PSYCHOLOGY MISCELLANY

No.185 - Mid-June 2023 Reproductive Biomedicine

Kevin Brewer

ISSN: 1754-2200

orsettpsychologicalservices@phonecoop.coop

This document is produced under two principles:

1. All work is sourced to the original authors. The images are all available in the public domain (most from http://commons.wikimedia.org/wiki/Main_Page). You are free to use this document, but, please, quote the source (Kevin Brewer 2023) and do not claim it as you own work.

This work is licensed under the Creative Commons Attribution (by) 3.0 License. To view a copy of this license, visit <u>http://creativecommons.org/licenses/by-nc-</u><u>nd/3.0/</u> or send a letter to Creative Commons, 171 2nd Street, Suite 300, San Francisco, California, 94105, USA.

2. Details of the author are included so that the level of expertise of the writer can be assessed. This compares to documents which are not named and it is not possible to tell if the writer has any knowledge about their subject.

Kevin Brewer BSocSc, MSc

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

A complete listing of his writings at http://psychologywritings.synthasite.com/. See also material at https://archive.org/details/orsett-psych.

CONTENTS

Page Number

1.	Reproductive Autonomy	4
2.	Fertility Awareness	25
3.	Fertility Clinics	34
4.	ART Families	41
5.	Ignorance Production	49
6.	Genetic Counselling	61
7.	Biological Clock	65
8.	The Embryo	72

1. REPRODUCTIVE AUTONOMY

- 1.1. Institutional coercion
- 1.2. Reproductive coercion
- 1.3. Reproductive decision-making
 - 1.3.1. Peru
 - 1.3.2. Perceived inability to procreate
 - 1.3.3. Unrealised fertility
- 1.4. Medically assisted reproductive
 - 1.4.1. Egg freezing
- 1.5. Reproductive travel
- 1.6. Appendix 1A Metabolic factors and fertility
- 1.7. Appendix 1B Egg freezing
- 1.8. References

1.1. INSTITUTIONAL COERCION

"Reproductive autonomy" is an "individuals' ability to be fully empowered agents in their reproductive needs and decisions and to access reproductive health services without interference or coercion" (Senderowicz and Higgins 2020 p147).

Threats to this autonomy can include from interpersonal relationships, health systems, and social structures (eg: systemic discrimination). For example, in the USA, State regulations on access to abortion services, or the practicalities of the covid-19 pandemic restricting availability of contraceptive services. Coercion can include enforcing "long-acting reversible contraceptive" (LARC) methods in the Global South (Senderowicz and Higgins 2020).

Senderowicz and Higgins (2020) stated: "we remain concerned about linking the use of modern contraceptives (LARCs in particular) with poverty reduction, both in the United States and globally. For years, some politicians, policymakers and researchers have argued that increased contraceptive use among individuals living in low-income communities can alleviate poverty. Implicit in these arguments is the notion that poverty and a range of other social ills are fuelled by women having too many children, rather than by long-identified structural inequities that deprive many low-income individuals - in particular, people of colour - of living wages, safe housing, high-quality education, and other forms of social and economic inclusion" (p148).

Senderowicz (2019) observed: "Global family planning programmes have many supporters, but the rationales for Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer

their support can vary greatly. Feminists promote safe, affordable contraception because women's ability to control their own bodies is central to the pursuit of gender equity... Environmentalists promote family planning to mitigate climate change... Public health advocates promote family planning to reduce maternal mortality... And development scholars promote family planning to achieve a range of micro- and macro-economic goals" (p1). Hodgson and Watkins (1996 quoted in Senderowicz 2019) described these different groups as "strange bedmates".

Development organisations can see contraception uptake in terms of numerical targets, and "such targetdriven contraceptive programmes may incentivise coercive practices" (Senderowicz 2019 p1).

Senderowicz (2019) explored this concern through 49 in-depth interviews with women of reproductive age in two anonymised Sub-Saharan African countries. Coercion can be viewed as "downward" (ie: family planning programmes do not exist to allow women a choice) and "upward" (ie: family planning programmes that exist but do not respect the woman's decision). The latter could include "forced sterilisation", and the former is seen in terms like "medical barriers" (Senderowicz 2019).

Analysis of the interviews elicited the following key themes:

i) "They give it to everyone without exception" -The availability of contraceptives for all women challenged the idea of downward coercion (ie: no lack of services or restricted access within a service).

ii) "Coercion as a spectrum" - Senderowicz (2019) noted many examples of upward coercion, varying "from things that subtlely constrain autonomy, to more overt action" (p5).

a) Subtler forms - eg: "biased" or "directive counselling" to promote hormonal implants.

b) Moderate forms - eg: "scare tactics". For example, "Cindy" said: "When I brought my child into the world, I went back for the 45th-day check-up and they [the nurses] asked me to see if I was going to use a contraceptive method to space my births and I said no. They told me that if I decided to not use [family planning] and then later I have problems and start to run panicked in the midday sun to say that people should help me, it's complicated. When they spoke like that, in all

honesty, it made me scared" (p6).

c) Overt forms - eg: refusal to remove a LARC at a woman's request.

The attitudes towards health workers by the interviewees were contradictory - women had faith in them, and/or "expressed anger, confusion and frustration about what they considered to be heavy-handed approaches to family planning counselling and provision" (Senderowicz 2019 p8).

Senderowicz (2019) pointed out: "Much of the coercion reported has roots in structural causes rather than any apparent malice on the part of individual providers. Health centres are incentivised to meet specific contraceptive uptake targets, with financial benefits to increasing uptake and providers accountable to their supervisors if targets are not met" (p8).

Senderowicz and Kolenda (2022) researched the overt form of coercion via seventeen focus group discussions with 146 women of reproductive age in an anonymised Sub-Saharan African country. Three key ideas emerged from the discussions:

i) Providers' refusal to remove a LARC without giving a reason, or a "medical" reason given (eg: dangerous; complicated; wasteful).

ii) The woman's desire to remove a LARC not accepted as a sufficient reason it itself.

iii) Women finding reasons for their request -Senderowicz and Kolenda (2022) explained: "We use the term 'legitimating practices' to refer to range of acts (including developing rationales, gathering evidence, marshalling social support, and other tactics) that women used to convince healthcare providers that their request for method removal was legitimate enough to be granted" (p5).

The researchers concluded that the findings "indicate that the driving concern for family planning programmes in this setting may not be to enable a woman to achieve her own reproductive desires, but rather, to enforce compulsory birth spacing and achieve other global family planning programmatic priorities" (Senderowicz and Kolenda 2022 p6).

1.2. REPRODUCTIVE COERCION

"Reproductive coercion" can be defined as "actions taken by a person's partner or family member to prevent or promote pregnancy, irrespective of their wishes" (Rowlands and Holdsworth 2022 pl). "Pregnancy promoting" actions include (forced) sex without contraception, or sabotaging or denying access to contraceptives, while "pregnancy preventing" behaviours are coercion to force a termination, physical violence to induce a miscarriage, or covert administration of abortifacient (abortioninducing) agents (Rowlands and Holdsworth 2022).

"Although abusers are most often intimate partners who are heterosexual, cisgender men, reproductive coercion can come in many guises. It can be perpetrated by cisgender women upon cisgender men; and although few studies exist on reproductive coercion among LGBTQ+ people, it may still occur. It can come from the wider family and can also be carried out in the contexts of conflict, sex trafficking, and sexual exploitation" (Rowlands and Holdsworth 2022 p2).

A survey on behalf of the BBC of over 1000 women of reproductive age in the UK found that half reported some form of reproductive coercion (quoted in Rowlands and Holdsworth 2022). More formally (Rowlands and Holdsworth 2022), a US study of health service attendees found 8-30% (Rowlands and Walker 2019). In an Australian sexual health clinic survey (Latimer et al 2018), one-third of heterosexual women had experienced non-consensual condom removal. Around 10% of married women in a large population survey in India had experienced reproductive coercion from their husband or in-laws (Silverman et al 2019).

Certain heterosexual women are at higher risk of reproductive coercion, including unemployed and social disadvantaged, socially isolated and marginalised (eg: migrants; non-dominant language speakers), and drug and/or alcohol users (Rowlands and Holdsworth 2022).

Reproductive coercion is usually in the context of "coercive control". This is "when an abuser repeatedly behaves in a way that makes a person feel controlled, dependent, isolated, or afraid" (Rowlands and Holdsworth 2022 p2).

1.3. REPRODUCTIVE DECISION-MAKING

"Reproductive decision-making" relates to when to have children, and the late 20th and early 21^{st} centuries,

this is linked to individual choice discourses. But there are also social norms, and biological aspects of ageing, as well as pre-conditions for parenthood like economic stability and personal readiness (Bodin et al 2021).

Bodin et al (2021) explored intergenerational changes in reproductive decision-making with twenty-six focus groups in Sweden, which included 110 participants aged from 17 to 90 years old. Six themes emerged from these group interviews:

a) Proving economic security - All ages agreed upon this pre-condition for parenthood, but there were differences in how this was seen. Older participants talked of getting a job and finding somewhere to live, while younger participants referred to finishing their higher education, and/or "Get out and travel, do stuff" ("Adam"; p18).

b) "A growing smorgasbord of choices and requirements" - "When looking at the different generations, it is clear that decision-making has become a more complex phenomenon. To make conscious choices in all aspects of life was presented as a contemporary norm which could have a delaying effect on childbearing" (Bodin et al 2021 p18). Older participants often saw children as "something that just happened" (p18).

c) "Parenthood becoming a project" - "Older participants expressed concern that having children today has become too much of a project. Britta (66) believed that today's family planning has become 'an entire company', and felt unease when thinking about how her children wanted everything to be ready before having children. Most of her peers agreed that the planning has gone too far, at least among the highly educated" (Bodin et al 2021 p18).

"Tuva" (25) expressed it thus: "There is so much you have to do and fulfil to be a good mother, there is a lot of pressure on how it should be, for the child to be well. Because you don't want to expose them to unnecessary trauma, to troubles" (p19).

d) "Stretched out life stages" - With life expectancy increasing, so life stages have "expanded". For example, "Lisa" (32) said: "But isn't it also like this, that you get tired of all this other stuff that is great fun when you are 20? And then when you turn 30 you start feeling that you need something else in your life?" (p19).

e) "(Im)possibilities to procreate" - "Involuntary childlessness" was less of an issue today with artificial reproductive technology available.

f) "Intergenerational pro-natalism" - All generations favoured children, as Bodin et al (2021) explained: "The interviews displayed high expectations of continuity of the family line. Parents usually said that they tried not to interfere with their children's reproductive choices, referring to how their own parents, or parents-in-law, had been too involved in their decisions. Still, many young adults felt more or less subtle pressure to give their parents grandchildren. When a child wanted to remain child-free, this could be difficult for a parent to understand, and the urge to interfere could become too strong" (p20).

Bodin et al (2021) pointed out key differences between the younger and older participants, including the importance of planning parenthood now, varying aspects of love and relationships, and the emphasis on the "modern self-reflexive individual]Giddens 1991]; a person who views the life course as made up by separate passages and who links progression to self-reflection. It could be that older people, in retrospect, view some preconditions as less important than they did when they were young. Still, the discussions clearly point to the fact that young people today are more insecure about whether they will be able to meet the needs of children as they expect parenthood to involve higher demands" (p21).

1.3.1. Peru

Reproductive decision-making has been impacted in countries vulnerable to Zika virus (ZKV). The virus is transmitted in the main by the Aedes Aegypti mosquito, but also by unprotected sex, and from mother to foetus. "Official responses advocating for abstinence, use of contraception, and staying indoors as ways to avoid the disease, place the responsibility for prevention on women... An underlying and problematic assumption is that women are indeed in a position to act; concealing the constraints of the gendered dynamics of everyday life and profound disparities in access to reproductive health" (Guerra-Reyes and Iguiniz-Romero 2019 p310).

Guerra-Reyes and Iguiniz-Romero (2019) explored this topic in Iquitos, Peru, in three focus groups, and individual interviews with men and women, and with

reproductive health providers. A number of key emerged about condom use and contraception generally:

i) "Playing the field" - Socially expected patterns of sexual behaviour in the late teens were different for men and women. Men would "play the field" and have sex with different women including "of-the-street" and "party girls", where condom use was advised because of sexually transmitted infections, as opposed to "girls of-thehouse". The latter were the potential for stable partners, who "should have very little experience or knowledge of sex; while it was conversely better that a man have 'lots of experience'. This generally led to men being older than females in relationships. Women were cognisant of the need to fall into an of-the-house category, defined by male participants as a 'girl who stays at home, doesn't go out much, and doesn't party' (Mirko 31yrs)" (Guerra-Reyes and Iguiniz-Romero 2019 p313).

ii) Pre-union sex - As a relationship developed (ie: not "casual sex"), condom use was less common, and the onus was upon the woman to use the contraceptive pill. "Male perspectives on condoms and contraception were immensely influential in guiding their use in pre-union sexual encounters" (Guerra-Reyes and Iguiniz-Romero 2019 p314).

iii) Unplanned pregnancy - Many committed couples used the calendar or withdrawal method of contraception, and were surprised by unplanned pregnancies. Guerra-Reyes and Iguiniz-Romero (2019) commented that "many pregnancy narratives... followed the same interesting sequence: participants (male and female) first said they did not want a pregnancy, then over time they relaxed into a relationship reducing their concern for contraception if any had existed, and then finally being blind-sided by the pregnancy" (p316).

Abortion was illegal, but abortifacients (eg: pills; herbs) were commonly known about. "A common belief among both men and women in Iquitos was that unsuccessful abortion damages the foetus. Thus, any child with a disability, be it cognitive or physical, is treated as a moral indictment of their parents... This belief has implications for congenital Zika Syndrome. It is likely that any cognitive or physical sign Zika virus damage to the child will be attributed to a woman's desire to abort, marking her as morally reprehensible. This could have consequences in her ability to leverage social

support to care for that child" (Guerra-Reyes and Iguiniz-Romero 2019 p317).

iv) Post-union contraceptive use - Generally, "it was only after a union had been established, and the first child of that union born, that any conversations between partners about future planning occurred" (Guerra-Reyes and Iquiniz-Romero 2019 p317). But condom use was still viewed with suspicion at this time. If one partner wanted to use a condom, it was perceived as a sign of their infidelity. Specifically, "a woman asking for her regular partner to use a condom marks her as being 'ofthe street', likely unfaithful and disease-laden. Thus, women in committed relationships lose not only the ability to negotiate condom use with their partner for disease prevention, because it is the male responsibility to care for her, but also, the ability to call on condom use for contraception" (Guerra-Reyes and Iguiniz-Romero 2019 p319).

Guerra-Reyes and Iguiniz-Romero (2019) summed up: "The sexual lives of women and men in Iquitos develop in a context of profoundly unequal gender expectations. Women need to perform purity in Butler's (1988) sense, to be able to be considered viable long-term partners by men. Thus, women must embody the characteristics of a girl-of-the-house, which involves appearing innocent about sex, contraception and sexually transmitted infections, thus limiting the scope of acceptable discussion for women. This is especially significant as it runs contrary to public health efforts to promote sexual health education, for example among younger people" (p319). The upshot is that women have limited scope in reproductive decision-making, even in the context of ZKV risk.

1.3.2. Perceived Inability to Procreate

There is a relationship between perceived inability to procreate (ITP) (or "enforced childlessness") and less life satisfaction as compared to those who can and have children, and "child-free" adults (McQuillan et al 2022). For example, in a Germany study of 275 women at an infertility clinic (Wischmann et al 2001), life satisfaction scores were lower than general population norms on the scales used. This has been confirmed in general population studies (eg: USA; McQuillan et al 2007).

"Most studies of infertility and life satisfaction are cross-sectional, thus limiting the ability to draw causal inferences. Some studies have followed people who sought treatment for infertility and re-assessed their well-being a number of years after the baseline study. The goal of such studies is to estimate whether a birth after treatment (ie: 'success') is associated with changes in life satisfaction... The strength of these studies is their ability to account for time order (ie: by measuring life satisfaction before and after treatment), but they include only those individuals who sought treatment for infertility" (McQuillan et al 2022 p89).

