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CONTENTS

1. RICH, POOR AND ELITES

1.1. PREJUDICE AGAINST RICH

Zitelmann (2020a) began his article on "upward classism" thus: "In many countries the rich are increasingly being singled out as the enemy. And what was already an ongoing trend has been further exacerbated by the coronavirus pandemic, as demonstrated by widespread conspiracy theories blaming the super-rich, including Bill Gates and the Rothschilds, for the covid-19 catastrophe" (p162).

"Upward classism" describes prejudice against the rich (as opposed to "downward classism" which involves prejudice against the working class and the poor), and it is a topic that "has been almost completely neglected" (Zitelmann 2020a p164).

Fiske et al (2002) investigated outgroup prejudice along two dimensions - warm-friendly/cold-unfriendly (warmth) and competent/incompetent (competence). Assessing different social outgroups (ie: not the group that the individual belongs to), the rick were rated as high competence but low warmth (along with Jews and Asians), which suggested "mixed feelings of admiration and envy" (Zitelmann 2020a p164).

"Upward classism" is built upon such stereotypes, and poorer individuals can deal with the envy by compensation strategies, like: "'I might not be as rich as X, but I'm better educated, or a nicer person'. Enviers can also downplay the importance of the domains in which they are inferior and emphasise the domains in which they compare favourably" (Zitelmann 2020a p165).

Zitelmann (2020a) explored these ideas with surveys in four countries (USA, Great Britain, Germany and

France) [1]. "Social envy" was measured indirectly by three statements:

1. I think it would be fair to increase taxes substantially for millionaires, even if I would not benefit from it personally.

2. I would favour drastically reducing [high-earning] managers salaries and redistributing the money more evenly amongst their employees, even if that would mean that they would only get a few more pounds (dollars/euros) per month.

3. When I hear about a millionaire who made a risky business decision and lost a lot of money because of it, I think it serves him right (Zitelmann 2020a p168).

Agreement with all three statements was classified as "envier", and disagreement as "non-envier" (with "ambivalent" for individuals who agreed and disagreed). Approximately 20-30% (depending on the country) were classed as "enviers".

The participants were also asked about the personality traits they associated with the rich, and "enviers" choose predominantly negative ones, like self-centredness, ruthlessness, arrogance, and cold-heartedness. "In contrast, non-enviers most frequently described rich people as industrious, intelligent, bold, materialist, imaginative and visionary" (Zitelmann 2020a p168).

Next the survey investigated how susceptible individuals were to scapegoating with the following statement: "Those who are very rich and want more and more power are to blame for many of the major problems in the world, such as financial or humanitarian issues" (p169). Overall, between 25-50% of respondents agreed, but this was higher among "enviers". Such individuals also agreed with the zero-sum belief statement: "The more the rich have, the less there is for the poor" (pp169-170) [2].

Zitelmann (2020a) concluded: "Prejudices not only harm the rich, they damage society as a whole. If people do not understand the real causes of crises and negative events, choosing instead to believe simple explanations and to blame the rich as scapegoats, this error gets in the way of finding real solutions to very real problems" (p177).

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[1] "The Rich in Public Opinion" (Zitelmann 2020b) surveyed at least 1000 people in each country in mid-2018.

[2] "Research has highlighted the link between envy and the belief that life is a zero–sum game, in which the advantage of one inevitably means the disadvantage of the other. A zero–sum game is a game in which the payoffs to the players sum to zero. One player's gain is automatically another's loss" (Zitelmann 2020a p167).

1.2. ELITES

Traditionally, the elites in a society are at the top of hierarchical institutions (corporations, military, and State). Mills (1999/1956) used the term "power elite", and defined it as "those political, economic, and military circles which as an intricate set of overlapping cliques share decisions having at least national consequences. In so far as national events are decided, the power elite are those who decide them" (quoted in Davies 2017).

The elite are separate from others in this view. "By virtue of their extreme seniority and power, they develop a shared psychology and culture, which makes their positions virtually interchangeable, despite the differences between the institutions below them. Most crucially, they are able to co-ordinate their actions so as to pursue deliberate political agendas together..." (Davies 2017 p232). Put simply, the "power elite" is a single entity, according to Mills.

This view is seen as outdated. The growth of global markets as in neoliberalism in the last quarter of a century approximately has meant a breaking away from the "control" of a small group of elites in a society. The "elite reinvented" in this situation have "capillary power" (Savage and Williams 2008) - ie: "elites come to occupy positions as translators of quantitative data" (Davies 2017 p240).

Davies (2017) described two types of elites here - "cyborg intermediaries" and "diplomatic intermediaries". The former are individuals in the financial industry, say, (eg: financial traders) who work with data in relation to prices and markets. "These cyborg intermediaries are defined in terms of their capacity to sense what is going on in real-time, not to perceive it at a distance" (Davies 2017 p242). "Diplomatic intermediaries" interpret what the markets are "saying" (eg: CEOs in financial industry). "Where 'diplomatic intermediaries' are arguably most crucial is in translating the mood of 'the markets' to political agents and states" (Davies 2017 p243).

The traditional elite consciously made decisions using their power to affect society, whereas the "elite reinvented" are making decisions related to profits, say, which have the "unconscious" consequence of impacting society (Davies 2017).

1.3. ALPHA TERRITORIES

Burrows et al (2017) considered the areas of London "that have been transformed in recent years by dramatic changes in the global distribution of wealth. It is not just neighbourhoods such as Notting Hill that have 'come up' that are subject to change, even in 'traditionally elite' neighbourhoods... what we might think of now as the 'merely wealthy' are being challenged by the raw money power of the global 'super-rich'... This phenomenon is not just an extension to, or intensification of, 'super-gentrification' processes...; rather it is an 'upward' colonisation by capital that can perhaps best be characterised as the emergence of a plutocratic city in which raw money-power increasingly dictates the social, political and symbolic landscapes of the urban" (p185).

The "global super-rich" are benefiting from the rate of return on capital and the accompanying wealth rather than from work-related income, as Piketty (2014) has argued. "For Piketty, unless action is taken or unless the wealthy spend their returns on capital rather than saving it and passing in on to their children, we will see a return to the kind of conditions found in the nineteenth century in which the most affluent people in the world are the offspring of the existing super-elite; the rich and their descendants will get richer and, even if economic growth is sustained, concentrations of wealth and ever-greater levels of social inequality will continue apace" (Burrows et al 2017 p186).

York (2013) gave a snapshot of the world of the super-rich in London: They "come from absolutely everywhere to live, work and trade in twenty-first-century Mayfair. As house buyers, they particularly come from Western Europe, Eastern Europe and the Middle East... They're usually often absentees... non-doms... The tiny clutch of Brits in at that level are really non-doms too, defined by their tax status and time spent in their various houses and offices around the world" (quoted in Burrows et al 2017). Mayfair is an example of an "Alpha Territory" (Burrows et al 2017). Ley (2010) used the term "millionaire migrants", while Short (2016) described "their" city as "pretty much any urban area that offers the right ingredients of under-valorised housing, loose fiscal regimes, personal safety, and bundles of established and new cultural infra-structure that help to underwrite any possible risks to their investments" (Burrows et al 2017 p187).

1.4. VIP NIGHTCLUBS

Mears (2015) asked: "Why do workers consent to their own exploitation?"; answering: "Previous top-down approaches over-emphasise managerial control..., whereas contemporary labour scholars study workers' participation in their own worlds of work" (p1099).

Mears (2015) felted that these explanations were not complete for modern, precarious, and unpaid work. The concept of "relational work" was applied by the author to the case of women's unpaid work in VIP nightclubs.

Zelizer (2012) described relational work as the "creative effort people make in establishing, maintaining, negotiating, transforming, and terminating interpersonal relations" (quoted in Mears 2015). "To do this, people erect boundaries around a category of social relations, establish a set of distinctive understandings and practices that operate within that boundary, allow certain kinds of economic transactions to happen, and adopt certain kinds of media such that those transactions feel appropriate" (Mears 2015 p1102). Examples of this exchange include computer programmers doing unpaid coding to build up their experience and portfolio, or a journalist writing a free article in the hope of future benefits from the exposure (Mears 2015) [3].

Returning to Mears's (2015) fieldwork, eighteen months, studying the VIP party circuit for the global elite, and including interviews with promoters of the events, "girls", and male clientele. The promoters organised the parties and made money from them. At these exclusive parties/nightclubs, there is a "bottle service". "Rather than order drinks at the bar, VIP clients rent tables and purchase whole bottles of alcohol, carried by 'bottle girls' — attractive cocktail waitresses in revealing clothing — to clients' tables..." (Mears 2015 p1103). The women ("girls") who interested Mears (2015) were the unpaid "partygoers".

