Couples and Clinics: Online Learning and Information Provision to make Decisions about Fertility Treatment in the Context of Neoliberalism and Patriarchy in the U.K.

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Abstract

Infertility, a complex medical and social issue, affects one in six couples worldwide. This study explores the experiences of heterosexual couples with infertility by analysing data from semi-structured interviews and delves into the dynamics of learning about infertility and making decisions about treatment within the United Kingdom. This study adopts a dual theoretical lens, situating data within the context of neoliberal and patriarchal policies and perspectives to explore the intricacies of choice and the burdens on couples to learn about infertility.

Using Reflective Thematic Analysis, the findings reveal that the lack of adequate information provided through schools, media, GPs, and fertility clinics leads couples with infertility to Google. Seeking health information online can be empowering but there is a lack of consensus within the field of infertility, for both what practitioners recommend and what is available on the internet. Therefore, searching for information online can be confusing and overwhelming, which renders the process burdensome for couples. Despite the shared nature of infertility diagnoses within a couple, there is an unequal distribution of labour for seeking health information online; women bear the burden of learning about and making decisions regarding infertility.

Drawing upon the findings, this study argues neoliberal policies and perspectives, specifically the focus on privatisation of care, individual choice and responsibility, and profit over care, have placed the burden of learning on couples. Additionally, within those couples, patriarchal influences have disproportionately placed the burden on women. Thus, to reduce imbalances in learning about infertility, this study calls for more regulation of the fertility industry and a move towards patient-centred care in the infertility industry. Online resources could be greatly improved to better support couples; however, health practitioners should actively engage with both partners within a couple to balance the burdens of learning, educating, and decision making across the triad and ensure that the couple's perspectives and preferences are considered in the fertility treatment process.

Ultimately, this study contributes to previous research on the lived experiences of infertility and online health information seeking behaviour and aims to contribute to social change.

Keywords: infertility, UK, learning, OHISB, internet, feminism, neoliberalism

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Chapter 1: Introduction

The NHS defines infertility as “when a couple cannot get pregnant (conceive) despite having regular unprotected sex” (NHS, 2017b). Inhorn and van Balen (2002) state it more simply: “the process of not being have to have children”. It has been defined as a disease (Vander Borght & Wyns, 2018) and “a failure to fulfill the personal desire to beget a child” (Sandelowski, 1990a, p. 477). Current estimates are that 1 in 6 couples worldwide will experience infertility at some point (World Health Organization, 2023), thus infertility is worthy of study.

Infertility can be treated through fertility treatments which can include medication, surgery, or technologies such as in-vitro fertilisation (IVF). Most research on infertility is in biomedicine, specifically focusing on improving treatment success rates. However, more research on and care for the psychological and emotional struggles of infertility are needed (Daniluk, 2001; Schmidt, 1998; van Empel et al., 2010), as dealing with infertility has been shown to be as upsetting as living with cancer (Cousineau & Domar, 2007). Additionally, ample research has demonstrated low fertility awareness among the general population which could be increasing the rates of involuntary childlessness (Bayoumi et al., 2018). Therefore, more “research ought to be undertaken on practical means of improving fertility education to enable both women and men to be better informed about fertility, infertility and its treatment” (Chauhan et al., 2021, p. 53).

In this study, I set out to explore how residents of the U.K. learn about infertility and fertility treatment, the role of the internet, local policy, and institutions in this process, and what could be improved. Like Grace et al. (2023), I believe that “understanding how reproductive health information is accessed, can provide opportunities for effective communication and dissemination” (p. 1). This has led me to explore online health information seeking behaviour (OHISB) and the intricacies of decision making related to fertility treatment. Infertility is an excellent case study because, while it is prevalent, it is unique; as Kinloch (2018) says, it is “at the intersection of the social, ethical, personal and medical” (p. 1). Inhorn and van Balen (2002) explain it is an excellent lens “through which so many other compelling issues may be brought into focus” (p. 5). Infertility is an invisible diagnosis with many different aetiologies and is quite stigmatised (Allison, 2011). People who seek fertility treatment are a unique group in healthcare because they tend to be young, well educated, and committed to treatment (Mounce, 2013). Additionally, most treatment seekers are heterosexual couples, so decisions need to be shared between multiple people in situations with complex contexts. Fertility treatment is also unique for being simultaneously impacted by both neoliberal and patriarchal policies and perspectives, including medicalised and stratified reproduction, technological solutionism, and consumerism (Kinloch, 2018).

There is a considerable body of quantitative research on who seeks health information online, but Chu et al. (2017) have called for more qualitative research to better understand how and why people seek health information online. To this end, in this study I sought to hear the voices of those with infertility. Therefore, I conducted semi-structured interviews with people who identified as having infertility, all of whom were in heterosexual relationships. They spoke about their fertility journeys and their agency in seeking health information online, which empowered them to ask questions and advocate for themselves. They described their experiences with NHS care and private fertility clinics, and it became clear that truly informed and shared decision making was not occurring. Instead, the couples, specifically the women, were responsible for learning about infertility and making most of the decisions. This was a considerable burden since they did not learn about fertility elsewhere and the internet was often difficult or distressing to navigate. By exploring the data through the lenses of neoliberalism and feminism, I argue that, in heterosexual couples dealing with health practitioners, the responsibility to learn about infertility, self-advocate, and make decisions is disproportionately weighted towards women.

Language Choices

In this work, I take a firm feminist stance, which posits that people are not required to have children but should be able to exercise choice in the matter. Those with infertility deserve respect and are not victims of medicalisation and patriarchy, but rather they have agency and are doing their best to navigate difficult systems to seek care and support. I believe that writing about those with infertility should help uplift them and not be judgemental of or triggering to them.