Another issue is the age of the respondents (ie: where they are on the life course). Perceived ITP may be different in a woman's 20s than in her 30s, say, and if the woman has child(ren) already (ie: "secondary infertility"). "One would also expect both perceptions of procreative ability and life satisfaction to vary with partnership status" (McQuillan et al 2022 p89). Gender is another variable.

Life satisfaction is influenced by many factors, and so untangling them in order to establish a causal link between childlessness and lower life satisfaction is a challenge. McQuillan et al (2022) tried to control such variables in their analysis of German data. The German Family Panel (Pairfam) for 2008-9 to 2017-18 included the equivalent of over 42 000 respondents. Life satisfaction was measured on a ten-point scale. Perceived ITP was self-reported. Questions were also asked about variables like desire for a child, number of children, subjective general health, views on children, and gender roles.

In summary: "Life satisfaction was substantially lower when people perceived an inability to procreate, and this relationship persisted after controlling for a number of variables which theory and previous research suggested might influence the relationship" (McQuillan et al 2022 p95). This was true for both men and women. However, there were some gender differences - for example, single men who perceived an ITP had very low life satisfaction. "It might be that single men who perceive an inability to procreate constitute a special group of men who discover a problem earlier in their lives, perhaps due to cancer treatment or other toxic exposures" (McQuillan et al 2022 pp95-96). But among partnered men (but not women) "life satisfaction is not associated with whether or not they perceive an ability or not to procreate" (McQuillan et al 2022 p96). The study allowed the comparison of the same

individuals over a number of years. Thus, it was found that "in years when men intended to have a(nother) child and perceived an inability to procreate, they had significantly lower life satisfaction compared with years in which they perceived an ability to procreate. Among women, the same pattern appeared, but it was not statistically significant" (McQuillan et al 2022 p96).

Overall, the relationship between perceived ITP and life satisfaction is a nuanced relationship that can vary over time, and depends on certain variables.

1.3.3. Unrealised Fertility

The intention to have children at a later date is not the same as actually having them. The difference is "unrealised fertility" (or "unwilling childlessness") (Beaujouan 2022).

In terms of studies in different countries, in Italy in 2009, for example, 64% of childless women aged 35-39 wanted a child, but only 31% actually had a child at that age (Beaujouan and Sobotka 2017 quoted in Beaujouan 2022).

While in Austria, "unwilling childlessness" was between 5-12% of the women in their late 30s and early 40s (Beaujouan 2022). Beaujouan (2022) analysed data from the Austrian Micro-Census from 2008-9 and 2012-13. The age groups 35-39, 40-42, and 43-44 years old were the focus. Fertility intention (ie: number of children wanted) was measured in 2008-9, and number of children in 2012-13.

Unrealised fertility may be due to the individual's decline in fertility, as much as unexpected life events (eg: partnership break-up) (Beaujouan 2022).

1.4. MEDICALLY ASSISTED REPRODUCTION

"Medically assisted reproduction" (MAR) is a more general term that includes assisted reproduction technology, and surgery to treat infertility (appendix 1A). There is limited use and access to MAR in Germany, which Koppen et al (2021) investigated via the German Family Panel annual survey from 2008-9 to 2018-19 (ie: eleven waves). Data from respondents and their partners 25 years and above who had tried to get pregnant in the last year or were pregnant were the focus (n = 1446). The majority of couples (87%) reported no fertility

problems, but 3% of them had used MAR compared to one-

third of the 13% of couples who reported fertility problems for at least one partner (figure 1.1). Overall, 8% of the whole sample had used MAR.



(Data from table 1 p55 Koppen et al 2021)

Figure 1.1 - Percentage of couples using MAR based on self-identified fertility.

The most common methods used were calculating the woman's ovulation date, and medication, followed by surgery, and in-vitro fertilisation (IVF). Users of MAR were likely to be female, higher income, married and childless, slightly older, have poor subjective health, and believed in the importance of having children.

Overall, there was a social selectivity to MAR use ie: higher income, married couples. This may be due to the system in Germany where private medical insurance and/or co-payment covers MAR. Koppen et al (2021) stated that "the findings reflect a pattern of cumulative disadvantage: younger couples with a less solid financial background, particularly those who were not married, appeared to have faced barriers to the use of MAR because of restrictive guidelines, corresponding legislation and limited insurance coverage" (p59).

1.4.1. Egg Freezing

"Egg freezing" (EF) (or oocyte cryopreservation, more correctly) was originally offered to women who faced premature infertility through illness (eg: chemotherapy for cancer; premature ovarian insufficiency). This is called "medical EF" (Johnston et al 2022). But the increase in demand in recent years for EF (eg: 300% between 2010 and 2015 in Australia/New Zealand) suggests "non-medical EF" (Johnston et al 2022). "Women seek nonmedical EF as a pre-emptive measure to increase their chance of conceiving later in life when their fertility may be compromised due to age-related fertility decline" (Johnston et al 2022 p33) (appendix 1B).

EF is expensive, and the funding varies around the world, from public funding to self-financing. In terms of attitudes towards funding, a Canadian survey of 500 childless women (Daniluk and Koert 2016), for example, found greater support for public funding of medical than non-medical EF (80% vs 46% respectively) (Johnston et al 2022). While in Hong Kong, in a survey of seventy-one women (Hong et al 2019), the support was 93% and 79% respectively. Specifically, on non-medical EF, half of 900 female students in Italy favoured self-funding, and one-third public funding (Tozzo et al 2019). A minority (2.5%) in this study suggested that employers cover the cost for their female staff (Johnston et al 2022).

Johnston et al (2022) used Daniluk and Koert's (2016) questionnaire with 656 women in Australia recruited via social media. The majority favoured public funding (full or partial) for medical EF compared to less than half for non-medical EF (table 1.1). The support for wholly public funding was much less - 46% for medical EF and 6% for non-medical EF. Full public funding for

FUNDING METHOD	MEDICAL EF	NON-MEDICAL EF
Wholly public funded	46	6
Wholly self-funded	2	31
Self & public combined	11	21
Private health insurance	8	23
Public & private health insurance combined	31	15

Table 1.1 - Percentages supporting funding of medical and non-medical EF.

medical EF was supported by partnered than single participants, and those with children (versus childless). Self-funding of non-medical EF was more likely to be supported by older participants (above 40 years old), and married women.

In terms of issues related to EF, there is a debate as to "whether EF enhances reproductive freedom or constitutes undue pressure and promotes pro-natalist views" (Johnston et al 2022 p33). Another issue is what to do with unused eggs, including donating them to others. The rate of use of eggs varies between 3-12% of women (Johnston et al 2022).

Is EF cost effective, and how to assess that? Quality-adjusted life years (QALY), which is used generally with medical treatments, may not be appropriate, as with ART as a whole. "First, the question arises as to which life or lives to assess in calculating the QALY gained following ART - the individual, the couple, the child, the family or the extended family. Second, it is difficult to measure the value of ART and fertility treatment as the benefits are multi-faceted and the outcomes are varied. Although there are concerns about the use of QALY to assess cost-effectiveness, robust alternatives have not been identified" (Johnston et al 2022 p37). The benefit of EF is vague in this sense, as some women enjoy "the feeling of reassurance provided by taking up the opportunity to safeguard or increase the chance of having a baby in the future..., and many do not regret undergoing EF even if it proves to be unsuccessful" (Johnston et al 2022 p37).

1.5. REPRODUCTIVE TRAVEL

"Reproductive travel" or "cross-border reproductive care" (CBRC) (or "reprotravel"; Inhorn 2015) is "the movement of people - including patients, staff and reproductive assistors (ie: gamete donors and surrogates) - and biological materials between countries to enable treatment with assisted reproductive technology (ART)" (Moll et al 2022 p272). ART services are not evenly geographically distributed, and so individuals from the countries lacking services will be attracted to the "reprohubs" (Inhorn 2015).

Concentrating on sub-Saharan Africa (SSA), Moll et al (2022) noted that fifteen countries have registered fertility clinics, with the most in South Africa, Nigeria and Ghana. Research on reproductive travel to, from and

within SSA is limited (compared to Europe and North America). Moll et al (2022) found thirty-three relevant articles on the subject.

The findings were summarised under the following headings:

i) Intended parents' decisions to travel - Lack of services, or lack of trust in services in own country was the main reason within SSA, while incomers from outside often sought to circumvent restrictions at home. Desires for privacy and related concerns were also important as with, for example, "the experiences of West African women seeking reproductive assistance in France, emphasised the shame and stigma associated with infertility for individuals and families" (Moll et al 2022 p281).

ii) Sources of information - The internet and online advertisements were most common, followed by "mouth-to-mouth referrals" (Inhorn 2015).

iii) Patterns of travel - South Africa is a major destination both for African and global "reprotravellers".

"As documented for medical travel more broadly..., the choice of destination for CBRC often follows historical patterns featuring a former colonial power, reflecting opportunities afforded through trade, language, visa access and diasporic networks" (Moll et al 2022 p282). Having local contacts helped if a long study was required in the country.

Practically, the ease of obtaining visas played a role.

iv) "Reproductive assistors" movements - "There has been an increase in patterns of 'hybrid' (Whittaker 2018) reproductive care in which treatments occur across several jurisdictions to circumvent either legal restrictions on treatment options or because of a shortage of ova. Thus, several regions, nationalities and reproductive assistors, such as egg and sperm donors and surrogates, are involved. Reproductive assistors, particularly ova donors from South Africa, have been traced travelling to India... and Cambodia" (Moll et al 2022 p283).

"Fly-in, fly-out" staff (Whittaker 2018) who travel from Europe, say, for a short time to a clinic in a SSA country.

v) "Stratified reproduction" (Colen 1995) - As is Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer the case generally, only individuals from certain social classes/income groups can afford the services, and to travel to the services. Meanwhile, poorer individuals were "bioavailable" (Cohen 2005) to provide ova and sperm, and gestational services.

vi) "Situational support networks" (Faria 2018) -This refers to "how infertile people find support with fellow repro-travellers in their search for reliable information about clinics and procedures, but also emotional and instrumental support, and... shared accommodation" (Moll et al 2022 pp284-285). This contact may develop in waiting rooms. There are also patient blogs and web forums.

vii) A racial element - eg: "In South Africa, white women are disproportionately represented in the ova donor group (40-57%), even though they only represent 8% of the population... This reflects the market demand for white phenotypes, both in the population in South Africa seeking infertility treatment and in the 'export' ova market" (Moll et al 2022 p285).

Moll et al (2022) felt that their scoping review had shown the growing market for ART in SSA (and its study), and had confirmed "the relevance of existing concepts" as well as revealing "new conceptual tools and new social settings in which to explore the circulation of global technologies of IVF and offers productive avenues for comparative research" (p286).

1.6. APPENDIX 1A - METABOLIC FACTORS AND FERTILITY

ART is a "successful means of overcoming infertility", but, on the other side, there are the causes of female infertility, specifically "metabolic risk factors", "especially within the context of widespread obesity and the opposite phenomenon of the female athlete triad (eating disorder, amenorrhoea and osteoporosis)" (Westerman and Kuhnt 2022 p67).

In the West, the leading causes of infertility are ovulation disorders, tubal problems, and chronic endometriosis, but there is also "idiopathic infertility", where the cause is "unknown", and metabolic risk factors may be important here (Westerman and Kuhnt 2022).

Westerman and Kuhnt (2022) found fifty relevant studies for their narrative review of metabolic risk

factors in female infertility.

i) Obesity - Obese women have a higher risk of infertility than non-obese women (eg: three times higher; Wise et al 2010). It has been estimated that the probability of pregnancy is reduced by 5% with every unit of Body Mass Index (BMI) above 29 kg/m² (Westerman and Kuhnt 2022).

Obesity also exacerbates the main causes of infertility (eg: higher total body fat and polycystic ovary syndrome (PCOS)), while ART success is reduced with a BMI above 30 kg/m² (eg: Supramaniam et al 2018) (Westerman and Kuhnt 2022).

ii) "Female athlete triad" - In this situation, it is underweight (and excessive physical exercise) that is the issue, leading to menstrual dysfunction, like amenorrhoea. Also seen in anorexia nervosa, changes in sex hormones occur.

There is less research on underweight and infertility, and ART success (Westerman and Kuhnt 2022).

iii) Inflammation (and oxidative stress) caused by environmental factors (eg: pollution) or lifestyle factors (eg: cigarette smoking) - The "potential mechanisms of action are not clearly understood. Oxidative stress is an imbalance between pro-oxidants and anti-oxidants that induces several reproductive disorders, such as PCOS and endometriosis, and which may contribute to explaining idiopathic infertility" (Westerman and Kuhnt 2022 p70).

In summary, "metabolic risk factors are comorbidities of infertility and could also be seen as markers of infertility" (Westerman and Kuhnt 2022 p71). More research, particularly large-scale studies, is needed, however (Westerman and Kuhnt 2022).

1.7. APPENDIX 1B - EGG FREEZING

Van de Wiel (2020) commented: "Celebrated as empowerment and criticised as exploitation of women, egg freezing is a contested new reproductive technology that has brought the human egg into the public eye with renewed prominence" (p1). EF has been described as the "holy grail of fertility medicine" (Richards 2013 quoted in Van de Wiel 2020).

The first babies (twins) "created from frozen eggs" Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer

(p5) were born in 1986, though children born from previously frozen sperm had occurred in the 1950s (Van de Wiel 2020). The problem was that "the egg - the biggest cell in the human body at 0.1 millimetres - has a relatively large liquid volume, which is sensitive to freezing damage from ice crystal formation" (Van de Wiel 2020 p5). The technique of vitrification has proved most successful. This "entails freezing the eggs so rapidly that the liquid in the cells does not form ice crystals, but transforms into a glass-like state. These vitrified eggs, then, do not so much exist in vitro (in glass), but rather are vitreum (as glass) within the liquid nitrogen tanks. In fact, the vitrified egg is no longer held by the glass referenced in IVF (in vitro fertilisation), but is rather stored on a thin film strip" (Van de Wiel 2020 p6).

Studies of the motivations of women to freeze their eggs can be categorise them as the absence of a (desirable) partner at the current time, concern about the biological clock (in the future), and professional (or social) pressures on time at the moment (Van de Wiel 2020).

Roberts (2017) criticised the elitist aspect of ART. EF is "a further extension of high-tech reproductive interventions that are geared towards encouraging the reproduction of the most privileged in society. Meanwhile, non-reproductive technologies and policies have been used to discourage less affluent and less privileged women from having children" (Van de Wiel 2020 p10). This has been called "selective pro-natalism" (Smietana et al 2018). However, only 5% of women return to use their eggs, and only one-fifth of them have a baby conceived from the eggs, so "hardly driving up birth rates among the privileged" (Van de Wiel 2020 p11).

Van de Wiel (2020) noted that "if female fertility is understood as the ability to conceive with a chosen partner or donor, the presence of frozen eggs after the onset of age-related infertility gives rise to a state that can be characterised as neither fully fertile nor fully infertile, but rather as what we may call 'postfertile'. Likewise, when frozen eggs symbolise a timeless and 'extended' fertility alongside the body's finite and ageing fertility, the relation between fertility and infertility becomes further complicated. Post-fertility, then, denotes the ambiguously in/fertile states that emerge when the possibility of egg freezing reconfigures

the temporal logic of reproductive ageing" (p16). The post-fertile condition did not begin with EF, rather with the contraceptive pill, and then IVF, but EF does allow "the relation between fertility and ageing to become modifiable, contingent, and mediated in novel ways" (Van de Wiel 2020 p17).

EF "emerges at a time when growing biomedical and 'cosmeceutical' industries cater to a general 'will to youth' - Michelle Smirnova's [2012] term for 'a civic duty of the ageing female to pursue eternal youth' - that shapes many aspects of social life, including the lived experience and popular understanding of the body" (Van de Wiel 2020 p18). Van de Wiel (2020) continued: "Gender is a key organising factor in contemporary biopolitics of ageing, which, Brett Neilson [2003] argues, pertains to both the disciplinary effects of knowledge production about ageing and the control exerted through the nationstate and the market logic of global capitalism, in which ageing is increasingly understood as an individual risk rather than a collective responsibility. This intersection of gender and age is at the heart of the particular reproductive politics emerging with egg freezing" (pp18-19).

