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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 <u>http://psychologywritings.synthasite.com/</u>. See also material at <u>https://archive.org/details/orsett-psych</u>.

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#### <u>1. FERTILITY ETC</u>

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#### 1.1. EGG FREEZING

"Egg freezing" (or more correctly, ocyte cryopreservation; OC) is a fertility treatment growing in popularity, and along with "fertility MOTs" (fertility check-ups or proactive fertility management), van de Wiel (2020) saw "a speculative turn" in contemporary IVF (in vitro fertilisation), "which is characterised by an increasing number of tests and treatments that are future-oriented, risk-focused and speculative in nature. Beyond a treatment for current experiences of infertility, IVF is increasingly oriented towards the pre-emptive and proactive treatment of future infertility" (p306).

van de Wiel (2020) commented: "Younger, fertile women are freezing their eggs in preparation for future infertility, while frozen eggs enable the possibility of conception after the onset of age-related infertility. Through this double movement, categories of fertility, infertility and what we may call 'post-fertility' are mobilised in new ways" (p307). Specifically, the financialisation of fertility", especially in the USA, where financial products like subscription plans and insurance make expensive treatments more widely accessible (van de Wiel 2020). Jackson (2017) observed that "the representation of egg freezing as a responsible choice for all women who might want to have children in the future is at odds with [...] its unaffordability for almost all women" (quoted in van de Wiel 2020).

OC can cost around \$10 000 per egg cycle, but subscription plans are offered at \$99 - 300 per month in the USA (van de Wiel 2020). Fertility clinics become providers of consumer credit. van de Wiel (2020) commented: "Although the debt financing of IVF can expand access, legal scholars have raised concerns about the potential conflict of interest arising from arrangements between clinics and lenders, given the power and trust relation between doctors and patients and the potential financial incentives for prescribing both particular treatments and the means to finance them... So while they Psychology Miscellany No. 162; February 2022; ISSN: 1754-2200; Kevin Brewer may be valuable to patients struggling to afford treatment, fertility loans may also change the dynamics between financial and reproductive decision making for patients and professionals alike" (p319). van de Wiel (2020) referred to this as the "debt financing model of egg freezing".

That is one side of the growth in the industry, but there must be a basis of demand. van de Wiel (2020) explained: "Dominant discourses of egg freezing particularly so in the US context - align neatly with neoliberal rationalities by appealing to ideas about 'self-responsibilisation' for the ongoingness of fertility and maximisation of one's 'human capital' through the enhancement of future reproductive potential" (p308).

In terms of actual treatments, OC is below 5% of US IVF, but it is offered in most clinics. This process of attracting investment in the clinics from private equity and venture capital (van de Wiel 2020).

But in order to attract investors, who want profits from their investment, a vision of the future must be presented ("speculative fertility") which blurs the boundary between who does and does not need fertility treatment. This can be seen in Sunder Rajan's (2006) words about genomics generally as "a reconfiguration of subject categories away from normality and pathology and toward variability and risk, thereby placing every individual within a probability calculus as a potential target for therapeutic intervention" (quoted in van de Wiel 2020). For example, one company, "Prelude Fertility", their founder stated: "As opposed to people who solely rely on sex to make babies, people who rely on both sex and Prelude have a much greater chance of achieving their parental goals of having healthy babies when they are ready. Prelude uses the technology available to infertile people, on fertile people. At Prelude we believe that something as important as having [...] a healthy baby, should not be left to chance" (quoted in van de Wiel 2020).

The same company in its marketing of OC said things like: "Find that right person. Focus on your career. Finish your education. The age of your eggs (not you) is the number one cause of infertility; Stop the hands of the biological clock with Prelude; It used to be that women had few options, but not anymore" (quoted in van de Wiel 2020).

van de Wiel (2020) ended that "the introduction and financial backing of egg freezing presents not simply another reproductive option, but has instigated a step-

change in IVF and is changing what it means to be fertile in the twenty-first century" (p322).

