of the normal into the everyday. In so doing, the extremes make the present into the future, thereby unfolding new possibilities, capacities and normative regimes" (Wolf-Meyer 2009 p258).

For example, in the 2000s, the Defense Advanced Research Projects Agency (DARPA) in the US began a project to eradicate the negative effects of sleep deprivation (eg: poor judgment and reduced physical performance). As one DARPA document said: "Imagine if we could remove the need to sleep for periods up to one week without a reduction in our ability to process sensory input, make decisions, and respond to the external environment with focus and intention" (quoted in Wolf-Meyer 2009 p259). The rhetoric of the project with the search for relevant genes, for instance, "firmly root the future in the biological, not the cultural or social", and more generally in the "24-hour existence" (Wolf-Meyer 2009).

In the sporting context, sleep reduction is attractive in one-person long-distance sailing (eg: Vendee Globe - from France to Antarctic and back). The solution is to break sleep into short naps. Wolf-Meyer (2009): "To be a competitive sailor in the Vendee Globe means also being a competitive sleeper, and acquiring the ability to alter one's sleep schedule efficiently and at will sets many racers apart from the otherwise untrained, sleep-deprived sailors who attempted to maintain normal sleep patterns while at sea" (p267).

In both these examples, sleep is seen as holding individuals back in some way, and limiting their ability to fulfil their potential. But chronic insomnia, as seen in the rare genetic condition fatal familial insomnia, "is is a slow torture, not a productive, alert means of being in the world...; it is a radical disruption of basic human biology, and one which leads, inevitably, to an estrangement from everyday life, despite being able to be present at all times" (Wolf-Meyer 2009 pp269-270). The "fantasies" of banishing sleep are far from the realities of "actual sleepless bodies".

In the desire to produce, consume, fight, or compete without stopping, the human being is the weak link. The "production" of a human being who does not need to stop will be "an enormous leap in the arms race. This 'arms race', if successful, could lead to new 'social races', new configurations of the social based upon altered biologies..." (Wolf-Meyer 2009 p270). Put another way, as with so many developments or potential developments in biotechnology, what does it mean to be human?

16.6. HEALTHCARE

Behaviour change is an important part of health promotion, and this has traditionally been separate to genetic bases to illness. However, this is changing. "Epigenomics in particular, by exploring how environmental stimuli 'mark' and alter the regulation of genes, emphasises the importance of behavioural factors for health" (Lucivero and Prainsack 2015 p44). Thus the opportunity to market "consumer goods with remedial qualities" and "personalised" services - "companies offer personalised health and diet recommendations on the basis of the micro-organisms inhabiting their bodies, on their blood type, or on their DNA" [102] (Lucivero and Prainsack 2015 pp44-45).

DTC genetic testing (genomics) appeared at the beginning of the 21st century, initially related to medical conditions, but also to offer advice on lifestyle changes at the boundary between "medical devices and consumer products" (Lucivero and Prainsack 2015) (which is also seen in the growth of digital mobile devices (m-health [103]) like "apps" to analyse caloric intake [104]). "These innovations occupy the ambiguous space between the highly regulated medical domain and the less regulated consumer market, where pre-market approval is easier to obtain and integration in the clinical pathway through public procurement is not required" (Lucivero and Prainsack 2015 p45).

Lucivero and Prainsack (2015) described DTC genomics and m-health as "technologies of healthy lifestyle", which blur traditional boundaries like "healthy" and "sick". For example, it is possible to be "sick" at a molecular level as shown by DTC genomics, but appear and feel "healthy" in everyday life. Timmermans and Buchbinder (2010) used the term "patients-in-waiting" (ie: not healthy but not ill enough to need a physician at this time). "Genomics blurs the boundaries that make such clear distinctions possible. A genome scan reveals information that is medical, genealogical and recreational. And those who scan and interpret the data are not distinct bodies of experts, but instead, novel configurations of geneticists, customers, ethicists, bioinformatics experts and new media executives" (Lucivero and Prainsack 2015 p47).