To this end, I have made deliberate choices regarding the language used in this work; as Braun and Clarke (2021a) say, “the detail, specificity and nuance of language matters” (p. 122). I choose to use people-first language to imply that infertility is not an individual’s defining characteristic. When I mention couples, I am referring to heterosexual couples, as most patients in fertility clinics are in heterosexual relationships, though many people pursue fertility treatment for social reasons, such as being in a homosexual relationship. Therefore, most past research has been conducted with those in heterosexual relationships and, despite trying to recruit a diverse participant group, I was only able to interview those in heterosexual relationships. Moreover, I am interested in the shared diagnosis of infertility held by two people, their shared decision making, and the gender interactions that occur. Where possible, I avoid discussing treatment outcomes in terms of success or failure, instead describing treatment as having worked or not. I do not describe people with infertility negatively, for example, they are not desperate (Letherby, 2002). I also do not view people pursuing treatment merely as consumers, a term that can “cheapen their motivations, transform infertility into a marketing problem, or reduce having a baby to a matter of dollars and cents” (Inhorn & van Balen, 2002, p. 41). Additionally, I generically refer to the many different professionals that a fertility patient might see over the course of diagnosis and treatment as practitioners, except where it is necessary to specify a role for context or to avoid confusion. And I try to avoid overusing medical terminology as the focus of this work is sociological. Where I have found it necessary, I define the terms in a footnote.

Dissertation Outline

This dissertation starts with a literature review of research from multiple countries and fields and an exploration of relevant theory through which I view this work. I then detail the methodology I undertook to generate and analyse data with a group of participants from the United Kingdom. Next, I move to my findings from lived experiences of my participants, where I explore why my participants engage in OHISB, their struggles with learning about infertility, the role of practitioners, and the gender differences. In the discussion, I situate those experiences within broader contexts and analyse my findings in relation to neoliberal and patriarchal policies and beliefs within the United Kingdom. I end with my conclusions and some suggestions of how social change might be enacted in this space. Some advice is shared for individuals to help them navigate online information regarding infertility but with no intention that this would stand in for substantive structural change.

My Positionality

I have infertility. My positionality has motivated this research and influenced my recruitment and my analysis. I am a cis-gendered white woman in a heterosexual relationship living in the United Kingdom. My partner and I have significant privilege in that we can afford to seek fertility treatment for our first child, using our own gametes and bodies. I am a member of many online communities dedicated to infertility, and I volunteer for Fertility Network UK (FNUK), running a local online support group. However, I am not involved in communities for those pursuing treatment as a single person, as part of a homosexual relationship, for a second child, or for third party reproduction[1]. This position affected who I was able to recruit to participate in this study. I am motivated to create social change that will uplift the communities I am part of, and I hope to expand my work to other communities in the future.

I have chosen to announce my insider status upfront while conducting this study, as it influences every aspect of my work. Sundby (1999) found that announcing her status as infertile increased her access to people with infertility. Other researchers in the field have also shared their insider status (e.g., Joyce Harper and Gay Becker), however, they tend to write from a position of having finished a fertility journey. There are only a few academic publications from the perspective of someone in the midst of their journey (e.g., Griffiths, 2021), so I have a unique perspective to share. However, self-disclosure does limit my own (and my partner's) privacy. Everywoman (2013) wrote a purposely anonymised account of her fertility journey, perhaps because of stigma associated with infertility. Nevertheless, contributors to *Infertility Around the Globe* say that their studies are richer for being driven by personal experience, empathetic connection to their participants, and desire to give voice to those with infertility, "in an attempt to promote greater public understanding and compassion" (Inhorn & van Balen, 2002, p. 18). Thus, I think embracing my researcher vulnerability and sharing my position is valuable.

Conducting this study has often been personally upsetting. I shared a sanitised version of my story with participants which often resulted in them sharing advice and inspiration with me. I was not able avoid having emotional reactions during interviews, with many stories triggering embodied responses within me, similar to Harris' (2015) work. I cried with some participants as they recounted traumatic events, upsetting medical care, and hurtful comments from loved ones. I often saw myself reflected in participants' stories, but they led me to reconceptualise my own narrative. Thus, I have kept a reflective journal to help process these emotions and engage in reflexivity throughout the process. This process has resulted in a personally driven study and my ultimate goal with this dissertation is to share what I have learned in a way that uplifts my community.

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[1] Reproduction involving donor gametes or surrogates.

Chapter 2: Literature Review

This chapter sets the scene by exploring research on fertility awareness and what information about infertility and fertility treatment is provided to people in multiple countries. It then focuses on infertility as a case of OHISB and considers how seeking information online can be empowering but insufficient for informed decision making. While research in this area is growing, it is not abundant, therefore, I reference international research throughout. This chapter then moves to explore patient-centred care and decision making in relation to fertility care. It ends with the research questions that I address within this study.

People do Not Learn Enough About Infertility

Fertility Awareness is Poor

People do not receive enough information about fertility and infertility in their day-to-day lives. Maslowski et al. (2023) recently found that “many young people in the UK are at risk of leaving school with inadequate understanding of concepts that have important implications for their reproductive health” (p. 1). Participants in Grace et al.’s (2023) study in the U.K. reported gaps in their education, particularly “factors affecting fertility and the protection of fertility” (p. 5). When infertility is discussed in mass media, the focus is on biomedical technology and miracles (Letherby, 2002). In the few instances where media speaks of individuals with infertility, it does so in a judgemental tone that promotes stereotypes of desperate women and blames them for deviating from social norms by, for example, wilfully waiting too late to have children (Kinloch, 2018). In the few cases where men are discussed, they are an addendum, and male infertility is talked of as a public health threat to society (Kinloch, 2018). The media also gravitates towards stories of “shocking” new family arrangements, controversial legal cases, and reports of celebrities having children at an older age, which can warp the public’s understanding of fertility (Almeling, 2020).