In her book "Freezing Fertility", Van de Wiel (2020) highlighted a number of issues around and riased by EF, including:

a) Media coverage of EF.

b) The "new cultural and clinical practices of anticipating bodily futurity" (Van de Wiel 2020 p24) (ie: making decisions to freeze eggs to maintain motherhood in the future).

c) The capital investment in the cryro-preservation industry.

d) "Older motherhood" (ie: women having children at later ages than traditionally, even post-menopausal).

e) International trade in eggs - "Once frozen, the eggs become as portable as the liquid nitrogen tanks that hold them; egg freezing is thus a key condition for the development of global flows of eggs" (Van de Wiel 2020 p26).

1.8. REFERENCES

Beaujouan, E (2022) Late fertility intentions increase over time in Austria, but chances to have a child at later ages remain low Reproductive BioMedicine and Society Online 14, 125-139

Bodin, M et al (2021) Pre-conditions to parenthood: Changes over time and generations <u>Reproductive BioMedicine and Society Online</u> 13, 14-23

Butler, J (1988) Performative acts and gender constitution: An essay in phenomenology and feminist theory <u>Theatre Journal</u> 40, 4, 519-531

Cohen, L (2005) Operability, bioavailability, and exception. In Ong, A & Collier, S.J (eds) <u>Global Assemblages: Technology, Politics</u> <u>and Ethics as Anthropological Problems</u> Williston, VT: Blackwell Publishers

Colen, S (1995) "Like a mother to them": Stratified reproduction and West Indian childcare workers and employers in New York. In Ginsberg, F.D & Rapp, R (eds) <u>Conceiving the New World</u> <u>Order: The Global Politics of Reproduction</u> Berkeley, CA: University of California Press

Daniluk, J.C & Koert, E (2016) Childless women's beliefs and knowledge about oocyte freezing for social and medical reasons <u>Human</u> <u>Reproduction</u> 31, 2313-2320

Faria, I (2018) Therapeutic navigations and social networking: Mozambican women's quests for fertility <u>Medical Anthropology</u> 37, 4, 343-357

Giddens, A (1991) <u>Modernity and Self-Identity: Self and Society</u> <u>in the Late Modern Age</u> Cambridge: Polity Press

Guerra-Reyes, L & Iguiniz-Romano, R.A (2019) Performing purity: Reproductive decision-making and implications for a community under threat of Zika in Iquitos, Peru <u>Culture, Health and Sexuality</u> 21, 3, 309-322

Hong, Y.H et al (2019) A survey on the awareness and knowledge about elective oocyte cryopreservation among unmarried women of reproductive age visiting a private fertility centre <u>Obstetrics and</u> <u>Gynecology Science</u> 62, 6, 438-444

Inhorn, M.C (2015) <u>Cosmopolitan Conceptions: IVF Sojourns in</u> Global Dubai Durham, NC: Duke University Press

Johnston, M et al (2022) Financing future fertility: Women's views on funding egg freezing <u>Reproductive BioMedicine and Society</u> Online 14, 32-41

Koppen, K et al (2021) Who can take advantage of medically assisted reproduction in Germany? <u>Reproductive BioMedicine and</u> <u>Society Online</u> 13, 51-61

Latimer, R.L et al (2018) Non-consensual condom removal, reported by patients at a sexual health clinic in Melbourne, Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer Australia <u>PLoS ONE</u> 13, 12, e0209779 (Freely available at https://journals.plos.org/plosone/article?id=10.1371/journal.pone.020 9779)

McQuillan, J et al (2007) Infertility and life satisfaction among women <u>Journal of Family Issues</u> 28, 955-981

McQuillan, J et al (2022) Is perceived inability to procreate associated with life satisfaction? Evidence from a German panel study <u>Reproductive BioMedicine and Society Online</u> 14, 87-100

Moll, T et al (2022) Reproductive travel to, from and within sub-Saharan Africa: A scoping review <u>Reproductive BioMedicine and</u> Society Online_14, 271-288

Neilson, B (2003) Globalisation and the biopolitics of ageing CR: The New Centennial Review 3, 2, 161-186

Richards, S.E (2013) <u>Motherhood, Rescheduled: The New Frontier</u> of Egg Freezing and the Women Who Tried It New York: Simon & Schuster

Roberts, D (2017) <u>Killing the Black Body: Race, Reproduction</u>, and the Meaning of Liberty (2nd ed) New York: Vintage

Rowlands, S & Holdsworth, R (2022) How to recognise and respond to reproductive coercion BMJ $\,$ 378, e069043 $\,$

Rowlands, S & Walker, R (2019) Reproductive control by others: Means, perpetrators and effects <u>BMJ Sexual and Reproductive Health</u> 45, 1, 61-67

Senderowicz, L (2019) "I was obliged to accept": A qualitative exploration of contraceptive coercion <u>Social Science and Medicine</u> 239, 112531

Sendorowicz, L & Higgins, J (2020) Reproductive autonomy is non-negotiable, even in the time of covid-19 <u>International</u> Perspectives on Sexual and Reproductive Health 46, 147-151

Senderowicz, L & Kolenda, A (2022) "She told me no, that you cannot change": Understanding provider refusal to remove contraceptive implants <u>SSM - Qualitative Research in Health</u> 2, 100154

Silverman, J.G et al (2019) Reproductive coercion in Uttar Pradesh, India: Prevalence and associations with partner violence and reproductive health <u>SSM - Population Health</u> 9, 100484

Smietana, M et al (2018) Introduction: Making and breaking families - reading queer reproductions, stratified reproduction, and reproductive justice together <u>Reproductive BioMedicine and Society</u> <u>Online</u> 7, 112-130

Smirnova, M.H (2012) A will to youth: The woman's anti-ageing elixir <u>Social Science and Medicine</u> 75, 7, 1236-1243

Supramaniam, P.R et al (2018) The correlation between raised body mass index and assisted reproductive treatment outcomes: A Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer systematic review and meta-analysis of the evidence <u>Reproductive</u> Health 15, article 34

Tozzo, P et al (2019) Understanding social oocyte freezing in Italy: A scoping survey on university female students' awareness and attitudes Life Sciences, Society and Policy 15, article no.3

Van de Wiel, L (2020) <u>Freezing Fertility: Oocyte Preservation</u> and the Gender Politics of Ageing New York: New York University Press

Westerman, R & Kuhnt, A-K (2022) Metabolic risk factors and fertility disorders: A narrative review of the female perspective Reproductive BioMedicine and Society Online 14, 66-74

Whittaker, A (2018) <u>International Surrogacy as Disruptive</u> <u>Industry in South-East Asia</u> New Brunswick, NJ: Rutgers University Press

Wischmann, T et al (2001) Psycho-social characteristics of infertile couples: A study by the "Heidelberg Fertility Consultation service" Human Reproduction 16, 1753-1761

Wise, L.A et al (2010) An internet-based prospective study of body size and time-to-pregnancy Human Reproduction 25, 1, 253-264

2. FERTILITY AWARENESS

2.1.	Overview
2.2.	Knowledge about assisted reproductive
	technology
2.3.	Appendix 2A - FertiSTAT
2.4.	Appendix 2B - Fertility awareness survey
	2.4.1. Australia
	2.4.2. Disadvantaged groups
2.5.	References

2.1. OVERVIEW

Fertility awareness tools are designed to help women assess preventable risk factors about pregnancy and infertility, and when to seek medical help. One such tool is "FertiSTAT" (Bunting and Boivin 2010; appendix 2A), which has twenty-two questions covering lifestyle and reproduction, and provides personalised fertility guidance (ie: behaviour that could be changed) (Bayoumi et al 2021).

FertiSTAT was developed in the UK, and is used in high-income countries. Bayoumi et al (2021) investigated its use in low- and middle-income countries with the example of Sudan. An Arabic version was tested with a convenience sample of seventeen women and three men attending a clinic for infertility issues. Overall, it was found that "fertility education was perceived to be necessary and beneficial, and that the FertiSTAT would be acceptable, and its implementation would be feasible only if challenges were addressed in a culturally sensitive manner. These challenges included the difficulty of accepting communication about sensitive topics, issues of self-disclosure, and understanding of being at risk" (Bayoumi et al 2021 p93). Questions related to sexual history were perceived as difficult when traditional norms were strong (eq: forbidding pre-marital sex), as well as disclosing "less favourable aspects of the self" (p94).

Traditional beliefs and risk perception can be seen in the example of "the common belief that unmarried girls should not seek treatment by a gynaecologist, even if they are having menstrual problems. This belief results as a combination of two factors. First, the misconception that gynaecologists treat issues related to sexual health alone (eg: sexually transmitted infections and infertility). Second, the pervasive cultural assumption that unmarried girls are not having pre-marital sex. The Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer combination of these two ideas would suggest that unmarried girls should not see a gynaecologist; even if there is an understanding that menstrual problems can lead to infertility, it would be culturally more acceptable to go to the gynaecologist after marriage" (Bayoumi et al 2021 p94).

2.2. KNOWLEDGE ABOUT ASSISTED REPRODUCTIVE TECHNOLOGY

Fertility awareness can include knowledge about assisted reproductive technology (ART), of which there are many misconceptions. For example, the belief that ART will work until menopause. "Although technological options can help to a degree with age-related fertility issues, they cannot compensate completely for the drop in fertility rate... as the success rate of ART declines among women aged > 40 years" (p76) (eg: rate of live births after ART around 15% for women in their early 40s compared to one-third in the early 30s) (Szalma and Bito 2021).

Szalma and Bito (2021) undertook an online survey of 1370 adults in Hungary using a version of the "Fertility Awareness Survey" (FAS) (Daniluk et al 2012; appendix 2B). This has sixteen knowledge-based questions for women and twenty for men. A combination of eight items was used in this research. The majority of the respondents rated themselves as "very knowledgeable" or "fairly knowledgeable" about the subject before beginning the questionnaire (figure 2.1).



(Data from table 1 p78 Szalma and Bito 2021)

Figure 2.1 - Self-rating of knowledge about ART (%). Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer In terms of general knowledge about ART, around 60% of respondents got at least three of eight questions correct. Specifically, half the respondents were correct about the success rate of ART, but the majority did not know about age limits for access to ART in their country, nor the risk of health problems for children conceived via ART, though around two-thirds were correct in terms of the cost of ART (figure 2.2). The participants had tended to overestimate their ART-related knowledge.



(1) "Most Hungarian fertility clinics will not provide treatment to women over 45 years of age".

(2) "Children conceived through the use of assisted reproductive technology have more long-term health problems than children conceived without the use of fertility treatments".

(3) "The upper age limit for a man to be treated at most Hungarian fertility clinics is 55 years".

(Data from table 2 p80 Szalma and Bito 2021)

Figure 2.2 - Responses to selected true statements about ART (%).

Overall, the general level of knowledge about ART was higher here than in Canada (Daniluk et al 2012; 2013), for example. This "may be due to the different sample compositions: in the present sample, highereducated people were over-represented. As well as childless men and women, the sample included parents, who seemed to have higher levels of knowledge. Furthermore, the present research was conducted in 2020, whereas the Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer Canadian research was conducted 10 years previously; knowledge about ART may have become more pervasive over time due to social media and the increasing prevalence of ART" (Szalma and Bito 2021 p80).

2.3. APPENDIX 2A - FertiSTAT

FertiSTAT was designed after a survey of risk factors for reduced fertility, which Bunting and Boivan (2010) extracted from fifty-eight studies. In total, thirty-one risk factors were identified as relevant, grouped as demographic (eg: older age), reproductive (eg: menstrual cycle irregularities; sexually transmitted diseases), lifestyle (eg: smoking; stress; unprotected sex with multiple partners), and non-reproductive medical (eg: cancer; heart disease). A panel of experts reduced the number based on weight of evidence (removing all nonreproductive medical factors).

The final FertiSTAT (covering 22 indicators of reduced fertility) included age (older than 34 years), menstrual problems, and lifestyle factors. The latter included smoking (>10 cigarettes per day; marijuana more than four times per week), stress (which cannot be coped with), alcohol (>14 units per week) and caffeine (>7 cups per day) consumption, overweight (>13 kilos), and unprotected sex with multiple partners (no numbers specified).

FertiSTAT was tested with over 1000 women (mostly in the UK). The sample included those who were pregnant, and those who had been trying to conceive for more than twelve months (or six months if older than 34 years). A higher FertiSTAT score (ie: more risk factors) was significantly associated with infertility (ie: being a member of the group trying to conceive).

Bunting and Boivin (2010) explained the advantage of FertiSTAT over other online fertility awareness tools: "They do not take into account specific critical thresholds for risks (number of cigarettes smoked), their differing importance/weight in predicting fertility (smoking versus amenorrhea) or the multiplicative relationships that occur (age, years infertile), which together lead to different guidance" (p1729).

2.4. APPENDIX 2B - FERTILITY AWARENESS SURVEY

In the context of the age of first childbearing rising for women, Daniluk et al (2012) asked this Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer question: "Would women for whom motherhood is an important life goal continue to delay childbearing into their late 30s, 40s, and even 50s if they were aware of age-related fertility declines, the costs and limitations of assisted reproductive technologies to compensate for these declines, the negative maternal and child outcomes with advanced maternal and paternal age, and even the possibility of permanent childlessness?" (p420). Thus, the importance of knowledge about fertility issues, and consequently the development of the FAS.

Daniluk et al (2012) noted a number of points from their literature review:

- Poor basic knowledge about fertility and biology of reproduction among women around the world.
- Overestimation of the chances of pregnancy at the time of ovulation.
- Little understanding of the relationship between sexually transmitted diseases and subsequent infertility.
- A lack of knowledge about age-related decline in fertility, and many women "assume that good health and fitness are correlated with prolonged fertility" (Daniluk et al 2012 p421).
- "Women are also not very knowledgeable about the increased maternal and infant developmental health risks associated with advanced maternal age" (Daniluk et al 2012 p421).

Knowledge about ART is also limited (eg: cost, availability, practicalities). It is assumed that ART will overcome the effects of age (eg: over three-quarters of over 700 women attending a fertility clinic; Maheshwari et al 2008). Media coverage of celebrities confirms this belief (eg: Celine Dion giving birth to twins at 43 years old after six rounds of IVF) (Daniluk et al 2012).

This was the context and basis to the development of the FAS, and the sixteen knowledge questions used (table 2.1). In 2010 these items were placed online for over 3300 Canadian childless women to answer. Overall average knowledge was scored as 3.3 out of 5, and there was only a low correlation between self-perceived knowledge level and actual knowledge. Around half of the sample answered

six or more items correctly.

- A woman's weight affects her chances of conceiving (true).
- Egg freezing before the age of 35 can significantly prolong a woman's fertility (true).
- The total cost of one cycle of in vitro fertilisation (IVF) is under \$5000 (false based on costs at time).
- Taking birth control pills for more than five years negatively affects a woman's fertility (false).
- The age of the male partner is an important factor in a woman's chances of becoming pregnant (true).
- For women over 30, overall health and fitness level is a better indicator of fertility than age (false).

(Source: Table 1 p423 Daniluk et al 2012)

Table 2.1 - A selection of items from the FAS.

2.4.1. Australia

In Australia, "Your Fertility" was set up by the government in 2011 to raise awareness about fertility. The programme commissions research, and Hammarberg and de Silva (2022) reported one such survey. Over seven hundred adults (aged 18-45 years) from an online participant panel completed the survey in early 2019 via a combination of online and telephone means. General questions were asked about parenthood aspirations (eg: ideal number of biological children), and experiences, knowledge and beliefs about infertility (table 2.2).

Of those who wanted children or more children in the future, the majority preferred one or two in total (figure 2.3). Women were more likely than men to want a large number of children (ie: three or more).