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[102] The "lifestylisation of healthcare" (Lucivero and Prainsack 2015). This also takes place to the wider context of the neoliberalisation of knowledge (appendix 16A).

[103] Lucivero and Prainsack (2015) stated that there were 97 000 mobile health apps available at the time of their writing.

[104] "In the case of apps for measuring sleeping and exercising patterns, calories intake, or blood oxygen level, it is unclear how the extracted data about people's behaviour and lifestyle has a health impact and can be used for medical purposes as the correlation between this information and health conditions are still uncertain" (Lucivero and Prainsack 2015 p48).

16.7. APPENDIX 16A - NEOLIBERALISM AND KNOWLEDGE

Neoliberalism is based on the idea of "the market as the central agent in human society, and the role of the government is "market creation and protection" rather than public welfare - ie: "faith in the ability of properly functioning markets to improve social welfare with a new political commitment to expand market relations into traditionally public arenas such as healthcare, education, and environmental management" (Lave et al 2010 p661).

While traditionally political liberalism takes a laissez-faire approach that leaves the market to work everything out, neoliberalism argues that "their political programme will only triumph if it becomes reconciled to the fact that the conditions for its success must be constructed, and will not come about 'naturally' in the absence of concerted effort" (Lave et al 2010 p661).

Applying neoliberalism to knowledge, there is a "shift towards market-based solutions" with private funding of education and research (rather than public money), and "marketplace of ideas". "The fundamental role of the market is not, according to neoliberalism, the mere exchange of things, but rather the processing and conveyance of knowledge or information. No human being (and no state) can ever measure up to the ability of the abstract marketplace to convey existing ideas and to summon forth further innovation. Hence the novelty of neoliberalism is to alter the ontology of the market, and consequently, to revise the very conception of society. By its very definition, the market processes information in ways that no human mind can encompass or predict" (Lave et al 2010 p662).

Lave et al (2010) summarised the neoliberal view of knowledge in "eight grossly telegraphed propositions":

1. "The Market is an artefact, but it is an ideal processor of information. Every successful economy is a knowledge economy" (table 16.1).

2. "Neoliberalism starts with a critique of state reason".

3. "Politics operates as if it were a market, and thus dictates an economic theory of 'democracy'".

4. "Governmental institutions should be predicated on the government of the self".

5. "Corporations can do no wrong, or should not be blamed if they do. Competition always prevails".

6. "The nation-state should be subject to discipline and limitation through international initiatives".

7. "The Market (suitably re-engineered and promoted) can always provide solutions to problems seemingly caused by The Market in the first place".

8. "Redefinition of property rights is one of the most effective ways the state exerts neoliberal domination, since once such rights become established, they are treated from then on as 'sacred'".

- Rossiter and Robertson (2014) noted that "the rise of the neoliberal knowledge economy has been marked by a turn away from curiosity-driven research with potentially unpredictable outcomes, and a turn toward an increased demand for knowledge that is outcome-driven, with results are predictable, measurable and amenable to economic rationalisation" (p198) [105].

- Rossiter and Robertson (2014) stated: "knowledge has been redefined not as an external resource for growth and production, but rather a central object or goal of production, whether through the creation of 'innovative' new technologies and/or applications, or through the development of human capital... Here human capital may be described as knowledge embodied within trained individuals or organisations" (p200). Thus "knowledge has been recast as an economic good".

- Other outcomes of the knowledge economy include the focus on "innovation" (ie: "not just something new and noteworthy, but something that is productive in terms of economic growth or knowledge productivity"), and the importance placed on measurement and evaluation (especially quantitative methodologies that "reduce knowledge to standardised units").