Mears (2015) described some of the key elements of the situations:

a) "The most valuable girls are working fashion models with reputable agencies, followed by girls who look like they could be models, called 'good civilians' for their height and slenderness" (p1106).

But there is a negative side with "civilians" and "pedestrians" (ie: "women with low conformity to fashion

standards; these women are regularly denied entry at the door"; p1106), and "short and heavy women" "who are discussed with vitriol as liabilities for the reputations of clubs and promoters" (Mears 2015 p1106).

b) "Clubs pay wages to dozens of employees, like bouncers, bus boys, bartenders, and waitresses, but girls are not paid. It is the promoter's job to bring girls to the club, where they are given access to freebies and perks, such as dinners and drinks in expensive restaurants and sometimes all-expenses-paid trips to VIP destinations" (Mears 2015 p1106).

c) "Without girls, clients are less likely to spend money, and the status and earnings of the club will decline" (Mears 2015 p1106).

Mears (2015) summed up the situation: "Girls do not share in these profits, nor are they fully compensated for the value of their efforts. Promoters benefit from an uneven exchange relationship with girls by extracting surplus value from them — the very definition of an exploitative relation. Why do girls consent to this arrangement?" (p1107). She presented four stages to explain the women's consent in the context of the relationships with those involved:

i) Recruitment - The promoters presented themselves as "desirable companions" for the women.

ii) Mobilisation to the work site - Initially, gifts are given to the women to encourage them to come to the nightclubs, and so "nurture relations of reciprocity and obligation" (p1109).
Mears (2015) explained: "In addition to the draw of free meals and drinks, girls are motivated to join a promoter's social network. Nearly all the girls I met at promoters' tables were relative newcomers to the city [New York], and many did not know where or with whom to socialise. They were also young; I frequently met girls in clubs who were younger than the US drinking age of 21 and even younger than the European limit of 18. Accompanied by a promoter, entering a club is usually a simple affair for underage girls. Promoters thus offer girls participation in an elite scene they could not otherwise access given their limitations in income, age, and social networks" (p1109).
The promoters' relational work could include romantic and sexual relationships with the women. Mears

(2015) described it thus: "Promoters perform a version of sex work by flirting and sleeping with girls for economic gain, like the pimp who must keep the sexual interest of his prostitutes to maintain ownership claims over them, and like the sex worker who performs emotional labour in the 'girlfriend experience' (Bernstein 2007)" (p1110).

iii) Performance of the work - This stage involves the women coming to the nightclub/party "looking good, dancing, visibly having a good time, and helping him rouse affect to create a good party atmosphere" (Mears 2015 p1111).

iv) Labour control - At this stage, the "promoters control girls' time, movements, and their looks" (Mears 2015 p1113).
In some cases, particularly if there were "relational mismatches", the promoters may use "disciplining practices" (eg: scolding and shouting; loss of perks).

The "promoters' girls" had a status above "bottle girls" or "table girls", who were described as "'slutty' women who are presumed to sell sex foe economic gain" (Mears 2015 p1116). "Because they go unpaid, promoters' girls are seen as distinct from and superior to escorts and other hired women in clubs..." (Mears 2015 p1116).
Within the context of a relationship, the women came to the nightclubs had a good time, and enjoyed perks from "their" promoters [4], not aware that the promoters gained prestige and profit from their presence.
Mears (2015) noted the limited success of female promoters: "Because the VIP scene is predicated on heterosexual desire, male promoters are able to construct the kinds of sexualized intimacies that compel girls to participate, suggesting that gendered and sexualised contexts affect the success of relational matches and who is best positioned to achieve them" (p1118).

1.5. PRO-SOCIALITY

Is help to a stranger more likely to be offered in an urban or a rural setting? The traditional view is that "people living in urban locations are less likely than those living in non-urban locations to complete and return a postal survey, to help a stranger in distress, to correct an accidental overpayment in shops, or to

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[4] Mears (2015) reported stories of loyalty demanded by promoters, including upon herself.

donate to charity" (Zwimmer and Raihani 2020 p1). But a meta-analysis (Steblay 1987) of 46 studies showed a more mixed picture with urban residents being more likely to help a stranger in nine studies, and ten studies found no difference (Zwimmer and Raihani 2020).

Zwimmer and Raihani (2020) noted a number of confounding factors in studies that compare the same behaviour in an urban and a non-urban setting. These include:

i) It could be that "people living in cities may experience a faster pace-of-life and increased perceptual load, both of which could make people less likely to offer help, either because they do not note that help is needed or do not have time to offer help" (Zwimmer and Raihani 2020 p2).

ii) The willingness to help is reduced by the diffusion of responsibility - ie: the more people present, the less likely an individual feels responsible to help.

iii) "City life might also reduce the willingness to help strangers because people have a higher number of one-shot encounters with strangers, where any downstream consequences of pro-social action (or inaction) are less likely to be realised. Indeed, individuals are apparently less likely to behave pro-socially in one-shot settings when they cannot be identified by others" (Zwimmer and Raihani 2020 p2).

iv) Neighbourhood deprivation.

Zwimmer and Raihani (2020) took these factors into account in their experiments in 37 neighbourhoods in twelve UK cities and twelve towns and villages. For example, direct requests for help so that individuals were clear what was required of them.
Helping behaviour (pro-sociality) was measured in three different ways:

a) Lost letter - A stamped and addressed letter was dropped (indirect request) (n = 439), or left on a car windscreen with a note saying, "Could you post this for me please?" (direct request) (n = 440).

b) Dropped items - The experimenter dropped a handful of twenty cards in front of an individual pedestrian, and either asked for help (n = 174) or not (n

= 224) in picking them up.

c) Road-crossing - The experimenter moved to cross the road in front of a slow driving individual car to see if it would stop to let her cross.

Overall, 55% of letters were returned, 33% of times dropped items were picked up, and 31% of cars stopped. "The main variable influencing whether help was offered across all experimental conditions was neighbourhood wealth" (Zwimmer and Raihani 2020 p4) (ie: more help in wealthier neighbourhoods). Urbanicity (ie: urban vs rural) was not a factor.

Zwimmer and Raihani (2020) explored the possible reasons for this negative association between neighbourhood deprivation and helping a stranger. One possibility is that harsh environments (ie: high deprivation) produce a focus on immediate rewards, while the benefits of helping a stranger are "typically delayed and/or uncertain" (Zwimmer and Raihani 2020 p6).
Another possibility seen in other research is a negative association between material deprivation and generalised trust. For example, Ananyev and Guriev (2009) calculated a 10% drop in national income in Russia after the 2009 recession was associated with a 5% decrease in social trust.
Linked to this explanation is the role of national security, and the idea that as this increases, "people are more able to expand their social network, offering impartial help and co-operation to people beyond their own social group of known and regular interaction partners" (Zwimmer and Raihani 2020 p6).
Zwimmer and Raihani (2020) ended that their study "supports the hypothesis that deprivation reduces the willingness to extend impartial norms of co-operation towards strangers" (p7).

1.6. PRECARITY

The distinction can be made between precariousness and precarity. The former is "an inherent state of vulnerability and dependence resulting from the relational structure of society", and the latter "a political condition that is the consequence of uneven power relations" (Harris and Nowicki 2018 p387) [5].

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[5] Lorey (2009) distinguished between precariousness, precarity, and precarisation - "While precariousness is a shared condition of relationality, precarity is defined as a category of order, a

These ideas have been explored in recent years in "the disintegration of security within labour markets", or, as Harris and Nowicki (2018) noted, the perception of "precarious modes of living in contemporary society..., for example, as innovative, flexible and entrepreneurial" (p387).

For example, Ferrari and Dawson (2018) showed this with "property guardianship" (appendix 1A).

Harris and Nowicki (2018) drew out five themes to such precarity:

i) Imaginaries - For example, "imaginaries of flexibility, urban adventure and resourcefulness sugarcoat precarious living conditions so that their precarity is in fact not experienced primarily as precarity... This encourages a 'self-precaritisation' of middle class young people in London at a time of widespread housing crisis by normalising, even glamourising insecure urban living" (Harris and Nowicki 2018 p388).

ii) Temporality - A focus on the short-term (and "getting by") rather than longer term planning.

iii) Micro space-times - Precarity is experienced at many levels, including in "mundane, daily routines" (p389).

iv) Affective materialities - The emotional experience of precarity linked to physical objects.

v) Place - The experience of "place making" in the contemporary world.