Before people express interest in conceiving, they tend not to learn about fertility from health practitioners (Earle & Letherby, 2003). Thus, it is rare for people to passively learn useful information about fertility and it is not surprising that Hampton and Mazza (2015) found only 2.1% of women accessing general practitioners (GPs) in Australia had high fertility awareness. Awareness among women specifically seeking fertility treatment was higher, but still only 12.7% had high awareness and both high and low awareness groups overestimated their knowledge (Hampton & Mazza, 2015). Participants in Porter and

Bhattacharya's (2008) study at a UK hospital reported not receiving sufficient advice on how to conceive unassisted. These findings are paramount as poor fertility knowledge is linked to unintentional childlessness (Bayoumi et al., 2018).

Poor Information Provision for Informed Decision Making

Fertility treatment involves weighty decisions, such as choosing to undergo surgery or use donor gametes; therefore, patients rate information provision as crucial to good care (Schmidt et al., 2003). In the U.K., the Human Fertilisation & Embryology Authority (HFEA), the fertility regulatory body, states patients should receive "sufficient, accessible and up-to-date information in order to allow them to make informed decisions" (HFEA, 2021, p. 13). Informed choice requires "the provision of unbiased, good-quality information (i.e., evidence) in a form that is accessible to the patient" (Perrotta & Hamper, 2023, p. 228).

When people suspect they have a problem conceiving, they turn to the internet to determine when to visit their GPs (Wingert et al., 2005). Over 90% of patients surveyed in Australian general practices said that "women should receive fertility-awareness education when they first report trouble conceiving" (Hampton & Mazza, 2015, p. 843). However, couples in the U.K. report that GPs do not provide much information about fertility (Peddie et al., 2004; Porter & Bhattacharya, 2008). The usual lifestyle advice (e.g., lose weight, quit smoking, etc) that is provided is not helpful, as most couples will have already attempted as much before visiting a GP (Porter & Bhattacharya, 2008).

Unfortunately, according to research in a variety of countries, when patients arrive at fertility clinics, information provision may not be much better. For example, only 14% of patients in Dutch fertility clinics were given information regarding general treatment risks prior to starting, thus, couples may not have been able to make informed decisions (Mourad et al., 2009). Daniluk (2001) found that fertility patients in Canada felt they were on an assembly line, where they had no control and lacked sufficient information, with one participant saying:

> Either they didn't know it or the doctors who did know it didn't have time to tell us. A lot of things were kind of vague so it was always up to us, as a couple, to do the digging and the researching and to find the answers to our questions. (p. 126)

While less research has been conducted on information provision in U.K. fertility clinics, they often advertise additional treatments that have not been proven effective, without mention of possible and known negative effects (van de Wiel et al., 2020).

When fertility clinics do provide information, patients may struggle with complexity of information and timing of provision, needing to discuss it with others to fully absorb it (Hershberger et al., 2012). Takefman et al. (1990) suggested that information regarding fertility treatment should be introduced only when needed. However, simplifying information has downsides. Clinics often show linear and predictable treatment pathways which may give a false impression of treatment ease and “success” rates (Mounce, 2013). Clinics also struggle to communicate challenges of treatment, which can be substantial (Rauprich et al., 2011). Therefore, patients may start fertility treatment without having learned enough information from practitioners to make informed decisions about their treatment. Thus, researchers debate if informed decision making is truly possible (Carroll & Waldby, 2012). For example, Franklin (1997) explained that women in her studies did not foresee the stress of treatment and were not prepared for the difficulties. Mounce (2013) points out that this debate shows the importance of experiential knowledge in understanding fertility treatment, thus patients are likely to turn to other patients to understand. Given these issues, it is unsurprising that many people seek out information about infertility from sources other than practitioners.

People Seek Health Information Online

Health information seeking behaviour is how people find, manage, and take in information about their health, and it can improve quality of life for those living with chronic conditions (Longo et al., 2010). Many people engage in OHISB when they perceive that they are affected by a problem without immediate resolution and do not have sufficient knowledge to deal with risks (Wang et al., 2021). The internet allows people to autonomously and anonymously seek information about sensitive and stigmatised health topics, including infertility. People are more likely to trust information that comes from official sources, such as universities and hospitals (Shamlou et al., 2022). In the U.K., Powell et al. (2011) found that people visited the NHS website to seek a second opinion or to supplement information provided by practitioners. People also used the internet to circumvent barriers to accessing healthcare through the NHS, including stigma and difficulty getting an appointment (Powell et al., 2011). In one of the few qualitative studies on OHISB, Chu et al. (2017) found practitioners in Hong Kong did not have time to discuss issues in detail, though most participants still deferred to expert authority and used the internet to help them prepare for appointments, and a few used the internet to question practitioners. Wang et al. (2021) noted that for specific conditions, people were more concerned with finding relevant information that suited them than the trustworthiness of such information.

People with infertility may be drawn to the internet over other informational sources because of its affordances. Grace et al. (2023) conducted a U.K. wide survey of the general population and found that Google was particularly popular for seeking fertility and reproductive health information because it was easily accessible and anonymous. Furthermore, people may prefer online videos over text (Jones et al., 2020), and social media allows people to engage anonymously while conversing with others (Grace et al., 2023). The internet offers easy access to experiential knowledge from others who have undergone fertility treatment, a type of information that practitioners cannot offer.

OHISB can Empower Fertility Patients

It is therefore not surprising that people with infertility partake in OHISB to feel more informed (Zillien et al., 2011). Fertility patients tend to be motivated (Huisman et al., 2009) and "hungry" for information which can enable them to reach their goal (Porter & Bhattacharya, 2008), even describing their information needs as "infinite" (Lemoine et al., 2021). They seek to understand their diagnosis, treatment options, and success rates (Brochu et al., 2019; Haagen et al., 2003). They also look for information about treatment providers so they can choose the best clinics (Brochu et al., 2019). Kahlor and Mackert (2009) found that online information and support allowed participants to communicate better with their partners and practitioners. Fertility patients also seek emotional, social, and psychological support online (Tuil et al., 2009; Zillien et al., 2011). Searching online may help patients feel less alone (Kahlor & Mackert, 2009; Wilkes et al., 2009) and reduce stress (Lemoine et al., 2021). Online forums and support groups allow fertility patients to support and form relationships with others like themselves (Porter & Bhattacharya, 2008; Wingert et al., 2005). Patients simultaneously seek experiential and medical knowledge, so they move between platforms that offer information, conversation, and professional advice (Kinloch, 2018; Sykes et al., 2020).