Overall, 11% of the sample reported infertility (defined as twelve months or longer of trying to conceive unsuccessfully), and this figure increased with age. Confidence about fertility knowledge was 6 to 9 out of 10 on average depending on the item. For example, greater confidence about avoiding unwanted pregnancy than how weight affects fertility. Around one-third of respondents were correct that female fertility starts to decline in the early 30s, while about half said older (including 18% after 40 years old) (figure 2.4). This is better than an



(Data from table 1 p267 Hammarberg and de Silva 2022)





(Correct answer is 30-34 years old; Hammarberg and de Silva 2022) (Data from table 3 p268 Hammarberg and de Silva 2022)

Figure 2.4 - Beliefs about age at which female fertility starts to decline (%).

Australian survey approximately ten years previously, when 42% believed that female fertility started to decline in the 40s (Hammarberg et al 2013).

Hammarberg and de Silva (2022) summed up: "This Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer

snapshot of people in Australia shows that most women and men want to have children or more children in the future, but lack confidence in their understanding of the factors that affect fertility and underestimate the effects of age on the ability to achieve pregnancy" (p268).

STRENGTHS	WEAKNESSES		
1. Sample representative of	1. Self-selection bias (ie: volunteers who interested in topic).		
general population of reproductive age in	2. Brief survey, which did not allow for "in-		
Australia.	depth understanding of how respondents'		
	circumstances might influence their		
2. Large of sample of	parenthood aspirations and knowledge about		
both males and	fertility" (Hammarberg and de Silva 2022		
females.	p268).		

Table 2.2 - Key strengths and weaknesses of Hammarberg and de Silva (2022) study.

2.4.2. Disadvantaged Groups

Global geographical variation in fertility awareness has been found (eg: Bunting et al 2013), though there are few studies in the Global South, and with minority groups in highly-developed countries (Milewski and Haug 2022).

In the latter case, Milewski and Haug (2022) undertook a study of women with a "migrant background" in Germany. The total sample was 962, which included 182 non-migrant Germans. The sample was recruited from telephone directories based on family names ("the onomastic method"). The key question was: "At what age do you think female fertility starts to gradually decline?", with a choice of age categories offered. A "correct" answer was defined as "from age 25 onwards" and "from age 30 onwards".

Overall, 43% of the non-migrant women chose the correct answer, while this figure was lower for migrant women (20%), with variations based on country of origin (table 2.3). "The gap in knowledge levels mainly occurred in first-generation migrants, and only carried over partially to second-generation migrants" (Milewski and Haug 2022 p234).

Total sample	
Non-migrant Germans	
All migrants	20
Turkey (Post-Soviet) Commonwealth of Independent States (CIS) Poland Balkan countries	14 19 20 29

(Data from figure 1 p232 Milewski and Haug 2022)

Table 2.3 - Percentage of the sample choosing the correct answer based on background.

2.6. REFERENCES

Bayoumi, R.R et al (2021) Determining the need for fertility care and the acceptability and feasibility of administering a fertility awareness tool from the user's perspective in a sample of Sudanese infertility patients <u>Reproductive BioMedicine and Society</u> <u>Online</u> 13, 85-97

Bunting, L & Boivin, J (2010) Development and preliminary validation of the fertility status awareness tool: FertiSTAT <u>Human</u> <u>Reproduction</u> 25, 1722-1733

Bunting, L et al (2013) Fertility knowledge and beliefs about fertility treatment: Findings from the International Fertility Decision-Making Study <u>Human Reproduction</u> 28, 385-397

Daniluk, J.C et al (2012) Childless women's knowledge of fertility and assisted human reproduction: Identifying the gaps Fertility and Sterility 97, 2, 420-426

Daniluk, J.C et al (2013) The other side of the fertility coin: A comparison of childless men's and women's knowledge of fertility and assisted reproductive technology <u>Fertility and Sterility</u> 99, 3, 839-846

Hammarberg, K & de Silva, R (2022) Parenthood aspirations and understanding of factors that affect the chance of achieving them: A population survey <u>Reproductive BioMedicine and Society Online</u> 14, 265-270

Hammarberg, K et al (2013) Knowledge about factors that influence fertility among Australians of reproductive age: A population-based survey Fertility and Sterility 99, 502-507

Maheshwari, A et al (2008) Women's awareness and perceptions of delay in childbearing <u>Fertility and Sterility</u> 90, 1036-1042

Milewski, N & Haug, S (2022) At risk of reproductive disadvantage? Exploring fertility awareness among migrant women in Germany <u>Reproductive BioMedicine and Society Online</u> 14, 226-238

Szalma, I & Bito, T (2021) Knowledge and attitudes about assisted reproductive technology: Findings from a Hungarian online survey <u>Reproductive BioMedicine and Society Online</u> 13, 75-84

3. FERTILITY CLINICS

- 3.1. Advertising
- 3.2. Shortages
- 3.3. Transition to specialist
- 3.4. Covid-19
- 3.5. References

3.1. ADVERTISING

Many fertility clinics offer in-vitro fertilisation (IVF) "add-ons". These are laboratory, clinical and complementary treatments beyond "the 'normal' IVF cycle" (Stein and Harper 2021 p25).

In the UK, the Human Fertilisation and Embryology Authority (HEFA) in 2020 introduced a "traffic light" system of advice using evidence-based medicine (EBM). "The system grants a green rating to add-ons when more than one good-quality randomised controlled trial suggests that the procedure is both beneficial and safe. An amber rating is given to add-ons where more research is needed or there is contradictory evidence, and a red rating is allocated to those add-ons with no evidence of efficacy or safety" (Stein and Harper 2021 p25). No addon received a "green light", and half of the common addons had a "red light" (eg: assisted hatching; preimplantation genetic testing for aneuploidies (PGT-A)) (Stein and Harper 2021).

Complementary therapy add-ons, however, are not included in the HEFA rating system. Based on patients reports, acupuncture, massage, and meditation were common such add-ons (Stein and Harper 2021).

Stein and Harper (2021) inspected sixty-six websites of UK fertility clinics in December 2019 for their marketing of complementary therapy add-ons. Most websites (around three-quarters) did not advertise such add-ons, leaving seventeen websites for the analysis. Most of these websites referred patients to affiliated practitioner websites. Less than half the clinics provided the services themselves, and the main complementary therapies were (in order of frequency):

i) Acupuncture - Packages of treatment ranged from £200 to £600. In terms of benefits claimed, relaxation and destressing were mentioned most often. Physiological claims were also made: "Clinic 26, for example, stated that acupuncture 'can help decrease the effects of... fertility issues such as endometriosis, ovulation issues, Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer menstrual cycle irregularities and recurrent miscarriages'. Other physiological claims suggested that acupuncture could 'improve ovarian function to produce higher quality eggs' (Clinic 1) and 'increase blood flow to reproductive organs, balance hormone levels [and] regulate the menstrual cycle' (Clinic 36)" (Stein and Harper 2021 p29). The affiliate practitioner website of one clinic stated that "[r]esearch shows acupuncture improves implantation rates by as much as 60%" (p29).

Stein and Harper (2021) stated: "In our view, acupuncture should be rated amber by HEFA, based on the inconsistency of evidence found in meta-analyses" (p34).

ii) Reflexology - A median cost of £450 for a treatment package. In terms of benefits, for instance, "[C]laims regarding the effects of reflexology on IVF treatment success were vaguer than in the case of acupuncture. No clinic websites said that reflexology was effective with respect to infertility, and even the affiliated practitioner claims were ambiguous. Affiliated Reflexology Providers 1, 6 and 8 simply stated that reflexology was 'non-intrusive yet extremely effective', 'shown to be an effective treatment' and 'personal, holistic and effective', respectively" (Stein and Harper 2021 p32).

Stein and Harper (2021) commented: "For reflexology, there are no meta-analyses to compare website claims. Due to the lack of studies, it should be rated red by HFEA" (p34).

iii) Nutritionist services - A median cost of £240 per package.

iv) Other (eq: hypnotherapy; meditation; Reiki).

Stein and Harper (2021) ended: "The evidence presented suggests that misleading advertising and high costs risk compromising patient welfare and consumer rights. Should HFEA be more stringent in its regulation of these complementary therapies, clinics must accept that any treatments they wish to offer, or be affiliated with, should adhere to EBM principles" (p35).

3.2. SHORTAGES

The shortage of eggs and sperm in fertility clinics have resulted in waiting lists, and the idea of paying donors. "Payment for donors may cover a range of

transactions involving money, including payment as 'recompense' [defined as payment in recognition of losses experienced, including material losses related to donation (reimbursement), as well as non-financial losses, such as inconvenience, time or discomfort (compensation)] and payment as 'reward' [defined as material advantage that goes beyond recompense]" (Goedeke et al 2022 p9).

Some countries do have a free market system (eg: USA). Opponents of this system raise concerns like "financial coercion and exploitation of donors, particularly those from disadvantaged backgrounds...; the recruitment of donors who may misrepresent background psychosocial and physical histories relevant to treatment in order to be accepted into donor programmes, or who may lack interest in the outcome of their donation (ie: the donor-conceived person)...; and commodification of, and devaluation of, human life contrary to religious and cultural mores" (Goedeke et al 2022 p9).

In Australia and New Zealand, reimbursement of costs is allowed. Goedeke et al (2022) surveyed 434 adults in these countries recruited via fertility centres about the payment of donors. The greatest concern was raised over two issues - that payment may attract donations for the "wrong" reasons, and that the cost fertility treatment may go up as a consequence.

Concerning the "wrong" reasons, comments included "ego-driven" individuals, "junkies... funding a drug habit", or "scammers" giving "misleading information to be able to get the money" (p12). "It was further postulated that paid donors might use donation as a means to earn money and thus 'donate multiple times' (female professional) and 'travel between multiple clinics and create numerous offspring who would then be unknown to each other' (donor-conceived person), even potentially '(using) false information and go to different providers' (female sperm recipient). They were thus portrayed as materialistic and potentially deceitful" (Goedeke et al 2022 p12).

The sample was self-selecting, and included professionals working in the ART industry, and was mostly female, with personal experience of infertility and use of ART. A small number of donors (n = 43) and over one hundred were recipients of donations.

3.3. TRANSITION TO SPECIALIST

In the USA, for example, 8% of childbearing-age Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer
women are diagnosed as infertile, and around half of them seek fertility treatment (Leyser-Whalen et al 2022).

The process of seeking fertility treatment involves a transition from treatment by obstetrician (OB) or gynaecologist (GYN) to reproductive endocrinologist (ie: from generalist to specialist). What is that transition like for patients? Leyser-Whalen et al (2022) interviewed twenty women and eight men in the USA who had experienced that change.

"Women were often the initiators of seeking medical help, many associating fertility with women's bodies. Most women initially brought their fertility concerns to their OB/GYNs, some as part of an appointment that was already scheduled for other purposes. Other women made a special appointment because getting an appointment with an OB/GYN was easier and quicker than seeking an infertility specialist. Moreover, they hoped that their OB/GYNs, as pregnancy experts, would be able to resolve the potential problem with less invasive and less costly treatments, thinking (or hoping) that the problems were minor" (Leyser-Whalen et al 2022 p206). This was the first theme from the interviews - "starting the process".

Then came "waiting with the OB/GYN", which included the advice of these professionals to delay fertility treatment (for a year, say). The next theme, "a focus on women", described the assumption that the problem related to women's not men's bodies. "Ellen" said": "I go to a support group... The problem... lies with the husband somehow, and they still put those women on fertility drugs, which just blows my mind... they are putting a healthy woman on all those drugs. That... is... disappointing. That it's always the woman's problem even if it's not the woman's problem" (p208).

The lack of urgency by OB/GYNs produced, the next theme, "feeling dismissed". "Mai" described her experience: "Nobody was listening... I was tired of not being listened to. I stomped my foot and shook my fist at my gynaecologist... told the doctor to start listening to me" (p208). "Ellen" reported a lack of empathy from her physician: "The woman saw... my... file, that I was going through fertility treatment and she... said all the wrong things,... that she had 3 boys and something to the effect of 'you're lucky; there's a lot of days where I wish I didn't have kids'. And I was thinking, 'I'll take your children if you seriously mean that, but you don't'. And I think she saw that what she said upset me so then she tried to make it better by saying, 'But I do understand that it's such a special thing that two people come together and create something'. And I'm thinking,

'What if we can't do that?'. I started crying, and it was bad" (pp208-209).

"At the fertility clinic" (next theme) was quite different. There was a sense of urgency and action. "Bob" and Christine's" specialist said, "you try twice, then... on to the next step" (p209). While "Peter" stated: "We had extremely professional, competent people who seemed to care about the person, not 'this is a piece of meat'" (p210).

However, some women felt dismissed (eg: not dealing with the side effects of fertility medication). Women's narrative were often ignored, and there was "an overreliance on technology" (Leyser-Whalen et al 2022). "Edward" felt his wife had "dehumanising" treatment: "There wasn't a lot of focus on our individual situation by the medical people, at least that's the impression... I got. It was more the focus on 'this is what we do' and you're going through what they do rather than think about 'this is who you are, let's focus on you'... I'm fine with the medical stuff, but... wish they would focus more on individual patients... try to give the best possible experience rather than focusing on the treatments and how can we best give treatments to... patients" (p210). While "Jalila" described "a time when she felt emotionally and physically assaulted. A reproductive endocrinologist technician was very 'rough' with her vaginal sonogram, and then matter-of-factly told Jalila that the medication she was taking was not working, pulled the sonogram out, turned the lights on, and left the room. Jalila felt like it was 'completely dehumanising with my consent'. She continued, 'I felt like okay I am just one more vagina and I know she sees vaginas all day long. That felt invasive. I think that was my worst day'" (Leyser-Whalen et al 2022 p211).

"The profit motive" (next theme" as seen in the "sales pitch", for example, and "Leslie" felt that "None of that seemed like it was for the health of me" (p211).

The final theme was "feeling left in the dark". "Several respondents expressed dissatisfaction with feeling misinformed, inadequately informed, or even misled by their reproductive endocrinologists" (Leyser-Whalen et al 2022 p211).

Leyser-Whalen et al (2022) summed up: "It cannot be stated definitively that patients were more or less satisfied overall with generalists or specialists, due to the different patterns of patient concerns about each type of physician" (p212). However, common to both OB/GYNs and fertility specialists was little interest in the women's own body knowledge. "Women do not merely want

to be informed. They want to be listened to and treated as experts on their own bodies; this may help to explain why more educated patients and those of higher socioeconomic status are less satisfied with fertility treatment compared with less privileged women... Treating patients as equals presents a dilemma for physicians, in an inherently unequal relationship where the perception is that the responsibility to bring about a successful pregnancy lies almost completely with the physician" (Leyser-Whalen et al 2022 p213).

3.4. COVID-19

The covid-19 pandemic led to delays in fertility treatment with clinic closures. Initial research (eg: Bolvin et al 2020) reported stress, anxiety and depression for those affected (Gurtin et al 2022).

Gurtin et al (2022) provided more detailed data from an anonymous online survey in May-June 2020, completed by 457 female fertility treatment patients in the UK. The forty questions covered concerns about fertility clinic closures and reopening, sources of support, the impact of covid-19, and recommendations.

In response to a question about fertility clinic closures, participants could pick from forty words (half negative and half positive/neutral), and "powerless/helpless" was most popular, followed by "frustrated", and "anxious/nervous".

In relation to clinics reopening, ten issues were offered, and "very concerned" was chosen by most respondents for "The length of waiting lists and/or prioritisation of patients when clinics open again", and "Losing contact with clinic staff or being forgotten from lists".

Older participants (35 years and above) were more concerned about the delays, as were publicly (compared to privately) funded patients, and individuals who had been trying to conceive for a longer period. Those at the early stages of treatment were more concerned about delays than patients at the later stages. All participants were concerned about leaving the house during the pandemic and the risk of covid-19 infection. Table 3.1 gives a selection of qualitative comments.