1.7. ENDURANCE

Richaud and Amin (2020) asked: "What does life look and feel like when government-led urban development plans create landscapes where ruins, rubble, and emptiness become the contours of everyday spaces of dwelling, sociality, and economic transactions?" (p77). These researchers answered their question with reference to an area of Shanghai in China where most of the traditional buildings were bulldozed to make way for new ones since

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classifying designation of the distribution of precariousness in hierarchies of inequality. Precarisation, finally, refers to the governing of subjects through insecurity and destabilization and its accompanying subject formations" (Ferrari and Dawson 2018 p428).

2016. Though the residents expressed negative feelings in response to the changes (eg: "yali" ("pressure")), Richaud and Amin (2020) reported witnessing "the persistence of routines and lively sociality alongside and within uncertainty, confirming our sense that the destructions, laid over years of tough living as rural-to- urban migrants, fell short of generating sustained and severe mental distress" (p78).

These individuals had precarious lives, and often the reaction in other studies to such situations is mental distress, but the residents here "have been able to draw on self, sociality, and place in ways that can be read as practices of situated endurance" (Richaud and Amin 2020 p78).

"Endurance", which Povinelli (2011) defined as the "ability to suffer and yet persist" (quoted in Richaud and Amin 2020) (and is akin to resilience) was sustained by the residents in everyday practices, "producing moments of being that potentially enable those who find themselves stuck in a destroyed yet still place to feel and act otherwise. These moments of being — the effervescence of a card game, the laughter exchanged during chitchat, the rituals of living normally — alter the everyday in the lightest of ways, allowing stress and other dysphoric affects to recede, if temporarily, into the background" (Richaud and Amin 2020 p79).

1.8. WATER INSECURITY

The United Nations Sustainable Development 6 is water and sanitation for all. It is often assumed that physical lack of water is the problem (incomplete water access), but water access is relevant ("water insecurity" or "plumbing poverty"). This is where individuals live in cities, say, with networked water supplies but cannot access it (ie: are unplumbed).

"A lack of reliable water access hinders essential practices like drinking and cooking; causes physical ailments such as dehydration, injury, and diarrhoea; triggers stress, anxiety, and mental health problems; and impedes basic hygiene practices—such as frequent and thorough hand-washing—that are essential to good health and disease prevention. Transmission of highly contagious diseases, such as covid-19, can be accelerated simply because people do not have secure access or adequate supply of tap water at home" (Meehan et al 2020 p28700).

Meehan et al (2020) investigated water insecurity in the USA, concentrating on the 50 largest metropolitan

areas. It was estimated that over 220 000 households
lacked piped water access in their homes [6]. The
researchers stated: "Compared with the overall US
population, we find that unplumbed households are more
likely to be headed by people of colour, earn lower
incomes, live in mobile homes, rent their residence, and
pay a higher share of their gross income toward housing
costs" (Meehan et al 2020 p28701) (figure 1.1).
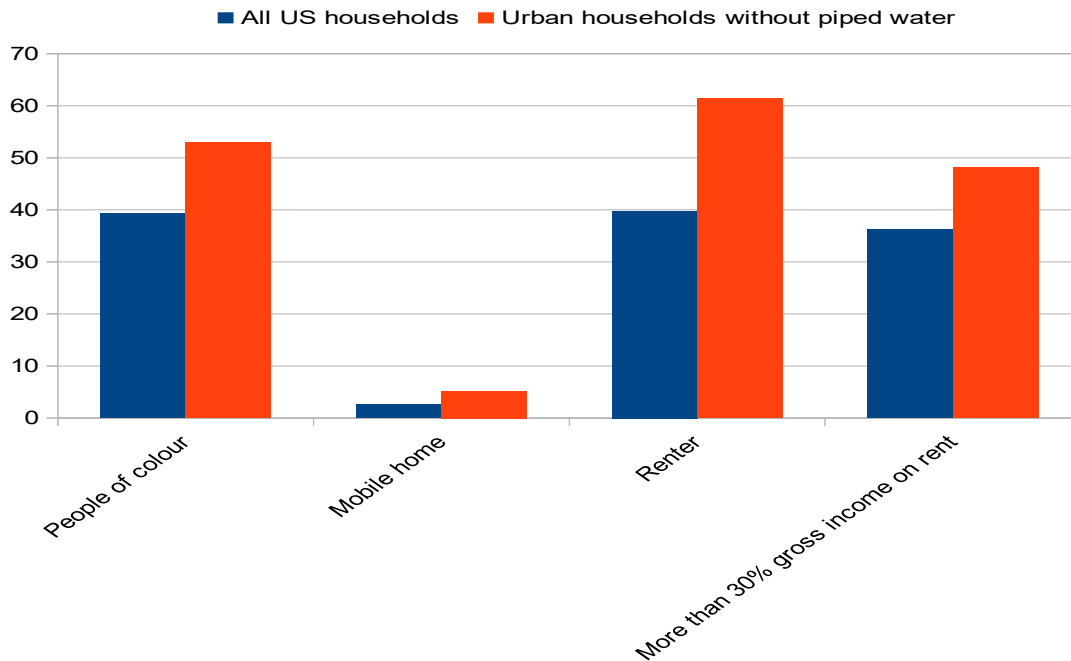
(Data from Meehan et al 2020 table 2 p28704)

Figure 1.1 - Percentage of urban US households without
piped water compared to the general population for
selected characteristics.

1.9. POVERTY AND MENTAL ILL-HEALTH

Individuals with the lowest income within a given
location are "typically" 1.5 to three times more likely
to experience depression or anxiety than the rich (Ridley
et al 2020).
The relationship between poverty and mental illness
is bidirectional. Poverty leads to poor mental health,
while poor mental health leads to poverty (Ridley et al
2020).
Ridley et al (2020) reviewed global evidence of the

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[6] The total for the USA was estimated at 471 000 households, of which over three-quarters were urban
dwellers (Meehan et al 2020).

causal relationships here:

    a) Poverty causes mental ill-health.

EG: Christian et al (2019) - Extreme rainfall in
Indonesia that led to reduced agricultural output, and
consequently income for farmers caused increased
depression and suicide.

EG: Haushofer and Shapiro (2016) - Unconditional cash
transfers led to less depression, stress and worries in
Kenya.

Possible mechanisms of causation:

  • Worries and uncertainty of poverty produce stress.

  • Poverty is associated with other disadvantages, like
    poor housing and environment (including increased
    risk of crime and violence) which impact mental
    health.

  • Lower income associated with poor physical health,
    and this affects mental health.

  • Low social status, shame, and discrimination.

    b) Mental ill-health causes poverty.

EG: Mojtabai et al (2015) - "After a diagnosis of
depression or anxiety, employment rates and incomes have
been estimated to fall by as much as half, relative to
the non-depressed or non-anxious" (Ridley et al 2020 p5).

EG: Biasi et al (2020) - Lithium treatment of bipolar
disorder reduced the "earnings penalty" associated with
bipolar disorder by around one-third in Denmark.

Possible mechanisms of causation:

  • Cognitive function is impacted by mental ill-health,
    which limits the ability to perform in a job.

  • Negative beliefs associated with depression, say,
    and a lack of confidence to find work.

  • Stigma of mental illness and discrimination by

employers.

Ridley et al (2020) ended: "The pandemic [covid-19] has disproportionately affected the poor and may have lasting adverse impacts on their economic and mental well-being. A massive investment in mental health was long overdue even before the pandemic and has become critically urgent now. Beyond more money, this is also an important opportunity to invest wisely in lower-cost innovations that provide quality care to low-income and disadvantaged communities and to integrate economic interventions with mental health care to reduce historic disparities in both wealth and mental health" (p10).

1.10. APPENDIX 1A - PROPERTY GUARDIANSHIP

Property guardianship (PG) involves guardianship companies providing "low-cost or cost-free property security by installing live-in 'guardians' on temporary licences" (Ferrari and Dawson 2018 p426). The use of PG is associated with its presentation as "a 'win-win' solution to both property vacancy and the need for affordable housing, but it is also celebrated as offering a 'nomadic' way of living that resonates with imaginaries of 'lifestyle squatting' [Hyland 2007] and with ideal visions of the city based on mobile and flexible uses" (Ferrari and Dawson 2018 p426).