- Rossiter and Robertson (2014) argued that the distinction between quantitative and qualitative methodology is no longer relevant, and a division based on political/epistemological underpinnings should be made. "In other words, rather than classifying research according to the practical components of study design and execution, one must understand how the researcher positions him or herself in relation to the question of what knowledge is, what it is for and how it is acquired, produced and disseminated... Namely, we propose.. move toward understanding the research process as either ends oriented and driven by the demands of the economised knowledge market (instrumental), or emergent and reflexively interpretive (hermeneutic)" (p199).

- Instrumental research creates knowledge that is "predictable, rationalisable and immediately applicable", while hermeneutic knowledge has a "commitment to knowledge generation as a creative process". Taleb (2010) pointed out the contradiction of instrumental knowledge - "Prediction requires knowing about technologies that will be discovered in the future. But that very knowledge would almost automatically allow us to start developing those technologies right away. Ergo, we do not know what we will know" (quoted in Rossiter and Robertson 2014).

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[105] Slaughter and Leslie (1997) used the term "academic capitalism".

- "Commercialisable knowledge" is the upshot of instrumental research. "In other words, commercialisable knowledge is knowledge that is deemed 'applicable' in terms of making people or systems operate in a more productive manner – faster, more complete, more efficient, more cost effective or more predictable in nature. Thus, commercializable knowledge products may be understood as tools that may engender certain forms of control over both people and systems... Our argument here is that certain types of knowledge, and the constraint of knowledge production in order to create these forms of knowledge, mark one channel through which the potential for domination over human subjects may occur within neoliberalism" (p213).

Table 16.1 - "Knowledge Economy" (Rossiter and Robertson 2014).

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17. GUN VIOLENCE AS A PUBLIC HEALTH ISSUE

17.1. GUN VIOLENCE IN USA

Gun violence in the USA is a major public health issue in the form of firearm-involved homicide and firearm suicides. The latter accounts for about 60% of all deaths by gunfire, mainly involving White males, and has been increasing in recent years [106], while homicide (more common with young Black males [107]) has been declining (Webster 2015) [108]. Wintemude (2015) referred to a "mismatch between perception and reality".

Over 313 000 individuals died from firearm-related injuries in the USA between 2003 and 2012 [109]. The mortality rate is 9.9 per 100 000 during this period (which is similar to death from motor vehicle accidents). The mortality rate from firearm violence is actually a drop from a peak in the 1990s, after increasing since the 1950s. Motor vehicle-related deaths, however, have declined 59% between 1969 and 2012 (Wintemude 2015).

US States vary in their level of gun violence as do their firearm policies. Policies that keep firearms from high-risk individuals can be effective based on comprehensive background checks at the point of purchase (Webster 2015).

Wintemude (2015) listed risk factors for firearm deaths:

- Mental illness - suicide, but "not a leading contributor to interpersonal firearm violence".
- Former and current members of military - rapid increase in suicides.
- Firearm ownership.

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[106] For example, between 1999 and 2012, an increase of around 30% in suicides by White males aged 35-64 years old (Wintemude 2015).

[107] At age 20-29, the risk is over twenty times greater for a Black male than a White male (Wintemude 2015).

[108] Suicide rates are higher in rural States and homicide rates are higher in urban areas (Wintemude 2015).

[109] In 2012, 11 622 firearm-related homicides and 20 666 suicides (ie: total of 32 288 deaths from firearm violence), which was 70% of all homicides and 51% of all suicides (Wintemude 2015).

- Alcohol and substance abuse.
- Prior history of violence.

Webster and Wintemude (2015) wisely noted: "Given the lethal capacity of firearms and evidence that access to firearms significantly increases risk of violence among individuals with a history of violence and criminality, policies designed to keep firearms from dangerous persons seem logical and have the potential to reduce violence, particularly lethal violence. The fact that a policy is logical or widely supported, of course, does not mean that it is effective or just" (p22).

Hahn et al's (2005) review of studies on the effects of firearms laws between 1979 and 2001 found insufficient evidence about restricting access to high-risk groups. Webster and Wintemude (2015) extended this review to cover studies published between 1999 and 2014.