#### **1.2. FERTILITY TRACKING APPS**

The "new era of digital self-tracking behaviours" (eg: sleep, exercise, blood sugar) includes mobile fertility tracking apps (FTA) (Ali et al 2021). These track the women's menstrual cycle to identify the fertile window (approximately six days in the month). "The fertile window is when conception can occur and is defined as the day of ovulation and the preceding 5 days based on spermatozoa and oocyte viability within the female reproductive system... Women who want to avoid pregnancy should avoid sexual intercourse within the fertile window, and couples wanting to conceive can time sexual intercourse during the window to maximise their chances of conception" (Ali et al 2021 p374).

Fertility tracking methods include calendars (which count the number of days since menstruation), body temperature (which rises slightly at ovulation), and changes in cervical fluid. The latter two are fertilityawareness-based methods (FABMs) (Ali et al 2021).

Ali et al (2021) identified 200 FTAs available in February 2019, of which ninety were relevant to the study. Nine different methods of prediction of the fertile window were distinguished. The calendar method figured in some way in most of the apps. A combination of methods was common (eg: calendar and a FABM).

Three-quarters of the apps were free, and the most expensive among the purchased ones was over £350 annually. Around half had disclaimers about accuracy, and 10% clearly advised against use of the app for contraceptive purposes. Half the apps had regular updates.

Ali et al (2021) drew together some important points:

a) Concern about the dominance of the calendar method. "It is impossible to predict the day a woman ovulates by simply looking at her menstrual cycle dates... It is alarming that calendar apps were found to be the most commonly available FTA... These apps are giving women inaccurate information about their fertile window" (Ali et al 2021 p277).

b) The actual method and algorithm, in a number of cases, was "extremely difficult or impossible to

determine" (Ali et al 2021 p277).

c) The limited number of apps advising caution about accuracy.

d) The unregulated nature of FTAs.

In summary, the FTAs are "heterogeneous in their underlying methods of predicting fertile days, the price to obtain full app functionality, and in content and design" (Ali et al 2021 p280).

#### 1.3. MISCARRIAGE

Increasing knowledge has shown that "miscarriage is very common": 1 in 5 known pregnancies, or even closer to half as the ability to detect early pregnancy improves (The Leader 2020). However, The Leader (2020) lamented that "the notion that miscarriage is rare - or is somehow the woman's fault - still widely persists" (p5). In one US survey, 40% of women who had had a miscarriage believed that they had done something wrong to cause it (Klein 2020).

The scale of miscarriages, particularly before women know that they are pregnant, was estimated in 1975 (Roberts and Lowe 1975) by calculating how many births would be expected.

Most miscarriages are unavoidable because they are caused by "chromosomal errors" in the embryo, and this increases with age, and thus so does the miscarriage risk (Klein 2020). Humans have more chromosomal errors than other mammals (eg: 80% in IVF vs 10% in mice) (Klein 2020). "In the case of animals that have litters, maybe they make ten embryos a month and only eight make it to live birth, but that still eight... Whereas we typically can only make one embryo per month, so if it isn't a good one, maybe it's better to try again next month" (Shaun Chavez in Klein 2020).

At five days after conception, the embryo burrows into the lining of the uterus (endometrium), and it is here that "quality control" happens. "By depriving them of essential nutrients, the endometrium appears to prevent embryos that are unlikely to survive from attaching to the uterus" (Nick Macklon in Klein 2020). So, a high miscarriage rate evolved in humans as the best way to guarantee embryo survival into adulthood and continuation of the species (Klein 2020).

#### 1.4. OVULATION AND CREATIVITY

The optimal time to become pregnant in a month is just after ovulation. Evolutionary theory suggests a change in behaviour among women at that time, including a preference for more masculine features, greater care over appearance, and increased intra-sexual competition (eg: detecting subtle fertility indicators of other women) (Galasinska and Szymkow 2021).

One subtle change is increased creativity (divergent thinking) during the ovulatory period (Krug et al 1994). Miller (2000) proposed that human creativity is a signal of genetic quality - that is that "creativity evolved through sexual selection and enhances an individual's ability to attract a mate independent of whether it directly enhances survival" (Galasinska and Szymkow 2021 p4). So, women being more creative at the time of ovulation makes evolutionary sense.