Ferrari and Dawson (2018) undertook a mixed-methods study that analysed materials produced by PG companies, and interviewed 29 current or former guardians in London between 2011 and 2014.
The PG companies' advertisements emphasised the properties - eg: "we get to live in mansions for free - so can you!" (p430). Also PG was presented as a way to "get a leg up onto the housing ladder" (p430) - ie: the money saved on rent could be used as a future deposit for a house. There was a presentation of PG as "lifestyle choice" (Ferrari and Dawson 2018).
Meanwhile, the interviewers described "survival techniques". "Embracing urban self-precarisation becomes a transformative process akin to learning strategies for living in wild or hostile environments" (Ferrari and Dawson 2018 pp433-434). For example, having few material possessions, as "Piero" described: "you're going be a little bit like a snail. You are going to always bring your house on your back" (p434).
"Emma" was aware of the stress and anxiety

associated with the precarity, as she said, "so many people drop out, they just have a certain tolerance point, where it's like, I can't take any more of this shit, and they they leave" (p434).

But, at the same time, there was an awareness that private renting in London was far from secure. For example, "Anne" explained: "of all the renting experiences I've had in London, yes Camelot [PG company] was stressful because you never knew when they were going to turn on you but, actually, out of the places I've lived in London, that's the place I stayed at longest, and in terms of location and value for money, it was probably the best!" (p435).

Ferrari and Dawson (2018) ended: "What has clearly emerged in our analysis is that the mobilisation of notions of flexibility and adventurousness belongs to a neoliberal discourse of individual adaptability to conditions of normalised precarisation; the 'nomadic' selves and values of representation and self-representation remain problematic at a time when such values appear 'to be closer to hegemonic constructs than ideals of resistance' [Sutherland 2014]" (p436).

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2. RISK: TWO DIFFERENT ANGLES

2.1. FATE, LUCK AND FORTUNE AND ENVIRONMENTAL RISK PERCEPTION

Fate, luck and fortune are important in how individuals make sense of "environmental risks", even today with the techno-scientific and probabilistic focus on risk (Eidinow 2019). For example, Solomon (2003) noted that "beliefs in fate, and attitudes of fatalism, maintain their hold on the popular imagination because it is so common to experience our lives as controlled by some sort of 'author', whether we call that entity, fate, destiny, god, or our inner selves" (Eidinow 2019 p1092) [7].

These are sometimes called "environmental risk narratives" (Burgess 2019). Burgess (2019) explained that they are "the terms in which we describe what has happened around us, whether it could happen again and what might be done about it. They are accounts, involving an identification of the cause of environmental impacts, who might be affected in future and how this might be avoided, woven in often evocative narrative terms. They are also distinct from a simple recording of events, not only in the banal sense that literary and journalistic accounts are inevitably dramatised and subjective. Rather, events are consistently framed in distinct, even curious ways, where those that affirm narrative bias are selected for attention, while complexity and contradictory evidence are ignored" (p1128).

This author continued: "Risk is a secular conception of what might happen in the future, informed by what happened in the past and the chance of its recurrence. In the terms of Mairal (2011): 'risk is not a fact, it is rather an artefact, a tool that is used to bring together objects, facts, events or any other entities which can produce harm and others which can be harmed'" (Burgess 2019 p1130).

The narratives of risk are also framed with blame

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[7] "Across the past two millennia, we have seen references to fate and luck appear in narratives that frame events outside of human control. By framing such events as an act of God or Mother Nature or just the luck of the Irish, individuals deny their ability to manage a particular risk. Fortune carries no such idea of pre-determination" (Witting and Dudley 2019 p1143).

(ie: who is responsible). "The consequences of such framing can be the establishment of environmental risk stigma, defined as a 'process of discrediting settings, places, objects, non-human lifeforms and surroundings, as well as people associated with these environments' through a process of metaphorical 'contamination' (Edelstein 2001). Radiation stigma is among the most powerful" (Burgess 2019 p1130).

Burgess (2019) described the historical development of this stigma through the Cold War, and nuclear power station incidents (eg: Three Mile Island). "The partial reactor meltdown in 1979 at Three Mile Island spawned nationwide protests though no recorded human harm. Yet this was a single, dramatic event that portended the possibility of mass destruction, and directly connected to the ultimate 'dread', of radiation, providing immediacy, imagery and untold speculation about effects" (Burgess 2019 p1137).

Wilkinson and Sherratt (2019) applied an evolutionary approach to risk perception and "superstitious behaviour" among non-humans [8]. They used the example of deciding if a certain food is safe to eat. Avoiding a food because it is inedible is rational, but avoiding edible food "because of a previous chance bad experience can be considered as something akin to superstitious behaviour... because with complete information it is an irrational thing to do" (Wilkinson and Sherratt 2019 p1118) (table 2.1).

TRUE SITUATION	DECISION - AVOID	DECISION - EAT
Inedible food	Correct	"False negative" (risk of illness)
Edible food	"False positive" (risk of hunger)	Correct

(Based on table 1 p1119 Wilkinson and Sherratt 2019)

Table 2.1 - Decision matrix for food.

Looking at the trade-offs, a "false positive" is "irrational", but it is optimal in terms of survival. Likewise, responding to a sound (that could be a predator) is better than not responding - ie: "it is

better to be safe than sorry". So, natural selection would favour superstitions that produced caution in a cost-benefit decision situation. In other words, a situation "where the cost of the superstition is low compared to the likely benefit" (Wilkinson and Sherratt 2019 p1125).

In relation to humans, "superstitions are more likely if individual's prior beliefs suggested they were true - this hints at the importance of cultural beliefs, prior learning in similar settings, and evolved instincts in affecting the probability of drawing false inferences about environmental and other risks" (Wilkinson and Sherrat 2019 p1125) [9].

2.2. GENETICS AND RISK

Beck (1992) talked of "risk society" to describe the special risks related to technological progress. "In a risk society, everybody can be affected by adverse events and as such, society evolves measures for risk management" (Hansson et al 2018 p101). The genomic revolution of the 21st century is one such example.

Hansson et al (2018) introduced a consideration of "different concepts of genetic risk and genetic risk information" (p101).

Relevant issues included "public understanding and the support of autonomy when making decisions, stigmatisation, the provision of risk information that is not actionable, and the fact that such information may give rise to unrealistic expectations, misunderstanding and/or anxiety" (Hansson et al 2018 p102). Such issues are manifest with direct-to-consumer testing.

"Traditionally, genetic testing was confined to specialist medical genetic services, focused on relatively rare, inherited diseases caused by highly penetrant causal mutations (eg: Mendelian disorders such as Tay-Sachs, Huntington Disease or Cystic Fibrosis). In contrast, common complex disorders such as heart disease, diabetes, arthritis and cancer are usually the result of variations in different genes, each contributing some portion of the genetic susceptibility, acting in concert with environmental, including epigenetic factors. Some of the environmental factors might be changeable (eg: smoking, nutrition, exercise, alcohol intake) while others are less able to be changed (such as environmental pollution or psychosocial stress). The complexities (and current uncertainties) of identifying and understanding

[9]   Some environmental risks may not be as high as assumed (appendix 2A).

the interplay between (multiple) genetic and
environmental factors also contribute to the difficulties
of risk assessment and communication in genetics"
(Hansson et al 2018 p102) [10].

Hansson et al (2018) outlined five implications of
genetic testing:

i) Individuals' understanding/misunderstanding of
the risk information provided.

ii) The emotional impact of the information.

iii) The impact on the quality of life of the
individual.

iv) The subsequent uptake of risk-reducing
opportunities.

v) Ethical implications (table 2.2).

- The phrase, "the mother of modern medicine" has been applied to
  African American tobacco farmer, Henrietta Lacks, born in 1920.
  This is not because of her scientific work, but that her cells
  have been used and cultivated throughout the world (without her
  consent) (Ahluwalia 2020).

- In 1951 she had a biopsy for cervical cancer, and part of the
  tissue was given to George Gey in the Johns Hopkins Hospital
  laboratory, who was able to keep the cells alive outside the
  body (for the first time). The cells replicated and have become
  the basis of much subsequent medical research (known as "HeLa
  cells") (Ahluwalia 2020).

- Skloot (2010) described how this story came to light. The HeLa
  genome was published in 2013 without the consent of the Lack
  family (Henrietta died in 1951). This case highlights the need
  for ethical guidelines in medicine, and particularly in
  genomics. Privacy and consent are the key concerns (Ahluwalia
  2020).