Any effective policy must identify high-risk individuals as well as prohibiting access to firearms. Legally, individuals convicted of domestic violence crimes or use of illegal substances, or those committed to a psychiatric institution cannot possess a firearm in the USA. Individual States can extend the prohibitions, and enforcement of the national rules can vary (Webster and Wintemude 2015).

There have been studies of the effectiveness of prohibition to high-risk individuals. For example, Vigdor and Mercy (2006) looked at rates of intimate partner homicides [110] in forty-six States between 1982 and 2002. The existence of firearm restrictions for domestic violence perpetrators was associated with a 8-10% drop in such homicides. But the "protective effects of these laws were evident only when states had sufficient records in criminal history databases used for background checks" (Webster and Wintemude 2015 p23).

A permit-to-purchase (PTP) policy for handguns was "most consistently associated with curtailing the diversion of guns to criminals and for which some evidence indicates protective effects against gun violence...[and] it appears that criminals who attempt to purchase firearms from licensed gun dealers and are denied are less likely to engage in violent crime" (Webster and Wintemude 2015 p34).

17.2. CURE VIOLENCE

Governments tend to deal with gun violence through suppression (eg: aggressive law enforcement with

[110] Intimate partner homicide is a specific type of violence like honour-based violence (appendix 17B).

"private"/illegal sales) and deterrence (eg: harsh penalties; "retailer accountability" [111]) (appendix 17A). "Scholars and practitioners alike in recent years have suggested that real and lasting progress in the fight against gun violence requires changing the social norms that perpetuate violence and the use of guns. Such strategies are consistent with the public health approach to violence reduction" (Butts et al 2015 p40).

One such approach is known as "Cure Violence" (CV) [112], and it aims to change social norms about the use of guns to settle conflict. Gun violence is viewed as an epidemic, and public health interventions are applied to change relevant attitudes and behaviours.

There are three key elements to CV (Butts et al 2015):

i) Interrupting the transmission of gun violence - eg: preventing retaliatory shootings; mediating in conflicts via individuals called "violence interruptors" (VIs).

Recruitment of the "right" people as VIs is crucial. "They need to be seen as credible messengers by the most high-risk young people in the community. Many VIs are former high-level or popular gang members who have changed their lives – often after a stint in prison. They need to know about the daily routines of people who are involved in criminal lifestyles. They cannot be judgmental or be perceived as outsiders, and they cannot be seen as police informants. Ideally, they should come from the same communities in which they are working, and they should demonstrate in their own lives and personal conduct that it is possible to be both law-abiding and respected in the neighbourhood" (Butts et al 2015 p41).

ii) Identifying potential transmitters (ie: high-risk individuals - eg: gang-involved; violent criminal history), and changing their thinking via outreach workers (OWs).

iii) Changing group norms about violence (ie: public education).

Butts et al (2015) reported five versions of the CV model in the USA in the 21st century, and their evaluations.

1. "Chicago-CeaseFire" (began in 2000) - Skogan et al (2009), using data on shootings over sixteen years, found a significant decline in four of seven neighbourhoods being evaluated, and neighbourhoods

[111] Prosecution of gun dealers who violate firearm sales laws.
[112] http://cureviolence.org/.

involved in the programme did better than matched control neighbourhoods. The "findings were mixed" as evidence of gang involvement in homicide and retaliatory gang killings varied. There were some problems with recruitment of staff, particularly VIs (which is common to many of the programmes) (Butts et al 2015).

2. "Safe Streets" (Baltimore) (began 2007) - Webster et al (2012), using monthly shootings data, found a significant decline in homicides (56%) and non-fatal shootings (34%) in one of the four participating neighbourhoods, but the other areas had mixed results (including an increase) (Butts et al 2015).

In terms of attitudes towards gun violence among young men approached in public places, strong support for it was significantly reduced by the programme, but moderate support did not change. This was based on a comparison of a sample at baseline and another sample one year later (Butts et al 2015).