In summary, the "delays and disruptions to fertility treatments were highly concerning, upsetting and anxietyinducing for patients" (Gurtin et al 2022 p262). But there were differences between patients depending on

- Age "that we missed our chance to become parents" (p260).
- Practicalities "Our embryos are in Spain, so we need to be able to travel there early July and hope that the quarantine will indeed be lifted as planned in Spain from 1 July" (p260).
- General "I am more concerned about my clinic NOT reopening or being forgotten about at the bottom of a long waiting list than I am about fertility treatment during a pandemic" (p261).
- Finance "...With the amount of money this country has lost, [I worry that] IVF funding would be taken away completely, or if this round didn't work, they wouldn't let us have our other two tries" (p261).

Table 3.1 - Four examples of qualitative comments from Gurtin et al (2022).

circumstances (eg: age; funding source). The vast majority of patients wanted to "start treatment ASAP" [as soon as possible] (p262).

3.5. REFERENCES

Bolvin, J et al (2020) Patient experiences of fertility clinic closures during the covid-19 pandemic: Appraisals, coping, emotions Human Reproduction 35, 11, 2556-2566

Goedeke, S et al (2022) Fertility stakeholders' concerns regarding payment for egg and sperm donation in New Zealand and Australia Reproductive BioMedicine and Society Online 14, 8-19

Gurtin, Z.B et al (2022) Fertility treatment delays during covid-19: Profiles, feelings and concerns of impacted patients Reproductive BioMedicine and Society Online 14, 251-264

Leyser-Whalen, O et al (2022) From generalist to specialist: A qualitative study of the perceptions of infertility patients Reproductive BioMedicine and Society Online 14, 204-215

Stein, J & Harper, J.C (2021) Analysis of fertility clinic marketing of complementary therapy add-ons <u>Reproductive BioMedicine</u> and Society Online 13, 24-36

4. ART FAMILIES

- 4.1. New family type
- 4.2. Disclosure
- 4.3. Birth registration
- 4.4. Views of sperm donors
- 4.5. References

4.1. NEW FAMILY TYPE

"In helping people to have the children they desire, assisted reproductive technology (ART) challenges conventional definitions and understandings of what constitutes a family. The nuclear family is still often considered as an entity defined only by biological ties, even though living arrangements with children (families) have become increasingly diverse in recent decades, with unmarried families, adoptive and step-families, and families with same-sex parents becoming more and more common. ART adds to this growing complexity by providing treatments, to single people and gay and lesbian couples as well as to heterosexual couples to whom the conventional definition of infertility applies" (Kuhnt and Passet-Wittig 2022 p289).

This means that biological and social parentage "no longer have to coincide" (Kuhnt and Passet-Wittig 2022 p289). "ART families" are increasing in number (eg: nine million infants born through ART since the first case in 1978), but also they are global as "the use of ART is not limited by national boundaries" (p289) (eg: 2.7 million treatment cycles in 2016 - not all producing children) (Kuhnt and Passet-Wittig 2022).

Nearly half of treatment cycles occur in Europe compared to 2% in Africa (in 2016) (Kuhnt and Passet-Wittig 2022). "Since many countries do not yet have ART registries, the number of treatment cycles performed worldwide is likely to be underestimated" (Kuhnt and Passet-Wittig 2022 p290). The "reproductive economy" is profitable (eg: \$US 12.5 billion in reported profits globally in 2018), and is expected to increase as "there are no signs that the market for ART is about to become saturated. Instead, new markets are opening up. In the Asia-Pacific context, the demand for IVF treatment is expected to increase due to fertility tourism and a growing awareness of ART through initiatives such as ASPIRE (The Asia Pacific Initiative on Reproduction)" (Kuhnt and Passet-Wittig 2022 p290).

All of this makes understanding ART families Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer important, argued Kuhnt and Passet-Wittig (2022). "Family formation through ART can have broader implications for the children and families involved, as well as for societies. For example, concerns have been expressed about the health and cognitive and psychological development of children born after ART. An important question that arises is whether the children conceived with the help of ART may be disadvantaged in terms of health. Recent research has shown that children conceived with the help of ART are more likely to be born pre-term, have a higher risk of peri-natal death, have a lower birth weight, and have a higher need for post-natal intensive care" (Kuhnt and Passet-Wittig 2022 pp291-292).

But, Kuhnt and Passet-Wittig (2022) accepted, "it is not clear whether the health issues observed in ART children are a consequence of the treatment itself, or are related to factors associated with infertility, the age of the mother, or the adverse birth outcomes mentioned above" (p292).

4.2. DISCLOSURE

Telling children if they are donor conceived is an issue itself. Children want to be told, according to surveys (eg: Schrijvers et al 2017), and to be told earlier. In other research (eg: Zadeh et al 2018), it was found that "when told early, donor-conceived individuals' feelings about their conception are mostly indifferent, positive or ambivalent. In contrast, when told later in adolescence or adulthood, telling is more likely to be associated with feeling upset, shocked, angry or confused" (Harper et al 2022 p2).

Parents tend to use one of two strategies - "seedplanting" or "right-time" (Mac Dougall et al 2007). The first strategy tells the children early, while the latter waits until they are "psychological mature" (Harper et al 2022). The decision to tell is influenced by a "myriad of intra-personal, interpersonal, social and family life cycle features" (Indekeu et al 2013 quoted in Harper et al 2022).

In the UK the "Donor Conception Network" (DCN) was established in 1993, and it produces materials for parents to use with their children (eg: "Our Story"). Harper et al (2022) surveyed over one hundred DCN members about their attitudes towards such materials.

The parents gained confidence about telling after use of the books (eg: knowing the right words to use), and most parents felt that their children's understanding

had increased (figure 4.1). The majority of the parents rated the books as 75 or above out of 100.

Harper et al (2022) outlined the key limitations to their research: With surveys of this type [self-selected sample ¹], it is not possible to know how representative the sample is which could bias the results towards a more favourable feedback about the books. There was no comparison conducted between the responses of those with younger children or with older children, or between the different family types, as the numbers were too low. Although reading the book daily was related to a positive assessment of the books, this was not assessed in terms of length of time reading at this frequency" (p7).



(Data from table 4 p6 Harper et al 2022)

Figure 4.1 - Confidence level about telling children about their conception (%).

4.3. BIRTH REGISTRATION

How does surrogacy impact birth registration? This is an issue being discussed in a number of countries in recent years (eg: Ireland, UK, Australia) (O'Callaghan 2021).

Some countries register the legal parents (usually with no reference to the surrogate), while others

¹ Half of the sample were aged 40-49 years, over three-quarters described themselves as "White -English/Welsh/Scottish/Northern Irish/British", and over 80% had at least a university degree. Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer

register the mother who gave birth and treat the intended mother as adopting the child (O'Callaghan 2021).

Also recording on the birth certificate that the individual was donor-conceived and/or surrogacy-born would overcome any failure to disclose by the parents, argued O'Callaghan (2021).

4.4. VIEWS OF SPERM DONORS

Since 2005 in the UK, sperm donors who donate through registered organisations have to agree that their identity will be available to the individuals born from their donation at eighteen years old (Graham 2022).

This removal of donor anonymity (or "identityrelease" donation) would reduce donor numbers, it was feared. For example, in one study, over half of 43 UK sperm donors stated that they would not continue donating when anonymity removed (Frith et al 2007). But after a short decline after 2005, donor numbers in the UK have increased (Graham 2022).

The realities of the removal of donor anonymity will come into force after 2024 as the donor-conceived offspring reach eighteen years old. Graham (2022) explored the views of UK sperm donors.

A survey was placed online in early 2017 for donors at the London Sperm Bank, and 168 men completed it. In response to the questions about removal of donor anonymity, 63% chose the option, "It's a good thing", and 9% "It's a bad thing". The remainder chose "Neutral". Offered the chance to explain their answer, 119 respondents provided information in a free-text box. The most common reason was support for the child's welfare and the ability to identify their biological father, along with the child's "right".

When asked if they expected to be contacted by the donor-conceived offspring, 37% answered "yes", 25% "no", and the remainder were unsure.

A small number of respondents expressed negative views about the removal of donor anonymity. For example, one donor said: "I don't see any merit in it. You are not their 'father' as you have not raised or loved them. I feel that could complicate matters both for the man who may have raised the child as his own (and they're who really count), and the donor" (p195). Some felt the donors should be able to choose to be anonymous, and one man said: "It would seem to make more sense to ask the donor at the time the child is 18, not to make that decision 18 years in advance" (p195).

Questions were asked about the impact of identityrelease donation upon themselves. The majority of respondents had no concern, except a few donors who were worried about their own family (eg: "Destroying a family I may create in the future"; p197), or the "psychological or emotional" impact of meeting the child. "The donors were also apprehensive about what the donor-conceived offspring would 'want' from them. Interestingly, although five donors were worried that the donor-conceived offspring would make financial demands of them, it was the 'emotional needs' that offspring may expect their donor to fulfil that were a more commonly expressed concern" (Graham 2022 pp197-198).

Asked their view on the relationship with the child, one-third chose "A 'genetic' relationship only", followed by "A special relationship", and "Like a friend's child". Fifteen donors ticked "No relationship" (figure 4.2). Table 4.1 includes a selection of the comments here.



(Data from Graham 2022 table 2 p197) Figure 4.2 - View on relationship with child.

- "The child will have their own parents, the DNA aspect is only a tiny part of who your parents truly are. I have a wide extended family, we share genetic material yet we are not close. We are completely different people, with different personalities, interests, etc. Other than a genetic link, any children won't be influenced by me in any way, we may not have anything else in common" (p199).
- "A unique connection, but not necessarily a strong connection. I would treat them as any other human, but I would understand if they saw me as something more, and try to be supportive of that if needed" (p199).
- "A relationship between a donor and donor conceived child, I think it is slightly different from the other options above" (p199).

Table 4.1 - Three comments on the relationship between the donor and the child.

Previous studies in Denmark and the USA had found that "sperm donors were clear to distinguish between 'biological' and 'social' parenthood, although many of the donors defined themselves as 'fathers' in some fashion" (Graham 2022 p194). In one US study (Jadva et al 2011), "A special relationship like a good friend" was most commonly chosen. This was not offered by Graham (2022).

In terms of the appropriate age of eighteen years old to allow the individual to find their donor, three comments represent the support for it:

- For the child "At 18, an individual has the ability to make their own decisions. I feel if they were much younger, they wouldn't be able to necessarily handle the information in the correct manner. I think a person should have had the chance to develop into a mature adult before the confusion of a potential extra parent figure is added into their life. Though I think it's good for the child to know about their conception, wherever possible the knowledge should come at a time when the child is emotionally equipped to deal with it. Ideally when they are an adult" (p196).
- For the parents "It is not my place to interfere in the parenting of the parents, if I knew about the child and where they were I would have an opinion on how they were being raised and want input" (p196).

• For the donor - "I've considered co-parent and donating to a couple, but I don't think I would like any direct knowledge of any children produced by my sperm without having assuming some sort of parenting role. This process allows me to know that a child has been born, but beyond that, I know nothing and they know little about me. I remain a donor and am in no direct way a parental figure" (p196).

Concerning whether children should be told that they are donor-conceived, only four sperm donors said "no". The rest were divided more or less equally between "yes" and "It's up to the parents".

Despite the majority of donors espousing support for identity-release donation, it was not clear what that mean to the men, and that it meant "different things to different donors" (Graham 2022 p200).

Similar to a Danish study (Mohr 2015), donors struggled to make sense of the potential relationship with the donor-conceived individual - "in making sense of these connections, sperm donors negotiate their social significance and in doing so consider new kinds of sociality, making sense of their connections to donorconceived individuals with reference to, but also beyond, kin relatedness" (Graham 2022 p200). Klotz (2016) called such connections "wayward relations" to describe "'complementary relations' that exist alongside and together with existing family and kinship relations. 'Wayward relations' lack social scripts for how they should be made meaningful, and making them meaningful is therefore the task of those who are connected through them... It is clear from the glimpses into the thoughts and feelings of the sperm donors in the current study that they were trying to work out their own script for the connections formed through their donation" (Graham 2022 p200).

4.5. REFERENCES

Frith, L et al (2007) UK gamete donor's reflections on the removal of anonymity: Implications for recruitment <u>Human Reproduction</u> 22, 1675-1680

Graham, S (2022) The opposite of step parent - The genetics without any of the emotion: "Sperm donors'" reflections on identityrelease donation and relatedness <u>Reproductive BioMedicine and Society</u> Online 14, 192-203

Harper, J.C et al (2022) Telling donor-conceived children about Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer

their conception: Evaluation of the use of the Donor Conception Network children's books <u>Reproductive BioMedicine and Society Online</u> 14, 1-7

Indekeu, A et al (2013) Factors contributing to parental decision-making in disclosing donor conception: A systematic review Human Reproduction Update 19, 6, 714-733

Jadva, V et al (2011) Sperm and oocyte donors' experiences of anonymous donation and their subsequent contact with their donor offspring Human Reproduction 26, 3, 638-645

Klotz, M (2016) Wayward relations: Novel searches of the donorconceived for genetic kinship Medical Anthropology 35, 1, 45-57

Kuhnt, A-K & Passet-Wittig, J (2022) Families through assisted reproductive technology: Causes, experiences, and consequences in an international context <u>Reproductive BioMedicine and Society Online</u> 14, 289-296

Mac Dougall, K.M et al (2007) Strategies for disclosure: How parents approach telling their children that they were conceived with donor gametes Fertility and Sterility 87, 3, 524-533

Mohr, S (2015) Living kinship trouble: Danish sperm donors' narratives of relatedness Medical Anthropology 34, 5, 470-484

O'Callaghan, E (2021) Surrogacy reform and its impact on the child's right to birth registration <u>Reproductive BioMedicine and</u> Society Online 13, 46-50

Schrijvers, A et al (2017) Being a donor-child: Wishes for parental support, peer support and counselling <u>Journal of</u> Psychosomatic Obstetrics and Gynecology 40, 1, 29-37

Zadeh, S et al (2018) The perspectives of adolescents conceived using surrogacy, egg or sperm donation <u>Human Reproduction</u> 33, 6, 1099-1106

5. IGNORANCE PRODUCTION

- 5.1. Introduction
- 5.2. Childbirth
- 5.3. Medication side effects
- 5.4. Mitochondrial donation
- 5.5. Endometriosis
- 5.6. Medication abortion
- 5.7. References

5.1. INTRODUCTION

Topcu and Maffi (2022) began: "Biomedical innovations have radically transformed reproductive processes at every level. Although many of them have changed lives for the better, the risks and side effects - in cases such as pregnancy drugs or contraceptive pills, for example - have been insufficiently studied or even ignored, until scandals or controversies made them public" (p216). It is the latter that links to ignorance production.

In an introduction to a symposium on "risk, innovation and ignorance production in the field of reproductive biomedicine", Bell (2022) noted two ideas -"undone science, which emphasises the role of social movements and politics, and ignorance/non-knowledge, which emphasises how modern and reflexive modernity have brought attention to and complicated the production of ignorance. Both agree that ignorance is produced alongside of knowledge and that ignorance is a routine part of knowledge-production" (p121).

She continued: Undone science consists of 'areas of research that are left unfunded, incomplete, or generally ignored but that social movements or civil society organisations [sic] often identify as worthy of more research' (Frickel et al 2010...). That is, it refers to 'the systematic absence of research identified by counter publics when they seek to document potential risks and uncertainties of technologies and industrial processes, and they find that the desired research has not been done or has been significantly underfunded' (Hess 2016...)" (p122).

Bell (2022) added: "Ignorance is tied to places, 'domains of imperceptibility or knowledge gaps... that can be mapped across space' (Frickel and Kinchy 2015...). Feminist scholars and women's health movements, for example, showed gendered ignorance about women's bodies produced in laboratories, hospitals, and clinics" (p122). Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer

Topcu and Maffi (2022) accepted that with "the accumulation of a tremendous amount of new knowledge and know-how, which has paved the way for the rise of advanced knowledge economies" (p217), it seems paradoxical to focus on ignorance. But this assumes that scientific knowledge progresses by a cumulative progress from what we don't know to what we now know. Critical researchers, however, argue that "each new knowledge is the result of a choice to invest in one field rather than another, or the effect of a specific 'epistemic form' modelling the approach to the world... Vast areas of 'undone science'... exist or have long remained unquestioned. The logic behind these phenomena is related to power, values, conformism, lack of social and economic interest..., or the will to avoid 'uncomfortable knowledge' (Rayner 2012)" (Topcu and Maffi 2022 p217).