People with infertility exercise agency in multiple ways, including engaging in OHISB and questioning practitioners. Wilkes et al. (2009) found that couples who retained control over decisions believed they had better treatment management experiences. Practitioners can act as gatekeepers to treatment, which may lead patients to seek information online so that they can negotiate access to care (Kinloch, 2018; Song et al., 2012). Despite power imbalances between practitioners and patients, fertility patients are not passive, but instead choose when to comply with treatment (Greil, 2002). Perotta and Hamper (2023) note that patients tend to become more involved in directing treatment after going through multiple treatment attempts and will take incremental risk with experimental treatment options as they learn more. Sandelowski and de Lacy (2002) say couples with infertility are not "dupes but protagonists encountering the greatest obstacle of their lives… with courage and even daring" (p. 43). Greil (2002) specifically describes women as "infertility contractors" because they learn as much as they can about infertility and respond strategically, though researching sometimes puts them in conflict with the practitioners. In fact, some patients critically evaluate scientific evidence regarding fertility treatment and use their learning to challenge practitioner decisions (Perrotta & Hamper, 2023). If social contracts between fertility patients and practitioners are not upheld by practitioners, patients will change clinics to gain more control of treatment (Greil, 2002). Thus, Greil (2002) concludes women with infertility are "strategists doing the best they can in the context of a system in which they lack substantive power" (p. 113).

OHISB Does Not Always Equate to Being Informed

However, seeking information independently does not necessarily mean patients will be informed. An early study suggests that providing patients with too much information before undergoing fertility investigations may be overwhelming, and focus participants' attention on the stressful elements of the investigations (Takefman et al., 1990). Gaining more information does not always equate to meaningful knowledge, thus adding to patients' feelings of not being in control which causes them considerable distress (Earle & Letherby, 2003; Franklin, 1997). Additionally, those with high levels of distress are less likely to have their informational needs met by the internet (Brochu et al., 2019; Mounce, 2013). Online information about fertility does not suit everyone's needs; "sometimes technical information or scientific journals information is pitched too high" (Grace et al., 2023, p. 3). Moreover, OHISB can have a negative impact if patients are exposed to misinformation or others' negative experiences (Malik & Coulson, 2010), are overwhelmed by the amount information, or are exploited by merchants selling alternative treatments online (Porter & Bhattacharya, 2008).

It is all the more concerning then, that approximately 40% of online reproductive health information is inaccurate (Kedzior et al., 2019). Skyes et al. (2020) found that participants in the UK struggled to judge the credibility of sources and deal with contradictory information, with participants noting they would actively seek an answer they desired. Disconcertingly, when searching infertility, commercial websites are more common, easier to find, and less accurate than NHS websites (Marriott et al., 2008). Grace et al. (2023) found that participants trusted medical sites, like the NHS, more than others, but only participants who were more highly educated reported assessing a site for bias or marketing. Thus, it is important to achieve the right balance of information so that patients do not make decisions based on “irrelevant, unreliable or misleading health-related information, which in turn could cause damage to their physical and emotional well-being” (Haagen et al., 2003, p. 2073). Therefore, fertility patients may not become sufficiently informed through OHISB alone. More qualitative research is needed to understand why people with infertility feel online information is not meeting their needs, which could help tailor resources and guide policy to promote effective help seeking (Brochu et al., 2019; Chu et al., 2017).

Through a discourse analysis of clinic websites, Kinloch (2018) found that clinics presume shared knowledge with informed consumers, and position practitioners as experts. This language can both imply that patients should be informed and are capable of making decisions, but at the same time occupy a passive role, expected to comply with practitioner advice. Fertility patients are more educated (Jain, 2006) than those receiving other kinds of care, which is correlated with demanding more information (Suhonen et al., 2005) and high literacy of online health information (Brochu et al., 2019). Generally, they are also young and well connected to the internet. However, because of this, clinics may assume that patients are more informed than they actually are (Mourad et al., 2009). This leaves patients in an intractable situation of attempting to balance the need to be informed with the burden of doing so. Regardless, models of informed decision making assume that access to quality information is all that is needed to empower patients (Greenhalgh et al., 2015). Conversely, research by Tuil et al. (2007) contradicts this. They tried to empower fertility patients by providing them with their health records online but found no change in their empowerment. The authors concluded that the patients were either already empowered or that highly rigid treatment plans allowed participants few opportunities for meaningful decision making. They proposed that treatments need to be redesigned to be patient-centred with the practitioners providing information so that patients can make decisions.

Patient-Centred Care and Decision Making

Patient-centred care is “being respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (van Empel et al., 2008, p. 1243). It is associated with wellbeing in fertility patients and includes the provision of high-quality information, which decreases anxiety and depression (Gameiro et al., 2013). Couples report that infertility management is good when they receive patient-centred care, particularly when communication is strong both within the couple and with the practitioner (Wilkes et al., 2009). Moreover, couples prefer patient-centred care and maintaining a good relationship over “success” rates (van Empel et al., 2011; Verkerk et al., 2022). On the other hand, couples perceive care to be inadequate when clinics have too many patients, which results in the practitioners not having enough time to support them (Zargham Boroujeni et al., 2014).

Unfortunately, patient-centred care is often forgotten and practitioners underestimate its importance (Dancet et al., 2010; van Empel et al., 2011). Fertility patients want to collaborate with practitioners and pool information (Earle & Letherby, 2003), but may not be aware of information that is crucial for informed decision making regarding treatment (Stewart et al., 2001). Boivin et al. (2012) suggest that providing information and involving patients in decision making could decrease their treatment concerns. Therefore, it is crucial to explore information provision and informed decision making in relation to fertility treatment.