Table 2.2 - Protecting genetic data.

Hansson et al (2018) noted that numeric
probabilities of risk can be interpreted differently by
patients and clinicians, and descriptors (eg: "likely")

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[10] The wide use of "genetic risk" means that it covers the risks of genetically mediated disease as well
as risks of losses in genetic diversity, and risks from mutations in other organisms, for instance
(Hansson 2018).

can compound this difference. Also "the severity of the disease and the lack of effective treatment may lead to risk estimates being described by patients as considerably higher compared with outcomes less severe even when objective risks are the same" (Hansson et al 2018 p103).

The special issue of the "Journal of Risk Research" (volume 21, number 2, 2018) included nine articles covering "a broad variety of approaches to genetic risk information; they discuss theoretical approaches from fields of risk research, sociology and philosophy of risk as well as medical risk" (Hansson et al 2018 p105).

1. Inthorn (2018) - Genetic Risk

Inthorn (2018) reflected on the concept of risk as used in medicine - "it can refer to a probability, eg: the risk of an individual to develop a disorder may be 50%; or as a negative event not necessarily attached to a number, eg: the general risk of having a severely ill child. The term may be used as a synonym of the term 'risk factor', eg: smoking is a health risk, or in statistical terms such as the expectation value, which is the combination of a negative outcome and the probability of it happening" (p110) [11].

There are also specific risk concepts related to genetics. For example, the term "genetic risk factor" refers to "a genetic variant that is known to influence health; this can be the health of the person being tested, either directly or in terms of the outcomes of therapy, or the health of any future children. The term risk is used to describe a possible negative future event, such as the development of a disease or the procreation of a severely handicapped child, in the light of the known or unknown probabilities of the event occurring" (Inthorn 2018 p110).

But in the case of complex diseases, genetic risk factors interact with environmental ones to increase or decrease the risk (Inthorn 2018).

Inthorn (2018) selected three examples of genetic risk factors to show "the heterogeneous nature of the application of genetic risk information" (p114):

i) Pre-conception genetic carrier screening - This test is taken by an individual before trying for a child

[11] Baptista (2005) defined an individual's genetic risk as "the probability of the individual carrying a specific disease-related mutation, or of being affected with a specific disorder" (quoted in Howard and Iwarsson 2018).

to see if they are a carrier of an autosomal recessive inherited disease. In this situation, an individual carries one of the two copies of the gene, and is usually not affected by the disease, but if their partner is also a carrier, there is a 25% risk that the offspring will be affected by the disease (Inthorn 2018).

A positive test can lead to difficult decisions: "Should the couple wish to (try to) avoid the birth of a child with the disease, there are non-medical solutions, such as changing partner, adopting a child or even refraining from having biologically related children. There are also medical solutions, such as using donor gametes, pre-implantation diagnostics in combination with in vitro fertilisation, or pre-natal testing and abortion if there is an affected child" (Inthorn 2018 p113).

ii) Rheumatoid arthritis (RA) - This disease is an example of a genetic risk and an interaction of environmental factors as to how the symptoms manifest. The patient experience is varied, and though "the genetic factors cannot be changed, the environmental risk factors can be modified, albeit there is no guarantee that this will be effective" (Inthorn 2018 p113).

iii) Pharmacogenomics - Genetic information can help in establishing how an individual will react to different pharmaceutical treatments (ie: to predict the outcome of the treatment). "This can help to avoid exposing potentially non-responsive patients to the adverse effects associated with the therapy but at the same time carries the risk of not providing treatment to a patient who could benefit from it if the test results are wrong" (Inthorn 2018 pp113-114).

In each of the examples, genetic risk means something different and so genetic counselling is important to guide the individual through difficult decisions.
"The usual assumption that actions and decisions are evaluated based on their consequences is another challenge for decision-making based on risk information... When using risk information, it is only the probability of an outcome that can be assigned to an action, and the interrelationships between different risk factors or between risk factors and preventative steps (as in RA) are not yet fully understood" (Inthorn 2018 p115).

2. Howard and Iwarsson (2018) - Whole Genome Sequencing

Howard and Iwarsson (2018) commented: "At a time when many authors predict a future in which genomic medicine will be the norm..., it is particularly relevant to discuss the unknowns surrounding this science, including the notions of risk and uncertainty" (p118). Consequently, these authors examined uncertainty in relation to whole genome sequencing (WGS).

The idea is that WGS of an individual will allow clinicians to spot single gene disorders (also known as monogenic or Mendelian disorders), and common complex disorders (involving multiple genes - ie: polygenic). "Mendelian genetics is simpler, yet it still harbours uncertainties" (Howard and Iwarsson 2018 p118).

Key to the uncertainty, for Howard and Iwarsson (2018), is "the sheer novelty and complexity of the technology (especially for non-experts) and the lack of experience with managing (in all its facets) all the data generated" (p119).

Han et al (eg: 2011) conceptualised uncertainty with three dimensions:

i) The source of uncertainty - Three main types: probability or risk, ambiguity (eg: lack of information), and complexity (eg: numerous potential outcomes).

ii) The issues of uncertainty - Three sub-categories: scientific (eg: diagnosis), practical (eg: process of care), and personal/patient-centred.

iii) The loci of uncertainty - This "has to do with where the uncertainty resides or who is experiencing the uncertainty; it could be the clinician, the patient, the researcher, and/or the policy-maker/funder" (Howard and Iwarsson 2018 p122).

Han et al's (2011) conceptualisation was developed in reference to specific diseases, like breast cancer, but Howard and Iwarsson (2018) applied the source and loci elements to WGS.

- Complexity - WGS is a complex process to non-experts, but this is less important to Howard and Iwarsson (2018) than "the fact that even if we use this approach to answer a seemingly narrow question,

the approach itself and more specifically, the fact
that it produces large amounts of data almost
simultaneously (and relatively cheaply) may give us
answers to questions we never 'intended' to pose"
(p124) (ie: "unsolicited findings"; UFs) [12] [13].

- Loci of uncertainty - UFs seem to be more of an
  issue for experts than non-experts. Biesecker et al
  (2014), for example, found that few laypersons
  considered complexity as a source of uncertainty
  with WGS.

- Ambiguity - This is uncertainty about how often UFs
  will occur with WGS.

Howard and Iwarsson (2018) ended: "At this, still-
early stage of implementation of WGS in health care and
research, it may not be surprising that a lot of the
uncertainty can be interpreted as coming from complexity
and that we expect it to reside mainly with expert
stakeholders (ie: researchers and clinical geneticists,
and other health care professionals involved with WGS,
like oncologists). Mapping out these uncertainties could
help clinicians and researchers better communicate them
to patients and research participants and consequently
empower them to make fully informed decisions regarding
WGS" (p126).

3. Falahee et al (2018) - Healthcare Professionals' Views

Direct-to-consumer (DTC) genetic testing (eg: home
testing kits) is increasing and will likely continue to
do so. Consumers, however, may want to discuss the
findings of such tests with healthcare professionals
(HCPs), quite probably non-specialists in clinical
genetics (eg: general practitioners). How do such
individuals perceive genetic testing and risk?
Falahee et al (2018) synthesised 28 qualitative
studies on the topic (mostly related to genetic risk
counselling for cancer), and drew out four themes:

i) "Value of genetic risk information" - This theme
covered three sub-themes:

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[12]   Note that UFs can occur with any test in medicine (Howard and Iwarsson 2018).

[13]   WGS may not result in UFs of a different disease, but in finding a novel variant, for which there is
no information ("variants of unknown significance") (Howard and Iwarsson 2018).

a) The clinical utility and validity of genetic risk information - "Many HCPs felt that genetic test results did not give useful information about disease risk over and above information already available to them from family history and/or environmental risk factors" (Falahee et al 2018 p144).

HCPs were also unsure about the evidence to support conclusions - eg: a Canadian family physician in one study said: "If you're going to do something which has a profound significance, you've got to be damn sure of the validity of your advice according to the results of that test. And I don't think we're in that position right now" (Carroll et al 2003 quoted in Falahee et al 2018 p145).

b) The speed of uptake of genetic testing and the future - HCPs reported concerns here as summed up a Canadian family physician: "The frustrating thing is all these tests become available so quickly and you're swept up into doing them or people are coming in and asking for certain things, and... you don't necessarily realise all the consequences at that point. You're being swept along in this wave of newer technology... It's really overwhelming. It's hard to know if you're doing good by ordering these tests" (Carroll et al 2003 quoted in Falahee et al 2018 p151).

c) The potential of genetic testing to promote health behaviour changes by patients - Genetic information was viewed by HCPs, on the one hand, as "potentially 'empowering', by encouraging individuals to make appropriate changes to their lifestyle..., whilst on the other hand this information was conceived of as potentially useful to align patient behaviour towards 'compliance' with medical advice" (Falahee et al 2018 pp151-152).