3. "Save Our Streets" (Brooklyn) (began 2012) - Picard-Fritsche and Cerniglia (2013) found a non-significant change compared to control neighbourhoods - a decline in gun violence in the programme areas versus an increase elsewhere. Attitudes of high-risk individuals questioned in surveys did not seem to change (Butts et al 2015).

4. TRUCE programme (Phoenix) (began 2010) - Fox et al (2015) used data from the Phoenix Police Department on shootings and violent crime. Once more the findings were mixed - there was a decline in overall violence in the CV programme areas, but an increase in assaults reported (Butts et al 2015).

5. "One Vision One Life" (Pittsburgh) (began 2004) - Wilson and Chermak (2011) used Pittsburgh Police data, and the evaluation suggested "that the programme had no effect on homicides and other measures of violence; it may even have had a deleterious effect" (Butts et al 2015 p47).

Butts et al (2015) addressed the evaluations of the projects and the mixed findings. The biggest problem was the use of quasi-experimental methods that cannot control "the many types of confounding factors [113] that influence violence apart from whichever intervention is being studied" [114]. An experimental design would include the random assignment of neighbourhoods to the programme,

[113] For example, violence and shootings have been declining in the whole USA during the period of many evaluations (Butts et al 2015).
[114] Eg: media violence (appendix 17C).

which policy-makers would not accept as they tend to choose the high-risk areas for participation.

Butts et al (2015) listed the questions still unanswered about CV programmes and their evaluations:

- Does the programme work by changing the attitudes of potential transmitters or the community as a whole?
- How many conflict mediations produce a change in gun violence behaviour?
- What is the causal pathway for the spread of social norms against gun violence?
- How long does it take to change social norms?
- Is support for CV needed from other public services (eg: education, social services)?
- Can the programme succeed without the support of law enforcement agencies?

The US Department of Justice [115] described CV as "promising" rather than "effective". Butts et al (2015) felt that CV was better than that as it is "potentially very cost-efficient", particularly in reducing costs to law enforcement and the criminal justice system (eg: less shootings mean less cost to investigate, convict, and imprison perpetrators). Webster (2015), however, observed: "As with many behavioural interventions, programme effects are likely to depend greatly on the individuals implementing the programme, how well it is managed, and the community context in which it is implemented" (p3).

17.3. APPENDIX 17A - FOCUSED DETERRENCE STRATEGIES

Focused deterrence strategies (FDS) "seek to change offender behaviour by understanding underlying violence-producing dynamics and conditions that sustain recurring violent gun injury problems and by implementing a blended strategy of law enforcement, community mobilisation, and social service actions" (Braga and Weisburd 2015 p56) [116].

The theory of deterrence is that the potential offender sees the costs as greater than the benefits of

[115] https://www.crimesolutions.gov/.

[116] In public health, this is tertiary prevention - ie: "minimise the course of a problem once it is already clearly evident and causing harm" (Braga and Weisburd 2015 p56).

the crime. FDS are an example of "special" deterrence (ie: focused on offenders) as opposed to "general" deterrence (for the whole population) (Cook 1980). The certainty, swiftness, and severity of punishment need to be made clear to the offenders, and the perception of these influences the success of deterrence (Braga and Weisburd 2015).

An example of FDS is "Operation CeaseFire" developed by the Boston Police Department in the USA in the mid-1990s. An analysis of increasing youth gun violence in the late 1980s and early 1990s suggested that the cause was vendetta-like conflicts by gangs. The police set about targeting such gangs in various ways, including prosecuting all crimes committed by them (even low level), restricting bail, and cultivating informants, while other community groups offered other services (Braga and Weisburd 2015) [117].

Braga and Weisburd (2015) stated: The deterrence message was not a deal with gang members to stop violence. Rather, it was a promise to gang members that violent behaviour would evoke an immediate and intense response. If gangs committed other crimes but refrained from violence, the normal workings of police, prosecutors, and the rest of the criminal justice system dealt with these matters. But if gang members hurt people, the working group concentrated its enforcement actions on their gangs" (pp57-58).