In terms of empirical data, Galasinska and Szymkow (2021) reported a study with 751 Polish women aged 18 to 35 years old, who were not using hormonal contraceptives. Ovulation was calculated from the self-reported first day of the last period. Divergent thinking was measured by an ambiguous picture <sup>1</sup>, and participants were asked to generate as many questions as possible about the picture content in five minutes. Four independent raters scored the ideas for originality, flexibility, and fluency. The study was performed online.

Individuals who took the divergent thinking test during their ovulation period showed significant greater originality and flexibility, but not fluency in their questions.

There are a number of methodological issues to consider with this study:

i) Sample - A large number of women recruited, whereas Krug et al (1994) had only seventeen participants (Galasinska and Szymkow 2021). They were volunteers who responded to social media advertisements at a Polish university, and the study took place online. So, women who were not able to see the advertisements (ie: not online), and did not volunteer, were excluded, along with women outside the age range of 18-35 years.

ii) Self-reported data - eg: first day of last menstruation, average length and regularity of ovulation cycle, and history of pregnancy, childbirth and

<sup>&</sup>lt;sup>1</sup> Picture at <u>https://osf.io/xjnry/</u>.

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breastfeeding. This information was collected after the divergent thinking task so as not to cue the participants to the research question.

No independent verification of this information. Measures depending on accuracy of recall have reliability risks. The best way to measure the ovulation cycle is regular hormonal measurements.

iii) Measurement of ovulation - The ovulation period was calculated from the first day of the last period using a standardised table of day-specific probabilities of conception rates (Stirnemann et al 2013).

iv) Measurement of divergent thinking - A task developed by Corbalan and Lopez (1992 quoted in Galasinska and Szymkow 2021) as a proxy measure of divergent thinking was used. It assumes creativity is linked to the capacity to ask questions.

It was scored by four independent raters for fluency ("the sum of all non-redundant ideas presented"), flexibility ("the number of semantic categories applied"), and originality ("quantitative measures of uncommonness, which was the average originality rating of all creative answers"; Galasinska and Szymkow 2021 p6).

The task was an indirect measure of creativity, and the validity of such measures can be questioned. Having multiple and different measures of creativity would be better.

Galasinska and Szymkow (2021) pointed out that "creativity correlates with intelligence, the level of education can play a role in between-subject comparisons. However, in our study, the participants were recruited mostly from an academic environment, so the education factor was not differentiated" (pp10-11).

v) Uncontrolled variables - Galasinska and Szymkow (2021) made the following admission: "It should be noted that fertility-related shifts in mating psychology may depend on relationship status and within-relationship factors such as partner's attractiveness or relationship satisfaction. We did not collect such data, as the procedure of our study did not involve any overt context of romantic relationships. There could also have been other factors potentially covarying with women's creativity or fertility that we did not control. For example, general level of stress may impair both creative thinking and women's fertility. We did not control for psychiatric and neurological diseases, nor for taking neuroactive medicine. Additionally, as experiencing pain

may affect cognitive abilities, it would be beneficial in future studies to consider the painful symptoms that may accompany menstruation" (p10).

The online nature of the study "naturally prevented standardisation of situational conditions in which the participants completed the survey" (Galasinska and Szymkow 2021 p11).

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# 2. MICRO-BIOPOLITICS

- 2.1. Micro-biopolitics and post-Pasteurism
- 2.2. Anti-microbial resistance
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#### 2.1. MICRO-BIOPOLITICS AND POST-PASTEURISM

Direct-to-consumer (DTC) gut microbiome tests examine microbial cells from the human gut found in faeces, and the results are used to advise diet changes. Considering their growing popularity in the USA and Canada, Widmer (2021) argued that the current iteration of the microbiome DTC test is "unlikely to accomplish widespread health benefits. Instead, this DTC test is part of wider systems pushing the commodification and financialisation of health practices" (p3).

Interest in the gut microbiome is part of "post-Pasteurian" models of health (Paxson 2008). These "promise new ways of relating with bacteria because, for example, we must contend with the fact that public health, agricultural, and biomedical practices premised on eradicating bacteria have led to anti-microbial resistance and cannot continue to be effective... Post-Pasteurian approaches to food and well-being... also emphasise the importance of tending to beneficial microbial-human relations through, for example, the consumption of artisanal foods, sometimes flying in the face of public health regulations based on the elimination of bacteria" (Widmer 2021 p4).