5.2. CHILDBIRTH

"Since the mid-20th century, childbirth has undergone a profound transformation worldwide, with the shift in focus from the home to the hospital, and the expanding recourse to obstetric technologies and pharmaceutical products in the management of birth risk and pain" (Topcu 2021 p2). This can be called a "technologisation of birth", which is not without problems (eg: "caesarean epidemic"; "epidural epidemic") (Topcu 2021).

In France, for example, epidural analgesia (EA) was introduced in maternity services in 1972, but now over 80% of births involve it (Topcu 2021). This growth has received criticisms "regarding the routinisation of EA as unjustified medicalisation, ... EA has become one of the areas targeted in feminist denunciations of 'obstetric violence'..." (Topcu 2021 p2). The medical profession has defended its use of EA seeing it "as a means to reduce time spent in labour, as a way to prevent foetal distress and as a safe alternative to 'risky' general anaesthesia in the event of an instrumental delivery or caesarean section... The (rare) risks that EA presents to women (eq: paralysis) and its side effects (eq: back pain and headaches) have been filed away under the 'unknown' or 'uncertain' categories by health professionals" (Topcu 2021 p2).

Quagliariello and Topcu's (2021 quoted in Topcu 2021) ethnographic study in a maternity hospital in Paris found that "anaesthetists and midwives (who manage the majority of vaginal births in France) were making

strategic or performative use of uncertainty. When the women reported backache after giving birth under EA at this hospital, the medical staff shrugged off their complaints as irrational beliefs. The anaesthetists claimed that there was no evidence for such a causal link" (Topcu 2021 p2). Topcu (2021) continued, that "by labelling certain events or situations as 'uncertain', they were fostering the very uncertainties they were highlighting while simultaneously shielding themselves from blame, because it is difficult to prove that someone is more certain about something than they are alleging" (p2).

Topcu (2021) surveyed the general, medical, and feminist press about EA in France since 1968. She painted a picture of how EA use grew based on three arguments -"a rejection or discrediting of the 'knowns' (or natural knowledge) as pseudo-science; an unlearning of 'know-how' (ie: 'natural' birth or birth with few interventions) in the name of safety; and an acknowledgement and maintainance of the 'unknowns' concerning the risks and side effects of EA with the promise that they would disappear as the technology improved" (Topcu 2021 p3). This produced a "technology-driven ignorance" - ie: "new knowledges, practices and 'know-how' that are generated by a technical innovation and that concern ways of living with or dealing with a given biological or ecological context. This type of movement is based on a set of mechanisms that consist of ignoring or unlearning previous or alternative ways or regimes of knowing and doing that are (or were) not centred on technology, which are then eliminated or pushed aside as a result. Technology-driven ignorance is, of course, not specific to childbirth or to EA. Indeed, the history of industrialisation provides many examples" (Topcu 2021 p3). It is also a means to silence these alternatives.

Tuana (2004) stated: "What was once common knowledge or even common scientific knowledge can be transferred to the realm of ignorance not because it is refuted and seen as false, but because such knowledge is no longer seen as valuable, important or functional. Obstetricians in the USA, for example, no longer know how to turn a breech, not because such knowledge, in this case a knowing-how, is seen as false, but because medical practices, which are in large part fuelled by business and malpractice concerns, have shifted knowledge practices in cases of breech births to caesareans. (...) Epistemologies of ignorance must focus not only on cases where bodies of knowledge have been completely erased, or where a realm has never been subject to knowledge production,

but also on these in between cases where what was once common knowledge has been actively 'disappeared' among certain groups" (quoted in Topcu 2021).

In another study of childbirth in France, Mirouse (2022) explored how episiotomy (the surgical enlargement of the vaginal opening during childbirth) became routine in the 1980s and 1990s, despite the WHO discouraging the practice. This was part of the medicalisation of childbirth, which considered birth to be "considered to be an unpredictable and risky event. Its safety was believed to depend on the availability of technical resources and the doctors' ability to intervene immediately" (Mirouse 2022 p43). Thus, the "normal" experience of childbirth became epidural, continuous monitoring, oxytocin injection to speed up labour, and (often) episiotomy (Jacques 2007 quoted in Mirouse 2022). Carricaburu (2005 quoted in Mirouse 2022) referred to this as "the increasing, daily and quasi-systematic technicalisation of each birth".

In terms of episiotomy and France, Mirouse (2022) applied the idea of "ignorance production" as in "artificially maintained controversies" (Sarda 2011). The tobacco industry is a classic example in funding "alternative" studies about smoking and lung cancer to create the illusion of controversy (Proctor 1995) "despite reliable scientific knowledge on the matter" (Mirouse 2022 p43).

Mirouse (2022) examined 192 French professional articles in the 1980s and 1990s for obstetricians and gynaecologists (OB/GYN) and midwives. "While the early 1980s saw a flurry of studies at international level questioning the benefits and highlighting the risks of episiotomy, a new dynamic research field was emerging in France on the prevention of urinary incontinence (UI), which promoted the benefits of episiotomy" (Mirouse 2022 p45).

Mirouse (2022) argued that French OB/GYN justified their routine use of episiotomy despite contrary international evidence "by constructing a vision of episiotomy that took into account not only international scientific evidence, even when frankly unfavourable to systematic episiotomy, but also their own definition of women's interests and needs, as well as the organisational and technical aspects of care. By developing a whole set of practices and protocols, and/or by switching techniques to improve (according to the players) the safety of the procedure, the focus shifted from the negative consequences of episiotomy, as

highlighted by the international studies, to the players' ability to manage them" (p50). There was no criticism of international evidence, rather the "constant generation of relevant new clinical data" (Mirouse 2022 p50) was the strategy. This was the process of the "production of ignorance" (ie: the production of "competing knowledge").

5.3. MEDICATION SIDE EFFECTS

Diethylstilbestrol (DES) is synthetic oestrogen created in the 1930s, and used to bring pregnancies to term (ie: to prevent miscarriage). In the USA, its use began in 1941, but was prohibited in 1971 after reports of serious side effects for the offspring (eg: clear cell adenocarcinoma; CCA) (Fillion and Torny 2022).

DES use continued in France, and Fillion and Torny (2022) explored this with document analysis and interviews. The authors noted: "French DES mothers, estimated to be 200,000 in number, did not know they were taking risks by ingesting this drug. Even after 1971, they had little information about the dangers of DES. Their daughters rarely knew about their condition, and were left to depend on a medical profession with little training, especially when it came to reproductive health, for help" (Fillion and Torny 2022 p108). Forty years after the USA banned DES, "robust epidemiological knowledge on French DES mothers and their offspring began to be produced, in order to break the cycle of ongoing ignorance" (Fillion and Torny 2022 p108).

This linked to the first of three elements identified by Fillion and Torny (2022) - namely, "a strong reluctance to import knowledge from the USA on its [DES] dangers and risks" (p101). Secondly, an "indifference" to the impact of side effects of DES on offspring. Finally, "'undone science' (ie: knowledge that could have been produced but was not)" (Fillion and Torny 2022 p106). Put simply, a lack of epidemiological research into DES in France.

Drawing a parallel with Nemec and Olszynko-Gryn's (2022) study of Duogynon in West Germany ², Fillion and Torny (2022) noted that "some processes of production and maintenance of ignorance are shared between the DES history and that of Duogynon: undone science, disqualification of whistleblowers, disqualification of

² "Duogynon" (or "Primodos" in Britain) was a "hormone pregnancy test developed in West Germany in the late 1940s. It was used until the 1980s, and subsequently campaigners (eg: in West Germany the "Interest Group for Duogynon-Damaged Children"; IGDGK) highlighted the side effects on offspring (ie: iatrogenic birth defects) (Nemec and Olszynko-Gryn 2022).

Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer

epidemiological studies that do not fit with gold standards, calls for pre-cautionary behaviours addressed to doctors by public authorities that remains unheard, weak participatory culture until recently etc" (p108).

5.4. MITOCHONDRIAL DONATION

Talking about "mitochondrial replacement techniques" (or mitochondrial donation; MtD), Herbrand (2022) introduced the idea of "ignored knowns" to describe "key issues which were side-lined, omitted or overlooked" (p54), and "acknowledged unknowns" (or "not yet knowns") ("the uncertainties associated with specific, recognised medical risks for future offspring"; p54).

MtD was legalised in the UK in 2015. It involves "replacing the mitochondria of maternal reproductive cells, including the mitochondrial DNA (mtDNA), which might be passed on to subsequent generations. The aim of mitochondrial donation is to prevent the transmission of maternally inherited mitochondrial disorders, which are caused by mutations of mtDNA situated in the cell's cytoplasm. These disorders can trigger various bodily dysfunctions, such as hearing loss, stroke or neurological problems, and potentially lead to severe or fatal diseases, such as dementia or myopathy" (Herbrand 2022 p54). Everyday language has described this process as producing a "three-parent baby".

Herbrand (2022) interviewed 28 women affected by mitochondrial disorders, and twelve stakeholders between 2012 and 2016, as well as analysing public documents related to the debate on legalisation of MtD.

Much of the debate was concentrated around the potential risks to future offspring, including the side effects of two different types of mitochondria, and the psychological effects of "having been conceived using genetic material from three people" (Herbrand 2022 p56). The safety risks were discussed openly, and Herbrand (2022) classed these as the "acknowledged unknowns".

The "ignored knowns" could be seen in that "some key scientific, medical, social and financial information affecting the impact of the technologies was rarely mentioned, including the heterogeneous profiles of the future users, limited access to the techniques, existing reproductive alternatives, and the costs involved" (Herbrand 2022 p57). For example, the beneficiaries of MtD were not discussed at length. "They were usually referred to as 'patients', 'women carrying maternal disorders' or 'women with mitochondrial disorders';

however, these broad descriptions did not provide a sense of the number and characteristics of women who could potentially benefit from the techniques. Only partial information was provided about the medical conditions and family situations of these women. The women featured in the media were usually healthy women with seriously ill children, or women who had lost a child and were desperate to have another one. People affected by mitochondrial disorders were therefore predominantly represented as a homogenous group, sharing a common experience of suffering and loss due to the severe illness of their child. It is important to note, however, that mitochondrial disease is a complex condition, highly variable, and is late-onset for many people. The representation of mitochondrial disease as only affecting seriously ill children does not reflect the experiences of many of those who are currently living with the disease as adults" (Herbrand 2022 p57).

The cost of the treatment would limit access for some women, and this was played down, as well as technical problems with MtD (eq: the type of mitochondrial disorder). Herbrand (2022) noted that during an interview with a Human Fertilisation and Embryology Authority (HEFA) official, "I was told that these genetic differences and their consequences were too complex and thus needed to be simplified in order to push the legislation through. It seems, however, that this oversimplification was not just a matter of facilitating the public's general understanding of the issue. I myself observed how some confusions were also introduced and maintained throughout the parliamentary debates. For instance, some patients whose children were affected by nuclear defects stated during a debate in Parliament that if 'they could, they would use the technology', which they could not as it was not suitable for them from a medical point of view. However, this was understood by the audience as meaning that they would use the technique if they could legally access it, contributing to reinforce a collective misrepresentation" (p58).

Existing alternatives were also pushed aside in the debate (eq: pre-natal diagnosis; PND).

Herbrand (2022) admitted that she could not tell if such issues were "just unfortunate omissions and misunderstandings resulting from a lack of time or effort, or whether they were intentionally generated and maintained in the debates, possibly for strategic reasons" (p60). A number of key actors (eg: scientists; patient groups) favoured legislation, and Dimond and Stephens (2018) argued that these groups "prepared and

organised a campaign in favour of the techniques from 2010, in parallel to the scientific developments" (Herbrand 2022 p60).

5.5. ENDOMETRIOSIS

Hudson (2022) focused her attention on the "missed disease" (Overton and Park 2010) of endometriosis (Endo). It is "described as a chronic gynaecological condition characterised by a diverse and complex range of symptoms including chronic pelvic pain, painful sex, heavy bleeding and infertility" (Hudson 2022 pp20-21). The number of cases has increased in recent years, though "persistent complexities in the classification and identification of the disease mean that the average time to diagnosis is still 7.5 years in the UK... Studies show how women experience delegitimisation of their symptoms before, during and following diagnosis, reporting that they are disbelieved by professionals or that their concerns are 'fobbed off'" (Hudson 2022 p21).

For Hudson (2022), Endo is an example of "undone science", as knowledge has been "inhibited by underinvestment in scientific research, despite the fact that it has been identified as worthy of policy attention and scientific research by women who are affected" (p21). This sits within "the historical and political situatedness of ignorance around women's bodies and health in the context of androcentric biomedicine..." (Hudson 2022 p21) (table 5.1).

- Seear (2014): Is it possible to "even speak about 'endometriosis' practice/medicine/etc, when their appears to be a lack of consensus about the central ontological referent?" (quoted in Hudson 2022).
- Denny (2009): This works "develops the categories of 'diagnostic uncertainty' and 'trajectory uncertainty' in order to demonstrate how biomedical expectations relating to endometriosis are contingent and unstable" (Hudson 2022 p23).
- Whelan (2007): Used "the notion of 'epistemological purgatory' in order to illustrate how women are caught in a liminal space regarding the definition of their experiences and embodied knowledge about endometriosis in relation to 'expert' knowledge" (Hudson 2022 p25).

Table 5.1 - Examples of feminist scholars on endometriosis.

Endo was formally identified in 1921 by Canadian gynaecologist John Sampson, and there were improvements in understanding with new pelvic endoscopic techniques in the 1940s, and laparoscopic biopsies in the 1980s. "However, conclusive evidence about the aetiology of endometriosis is still absent, and a range of theories, including those relating to genetic factors, faulty immune responses, environmental factors and retrograde menstruation ..., exist. There is also a lack of noninvasive diagnostic tests and, despite advances in the development of biomarkers (a naturally occurring molecule, gene or characteristic by which a disease can be identified) in diagnoses of a range of other diseases, no reliable biomarkers currently exist for endometriosis... Therefore, whilst some developments in diagnosis and treatment have been made during the 20th century, progress has been slow and production of nonknowledge - that is, the choice to accept gaps in a field of knowledge... - persists" (Hudson 2022 p22).

Where there are gaps in knowledge and ambiguity, myths have filled in. "The most persistent of these is that it is a 'career woman's' disease, as clinicians reported that women who had children later in life were more prone to the disease... This idea - that women's behaviour made them susceptible to endometriosis persisted into the 1990s and led to the practice of routinely advising women to become pregnant in order to reduce symptoms (because the absence of menstruation reduces symptoms)" (Hudson 2022 p23).

5.6. MEDICATION ABORTION

Maffi (2022) explored the case study of medication abortion in Tunisia in the 21st century: "Upon the introduction of medication abortion in the country, despite clinical studies proving its safety, many Tunisian doctors opposed its use, allegedly because they considered it to be dangerous to women's health. Some practitioners expressed concerns about the possible banalisation of the act and its moral and social consequences, and others opposed the use of pharmacological treatment because it makes women less dependent on experts' knowledge" (p112).

Based on interviews with health professionals and fieldwork in medical facilities in the Great Tunis area in 2013-14, Maffi (2022) showed the "varieties of ignorance" (Abbott 2010) about medication abortion as "linked to the specific political, social and economic

positions of the involved actors, the dominant gender regime, specific institutional policies and economic interests" (p112).

Abortion as a right was not known by many women, particularly those with a low level of education, attending clinics, and one form of ignorance was the presentation of abortion as a "cessation" (Amuchastegui and Flores 2013). One reason was ignorance of the law by the medical staff, while others found ways to refuse (eg: health of the woman). As noted also in other countries, "paternalistic attitudes towards patients who requested abortions were repeatedly justified by the idea that these women were undisciplined and irresponsible... In this case, the law was deliberately ignored in the name of the good of the patient and of the nation, as some providers insisted that all these abortions were a waste of money and time" (Maffi 2022 p116).