But, a few HCPs, "felt that an emphasis on genetic risk factors could even have a negative behavioural effect by detracting from the importance of lifestyle-related risk factors" (Falahee et al 2018 p152).

ii) Understanding of genetic risk information - This theme and three sub-themes covered the HCPs' abilities to understand genetic risk information:

a) Understanding - HCPs expressed concerns about their level of understanding, but they "clearly saw their own understanding of genetic risk as being qualitatively different, and superior to, the understanding of members of the public" (Falahee et al 2018 p153).

b) Perceptions of patients' understanding of genetic risk - HCPs adapted their responses to the perceived knowledge of the patients, and their desire to know, as described by a consultant physician in the UK: "Patients here actually fall into categories. On the one hand very well informed patients who want to know everything... And then the other extreme who are extremely frightened, don't want to know" (Will et al 2010 quoted in Falahee et al 2018 p154).

c) Facilitating understanding - Communicating risk in different ways , including the use of metaphors, and specially prepared leaflets.

iii) "Consequences of genetic risk information" - Three types of impact of information were noted:

a) Anxiety about test results - Both for the individual and their family member.

b) Discrimination and stigmatisation from genetic information - For example, a medical oncologist in the USA commented: "African American patients often times tend to be more suspicious about [genetic testing]... because they're so used to being pointed out all the time. And maybe they feel it's another way of [labelling them]" (Graves et al 2011 quoted in Falahee et al 2018 p157).

c) Impact on the family - A genetic test not only had implications for the individual, but also for genetic relatives. For example, a genetics specialist in the UK said: "Within genetics we are very aware of the family issues of genetic testing and we often feel that, you know, it can be described as being unethical to do genetic tests without consideration of the impact on other members of the family" (Harvey 2011 quoted in Falahee et al 2018 p157).

iv) "Responsibility for genetic risk information" - Three sub-themes about responsibility emerged:

a) "Genetic risk as a burden" and feelings of guilt - eg: "If the mother has the gene, she feels like she might have tainted her offspring. If a sister doesn't have the gene and her sister does, then the sister that doesn't have it might feel guilty" (US breast surgeon; Graves et al 2011 quoted in Falahee et al 2018 p158).

b) "Responsibility to act on risk information" - Whether to share or not the information with genetic relatives. For example, a USA genetic counsellor said: "In some situations, [it's] a disadvantage that the first person to be tested in the family gets the job of having to spread the information to everyone and that can be somewhat of a burden for people" (Graves et al 2011 quoted in Falahee et al 2018 p159).

c) Responsibility of HCP - "HCPs frequently attributed ultimate responsibility to interpret or respond to genetic risk to their patients... or to other professionals..., rather than themselves [...]. The consensual approach was described as being non-directive, with the role of the professional being to provide information and support to empower the patient make informed decisions" (Falahee et al 2018 p159).

Falahee et al (2018) summed up the themes and key points from their meta-synthesis thus: "The perceived value of predictive genetic testing was often low with little to add to existing practice. HCPs were concerned about the rapid introduction of new genetic technologies without the necessary evidence base to fully inform the use of these approaches in clinical settings. Patients' understanding of genetic risk was perceived to be limited, and subject to bias and external influence. The professional's role is conceptualised as an authoritative process of evaluation to untangle these multiple influences in order to assess patients' capabilities and needs and to tailor their approach accordingly" (p160).

The meta-synthesis had some limitations including:

- The studies were mostly from Europe and North America, and so "may not be representative of other cultural perspectives. There are likely to be important cultural differences in responses to genetic testing... The manner in which these differences impact on HCPs' perspectives and practice is an area for future research" (Falahee et al 2018 p161).

- Most of the studies concentrated on predictive genetic testing for hereditary cancers, and so, many "reflect issues that are specific to this disease context" (Falahee et al 2018 p161). Genetic risk information here is binary (gene present or not),

and "likely to be appraised differently than probabilistic estimates of risk for multi-factorial conditions" (Falahee et al 2018 p161).

- Pre-symptomatic predictive testing was the focus, and post-symptomatic genetic testing for diagnosis and/or treatment was excluded.

4. Bayliss et al (2018) - Public Perception of Predictive Genetic Testing

Identifying susceptibility markers for future risk of diseases, like rheumatoid arthritis or cardiovascular disease (CVD), is "rapidly increasing, with a range of predictive tests available in various health care settings as well as directly available to the consumer from private companies in the form of home self-testing kits" (Bayliss et al 2018 p168). This means that there will be more individuals, who having used such tests, find themselves classed as "at-risk". Bayliss et al (2018) explored the public perception of such predictive testing with a meta-synthesis of qualitative studies.

Eleven peer-reviewed papers, published between 1989 and 2014, covering predictive testing for chronic inflammatory diseases were included. Three sets of themes emerged related to the perceptions of testing, and recommendations for practice. Concentrating on the perceptions of predictive testing, five sub-themes were found by the researchers:

i) Perceived value of testing to establish the risk of future disease - Most "at-risk" individuals saw value in testing because of their reliability, though a few did not. Some of these latter individuals "thought that there was potential for health professionals to give false results..., while others thought the advice on behaviour change and risk following screening was often contradictory and should therefore not be trusted" (Bayliss et al 2018 p175).

Two quotes from Wijdenes-pijl et al (2011) showed both views:

- Positive - "You know it instantly [whether you're at risk], by taking some blood. Do I have predisposition, yes or no? Brief and effective; it's [DNA test] a good test".

- Negative - "If they want to prove that someone is at

risk, they can manipulate the results. I don't know
how, since it's quite new, quite precarious" (both
quoted in Bayliss et al 2018).

ii) Perceived barriers to predictive testing -
Concerns about confidentiality of findings, and potential
discrimination were mentioned, and it was seen as
"potentially unfair as a high-risk result from a test
does not guarantee that you will develop the disease in
question" (Bayliss et al 2018 p176).
Comments were made about who should be given
testing, and some individuals felt only very high-risk
groups (eg: where early symptoms had appeared) should be
so.
The tests were perceived in the context of general
attitudes towards doctors - ie: their job is treatment
not prevention. For example, in Eastwood et al's (2013)
study of South Asians in the UK, one woman said: "There
is a common saying that one should only visit a doctor if
one is ill, otherwise doctors will put false doubts in
one's mind. That is an understanding of people" (quoted
in Bayliss et al 2018).

iii) Behaviour change after the test results - "Test
results were perceived as empowering by several
participants as they have the potential to motivate a
person to make changes to their lifestyle to reduce their
risk of ill health" (Bayliss et al 2018 p177). For
example, a man with a high risk of CVD said: "That (risk
score) has terrified me … and I will quit smoking. My
intentions are to eat healthy, stop smoking altogether"
(Honey et al 2015 quoted in Bayliss et al 2018).
But some individuals were the opposite - "receiving
a low-risk result would probably result in a reduction in
the level of motivation to engage with healthy
behaviours" (Bayliss et al 2018 p178).
Others, with high CVD risk for instance, "believed
death from a heart attack would be preferable to dying
from a protracted illness or living into extreme old age.
This group also resisted change because they believed
that a short life of indulgence was better than a long
life of denial. Those participants who believed that
health outcomes are already predetermined or a matter of
luck, were also less motivated to change" (Bayliss et al
2018 p178). This man in the Honey et al (2015) study
said: "I know I am naughty because I quite like cream,
you know, and things like that but I think gosh I am not
going to be long on this mortal coil, I am not going to
make myself miserable to the point of being really ultra

miserable to maybe extend my lifespan by one or two years" (quoted in Bayliss et al 2018).

iv) Understanding the genetic risk information - "Some participants were unclear about the roles of environmental and hereditary factors in disease development and the integration of data relating to these variables into predictive testing strategies" (Bayliss et al 2018 p179). One man with high CVD risk said: "I don't know whether bringing this data together into one score is a very realistic thing to do... there might be methodological problems... I don't think you can add things like that together" (Honey et al 2015 quoted in Bayliss et al 2018).
Individuals with no current symptoms found it particularly difficult to think about lifestyle changes.

v) Impact of genetic testing on emotional well-being - Both positive and negative emotions were experienced after test results. On the positive side, certainty about knowing the risk was important, as expressed here: "I'd want to know whatever. You're better knowing and then you can plan, or at least get it straight in your mind, and then once it comes along you're ready for it, instead of really worrying. I mean it's always worse not knowing" (Shepherd et al 2001 quoted in Bayliss et al 2018).
On the negative side, unfulfilled expectations, uncertainty, and stress for themselves and others were mentioned. In the former case, individuals who took the test believing themselves low-risk, but had a result of high-risk, as described here: "Really and truly, I was absolutely horrified when it came back and said that I had it. I mean I really was horrified... It was a dreadful shock" (Ormondroyd et al 2014 quoted in Bayliss et al 2018).