Widmer's (2021) fieldwork explored the use of DTC microbiome tests online generally and in Canada specifically, and including attending events (eg: "Go with your Gut") related to diet changes. She described her social media feeds being bombarded by advertisements to attend such events, and "alternative health and lifestyle" ones (eg: "Your Moon Cycle: How It Influences Your Business and Career"). She stated: "I have clearly entered spaces where my interests have become data points to be sold. The microbiome is a marketing path and the DTC test is embedded in a context where data collection and mining form the dominant business model" (Widmer 2021 p5).

Widmer (2021) continued: "In following the microbiome and test users, discussions, I have learned that DTC gut microbiome tests are fundamentally part of the political economies of North American biotechnology Psychology Miscellany No. 162; February 2022; ISSN: 1754-2200; Kevin Brewer and biomedicine... and the financialisation of health in Canada... DTC microbiome testing works using similar techniques and principles to other sub-sectors of the biotechnology industry so as to harness the reproductive powers of biological materials in order to render them available for profit making... The stakes of people's everyday investments in this medical test therefore hinge on whether the science 'works', but also on the social and political meanings of health, labour, and lives welllived in a time of the financialisation of health" (p5).

The marketing of such tests (and health and wellbeing generally) can be summed up by advertising tag lines like: "Imagine living in a world where illness is optimal" (p6), or "Think of your diet as a bank account. Every deposit and investment counts toward the future of your health" (p7). Specific to the microbiome, "the human host is imagined as a manager who should, rather than play host to a community, harness microbes as a workforce. Due to their unique collection of microbes, consumers are told that they need individualised information to be healthy. The promised optimisation through precision nutrition advice is crucial to DTC test marketing..." (Widmer 2021 pp6-7). The companies who sell DTC tests are in many cases also producers of "nutraceuticals" to boost the microbiome.

"The DTC test companies' overall goal of collecting the genomic data of bacteria in the human gut is not only to sell individual health profiles to consumers, but also to assemble large sets of data that can be analysed and further monetised. The emergence of profitable DTC tests thus relies on context-specific constellations of scientific expertise; capital investments; skilled clinical labour; and, significantly, test users' willingness to do work in their domestic spaces, such as stool collection and subsequent diet alteration" (Widmer 2021 pp7-8).

#### 2.2. ANTI-MICROBIAL RESISTANCE

Drug-resistant diseases are responsible for about 700 000 global deaths per year, but estimates suggest that this could become ten million per year by 2050 (Plackett 2020).

Anti-biotic (AB) resistance has come from their over-use in the agricultural sector (eg: in 2013 China consumed around half of all ABs in the world, and half of those were administered to animals; Schoenmakers 2020), as much as from human misuse (eg: 70% of AB prescriptions

in the USA in 2016 were appropriate; Fleming-Dutra et al 2016) (Campbell 2020).

Anti-microbial resistance "has not crept up on us" (O'Meara 2020). Alexander Fleming warned of the risk in 1945 soon after his laboratory's discovery of penicillin (O'Meara 2020).

One solution is drug rotation, where doctors stop prescribing one AB for 2-4 years, and resistant bacteria are unable to survive for such a period, so that AB can be used again. Studies have shown that this approach only works if the replacement ABs are sufficiently different (Plackett 2020).

On the other hand, public health measures and infection prevention would mean less need for ABs (Campbell 2020).

New ABs could be another possibility. "But the lack of new anti-biotics is not just a biochemical problem it is also a considerable economic challenge. Antibiotics are not an attractive investment: development is costly, prices are low and new drugs are likely to be used sparingly" (O'Meara 2020 pS49).

Financial incentives could include a subscriptionbased model (or "Netflix model") where governments pay pharmaceutical companies upfront to encourage development of a drug rather than on a per-pill basis (Plackett 2020).

#### 2.2.1. Phages

Faced with AB resistance, a virus called a bacteriophage may offer an alternative. These phages, as with all viruses, can only multiple inside cells; in this case, bacteria. A phage attacks a specific bacterial species (Schmidt 2019).