Medication abortion was not covered in professionals' medical training, and so different medical professions did not know about the procedures; what called Maffi (2022) called "distributed ignorance". Add to this ignorance about contraception among some health professionals and women.

Another form of ignorance was health providers' lack of knowledge about the motivation of women seeking abortion. Maffi (2022) explained: "Many practitioners I met were convinced that women considered medication abortion to be an easy solution, often preferable to contraception because it is less invasive than surgical abortion. Clinicians often told me that medication abortion had brought about the banalisation of this act that many women do not think they are 'killing a baby' if they just have to take some tablets - and that it has caused a tremendous increase in the abortion rate. All these allegations are unfounded if we consider that the number of abortions has remained stable in the public sector since the introduction of medication abortion, that most women I met did use contraception... and that the procedure they had to go through to get an abortion was troublesome and thus not easily undertaken" (p117).

Finally, some health providers were "openly hostile to abortion for moral or religious reasons" (Maffi 2022 p117). Maffi (2022) placed this under the heading of "ignorance about the plurality of Islamic discursive tradition" (p118).

5.7. REFERENCES

Abbott, A (2010) Varieties of ignorance <u>American Sociologist</u> 41, 174-189

Amuchastegui, A & Flores, E (2013) Women's interpretations of the right to legal abortion in Mexico City: Citizenship experience and clientelism Citizenship Studies 17, 8, 912-927

Bell, S.E (2022) Symposium: Risk, innovation and ignorance production in the field of reproductive biomedicine <u>Reproductive</u> BioMedicine and Society Online 14, 121-124

Denny, E (2009) "I never know from one day to another how I will feel": Pain and uncertainty in women with endometriosis Qualitative Health Research 7, 985-995

Dimond, R & Stephens, N (2018) <u>Legalising Mitochondrial</u> Donation - Enacting Ethical Futures in UK Biomedical Politics Basingstoke: Palgrave Macmillan

Fillion, E & Torny, D (2022) Like mother, like daughter, like granddaughter... Transgenerational ignorance engendered by a defective reproductive health technology <u>Reproductive BioMedicine and</u> <u>Society Online</u> 14, 101-110

Frickel, S & Kinchy, A (2015) Lost in space: Geographies of ignorance in science and technology studies. In Gross, M & McGoey, L (eds) Routledge Handbook of Ignorance Studies New York: Routledge

Frickel, S et al (2010) Undone science: Charting social movements and civil society challenges to research agenda setting <u>Science, Technology and Human Values</u> 35, 4, 444-473

Herbrand, C (2022) Silences, omissions and oversimplification? The UK debate on mitochondrial donation <u>Reproductive BioMedicine and</u> Society Online 14, 53-62

Hess, D.J (2016) <u>Undone Science: Social Movements, Mobilised</u> Publics, and Industrial Transitions Cambridge, MA: MIT Press

Hudson, N (2022) The missed disease? Endometriosis as an example of "undone science" <u>Reproductive BioMedicine and Society</u> Online 14, 20-27

Maffi, I (2022) The production of ignorance about medication abortion in Tunisia: Between state policies, medical opposition, patriarchal logics and Islamic revival <u>Reproductive BioMedicine and</u> <u>Society Online</u> 14, 111-120

Mirouse, L (2022) Ignoring international alerts? The routinisation of episiotomy in France in the 1980s and 1990s Reproductive BioMedicine and Society Online 14, 42-52

Nemec, B & Olszynko-Gryn, J (2022) The Duogynon controversy and ignorance production in post-thalidomide West Germany <u>Reproductive</u> BioMedicine and Society Online 14, 75-86

Overton, C & Park, C (2010) Endometriosis. More on the missed Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer disease BMJ 341, c3727

Proctor, R (1995) <u>Cancer Wars: How Politics Shapes What We Know</u> and Don't Know About Cancer New York: Basic Books

Rayner, S (2012) Uncomfortable knowledge: The social construction of ignorance in science and environmental policy discourse <u>Economy and Society</u> 41, 1, 107-125

Sarda, G (2011) Artificially maintained scientific controversies, the construction of maternal choice and caesarean section rates <u>Social Theory and Health</u> 9, 2, 166-182

Seear, K (2014) <u>The Makings of a Modern Epidermic:</u> Endometriosis, Gender and Politics Farnham: Ashgate Publishing Ltd

Topcu, S (2021) Adopting an "unlearner" technology? Knowledge battles over pharmaceutical pain relief in childbirth in post-1968 France Reproductive BioMedicine and Society Online 13, 1-13

Topcu, S & Maffi, I (2022) Rethinking ignorance production in the field of reproductive biomedicine: An introduction <u>Reproductive</u> <u>BioMedicine and Society Online</u> 14, 216-221

Tuana, N (2004) Coming to understand orgasm and the epistemology of ignorance Hypatia 19, 1, 193-232 $\,$

Whelan, E (2007) "No one agrees except for those of us who have it": Endometriosis patients as an epistemological community <u>Sociology</u> of Health and Illness 29, 957-982

6. GENETIC COUNSELLING

Cystic fibrosis (CF) is an autosomal-recessive genetic disorder, which means that there is a risk for offspring. For example, two carriers of the gene (ie: one copy of the two alleles) (but not sufferers of CF themselves) have a one in four chance of a child with CF, while a sufferer (ie: two copies of the allele) and a carrier have a one in two risk for their offspring.

Part of the condition means that individuals with CF are infertile, but assisted reproductive technology (ART) is a way to overcome this limitation (appendix 6A). Kushary et al (2021) investigated genetic counselling for adults with CF possibly considering ART.

Thirty-five participants in the USA completed a survey before and after counselling (including a third time 1-3 months later), which involved twenty-one questions on inheritance of CF, and basic knowledge about ART. Based on the responses, participants were divided into four "family-building preference" groups - (i) wanted children in the future (n = 24), (ii) no intention of having children (n = 8), (iii) already had children and wanted more children in the future (n = 3), and (iv) already had children and did not want more in the future (n = 0). Participants received thirty minutes of genetic counselling appropriate to their group.

At baseline (ie: pre-counselling), most participants answered the questions about recessive inheritance risk correctly, but about half answered the questions about ART incorrectly. Correct answers increased in the postcounselling surveys (figure 6.1).

This study showed that genetic counselling could help increase knowledge about inheritance risks, and ART, in particular. But the study "did not find a significant difference in family-building preferences after genetic counselling, an increase in knowledge does not necessarily change an individual's perceptions and utilisation of different fertility options. There are likely other factors that play a greater role in these preferences. Cultural factors have been shown to play a major role in a couple's decision to pursue different fertility options given the relative importance of having a child in certain cultural groups" (Kushary et al 2021 pp43-44).

Around two-thirds of the sample stated that they had not discussed fertility options or received genetic counselling prior to the study. This was higher than a previous study (Fair et al 2000), where a quarter of women and nearly half of men with CF had not discussed Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer



Figure 6.1 - Mean percentage of correct answers on factual questions about inheritance, and ART.

fertility issues with a healthcare provider.

The sample was recruited by the "Emory + Childrens' Adult Cystic Fibrosis Center", and their genetic knowledge may have been higher than the average population (Kushary et al 2021).

APPENDIX 6A - GENE REPLACEMENT THERAPY

"Children with some rare genetic conditions who would once have died at just a few years old could now have typical life expectancies due to gene-replacement therapy" (Klein 2022a p20). One example is "leukocyte adhesion deficiency type-1" (LAD-1), a rare condition where would healing is inhibited, leading to early death without a stem cell transplant. Gene therapy that replaces a mutated version of the ITGB2 gene is a possibility (Klein 2022a).

Since 2019 nine children with LAD-1 have had this therapy and are currently prospering (as reported by Donald Kohn at the American Society of Gene and Cell Therapy 2022 annual meeting in Klein 2022a). Other small trials have also been reported with success at the same conference (eg: with X-linked severe combined

immunodeficiency; X-SCID 3) (Klein 2022a).

"In the early 2000s, gene therapies fell out of favour after some people receiving them developed leukaemia, but this was related to the particular mouse virus used to deliver the genes into cells" (Ewelina Mamcarz in Klein 2022a). But the therapies today use different methods.

"Primary Immune Deficiencies" (PIDs) is a general term describing many of these rare conditions. Stem cell transplant has been one treatment, but complications due to immunological differences between the donor and the recipient is an issue (Kohn and Kohn 2021). So, gene therapy is an attractive alternative.

Gene therapy for "absence of adenosine deaminase" (ADA) enzyme in SCID (ADA-SCID) was first shown to work in five patients in Italy in the early 2000s, while Kohn and Kohn (2021) noted fifty successful cases in Italy, the UK and the USA. But complications of ADA-SCID (eg: neurological deficits) "may not be corrected" (p3) except with stem cells (Kohn and Kohn 2021). There is also Artemis-deficient SCID, which Kohn and Kohn (2021) reported had been tried initially with three infants recently.

Kohn and Kohn (2021) described two other PIDs where gene therapy has been tried:

a) Wiskott-Aldrich Syndrome - First tried in Germany in 2006 with ten patients.

b) X-linked chronic granulomatous disease.

General issues with gene therapy include (Kohn and Kohn 2021):

i) The translation of experimental work in the laboratory to actual human therapy.

ii) Which gene to change when there is a choice?

iii) The vector to carry the replacement gene to the cell (eg: lentiviral vector).

iv) The technology to produce large numbers of vectors (eg: cells cultured in bioreactors), and this reduce the cost.

v) Improvements to post-therapy for patients.

³ There are twenty genes that when defective may cause a form of SCID (Kohn and Kohn 2021). Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer

vi) Regulation of gene therapy including the training of personnel, specialised licensed centres, and quality assurance.

A very rare condition is AADC deficiency (caused by a faulty variant of the DDC gene, with only 150 cases worldwide) (Klein 2022b). The upshot is the child being bed-ridden and dying at a young age. A gene therapy called "Upstaza" replaces the faulty DDC gene delivered to brain cells via a virus.

A clinical trial with thirty children in Taiwan since 2010 has found "dramatic improvements" (Wuh-Liang Hwu reported at the 2022 Society for the Study of Inborn Errors of Metabolism annual meeting, Freiburg, Germany in Klein 2022b). One father of a sufferer described his daughter going from "being unable to say any words, move or even lift her head to 'running, jumping, kicking a ball, riding a horse, swimming and speaking in multiple languages'" (Klein 2022b p9).

REFERENCES

Fair, A et al (2000) Attitudes to fertility issues among adults with cystic fibrosis in Scotland. The Collaborative Group of Scottish Adult CF Centres <u>Thorax</u> 55, 8, 672-677

Klein, A (2022a) Gene therapy on the rise $\underline{\text{New Scientist}}$ 4th June, p20

Klein, A (2022b) Gene therapy infused into the brain eases debilitating rare condition $\underline{New\ Scientist}$ 1st October, p9

Kohn, L.A & Kohn, D.B (2021) Gene therapies for primary immune deficiencies Frontiers in Immunology 12, 648951

Kushary, S et al (2021) Assessment of a novel genetic counselling intervention to inform assisted reproductive technology treatments and other family-building options in adults with cystic fibrosis Reproductive BioMedicine and Society Online 13, 37-45

7. BIOLOGICAL CLOCK

Majumdar (2022a) noted how the "increasingly prominent role of new reproductive technologies in assisting and extending all aspects of the reproductive cycle have both heightened the importance, and intensified the contradictions, of the 'biological clock' analogy" (p300). The "biological clock" is the idea that there is a limited period of fertility, particularly for women, but new reproductive technology can "counter depleting (feminine) nature, and its rhythmic cycles..., while at the same time referencing the fallacy of being able to control nature, despite the promise of 'assisting' reproduction" (Mujamdar 2022a p300).

Majumdar (2022a) introduced four papers on the topic around two themes - "time is money" and "ageing = decline?".

"Time is Money"

1. Van de Wiel (2022)

van de Wiel (2022) began: "In the last decade, the in-vitro fertilisation (IVF) sector has witnessed a shift from so-called 'reactive IVF' to a new model of proactive fertility care in assisted reproduction. Whereas IVF was traditionally developed to treat people who found they were unable to conceive, the indication for IVF has broadened significantly to include a much wider group of potential patients through a new focus on proactive treatment. This shift combines a number of new trends pertaining to preservation, prediction and private equity, all of which have gained increasing influence in contemporary assisted reproduction" (p240).

This researcher was interested in the "financialisation" of proactive fertility care, including egg freezing, and in particular, in the USA with companyor employer-sponsored health insurance. For example, in 2014, "Apple" and "Facebook" offered to pay employees' fertility preservation costs. "Since then, a number of specialised fertility benefits companies have been founded and have grown rapidly to cover millions of people working for well-known US employers such as JP Morgan, Netflix, Microsoft, Google and Uber" (van de Wiel 2022 p241).

Employers have presented their offering "fertility benefits" as female empowerment. "Critics have questioned this empowerment narrative and raised concerns about the Psychology Miscellany No. 185; Mid-June 2023; ISSN: 1754-2200; Kevin Brewer companies' other motives, including encouraging women to delay childbearing and offering the benefit as a distraction from more structural reforms... Scholars have highlighted that egg freezing benefits could result in female workers feeling 'subtle or significant pressure' to do so 'as a way to show their commitment to the company and their career' (Zoll et al 2015). "Some have argued that these benefits 'naturally plac[e] pressure on women to alter their bodies chemically and surgically in order to fit into the workplace ideal', which harkens back to the 'old-fashioned concept of man as breadwinner' (McGinley 2016...)" (van de Wiel 2022 p242).

More than that, fertility benefits "indicate a new, intensified involvement of the employer in women's reproductive decision-making, which normalises and institutionalises the option of egg freezing through the employers' coverage of the procedure... A further concern is that women are not adequately informed about the medical risks and limited success rates of egg freezing. It may, then, not only result in reproductive delay, but also in future involuntary infertility" (van de Wiel 2022 p242). Critics like Cattapan et al (2014) argued for structural changes, which include paid parental leave, affordable child care, better health insurance, and adequate wages (van de Wiel 2022).

Companies offering fertility benefits are able to present themselves as "family-friendly" or "femalefriendly" (van de Wiel 2022). In a study of women who are potential recipients of fertility benefits, Zeno (2020) found that "the women who receive the fertility benefits appreciate the coverage and understand it as a sign of their employer's generosity. However, notwithstanding the availability of having 'family-friendly' insurance coverage, the demand for such benefits particularly emerges when they are embedded in a workplace culture that penalises women for having children at 'the wrong time'" (van de Wiel 2022 p243).

2. Jacobson (2022)

Fertility treatment has its own "clocks" (separate to the "biological clock"). These include "ovarian reserve issues" (ie: the ocytes of the intended mother), financial, emotional, and psychological, and "to sustain additional treatment on the 'infertility treadmill'; to persist and remain hopeful that a baby awaits at the end of the next procedure" (Jacobson 2022 p146). Overall, there is an investment of time in the process.

Jacobson (2022) stated: "As Amy Speier (2016...) notes, 'when couples confront infertility, they often respond by embracing ideological notions of hard work in pursuing IVF'. This 'hard work' is time-intensive and is part and parcel of the contemporary biomedical model, as Clarke et al (2003...) articulate, in which 'health becomes something to work toward', a moral project, as Peter Conrad (1992) has discussed, in and of itself" (p146).

The use of a gestational surrogate is often the "last resort" of this hard work. What about the investment of the women who perform this "service"?

Jacobson (2022) introduced the idea of the "ART clock" to describe the experiences of gestational surrogates. Interviews were conducted with 32 US gestational surrogates between 2009 and 2016.