Research Questions

People with infertility may seek out information online because they are not provided with enough from school, media, GPs, or fertility clinics. They turn to the internet because of its numerous affordances, but OHISB might not be sufficient for informed decision making. This work builds on previous literature to address the following questions:

- How do people with infertility in the U.K. learn about infertility and fertility treatment to make decisions?
- What role does the internet play in this learning?
- How is this learning influenced by local policy, perspectives, and institutions?
- What improvements could be made to better support those with infertility?

Chapter 3: Theoretical Foundations

Currie and Wiesenberg (2003) argue that situating an individual in their sociocultural context and exploring gender equity advances a feminist approach to health promotion and research for women (and, I add, for men), rather than on them. Therefore, in this chapter, I will explore feminism and neoliberalism, and how they apply to my research questions and infertility in general, so that I can situate my participants' lived experiences within their context.

Feminism, Patriarchy, and Gender Imbalance in Healthcare

Early feminism ignored infertility, focusing on broader issues of gender inequality, and discussions of reproductive choice were reserved for contraception and abortion (Woollett, 1996). Thompson's (2002) review of early feminist writing explains that, following invention of IVF, many feminists critiqued these treatments for being invasive, taking a theoretical and dismissive stance. Some did not like glorification of motherhood and viewed maternity as the biggest barrier to true gender equality. Radical feminists believed the fertility industry was a conspiracy of "technopatriarchs" pushing pronatalism by exploiting desperate women for the sake of patriarchal medicine (Thompson, 2002). In general, feminists have suggested practitioners are overly focused on biomedical innovation, rather than on preventing infertility or exploring less invasive treatment, and they ignored lived experiences of patients undergoing treatment. More recently, interdisciplinary scholars have begun exploring lived experiences (e.g., Becker, 2000). They found practitioners had more diverse motives than previously assumed, some even having lived with infertility themselves (Thompson, 2002). However, Letherby (2002) explained that much feminist work is patronising, simplifies the pain experienced by those with infertility, and caricaturises women as desperate. She also said feminism challenges ideals of motherhood but ignores the "otherhood" of infertility. Therefore, I reject the feminist discourse above as "infertile women are marginalised in feminist writing and given no part in developing an understanding of, for example, the diverse meanings of motherhood" (Woollett, 1996, p. 75). Nevertheless, as gender is a crucial element in infertility, I will focus on some specific feminist authors who are inclusive and have shaped my understanding of infertility.

Historically, women have taken the blame for infertility, because it was assumed that otherwise, they would visibly embody pregnancy through obvious bodily changes. Practitioners throughout history have also blamed individual women's choices for infertility and their attempts for gender equality for decreased societal fertility (Sandelowski, 1990a). Fertility treatment is usually focused on women's bodies, meaning they undergo surveillance, give up bodily control, and assume medical risk, even if the biological barrier to reproduction lies with the male partner (Throsby, 2002b). In clinics this is represented by the woman being labelled as the patient, and only her name being included on the patient file and communications.

It could be argued that intense biomedical focus on women's bodies benefits them, as medicalisation through fertility treatment can help women with infertility conceive. In fact, receiving a diagnosis can help legitimise people's struggles by establishing that their lack of children is the result of an unwanted medical condition (Kinloch, 2018). By analysing women's language use regarding infertility, Kinloch (2018) concludes that they position themselves as "actively taking back control and ownership of the condition" (p. 93). Thus, it would be inappropriate to view women with infertility as victims of medicalisation. However, women with infertility experience more psychological distress than men (Abbey et al., 1992), bear the brunt of social backlash (Inhorn & van Balen, 2002), and are envisioned as villains in many narratives (Kimball, 2019). Therefore, I explore my research questions from the perspective of gender imbalances of the experience of infertility.

Martin (1991) explains how cultural scripts about gender influence scientists by anthropomorphising gametes. Sperm are described as masculine, active, strong, streamlined, they are survivors or warriors. They fire harpoons, go on a perilous journey, have a mission, and execute decisions. Eggs are described as feminine, passive, waiting, empty, and dependent. They drift, needing to be rescued by sperm that will penetrate and fertilise them. Men are venerated for producing many sperm each day and women are chided for wasting eggs. These ideas are commonly expressed in public spaces today and affect how people with infertility think about themselves. Unfortunately, new research has continued in this vein and the ideas are reiterated in textbooks and TV shows (Almeling, 2020). Men may associate fertility with virility and manliness, thus when fertility is questioned, it can threaten their identity, and so, they do not independently seek care (Inhorn & van Balen, 2002).

Almeling (2020) argues that a strong belief in gender dualism has led to rigid stereotypes that affect healthcare and knowledge making in diverse ways. Male bodies were considered standard, so men were subjects of much medical research, whereas women were seen as reproductive, and thus not appropriate test subjects. So, more is known, for example, about cardiovascular disease in men than women (Galick et al., 2015). These cultural scripts have influenced questions asked by researchers; most research on women focuses on reproductive health, often seeking to control it. This creates a contradiction where women’s reproductive systems have been heavily medicalised while the rest of their bodies have been ignored. However, within the purview of reproductive health, it is the men who have been ignored; questions about their role in reproduction go unasked, both in biomedicine and social science (Almeling, 2020). This nonknowledge (Croissant, 2014) is a classic example of how the gender binary harms all.