Phages could be used with ABs to treat multi-drug resistant (MDR) infections, or multiple phages in a "therapeutic cocktail", or genetically engineered phages (Schmidt 2019). A successful case study of the latter has been reported for an individual undergoing a double lung transplant who developed a MDR infection (Dedrick et al 2019). An "engineered cocktail of three phages" defeated the drug-resistant Mycobacterium abscessus (Schmidt 2019).

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# 3. ANTHROPOLOGY OF MEDICAL TESTING

- 3.1. Diagnostic testing
- 3.2. HIV status
- 3.2.1. Self-testing
- 3.3. Pre-cancer
- 3.3.1. Living "with" cancer
- 3.4. References

#### 3.1. DIAGNOSTIC TESTING

The process of diagnosis (ie: "assigning an individual with illness to a standard disease category"; p1) is the basis of modern biomedicine, but it is also "fundamentally a social and cultural practice... Diagnostic categories and processes are central to the production and distribution of biomedical authority... A recognised diagnosis confers legitimacy on the patient's status as 'sick' and mediates access to support and resources... It can be both a form of social control... and the basis for new solidarities and subjectivities" (Street and Kelly 2021 p1) <sup>2 3</sup>.

In the nineteenth century, disease was defined by the external manifestations (what has been called "bedside medicine"), while in the 20th century it became "hospital medicine", "in which expert investigators identified hidden pathogens as the cause of patient illness and categorised those pathogens as objective disease entities" (Street and Kelly 2021 p2). Jewson (1976) described this change as "medical practice became an appendage to the laboratory" (quoted in Street and Kelly 2021).

Today, diagnostic tests are central to medicine, often based on blood samples from the patient. This was seen particularly in March 2020 when the head of the WHO emphasised "test, test, test" as the way to deal with the covid-19 pandemic. "Perhaps the most striking aspect of

<sup>&</sup>lt;sup>2</sup> Rosengarten (2021) observed that "biomedical diagnoses proceed on the presupposition that they are contending with a first-order reality composed of material substances. Values, meanwhile, make up a second order. They are assumed as a creation only of the mind and thought to contaminate objective knowledge. This arrangement has led to the construction of what are presupposed as 'value-free' technical instruments and to clinical evidence achieved by 'value-free' methods" (p2). However, this "bifurcated nature" may not b e as clear-cut. This is another way of describing the "Cartesian dualism" of body and mind. This distinction comes to the fore in situations that challenge biomedicine. "For example, the 'novel' emergence of 'Ebola relapse' [Jacobs et al 2016] caught biomedicine by surprise and has led to a rethinking of the infection as 'persisting' in novel ways, despite situated diagnostic testing that showed it to be gone" (Rosengarten 2021 p6).

<sup>&</sup>lt;sup>3</sup> Nettleton et al (2014) referred to the "diagnostic illusory" - "ambiguities and nuanced complexities associated with the biomedical imperative to name and classify" (quoted in Frumer et al 2021). Psychology Miscellany No. 162; February 2022; ISSN: 1754-2200; Kevin Brewer

the 'new normal' for people living in these countries is the sheer ubiquity of covid-19 medical testing. In the UK, for example, members of the public with no medical background or laboratory training now routinely keep rapid test 'kits' - comprising sample swabs, bottles of buffer, test cartridges, and waste bags - in their kitchen cupboards, ready to lay out on a pre-cleaned surface at the slightest tingle of a sore throat" (Street and Kelly 2021 p4). Remembering that the picture in the Global South is different.

Medical testing has a "multi-valent nature" - ie: tests are "deployed as research tools...; as tools of epidemic control...; as instruments of subjectification and citizenship...; as the genus of epidemiological reason and aporia in clinical care...; as sites of economic exchange...; and as exercises in governmentality and extensions of sovereign power" (Street and Kelly 2021 p10).