The second theme found by Bayliss et al (2018) related to recommendations for use of genetic testing, and this included sub-themes around educating patients, considering when to use testing, and subsequent support of patients. The final theme of "priorities of patient partners" included education and information about testing as important.

Bayliss et al (2018) summed up that "predictive testing can be viewed by those at risk of developing chronic inflammatory disease as a reliable way to ease concerns about the risk of developing a condition, or gain valuable information to motivate behaviour change...

However, a number of papers discuss a lack of understanding about the type of information that a predictive test can provide, what that information means in terms of level of risk and how to reduce that risk... These perceptions may have a negative impact on how predictive testing for chronic inflammatory disease is viewed and utilised by those at risk" (p184).

This meta-synthesis only found studies from three countries (UK, USA, and the Netherlands), all developed countries, and related to three diseases (CVD, diabetes, and inflammatory bowel disease). The different predictive tests were not distinguished, and the "grey literature" (non-peer-reviewed papers) was not included (Bayliss et al 2018).

5. Bouder (2018) - Risk Tolerance

Presenting genetic risks as "exceptional" compared to other medical risks "can be dangerous. Overemphasising the downside of genetic information may lead to an emotional state of mind resulting in the stigmatisation of genetic technology. This, in turn, may delay the development of useful medical applications" (Bouder 2018 p192). The answer is to leave emotions aside, and "think more freely... about the risk and benefits of genetics" (Segerdahl 2014 quoted in Bouder 2018).
Risk is often seen as potential harm, which produces the emotional response, but it can also have a positive side (eg: entrepreneurs taking risks with investments for greater profits). "The view that risk is more complex than just a 'bad' is particularly relevant for the conceptualisation of genetic risk tolerance. In most cases, because genetic risks cannot be reduced to deterministic cause-effect relations, a balanced approach will help to conceptualise genetic risk more effectively. Genetic risk information should be conceptualised as information needed to improve the balancing of potentials, which may carry complex upsides and downsides" (Bouder 2018 p194).
The answer for Bouder (2018) is "genetic risk tolerance" (or acceptability). "A risk deemed 'tolerable' links undertaking an activity – which is considered worthwhile for the value-added or benefit it provides – with specific measures to diminish and limit the likely adverse consequences" (Renn 2007 quoted in Bouder 2018).

Bouder (2018) recommended a "traffic light model"

for acceptability decisions:
- Red - unacceptable.
- Orange - tolerable.
- Green - acceptable.

The "orange" situation is the one that needs a balance of risks and benefits. Such activities are "conceptualised as neither 'safe' or 'not safe' but can be made to be 'safe enough' (McQuaid 2007)" (Bouder 2018 p196).

Bouder (2018) proposed a set of basic questions to help assess genetic risk tolerance for individuals:

i) "What risk(s) are we talking about?" - eg: the implications of the test results.

ii) "Who makes the decision?" - Though an individual is making the decision to undergo the test or not, the decision is not in a vacuum. For example, "how genetic tests are being offered may have an impact on how the information is received – eg: whether a test is included in health insurance or needs to be paid out of pocket might lead to a tendency to use or not use the test" (Bouder 2018 p198).

iii) "How robust is the information?" – Probabilistic assessments giving numbers related to frequency or magnitude of a disease "may prove challenging when uncertainty is high" (Bouder 2018 p198).

iv) "What are the main cognitive factors susceptible to influence the decision?" - Even if numbers to describe the risk are robust, individuals perceive such numbers in certain ways (eg: more attention is paid to rate, high impact hazards than small impact, common ones).
Other concerns can exemplified by this patient's comment to Bouder (2018): "The big risk [resulting from more genetic risk information] is not so much for the people who are already aware. It is the general public who may see it as a silver bullet to solve all their problems" (p199).

Trust is an important factor as well. "The confidence in genetic risk is likely to be trust-dependant. The legitimacy of genetic testing has been undermined by aggressive DTC market practices..., unrealistic promises and media hypes... Fairness... has also been questioned. As genetic testing becomes more

widespread, people may end up being classified into groups according to their potential for developing certain diseases. The above-mentioned dichotomy between 'good genes' and 'bad genes' (Henneman et al 2012) may lead to fear of discriminations" (Bouder 2018 p200).

Bouder (2018) also added the role of the media, quoting the case of the actress Angelina Jolie. In 2013 she undertook a mastectomy to reduce her chances of developing breast cancer, which she reported had killed her mother and grandmother. Subsequently, the referrals to breast cancer clinics increased dramatically, in what was called the "Angelina Jolie Effect" (Evans et al 2014).

6. Hansson (2018) - Ethical Issues

Concentrating on ethical issues related to genetics, Hansson (2018) outlined four relevant areas:

i) Individual vs collective risk-benefit analysis - Hansson (2018) outlined the "collectivist risk-weighing principle", which stated that "[A]n option is acceptable to the extent that the sum of all individual risks that it gives rise to is outweighed by the sum of all individual benefits that it gives rise to" (p208). This is opposed by the "individualist risk-weighing principle", which weighs the risk and benefit to the same individual.

These different types of risk assessment are applied in different situations. For example, individual treatment is assessed individually, while nuclear power plants involve collective risk assessment. "It is the total number of persons killed or injured that is at stake, and the justification for the risk-taking refers to the advantages that the activity creates for society at large, not to advantages it creates for the risk-exposed individuals" (Hansson 2018 p209). But which principle to apply to genetic risk?

ii) Protection of sensitive groups - The need to adjust risk assessments to protect sensitive ("high-risk") individuals and groups. This can be achieved by "differential protection" or "unified protection" (Hansson 2018). The former involves reducing the risk of the sensitive group with extra measures, while the latter provides measures that limit the risk for everybody.

Hansson (2018) outlined six considerations when deciding on these two options:

- Difference in risk - "If the difference in risk is small between the sensitive group and the rest of the population, differentiated protection will not be meaningful" (Hansson 2018 p213).

- Costs of special measures - If such measures are inexpensive, then unified protection makes sense.

- Identifiability - Is it possible to easily distinguish the sensitive group?

- Privacy - Identification of sensitive groups could violate their privacy.

- Social exclusion - Does special protection disadvantage the individuals receiving it?

- Previous discrimination - Are those who would receive special protection already experiencing discrimination in some way?

Hansson (2018) concluded that "unified protection is in general socially preferable, but it is usually more resource demanding. In most cases, differentiated protection is better than no protection at all but worse than unified protection. It can be used as a provisional and temporary solution" (p213).

iii) Protection of the embryo - Many genetic risks are assessed on a foetus, who is not able to give their opinion. How to deal with that? This is a variation of the previous point about protecting sensitive groups.

iv) New issues raised by genomics - eg: "personalised medicine". Using genetic information about the individual to tailor treatment to an individual (group) seems like a benefit outweighing any costs/risks. But Hansson (2018) noted some ethical issues that arise, including:

- The decision as to which diseases and sub-populations are targeted by this approach. "Ideally, one would hope new drugs for personalised treatments to be developed primarily for the more serious conditions, even if the affected group is small. In practice, however, manufacturers have incentives to give priority to large groups of patients, and -

worse still – to diseases affecting patients who can either pay themselves for the treatment or have insurers who will do so" (Hansson 2018 p217).

- Equality. Hansson (2018) gave this example: "a new expensive drug against a malignant disease may increase the expected survival of most patients with only a few weeks, whereas a genetically identifiable sub-group of the patients may gain many months or even years. We can then expect insurers to pay only for the genetically 'good responders' (Fleck 2012). This can lead to a situation in which well-to-do patients pay for the drug themselves whereas others can only have it if they belong to the 'good responders'. If we take the ideal of equality in healthcare seriously, then this is far from a satisfactory situation" (p217).