Jacobson (2022) drew out four themes from the interviews:

a) "Expanding reproductive time" - Many of the women had finished having their own children, but wanted to experience pregnancy or birth again. This was shown by "April Palmer's" (pseudonym) comment: "After I had my younger daughter, we knew that we were done having children. [My daughters] were born very close in age, which was unexpected. And we knew we didn't want the risk of that occurring again. So I went ahead and had my tubes tied. But I knew that I wanted to... I loved pregnancy and I really couldn't imagine not having that experience again" (p148).

b) "Time as a surrogate" - "The shift from nonassisted personal reproduction to commodified ART thirdparty pregnancy results in an intense time commitment... Gestational surrogacy, which involves IVF, requires a regime of medications for multiple people, a battery of tests, multiple doctors visits with specialists, and medical monitoring - all of which were new to the women in this study at the time of their first surrogacy journey" (Jacobson 2022 p149). "Deidre Richards" explained: "when I first started [surrogacy] I had no idea really what to expect early on. And there's a lot involved early on. And a lot of waiting. And I think when a surrogate is ready to carry for somebody, they're like, 'Okay. Get me signed up! Make my appointment next week and we'll transfer some embryos!' And it doesn't happen that fast" (p149).

Surrogacy is also different to own pregnancy in other ways. "An important distinction of the labour in

which surrogates are involved, of course, is that surrogates are not experiencing infertility themselves; their bodily work is not being performed on behalf of their own health, fertility or parenting. This intense reproductive work is of them, but not for them. This idea is captured well by Waldby and Cooper (2008...) in their concept of 'clinical labour', with which they examine how reproductive workers' very bodies become the site of third-party reproduction via clinical 'access to the productivity of their in vivo biology, the biological labour of living tissues and reproductive processes'" (Jacobson 2022 p149).

c) "Extending time in third party reproduction" -Over 90% of the interviewees who had completed a successful surrogacy wanted to do another. A surrogate three-times, "Andrea Taylor" said: "I thought I would only do it once. I'll just do this one time. I'm young. I'm not having any more kids of my own right now. No big deal. But 'once' turned into another time and another time. And on from there!" (p150). Terms like "addicted" or "fell in love" with surrogacy were used.

d) "Surrogacy time constraints" - There are limits to surrogacy, including restrictions implemented by clinics (eq: based on concerns about the physical demand on the women), the US "surrogacy industry" (eq: fear of a "baby factory" image), and surrogates themselves (eq: family constraints). In reference to the latter, Jacobson (2022) stated: "Similar to there being a 'correct time' for reproduction on the biological clock, many women also told me they wanted to find a good time for surrogacy reproduction on the ART clock. For many women, the 'best time' to be a surrogate was one that aligned with their families' lives, when there was 'nothing major' going on, which would allow them to dedicate themselves to oftendelayed surrogacy journeys. They also considered the time of year in which the third trimester and birth would occur, noting the avoidance of summer, when it would be hot and their school-aged children would be home all day on summer break" (p151).

The "ART clock" as represented by these four themes showed how time played an important role in gestational surrogacy.

"Ageing = Decline?"

1. Buhler (2022)

An empowering narrative that counters the "biological clock" is that "women have the power to change" (Bolton 2020 quoted in Buhler 2022) with ART. In particular, egg freezing, which is "based on the idea of suspending time and making life 'latent' (Radin 2013)" (Buhler 2022 p170), and egg donation ("Based on a substitution principle - 'young' eggs for 'old' - and the logic of 'catching up' once infertility is diagnosed..."; Buhler 2022 p170). Experimental techniques have also emerged to improve "egg quality" "by supplementing 'energy' via the mitochondria of immature egg cells found in the ovarian lining" (Buhler 2022 p170). This has produced the possibility of the "post-menopausal mother", or "'queer' motherhood" (Buhler 2022).

Buhler (2022) saw these reproductive technologies going hand in hand with anti-ageing technologies. Put simply, if the biological clock for fertility could be managed, then so could the biological clock of the whole body.

2. Majumdar (2022a)

The extension of the reproductive age (or "aged conception") is possible with ART. Majumdar (2022b) described fieldwork from North India where older women and men (some in their late 50s and early 60s) struggled with the social stigma of infertility and childlessness undertook "risky pregnancies". There was also pressure around "son preference". The data were collected in 2018 at one IVF clinic via interviews with seventeen women and twelve men.

"The quest for children amongst ageing, postmenopausal couples is a continuous search for social legitimacy. This 'quest'..., is deeply embedded in the desire for conception. It is not the desire for a child alone but the seeking of conception, pregnancy and childbirth. This is where ART steps in to 'assist' nature through artificial, laboratory-induced conception and pregnancy" (Majumdar 2022b p184).

Note that adoption (an alternative possibility) is viewed negatively. Bharadwaj (2015) explained: "A publicly visible child incorporated into the family without any corporeal connectedness with the family unit makes the child and couple vulnerable to a more severe

level of social ridicule and stigma than that caused by infertility" (quoted in Majumdar 2022b).

The practicalities of ART (ie: donor sperm or eggs) can be hidden from society, and the couple have their own child to show the world. Genetic connectedness is kept secret (Majumdar 2022b).

REFERENCES

Bharadwaj, A (2015) <u>Conceptions: Infertility and Procreative</u> <u>Technologies In India</u> New York: Berghahn Books

Buhler, N (2022) The making of "old eggs": The science of reproductive ageing between fertility and anti-ageing technologies <u>Reproductive BioMedicine and Society Online</u> 14, 169-181

Cattapan, A et al (2014) Breaking the ice: Young feminist scholars of reproductive politics reflect on egg freezing <u>International Journal of Feminist Approaches to Bioethics</u> 7, 2, 236-247

Clarke, A.E et al (2003) Biomedicalisation: Techno-scientific transformations of health, illness and US biomedicine <u>American</u> <u>Sociological Review</u> 68, 2, 161-194

Conrad, P (1992) Medicalisation and social control <u>Annual</u> <u>Review of Sociology</u> 18, 1, 209-232

Jacobson, H (2022) The ART clock: Temporal limits to assisted reproduction <u>Reproductive BioMedicine and Society Online</u> 14, 144-155

Majumdar, A (2022a) Introduction: Reproductive technology and the conceptualisation of the biological clock <u>Reproductive</u> BioMedicine and Society Online 14, 300-301

Majumdar, A (2022b) Conceptualising aged reproduction: Genetic connectedness, son preference and assisted reproduction in North India <u>Reproductive BioMedicine and Society Online</u> 14, 182-191

McGinley, A (2016) Subsidised egg freezing in employment: Autonomy, coercion or discrimination <u>Employee Rights and Employment</u> Policy Journal 20, 2, 331-364

Radin, J (2013) Latent life: Concepts and practices of human tissue preservation in the International Biological Programme <u>Social</u> Studies of Science 43, 484-508

Speier, A (2016) <u>Fertility Holidays: IVF Tourism and the</u> <u>Reproduction of Whiteness</u> New York: New York University Press

van de Wiel, L (2022) Disrupting the biological clock: Fertility benefits, egg freezing and proactive fertility management Reproductive BioMedicine and Society Online 14, 239-250

Waldby, C & Cooper, M (2008) The biopolitics of reproduction: Post-Fordist biotechnology and women's clinical labour <u>Australian</u>

Feminist Studies 23, 55, 57-73

Zeno, E (2020) Synchronising the biological clock: Managing professional and romantic risk through company-sponsored egg freezing <u>Social Problems</u> 69, 2, 527-543

Zoll, M et al (2015) Corporate giants provide fertility benefits: Have they got it wrong? <u>European Journal of Obstetrics and</u> <u>Gynecology and Reproductive Biology</u> 195, December, A1-A2

8. THE EMBRYO

8.1. Sociological view
8.1.1. Reproductive justice view
8.2. Extra-embryonic tissue
8.2.1. Implantation
8.2.2. Evolutionary basis
8.3. References

8.1. SOCIOLOGICAL VIEW

The expansion of ART is changing reproduction and parenthood. "Meaning-making" describes how individuals make sense of the social world and their lives. Delaunay et al (2021) explored the "metaphors used by ART beneficiaries to describe the relationships they establish with (their) human embryos in vitro" (p63).

Metaphors are common in medicine generally (eg: "the body as a machine"; "the battle with cancer"). "Infertility metaphors can be found in patients' narratives about their experience, in the discourse of health professionals, in scientific medical books, and even in the media" (Delaunay et al 2021 p63).

Delaunay et al (2021) undertook thirty in-depth interviews with mostly female ART users in Portugal in 2019-20. Four categories of "embryo metaphors" were found in the interviews:

i) "Embryos as possibilities" - "As possibilities, an embryo may represent a new opportunity, in material and functional terms, to try to conceive a biological child as part of a parental project, and therefore it may be perceived as 'reproductive material' and a 'stage of the process' within ART treatment in order to achieve a pregnancy" (Delaunay et al 2021 p65). For example, "Laura" talked of the number of eggs implanted, while "Rita" reported the doctor saying: "You have three embryos. There are three very good embryos. One is wonderful, the other is very good and the third is... what a pity... it will remain, we will have to freeze it, but we will go for two" (p66).

ii) "Embryos as utilities" - "Embryos can be metaphorically conceptualised as utilities, as biological matter or hybrid objects that fall into the category of property, capable of being the locus of ownership and dispositional control" (Delaunay et al 2021 p66).
iii) "Embryos as offspring" - The embryo in vitro may "embody their baby in the future" (p66). As "Rita" said: "To think, hey, it's an embryo, with the same genetics, practically identical to your daughter's. It's a sister" (p67).

iv) "Embryos as a counter-gift" - "This metaphorical figure is understood in terms of a three-fold moral obligation supported by the relational dynamics 'givingreceiving-reciprocating', based on a logic of embryo donation (to other couples or to research) understood as a contribution without expectation of return or even as a form of retribution" (Delaunay et al 2021 p68).

Embryos in bioethics and legal debates are persons or property, and though ART users are aware of these discourses, there was a wider understanding in their meaning-making. Delaunay et al (2021) argued: "There is a need for a new paradigm that (re)contextualises the embryo created in a biotechnological environment, rendering visible its dependency upon both the pregnant woman's body and the technology by mobilising the cyborg metaphor (Fox 2000). Thus it might be seen as 'a hybrid of machine and organism' (Haraway 1987) or as 'embody[ing] the union of science and nature' (Franklin 1999)" (p69). Goedeke et al (2017) outlined eight discourses.

Delaunay et al (2021) described them: "the 'surplus embryo discourse', where the cryopreserved embryo is potentially problematic, particularly if it is not to be used by couples; the 'biomedical discourse', in which the embryo is a collection of cells or seeding material; the 'life discourse', with embryos being referred to as human life and given a childlike persona; the 'limbo discourse', in which the embryo has an interim status; the 'kinship discourse', where the embryo is referred to as a family member; the 'genetic blueprint and genetically dubious discourses', where IVF embryos emerge as potentially carrying unwanted conditions from their genetic parents or as having, in general, poorer quality than those created naturally; the 'property discourse', with the embryo seen as individual versus public property; and the 'personal investment discourse', in which the embryo is described as precious and valuable" (p69).

8.1.1. Reproductive Justice View

Taking a reproductive justice view, Russell (2022) stated: "Reproductive biomedicine, like other scientific and technological innovations, reflects the values of the socio-historical context in which it has developed. The process of human reproduction itself has never been and never will be entirely separate from social influences, including the value systems through which reproduction is both perceived and managed. Moreover, the concepts of race and reproduction are inextricably bound together in the history of western thought" (p28). Because of the deep connection historically between reproductive biomedicine and eugenics, critics argued that reproductive biomedicine is a "backdoor to eugenics" (Russell 2022 p29).

A reproductive justice approach challenges such a possibility as well as highlighting structural inequalities that influence reproduction. For example, poorer women around the world are more likely to have fertility problems, but less likely to receive treatment for them. ART, for example, tends to be a commercial industry, and so ends up focused on richer (usually White) individuals (Russell 2022).

8.2. EXTRA-EMBRYONIC TISSUE

"All emerging life must function while being built. The developing embryo requires an aqueous environment, a supply of nutrients, gas exchange and waste management. Extra-embryonic membranes accomplish these challenges by providing multi-functional organs and interfaces between the embryo and the outside world" (Sheng et al 2022 pl).

Extra-embryonic tissues (EETs) vary between animals (eg: yolk sac, amnion, chorion, and allantois protecting the embryo; figure 8.1).



(a = embryo; b = yolk sac; c = allantois; d = amnion; e = chorion)
(Source: Petter Bockman)

Figure 8.1 - Extra-embryonic tissues.

8.2.1. Implantation

After fertilisation, the zygote (cell) divides into around 100 cells with a central fluid-filled cavity, and is called the blastocyst. This subsequently implants in the lining of the uterus (the endometrium) to successful continue development (Jones and Jones 1997).

Embryo implantation is mediated by trophectoderm (the outer layer of the pre-implantation embryo) which differentiates to form the foetal portion of the placenta (Siriwardena and Boroviak 2022). There is considerable variety in this process in primates and mamals. For example, "inter-stitial implantation" in humans and chimpanzees compared to "eccentric implantation" in mice, and "superficial implantation" in rhesus macaques, for instance (Siriwardena and Boroviak 2022).

8.2.2. Evolutionary Basis

"Embryogenesis is a period of extraordinary change. The fertilised zygote develops to generate all tissue types, and to correctly organise these in space and time to produce the correct morphological form and physiological function of a complete organism. This delicate period of the life cycle must be buffered from the external environment" (Panfilio and Lopes 2022 pl). EETs develop in parallel with the embryo as a way of "protecting the embryo as well as directly fostering its development at mechanical, metabolic and genetic levels" (Panfilio and Lopes 2022 pl).

EETs of insects and amniote vertebrates (ie: mammals, reptiles and birds) are similar (ie: a fluidfilled amniotic cavity), but evolved independently because EETs were absent in the last common ancestor (an aquatic creature 500 million years ago) (Panfilio and Lopes 2022). "That both crickets and chickens, and mosquitoes and mice, develop within a fluid-filled amniotic cavity represents a convergent solution to common challenges, including the demands of a fully terrestrial lifestyle. Adaptations of the eqq to prevent desiccation, chiefly including the EE tissues, have enabled insects and amniotes to colonise diverse ecological niches away from the aquatic and humid habitats to which species such as amphibians and springtails are constrained" (Panfilio and Lopes 2022 pp1-2).

In both groups the inner EET is the amnion (directly surrounding the embryo), while the outer EETs mediate interactions with the outside world (called the serosa in insects and chorion in most amniotes) (Panfilio and Lopes 2022).

An amniotic cavity has been found in an insect fossil dated at 479 million years ago, and a vertebrate at 316 million years ago. Thus, "the insect amnion is evolutionarily older" (Panfilio and Lopes 2022 p2).

8.3. REFERENCES

Delaunay, C et al (2021) In-vitro metaphors: ART beneficiaries' meaning-making about human embryos in the context of IVF in Portugal Reproductive BioMedicine and Society Online 13, 62-74

Fox, M (2000) Pre-persons, commodities or cyborgs: The legal construction and representation of the embryo <u>Health Care Analysis</u> 8, 171-188

Franklin, S (1999) Making representations: The parliamentary debate on the human fertilisation and embryology act. In Edwards, J (ed) <u>Technologies of Procreation: Kinship in the Age of Assisted</u> <u>Conception</u> Manchester: Manchester University Press

Goedeke, S et al (2017) The fate of unused embryos: Discourses, action possibilities, and subject positions <u>Qualitative Health</u> Research 27, 10, 1529-1540

Haraway, D (1987) A manifesto for cyborgs: Science, technology, and socialist feminism in the 1980s <u>Australian Feminist Studies</u> 2, 4, 1-42

Jones, M & Jones, G (1997) <u>Advanced Biology</u> Cambridge: Cambridge University Press

Panfilio, K.A & Lopes, S.M.CdeS (2022) The extended analogy of extra-embryonic development of insects and amniotes <u>Philosophical</u> <u>Transactions of the Royal Society B</u> 377, 20210268

Russell, C (2022) Which lives matter in reproductive biomedicine? <u>Reproductive BioMedicine and Society Online</u> 14, 28-31

Sheng, G et al (2022) Extra-embryonic tissues: Exploring concepts, definitions and features across the animal kingdom Philosophical Transactions of the Royal Society B 377, 20210250

Siriwardena, D & Boroviak, T.E (2022) Evolutionary divergence of embryo implantation in primates <u>Philosophical Transactions of the</u> Royal Society B 377, 20210256