Introducing a special issue of the journal, "Medicine Anthropology Theory", on diagnostic testing, Street and Kelly (2021) outlined four themes:

i) Variations in medical "testscapes" - This theme is a reminder that the commonly used testing in highincome countries are often not available or very expensive elsewhere. These issues are "attenuated by infra-structural instabilities: the unstable supply chains, electrical outages, malfunctioning equipment, and poorly paid laboratory staff" (Street and Kelly 2021 p5).

ii) The relationship between testing and governance - This theme covers the "role of medical tests as technologies of governance and tools of subjectification" (Street and Kelly 2021 p7). This can be seen during the covid-19 pandemic where tests results determine certain rights (eg: to work or enter a place).

iii) The market for tests - The "commodification" of tests means that they are commercial products and so hold value for companies. At the extreme, "what appears to get lost in the marketisation of diagnostic tests is the question of what value a test might hold for the person being tested" (Street and Kelly 2021 p8).

iv) Tests and uncertainty - Tests are presented as "diagnostic certainty", whereas "the sociology of diagnosis has long highlighted the uncertainties and anxieties that diagnostic testing can generate,

especially when deployed for the purpose of screening 'healthy' populations" (Street and Kelly 2021 pp8-9).

#### 3.2. HIV STATUS

A diagnostic test may show that an individual is "at-risk" of a particular condition, and the individual may then have to disclose this information publicly, as in the HIV status of healthcare workers. There is a conflict between the right to privacy and the public health concern. There have been court cases in the USA, for example, about this conflict. "In some jurisdictions, it was the responsibility of healthcare workers to reveal their status to their employers. In turn, hospitals were responsible for managing information about the HIV status of their care providers... As laws determined whether and how healthcare workers should reveal their HIV status, many workers developed fears their HIV status would be disclosed against their will" (Whitacre 2021 pp4-5).

There was the concern that with the obligation to disclose, "people who might be at risk of HIV were not submitting to HIV tests and some who had completed HIV tests were not returning to receive their results" (Whitacre 2021 p5).

If individuals prefer not to disclose publicly their HIV status, doctors who performed the testing may feel obliged to break confidentiality. Cohen (2003) noted that a "bond of trust has its moral limits" as "in some cases in which HIV positive clients are sexually active with unsuspecting third parties" (quoted in Whitacre 2021). Whitacre (2021) called this idea "intimate ethics": "So, despite the sovereignty of the subject to know what one wills to know and to reveal what one wills to reveal, the withholding of that truth from an intimate Other causes the sovereignty of the individual to split open, meaning the subject then becomes answerable to another set of ethics - ie: that which concerns and governs encounters with the intimate Other" (p6). At the extreme, not revealing a HIV-positive status to a lover becomes a legal offence, and there are cases in the USA under the change of "sexual intercourse without disclosure of HIV", for instance. James Fyffe, for example, was 'accused of intentionally hiding the fact that he had HIV when he had sex with a woman' ... According to court records, several people told Fyffe to disclose his HIV-positive status to the woman, but he refused. Fyffe was charged with felonious assault" (Whitacre 2021 p8).

Research on HIV-positive status disclosure found

that social support, and stigma were key. For example, Miller and Rubin (2007) found certain patterns of disclosure in Kenya. "People disclosed to family and partners motivated by 'a sense of duty' as well as to seek material support. People disclosed to religious leaders, on the other hand, in order to seek advice. People hesitated to disclose to friends because of a lack of trust and, specifically, a fear that friends might tell others. Men are more likely to disclose directly to partners, while women use less direct communication methods. Overall, roughly one third of participants rely on a third party to disclose to an intimate partner" (Whitacre 2021 p9).

The disclosure of status can also mean the disclosure of sexual practices. This was particularly evident with clinical trials of an oral HIV pre-exposure prophylaxis (PrEP) (eg: Truvada) that deliberately recruited individuals with risky sexual practices. "To qualify to participate in clinical PrEP research, an individual was required to tell investigators that he or she was 'at risk' of acquiring HIV. This risk was measured by the number of sexual partners the participant had-the higher the number, the higher the risk - and by the participant's engagement in specific sexual practices, which varied depending on the risk group. For men who have sex with men (MSM), HIV risk was most closely associated with receptive anal intercourse. Meanwhile, for heterosexual women, risk was defined in terms of vaginal sex. For each of these groups, having sex without a condom constituted higher risk" (Whitacre 2021 pp13-14).