Conversely, Almeling (2020) also explains how men’s reproductive health has been ignored throughout history. In the wave of medical specialisation, gynaecology was one of the first to emerge but there was no cohesive speciality devoted to men’s reproductive health. Historically, poor reproductive health was associated with syphilis and immoral behaviour, associations that then transferred to those that treated them, who were ridiculed in turn. Today men’s reproductive health is partially served by a mixture of andrology, urology, fertility, and sexual health services and their sexual health is prioritised over their reproductive health. Stigma continues, as studying infertility has been labelled a “girly subject” (Inhorn & van Balen, 2002, p. 19). Therefore, it is unsurprising that most social science and psychological studies on infertility either purposefully recruit only women or struggle to recruit men (Culley et al., 2013). Unfortunately, studying only one gender “means studying one thing, one category, one half of the binary without explicitly taking into account the other half” (Almeling, 2020, p. 29). Research that has been done on gender, OHISB, infertility, or some combination of these finds clear gender differences. Women are more likely to engage in OHISB (Chu et al., 2017; Jia et al., 2021; Powell et al., 2011; Shamlou et al., 2022; Wang et al., 2021). In heterosexual couples, women always initiate investigations (Daniluk, 2001; Earle & Letherby, 2003; Sundby, 1999). Greil (2002) explains women take a more active role in managing treatment, however, couples want practitioners to address both partners, and men want to be involved, but this often does not happen (Dancet et al., 2011; Inhorn & van Balen, 2002; Verkerk et al., 2022). Kahlor and Mackert (2009) surveyed women and 94% reported assuming responsibility for gathering information about infertility. Brochu et al. (2019) found that women were more likely to search for diagnostic fertility tests and scientific literature. This imbalance is understandable given that most fertility treatment is focused on the women’s bodies, but it still leaves men feeling excluded from treatment (Culley et al., 2013).

Neoliberal Policy in Healthcare, Technical Fixes, and Personal Responsibility

The NHS and the fertility industry in the U.K. are affected by neoliberal policies and perspectives, so I will also view this research through this lens. Neoliberalism is a broad and contested term that “identifies a new set of ideas that rose to prominence across the capitalist world from the 1970s” (Cahill et al., 2018, p. 9). Neoliberalism in the U.K. has been growing since the Thatcher government, is characterised by market-logic, and has increased through various austerity measures which, by reducing reduce welfare costs, has disproportionately impacted women (Hamilton, 2016). Neoliberalism is an approach to government that includes many concepts, but here, I focus on elements of technological solutionism, individual choice and responsibility, privatisation, and profit. The focus on individual choice has enabled privatisation of the NHS (Hamilton, 2016) which is continuing with the recent announcement of plans to boost private sector partnerships (Allegretti, 2023). Neoliberalism requires people to accept privatisation of public services (Hyatt, 2001). It of course affects fertility services and has added to the discourse of personal choice and responsibility regarding reproductive health.

Neoliberalism often offers up technical solutions for social issues, and these solutions are usually privatised. For example, contraceptive pills were originally considered a technological fix to overpopulation (Oudshoorn, 1999). Hamilton (2016) argues that attachment parenting is a technical solution to a society that does not provide parenting support. In-vitro fertilisation could be seen as a technological solution to infertility, and in fact, Sandelowski and de Lacey (2002) argue that infertility was invented along with IVF, becoming a “product of technology” (p. 35). Feminists have even argued that all women “need is ‘strong, deep, feminist consciousness raising’ to dissuade them from the ‘technological fix’” that is IVF (Hubbard as cited in Sandelowski, 1990b, p. 45). I find this particular feminist view offensive and contrary to the lived experience of those in my community. However, it is critical to note that fertility clinics position themselves as the solution to the problem of infertility (Kinloch, 2018), echoing this notion of a “technological fix”.

Earle and Letherby (2003) argue that “the pursuit of technological solutions is commonplace in the West and needs to be seen historically as part of the developing impact of medicali[s]ation” (p. 176). Medicalisation has changed the view of the body, convincing us that modern science has triumphed over nature (Greil, 2002). Biomedicine tends to view bodies like machines, which need expert intervention to fix flaws, implying that practitioners are in control, not patients. However, engaging in treatment and distancing oneself from a flawed body, can allow women to both feel in control and less stigmatised for infertility (Kinloch, 2018). Medicalisation and scientific progress mean that involuntary childlessness is difficult for couples to accept; it is assumed in the era of reproductive choice and control, any health issue can be overcome (Greil, 2002). Unfortunately, practitioners may not be able to solve a couple's infertility, but because of medicalisation, stopping fertility treatment could be viewed as resisting the medical establishment (Greil, 2002).

Finally, neoliberalism expects individuals to be personally responsible for their health and maintain a normative and functional body through self-monitoring. While it can be beneficial for individuals to be engaged in maintaining their health, this view adds to the stigma of infertility as it implies that women are to blame. For example, those who are trying to conceive past a certain age or above a certain weight are considered at fault (Kinloch, 2018). Within clinics, patients are also expected to take on the responsibility to self-monitor, enact lifestyle changes, self-administer medications, and adhere to strict treatment protocols (Kinloch, 2018). Not only is this highly stressful, but it also means that if treatment does not work, women can be blamed for not engaging in treatment correctly. Additionally, Kahlor and Mackert (2009) found that because of high treatment costs, people with infertility are pressured to “go beyond the information-seeking that typify their other health-related information seeking” (p. 89). Overall, this personal responsibility adds to the burdens faced by people with infertility.

Choice at the Intersection of Neoliberalism, Feminism, and Patriarchy

Currie and Wisenberg (2003) argue that for a woman to be healthy and autonomous, “she must be able to control every aspect of her reproductive life” (p. 880). However, control and infertility rarely coincide; individuals with infertility must make decisions based on uncontrollable aspects of biology and context in which they sit. This is complicated by the belief that infertility may result from personal choice, as Sandelowski (1990a) explains,

> in a cultural milieu characteri[s]ed by the expectation that conception can be prevented, terminated, and initiated at will and in which individual habits and life-styles have been persistently implicated in the onset of cancer, heart disease, and other impairments, not having a child—even if by default and not by design—is still viewed partly as a product of individual choice. (p. 479)

Thus, how decisions are made regarding infertility and fertility treatment in a neoliberal and patriarchal society should be considered.