7. Kihlbom (2018) - Genetic Risk as a Special Kind of Risk

Kihlbom (2018) argued for genetic risk having "some special, but in not unique, features" (p223). For example, an individual with a gene that produces a risk for breast cancer "carries" that risk, and though environmental factors may play a role in the development of the disease, "the 'carriership' makes genetic risk special and may also influence evaluations of the risk and the way in which responsibilities for handling such risks are allocated" (Kihlbom 2018 p224).

Risk is usually talked about in reference to an "event", but "genetic risks concern states or processes that gradually start at a future point in time and then often continue for longer periods. It may be a state that one will be in for the rest of one's life, or it may stretch through the whole life of someone who has not yet come into existence – as, for instance, with some risks tested for in preconception genetic screening programmes. This temporal feature adds, obviously, to the difficulty of assessing genetic risk" (Kihlbom 2018 p224).

Another "special feature" of genetic risk is how it relates to values (as in the use of this term in moral philosophy - ie: "something" that is valued by the individual). So, happiness is positively valued, while suffering is negative.

Put another way, individuals would value not having a genetic risk for a disease. But that is not an option if an individual is carrying certain genes. Objectively

this has negative value, but subjectively the situation may be more complex. For example, studies have found that individuals with severe disease self-report quality of life similar to healthy individuals (Kihlbom 2018).

This can be seen in the case of "Kerry Andrew" (quoted in Kihlbom 2018), who tested positive for a high-cancer-risk BRCA1 mutation, and subsequently underwent a preventative double mastectomy. There is also a high risk of ovarian cancer. Andrew stated: "While I would not want other people to go through what I have been through, I do believe that carrying the BRCA mutation has helped me grow as a person. It has helped me gain an understanding of people that I might not otherwise have had and has given me an appreciation of just how precious life is. Of course, I regret that this gene took my mother away from me, but I do not regret that I have it. Having a faulty gene has in no way made my life less worthwhile" (quoted in Kihlbom 2018). This showed the subjective nature of value.

Kihlbom (2018) explained: "It is tempting to assume that there is a clear distinction to be made between the risk event, understood as a natural fact, ie: as a factor, an event or a probability, on the one hand, and the values that could pertain to that event on the other... However, such a separation of fact and value can be challenged, both in general and in particular in the context of risk" (pp230-231).

8. Schicktanz (2018) - Responsibility

The modern technological developments that allow the prediction of genetic risk bring with them responsibilities, according to Jonas (1984), both for the individual and for society.

Schicktanz (2018) observed that many writers have "conceptualised genetic risk information as empowering..., saying that it allows us to move away from our dependency on nature; it changes the role of determinism in agency. Hence, 'from fate to choice' is the optimistic slogan in this respect for many ethicists and geneticists. Whether information about genetic risk will lead to more choices and thereby to more responsible behaviour is, however, not very clear..." (p237). Some laypersons did not feel empowered by this information, as in the case of Duchene Muscular Dystrophy. The gene is carried by women, but the disorder is manifest in male offspring (Schicktanz 2018). Parsons and Atkinson (1992) interviewed women with a family history of the condition

who received genetic risk information about it. "For some this risk information is a social and emotional burden, leads to stigmatisation and is discrediting, for others social interaction helps to deal with critical periods of time (such as the decision about reproduction) but otherwise has low relevance" (Schicktanz 2018 p237).

Schicktanz (2018) discussed the concept of responsibility in bioethics, and distinguished three phases in its use in the last half century:

- "Collective forward-oriented responsibility" (in 1960s) - Responsibility towards humanity as a whole.

- "Professional responsibility towards individuals" (mid-1970s) - eg: informed consent of research participants.

- "Inter-relationship between social and individual responsibility" (since 1990s) - A balance of the rights ans duties of individuals.

Developing the last idea, Schicktanz (2018) talked of seven "relata" ("variables"): "someone (the moral agent) in a particular time frame (the time) is retrospectively/prospectively (the temporal direction) responsible for something/someone (the moral object) that is overseen by someone (norm-supervising authority/enforcement) on the basis of certain standards (norms) with certain consequences (the sanctions or rewards)" (p241). The key point is the relational nature of responsibility.

Schicktanz (2018) developed these ideas with case examples like a 60 year-old woman worried about Alzheimer's Disease, who undergoes genetic testing. Table 2.3 summarises some of the issues in this case example.

- The woman wants the test so that she can be prepared for what is assumed to come (her responsibility to self society).

- Relationships within the family, and the responsibility for caring for her.

- Limited scientific evidence for the test's validity (health professional's responsibility to make clear).

- Worry that the gene may have been passed to her offspring (her responsibility to future generations).

Table 2.3 - Some issues related to responsibility and

genetic testing for Alzheimer's Disease.

9. Oliveri and Pravettoni (2018) - Interpretative Phenomenological Analysis

Oliveri and Pravettoni (2018) reviewed studies using Interpretative Phenomenological Analysis (IPA) (Smith and Osborn 2003) as a means to understand how individuals make sense of genetic risk. IPA "represents an attempt to make sense of participants' lived experience in their 'life worlds'" (Oliveri and Pravettoni 2018 p260).

The researchers found eleven relevant studies using IPA, and semi-structured interviews about personal experience of genetic risk and testing, and/or hereditary diseases.

Four main themes were distinguished:

i) "Perceptions of control and coping strategies" - eg: individuals with a risk of Huntington's disease, which develops later in life, felt that genetic testing had given them the opportunity to prepare and make decisions about the future.

ii) "Past and future family identity" - eg: information about the genetic risk was weaved into a narrative about the family, "around which their personal identity, future plans and beliefs about the origin of illness were organised" (Oliveri and Pravettoni 2018 p262).

iii) "Personal perception of illness and health care" - eg: the genetic test as an answer to the experience of illness. "The experience of the genetic test was integrated into their long history of clinical examinations, suffering and constant peregrinations in the health-care system in a quest for the causes of their illness. In this situation, patients who tested positive perceived the opportunity to understand their illness better, and to find an explanation for it and their suffering. Their perception of the genetic test was a mix of great anxiety and relief that the question had been answered" (Oliveri and Pravettoni 2018 p262).

iv) "Genetic risk as something 'written in the body'" - eg: knowledge of being at risk led to vigilant monitoring of possible symptoms and the interpretation of ambiguous symptoms in a particular way (the "embodied experience of risk"; Oliveri and Pravettoni 2018 p263).

Oliveri and Pravettoni (2018) ended with these

comments: "On the assumption that genetic identity is 'fluid' (Klitzman 2009) and characterised by construction of a 'personal sense of vulnerability' (Walter and Emery 2005), individuals' perceptions must be understood through their own ways of experiencing the world, rather than with reference to abstract scientific categories that are potentially applicable to anyone. Invariably, the experience of living with genetic risk is already situated in historical, linguistic, cultural and embodied contexts. Moreover, the patient's body is embedded in a life-world, which reflects the patient's everyday (bodily) experience in a lived context. Accordingly, we must interpret a gene mutation or a patient's disease not as a physical dysfunction of the biological body, but in terms of a disorder of the embodied person's life-world and 'being-into-the world', with its intersubjectivity and relatedness to significant others" (p264).

2.3. APPENDIX 2A - EVACUATION

On 11th March 2011, an earthquake under the sea and subsequent tsunami caused the Fukushima Daiichi nuclear power station accident in Japan. in the following decade, research has been able to produce a picture of the effects of radioactivity on the environment.

Over 150 000 people were evacuated from the area surrounding the power station at the time, and the question is now being asked whether that was necessary.

Waddington et al (2017a) used a method to calculate life expectancy saved by moving people away from the potentially contaminated areas taking into account the cost of relocation and the impact upon quality of life [14]. The life expectancy lost was three months (Fitzpatrick 2021).

But Gareth Law disagreed: "I think the evacuation was appropriate: safety first. Understand what the contamination is and assess the problem. Can the levels or forms of contamination harm people? And if it's safe, then start to allow people to move back" (quoted in Fitzpatrick 2021).

Waddington et al (2017b) used the same method to show that urban decontamination (remediation measures) in Fukushima city was "highly cost-effective" (p60).

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[14] The "J-value": "the ratio of the amount spent or being contemplated to the maximum that can be spent without reducing the life quality of those involved. Hence a J-value up to 1.0 represents justifiable spending, but a J-value of more than 1.0 indicates that the action is not cost effective as the notional life quality of those affected will be reduced" (Waddington et al 2017b p50).

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