Participants in such clinical trials began as HIVnegative and received regular testing for seropositivity. Whitacre (2021) described such participation as "confessional labour" (drawing on Foucault's (1990) concept of "confessional technologies") - participants revealing "truths about themselves through words and blood samples (both these forms of truth are made to matter for pharmaceutical efficacy)" (p15).

Whitacre (2021) ended that these "confessions should be understood as a form of labour that enables the development of drug products and facilitates the growth of markets" (p16).

#### 3.2.1. Self-Testing

HIV self-testing (HIVST) is recommended by the WHO to help people discover their HIV status. Janssen et al

(2021) raised two concerns: "firstly, to deal with issues of uncertainty around how a person completes the test and interprets the results and, secondly, to help ensure that people who take the test do the 'right' thing after receiving a result by accessing the appropriate follow-up care" (p2).

These researchers also emphasised the uncertainties around HIVST - "For example: uncertainties about the validity of the testing method, uncertainties about personal risk, and uncertainty about when one should be tested" (Janssen et al 2021 p2). Their research focused upon a smartphone app called "HIVSmart!" to help in performing and interpreting an oral HIVST used in South Africa.

The individuals dealt with uncertainty generally in a number of ways, including (Janssen et al 2021):

a) Considering their risky behaviours - eg: One participant said: "Yeah, I trusted the result, because the last time I did the test I was negative. I continued using a condom with my partner, so I didn't think I could be positive anyway because I'm safe and I'm not doing anything different after, I didn't do anything different with my partner after that test" (p14).

b) Seeking reassurance from the app and/or healthcare staff - eg: One interviewee said after using the test for the first time: "Because it was a new test, a new way of testing, I didn't know if that's how the results will be showing [...] Maybe negative will show two signs, maybe, um, it's not conclusive [and] will show two lines. I didn't know. But from previous experience, I know if it shows two lines then you know it's positive. So when I saw that, and I compared it to [...] the results on the app and I looked at both the screen and the test [...], then I could compare the negative and the positive [...] to what was happening on the actual test" (p9).

c) Comparing different tests - eg: One participant said: "When the finger-prick one came, of which it tells the very same thing that the oral one was saying, then I was like oh okay, this oral [test] is working" (p13).

Janssen et al (2021) placed meaning on their findings: "Manderson (2020) highlights that illness cannot be divided into discrete blocks such as sickness, diagnosis, treatment, and cure; rather, it is a continuous thing with messy overlaps. She uses the

concept of 'living under' diagnosis (Martin 2007) to help illustrate the role of the diagnostic label in dictating symptom management, monitoring and measuring, directing actions and behaviour, individual diagnostic accuracy, and the possibility of the diagnosis being reversed (Manderson 2020). Our article suggests that, in communities where testing for HIV is often a constant (chronic) aspect of daily life, we can use the phrase 'living under' to think about HIV status, conceptualising it as 'living under' your HIV status or risk of HIV. This goes beyond 'living under' diagnosis, as it encompasses both HIV-negative and HIV-positive people: those not diagnosed, yet to be diagnosed, and already diagnosed" (p18).

#### 3.3. PRE-CANCER

"Pre-cancer" is "a new diagnostic category defined by the risk of developing the titular disease" (Perez 2021 pl). The ability to detect cancer early has great potential.

It is based in the "molecularisation of clinical research" - ie: a "microscopic gaze" that "'visualises life at the molecular level in terms of genes, molecules and proteins' (Bell 2013) and understands it as a set of 'intelligible mechanisms that can be identified, isolated, manipulated, mobilised, and recombined in new practices of intervention' (Rose 2007)" (Perez 2021 p2).

Perez (2021) continued: "Understanding health and illness at the molecular level leads us to perceive that 'dangers come from everywhere' and that 'everyone is potentially ill and no one is truly healthy as everyone has a particular risk factor profile that can be managed by a vigilant medicine' (Armstrong 2012)" (p2). I coined the phrase the "temporary state of undisease" (Brewer 2016) to describe such a situation where health is but temporary, transitory, or "illusory".

Early detection is thus a "boundary effect" (Lowy 1992), argued Perez (2021), and related it to pre-cancer. Importantly, early detection techniques assert certainty in a situation of great uncertainty. Perez (2021) reported eighteen months of fieldwork with scientists in Britain working in cancer biology.