Some decisions are made by the government, and some are pushed onto patients. The neoliberal goal to save money in healthcare affects what fertility treatments are funded and encouraged in the United Kingdom. The NHS requires many patients to undergo intrauterine insemination[2] before moving to IVF if the former does not work. While this has been posed as a more patient friendly treatment because it is less invasive, it could be motivated by finances as it is considerably cheaper. In a similar fashion, Hamilton (2016) demonstrates that, in the case of promotion of natural birth by the state, the state has co-opted the feminist push against medicalisation as a cost saving measure. The National Institute for Health and Care Excellence (NICE) said it "is value for money while putting the mother in control" (as cited in Hamilton, 2016). While natural birth is often seen as the feminist and empowered choice for giving birth, by pushing this control to mothers, the responsibility for good health is pushed to them as well, which could marginalise those seen to make 'poor' choices (Hamilton, 2016). Similarly, fertility patients are considered responsible for the outcome of treatment and health of any resulting children. Thus, decision making for fertility treatment needs to be devoted to providing the best care to patients, and not as a method of convincing patients to choose less expensive treatment with promises of comfort.

Feminists have been fighting for a long time for the right to choose whether to have children or not. But the discourse of choice around reproductive health can have downsides, particularly when linked to consumer rights. For example, Craven (2007) studied women in the US who used the rhetoric of "consumer rights" to advocate for legal access to midwives; ironically, the term "consumer" was considered a liberatory agentic alternative to a "patient" who was at the hands of a paternalistic doctor. However, wealthier supporters of this advocation focused on hiring the best practitioners, not on reproductive rights for all. Craven (2007) said this reflects the neoliberal shift away from a state that serves the needs of all citizens in favour of consumers who are self-sufficient. As healthcare systems become more privatised, reproductive options have become more stratified (Ginsburg & Rapp, 1995), meaning that many cannot benefit from "consumer choice" and only some are encouraged to reproduce. This is reflected in the eligibility criteria to receive NHS funding for fertility treatment, for example, those with higher BMIs are excluded. Currie and Wiesenberg (2003) argue that effects of life circumstances on health can only be overridden by those with access to options. Thus, many people with infertility are not able to access treatment despite having the "right" to do so.

While feminists have explored how reproduction is stratified based on economic circumstances (Ginsburg & Rapp, 1995), few have explored the idea that choice is also

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[2] A "fertility treatment that involves directly inserting sperm into a woman's womb" (NHS, 2017a).

stratified based on biological circumstances. Those dealing with infertility were not able to choose to have biological children until the advent of IVF, and even with that, they might not be able to fulfil the choice if treatment does not work. Thus, neoliberalism's focus on agency and responsibility to make individual choices is frustrating for couples with infertility, as ideas of choice and control over one's life and body do not apply (Greil, 2002). Couples can choose to seek treatment if they have the privilege to do so, but they cannot control the outcome. When positioned as consumers, couples with infertility are viewed as needing customer satisfaction (Greil, 2002), which can improve treatment, but can also lead to an overfocus on "success" rates as opposed to safety, informed choice, and comfort. Moreover, the consumer view trivialises the pain that couples with infertility experience and stereotypes them as monetising an experience that is seen as "natural" or commodifying children (Greil, 2002). Thus, focusing solely on economic stratification is insufficient, occasionally offensive, and complicates decisions for couples.

Reproduction is also stratified based on knowledge. Perrotta and Hamper (2023) explain how structural inequalities of choice include "unequal basis in terms of status, knowledge, and ability of judgement between patients/customers and professionals/experts" (p. 237). Most fertility patients value biomedical research but, as there is so much uncertainty in the field, they tend to contextualise information to their lived experience. Thus, they do not undergo unproven treatment out of desperation or because they are uninformed, but rather make complex choices with the little evidence available (Perrotta & Hamper, 2023). However, practitioners tend to prioritise biomedical information over lay perspective which can reify the idea that they are the experts, not the patients with lived experience. Therefore, those with less ability to judge biomedical evidence or to question practitioners could be at a disadvantage as they might not be able to engage in the decision-making process regarding treatment.

Therefore, neoliberalism, patriarchy, and feminism come together to create a complex situation where choices about infertility sit. Couples need to navigate many social messages and barriers to learn about infertility and decide how to act, yet, when they engage with fertility care services, they might not be able to make meaningful decisions. Nevertheless, they are expected to be personally responsible for their own health and advocate for what they need. However, this set of contradicting circumstances overfocuses on individual factors and behaviours which can occlude sociocultural determinants of health and disadvantage those without the time and skills to seek information and engage with practitioners. Currie and Wiesenberg (2003) argue that only individuals can empower themselves but that institutions can facilitate by creating enabling environments. Therefore, in this study, I wrestle with discourse around choice and decision making while attempting to balance the individual and contextual factors that affect those with infertility.

Chapter 4: Methodology

This chapter presents the methods I used to generate data to address the research questions. It starts with a brief note on my philosophical stances and moves to study design, then to a discussion of the recruitment process and interview schedule creation. It ends with a description of the analysis process, ethical considerations, and limitations.

Philosophical Stances

Critical realism postulates that a reality exists but it is experienced and understood through culture and language (Braun & Clarke, 2021a, p. 323). I gravitate towards this philosophy because it combines the best of both ontological realism and epistemological relativism (Alvesson & Sköldberg, 2017), which fits with my realist training in psychology and my current interest in contexts. Additionally, I take a contextualist view to understand the "ambiguous, context-contingent nature of language and meaning, the dependence on theory and interpretation for 'data' to have meaning and 'make sense,' and the political-ideological nature of research" (Braun & Clarke, 2021a, p. 341). This view allows me to explore the realities of living with infertility in a patriarchal and neoliberal society, while centring lived experiences of study participants. It also allows me to see a participant's narrative as situated and provisional, rather than being concerned with accuracy. Thus, in this study, I see my role as helping to generate data with participants and then interpretating those data within a broader context.