The publicity of FDS can have "spillover effects" (Clarke 1989) - ie: reductions in crimes in areas not covered by the intervention. This can be geographical (eg: nearby neighbourhood) or crime type (eg: decline in robberies) (Braga and Weisburd 2015). This is a diffusion of the benefits of the strategy. Potential offenders see an increased risk (diffusion by deterrence) and/or reduction in the benefits from the crime (diffusion by discouragement) (Clarke and Weisburd 1994).

The big question is whether FDS "work". For example, the original "Operation CeaseFire" in Boston showed a 63% reduction in youth homicides (Braga et al 2001), and a study of the post-2007 version found a 31% reduction in total shootings among gangs targeted relative to untargeted matched gangs (Braga et al 2014).

Braga and Weisburd's (2012) review and meta-analysis of ten evaluation studies in the USA, of which nine found significant improvements in crime control, produced a moderate effect. However, the studies were quasi-experimental designs (Braga and Weisburd 2015).

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[117] Braga and Winship (2006) believed that the participation of key community members, like Black clergy, was very important.

17.4. APPENDIX 17B - HONOUR-BASED VIOLENCE

"Honour"-based violence (HBV) is a form of violence against women and girls. It is "conceptualised as a form of reputation management that serves as a means of policing and punishing autonomous female behaviours considered transgressive of gendered social norms, particularly those related to sexuality and marriage" (Payton 2014) [118]. The "paradigmatic example of a crime of honour is the killing of a woman by her father or brother for engaging in, or being suspected of engaging in, sexual practises before or after marriage" (Abu-Odeh 1996 quoted in Payton 2014).

HBV is agnatic (ie: the perpetrator is of the same male line as the victim) [119]. "Women's 'honour', then, is a property pertaining to an agnatic collective – who share a common responsibility both for safeguarding their collective reputation, which is dependent on the socialisation of female members to normative standards for female behaviour, and for applying metanormative sanctions when kinswomen are perceived to have violated such norms" (Payton 2014 p2865).

Within tight-knit communities, the family is under pressure to maintain their "honour". Failure to do so could lead to stigmatisation by the community. So families can become involved in concealing "shame" from outsiders because "an allegation of 'shaming' behaviour to be accurate or evidenced for violence to be the result, nor for the family to avoid collective sanctions, so long as it is widely believed within the community... 'Honour' should then be seen in terms of a measure of reputation that is both generated and policed through social interactions, wherein an agnatic collective's ability to claim respect and inclusion within the community is dependent on the individual reputations of its female members" (Payton 2014 p2866).

The community involvement (ie: collectivity) is key in distinguishing HBV from intimate partner violence (IPV), which focuses on the dyadic nuclear family (ie: adult partners only). Payton (2014) explored this in her study of forty case files of Arabic- and Kurdish-speaking women at a London non-government organisation helping women facing violence (between 2009 and 2012) [120]. Half the cases were classed as HBV by the caseworkers and half as IPV. Payton (2014) recategorised the cases using criteria like the number of perpetrators, their relationship to the client, and the use of the concept of "honour".

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[118] The official police definition in the UK is "a crime or incident which has or may have been committed to protect or defend the honour of the family and/or community" (quoted in Payton 2014).

[119] The majority of perpetrators are male, but not exclusively so.

[120] In 2010 2823 crimes connected to "honour" were recorded by the UK police forces (Payton 2014).

Where "honour" was mentioned in the case files, the violence was more likely to be perpetrated by a "male collective" (agnatic) (ie: husband/partner, brother, father, male cousin) compared to where "honour" not mentioned. But "Husbands/partners were... involved in 33 of the 40 cases of abuse, demonstrating that HBV and IPV should not be considered mutually exclusive categories" (Payton 2014 p2872).