For example, "Sonia" was trying to develop an "organoid" (ie: an "experimental system") to model the natural history of breast cancer (ie: how the tumour evolves at a cellular level). The focus of the work was upon growing the cells, and in creating a model realistic

to human breast tissue. Perez (2021) observed that "the 'discovery' of signals used to understand cancer evolution might be brought about by the technology itselfitself [sic] - that is, not 'discovered' at all. Without an experimental system that works in the desired way, there are no cellular interactions to observe. The process of bringing about phenomena through an array of techniques is what the French philosopher of science, Gaston Bachelard (1953), understood as phenometechniques" (p9). Put very simply, meaning is being attributed to biological phenomena.

Another example was "Rose" who led a group working on "tumour oxygenation" in mice models. These were "knocked in" and "knocked out" mice, where genes had been manipulated. The mice were used as an environment to test signals (molecular pathways) found under the microscopic. Perez (2021) described how a presentation of the research avoided failures and setbacks, and the "dirtiness" of everyday science to leave out "the interventions executed by the scientists who engaged with the experimental system" (p13). This is not saying that deliberate falsification is involved, rather that scientific knowledge is a socially constructed process.

Perez (2021) explained further:

Finding a signal and being able to trace it back to the biological referent is not enough to produce a candidate biomarker. Scientists need to make sure that what they are seeing is cancer and not an artefact produced by the experimental system. This is tricky in early detection as there are no alternative proofs external to the experimental system to rely on. This absence makes the step of ensuring 'reproducibility' difficult to achieve. Therefore, scientists know that they cannot give the impression of too much certainty when communicating results to others; instead, they need to be aware of possible sources of error.

While communicating with others about the 'discovery' of facts concerning the natural histories of cancer, scientists navigate a space of uncertainty, forging some connections and disregarding others. 'Robust' results from multiple experiments, 'clean' distinctions in histograms, and 'beautiful data' are compelling allies in the process of fact-making, and all can help results travel beyond the laboratory and into the clinic. This, of course, goes on top of good storytelling. As Orit Halpern (2015) put it, 'The shift toward "data-driven" research [has been] adjoined to a valorisation of visualisation as the benchmark of truth, and as a moral virtue [of the scientist]' (2015)" (p18).

A signal of future cancer is "intimately entangled with the sensing technologies and analysis techniques used" (Perez 2021 p20).

#### 3.3.1. Living "with" Cancer

Talking about lung cancer specifically, Frumer et al (2021) stated: "Even with, and often because of, access to 'the best of technology'..., diagnosing severe illnesses is an uncertain guessing game that can spiral into myriad uncertainties and searches for closure" (p2). For the clinician diagnostic testing shows the small probability of a sign that could develop into the disease. But what is "the meaning and value of testing when it does not, and is often not expected to, lead to a definitive diagnosis", asked Frumer et al (2021 p3). These researchers called such an experience for the "patient" "in the meantime". "Life in the meantime is equally characterised by a dramatic mode of being — that is, waiting for death — and an ambiguous mode of being: feeling quite well" (Frumer et al 2021 p1).

Konrad (2003) introduced the concept of "foreknowledge" - "knowledge of an anticipated illness: you expect to become ill, but you do not know when the disease will show. Compared to this, 'in the meantime' describes an experience of potential illness: you might become ill, but you cannot know whether that will be the case" (Frumer et al 2021 p21).

"There is a 'social life' to diagnostics and testing", stated Frumer et al (2021 p5). They continued: "The acceleration of technological innovation in the Global North, the cultivation of particular forms of government that emphasise early diagnosis and prevention, and current patterns of resource distribution are all dominant in shaping the development of diagnostic practices and testing cultures" (Frumer et al 2021 p5). Early diagnosis minimises the risk of missing a developing cancer and thus allows for prompt treatment. This is the "good" side of the process, but such diagnostic practices bring the problem of "a general 'disease sensitisation' characterised by the representation of bodily signs of cancer as 'ever-present ''what ifs''' [Anderson 2017]" (Frumer et al 2021 p6).

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