Payton (2014) provided some examples of the abuse and violence experienced by the women:

i) IPV - "Zohra" experienced marital rape, strangling and controlling behaviour by her husband. But she had no fears about "dishonour".

ii) Individual agnatic violence - "Sahar", who escaped to a refuge after family abuse, was threatened with further violence by her father for such "dishonouring" behaviour. This type of violence is perpetrated by fathers reacting to the independence of their adult daughters.

iii) Collective partner-centred violence - This is perpetrated by the husband/partner and his relatives and/or friends. For example, "Faryal" was stalked and threatened by her separated partner and his daughter from another partner, and his friends.

iv) Collective agnatic violence - "Bayan" (14 years old) experienced violence from her brother, mother and father for non-sexual friendships with boys at school.

v) Bilateral collectives - "Hana" experienced attempts to kill her from her husband, aided by relatives, and her brothers.

Payton (2014) concluded: "The identification of HBV as a distinct and meaningful sub-category of violence against women appears to be in tune with Middle Eastern women's own understandings of the dynamics of power and violence within their marital and kinship relations, and is shown in the language they use to describe them. 'Honour', collectivity and agnation are overlapping characteristics of many Middle Eastern women's experiences of violence, whether singly or in combination" (p2878).

17.5. APPENDIX 17C - CARTOON VIOLENCE

Colman et al (2014) stated: "Rather than being the innocuous form of entertainment they are assumed to be, children's animated films are rife with on-screen death

and murder" (p1). The researchers compared the forty-five most popular children's animated films and ninety popular dramatic movies for adults. The first on-screen death of an important character was the main outcome measure.

Two-thirds of the animated films contained a death compared to half of the comparison movies. The death occurred earlier in the children's films than adult ones (mean: 1 hour 19 minutes vs 2 hours 4 minutes). The authors, however, admitted: "We considered only the first on-screen death in animated and comparison films. While results therefore indicate that characters in animated films die off more quickly, the total number of deaths could be higher in dramatic films targeted at adults" (p3).

The Lancet (2008) stated: "Violent or aggressive actions seldom result from a single cause; instead multiple factors converge over time to contribute to such behaviour. When one looks at juvenile violence across society, exposure to media violence comes pretty low down the list as a risk factor. Much stronger predictors include involvement in crime, poverty, family breakdown or abuse, drug use, and psychiatric illness. Most media violence research excludes the involvement of these factors and how they may interact" (p1137).

17.5.1. Violent Video Games

After the Columbine high school shootings in 1999 much was written in the popular press about the causes of the killers' behaviour. This fits with "a desire among policymakers and the public for ready answers" (Ferguson 2007). One such "ready answer" is media violence. Lawrence and Birkland (2004) found that this explanation was the second most discussed cause of the shootings at Columbine in two US newspapers, while less than 1% of news stories discussed the responsibility and moral character of the killers. "It thus appears that news outlets may promote media violence in general, and video games violence specifically as a direct cause of violent behaviour" (Ferguson 2007).

In terms of the academic literature, Ferguson (2007) raised two key issues - the size of the effect, and publication bias in relation to video game violence effects.

The size of the effect is usually described in the language of "statistically significant", but this is influenced by sample size. "Thus, it is worth considering not only whether a study's results are statistically significant, but whether the effect size is meaningful" (Ferguson 2007).

Studies are often laboratory experiments, and the

ecological validity of these is open to question. For example, the use of a computer noise blast level in a competitive reaction time test (known as the Taylor Competitive Reaction Time Test) as the measure of aggression.

Non-experimental studies look for correlations in real-life between playing violent video games and aggressive behaviour. But correlation is not causation, and the studies do not necessarily control for other variables like family environment or personality (Ferguson 2007).

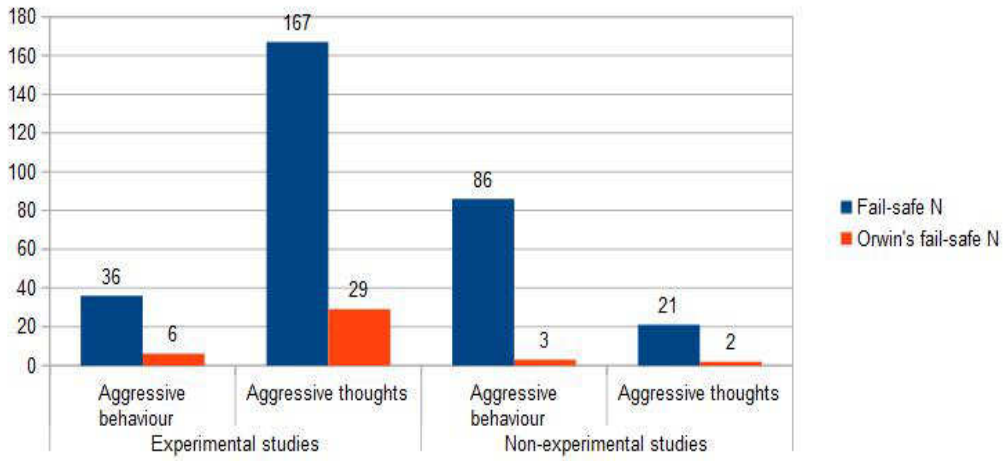
Meta-analysis combines all studies and seeks to establish the overall effect. But it is here that publication bias (or the "file drawer effect") can be an issue. There is a tendency for statistically significant findings to be published as compared to non-significant ones, either because academic journals prefer it, or because the researchers do not feel that their non-significant findings are interesting, even a mistake. "As a result, the extant literature in peer-reviewed publications may provide a biased sample of all of the studies actually carried out, portraying more positive findings that actually exist" (Ferguson 2007).

If certain studies are not published, there is no way of knowing the number of non-significant (or unpublished) findings compared to the published, significant findings. Statisticians, however, have developed methods of estimating publication bias risk. For example, the fail-safe N (FSN) (Rosenthal and Rosnow 1991) involves calculating how many additional studies with no effect would be required to change the significant effect to non-significant. If it is many (eg: 100s), then publication bias is assumed as not a problem. Orwin's fail-safe N (OFSN) (Orwin 1983) calculates the number of additional studies to reduce the "practical significance" rather than "statistical significance". "As meta-analyses profit on combining sample sizes to very large numbers, it is quite possible to produce results that are statistically significant, yet nearly meaningless on a practical level" (Ferguson 2007).

Ferguson (2007) took into account publication bias in his meta-analysis of experimental and non-experimental studies of violent video game exposure and aggressive behaviour between 1995 and 2005. Twenty-five published studies were found. The experimental studies showed a significant effect, but also publication bias for aggressive behaviour. The FSN was calculated as thirty-six non-significant studies to change the overall effect to non-significant, which is not many. The FSN was better for aggressive thoughts as the outcome measure (167 additional studies needed). The OFSN was smaller in both cases (figure 17.1). For non-experimental studies, publication bias was evident for both aggressive

behaviour and thoughts. Overall, Ferguson (2007) stated: "a relatively small number of unpublished or suppressed studies would render the results of this meta-analysis insignificant and/or trivial. As such this meta-analysis indicates that the extant literature on video game violence effects... has not provided compelling support to indicate either a correlational or causal relationship between violent game play and actual aggressive behaviour" (pp479-480).

Ferguson (2007) explained this finding as "unreliable methodologies from media violence research in general". He recommended standardised procedures, reliable and valid outcome measures, and the use of individuals who commit violent crimes rather than "healthy" individuals. Care should also be taken about moderating variables.



(Data from Ferguson 2007 table 2 p476 and table 4 p479)

Figure 17.1 - Number of additional non-significant studies needed to change a significant meta-analysis finding to non-significant based on two methods of calculating publication bias.

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