Research Design

Qualitative Approach

I approached my research questions using semi-structured interviews which offer a holistic way of exploring depth and complexities (Punch & Oancea, 2014), and are appropriate given my critical realist and contextualist perspectives. Past studies exploring fertility awareness (e.g., Chan et al., 2022; Daniluk & Koert, 2015) and sources of information about infertility and perceptions (e.g., Kahlor & Mackert, 2009) used a quantitative lens. Given my positionality, I endeavoured to hear more directly from people about lived experiences and explore reasons for and consequences of their information seeking behaviours regarding infertility.

Interview Schedule

I crafted the interview schedule to be semi-structured as is common in related studies: OHISB with chronic illness (K. Lee et al., 2015), understanding decision-making around multiple IVF cycles (Copp et al., 2020) and the role of the internet in supporting diagnosis and treatment of endometriosis (Sbaffi & King, 2020). The semi-structured nature enabled me to tailor my questions to participants' journeys and reported information sources, as well as to ask follow-up questions. I aimed for an informal approach to elicit what participants wanted to share, recognising that perspectives could change over time or that they might not represent entire journeys. I was not concerned with capturing whole stories or purely factual data, reflecting my critical realist and contextualist stance, as I do not believe there is one truth to be uncovered. Given that, I hoped to recruit participants at various stages of their journeys to elicit a broad range of perspectives.

I developed my schedule through multiple iterations, first brainstorming basic questions I wanted to ask based on the research questions, then adding questions informed by literature research, such as "What criteria do you use to decide what to read?" (Kahlor & Mackert, 2009), and "Have you talked to your doctor/nurses about the information you have seen online?" (Souter et al., 1998). I piloted the schedule and from this experience, I grouped questions into broad topics and arranged them into a table (see Appendix A). The topics were: journey, diagnosis, explore, quality, other sources, partner, influences, suggestions, and other. As the content did not change substantively, I included this interview data in my findings. During interviews, I asked at least one question from each topic to get a broad spread of responses while not exhausting participants. I also collected demographic data from participants including their gender identity, relationship status, and education and income levels.

Recruitment

I recruited through multiple routes, until I achieved good richness of information in relation to the study aims (Braun & Clarke, 2021b). The inclusion criteria were: self-reported medical diagnosis of infertility for themselves or their partners, unable to conceive or achieve live birth after a year or more of trying, or considering pursuing fertility treatments for any reason; English speaking; and access to the Internet. The exclusion criterion was: never used the internet to access information regarding infertility. I only sought participants from the U.K., as OHISB is particular to geographical context (i.e., using the NHS website). Additionally, given my situatedness within a U.K. charity and desire to effect social change, it is fitting to focus on this area and to give back to this community.

I first recruited through the charity FNUK. It hosts a variety of online support groups, so members were comfortable speaking online about infertility, and thus less likely to find participation distressing. The Network often advertises calls for research participants and members are eager to engage. I also shared the study through social media and used snowball sampling to recruit the remaining participants. I was able to recruit four men through a contact, which I believe was crucial in gaining their trust.

Participants

I recruited 15 participants in total. Eleven participants identified as female and four as male. One lived in Wales and the rest were spread around England. There was a concentration of participants living in Oxfordshire, where I live, a consequence of recruiting through my personal networks. Six participants were over 40 and the rest were in their 30s. Two participants identified as coming from ethnic minorities, one participant identified as Irish, and the rest identified as white or white British. All participants were in heterosexual relationships at the time of the interview, but only one member from each couple participated. All participants originally sought medical investigation for primary infertility and all but two had undergone some form of fertility treatment by the time of the interview. Five participants were finished with their fertility journeys having either had children through treatment or adoption, two had children and wanted to continue treatment for more, and one was pregnant from treatment at the time of interview.

Procedure

I conducted interviews between February and June 2023, and they lasted between one and two hours. The pilot interview was done in person at the participant's request. The remaining interviews were conducted via Microsoft Teams and recorded with the automatic transcription function, which I edited afterward as the quality and accuracy were poor. I focused on accurately capturing what the participants said but I balanced that with coherence by, for example, removing some nonverbal utterances. I tried to capture nuances, such as sarcasm, reported speech, important facial expressions, and gesticulations. I also deidentified transcripts. After each interview, I wrote field notes of my impressions and my reflections (Mauthner & Doucet, 2003).

Analytical Process

I used Reflective Thematic Analysis (RTA) as my method of analysis and NVivo as a tool to support the process. I chose RTA because it is theoretically flexible and values subjectivity, which is key to feminist research (Ramazanoğlu & Holland, 2002), and allows for "giving voice" to my participants while also locating them within the sociological context (Braun & Clarke, 2021a, p. 64). Additionally, I was drawn to RTA as it is appropriate for those seeking “nuance, complexity and even contradiction” (Braun & Clarke, 2021a, p. 53). Reflective Thematic Analysis has six phases that I moved through recursively.

The first phase is familiarisation with data, which I gained through conducting interviews and editing transcripts myself. I created brief summaries of each participant’s journey to situate myself in their individual experience whenever reviewing separate quotes. Phase two is initial coding, which is the process of capturing meaning by assigning brief labels to segments of data (Braun & Clarke, 2021a). I identified some codes I wanted to use immediately, for example, “Journey” for the narrative of diagnosis and treatment the participants shared. I asked participants for suggestions and advice, so I coded those as such. I also asked about specific sources where people sought information, such as “Apps,” “Forums,” and “TV.” Braun and Clarke (2021a) say interview segments can have multiple codes, so I did not worry about trying to break down transcripts into each individual thought. My early codes lacked nuance (Braun & Clarke, 2021a), so I then focused on coding inductively, “where the analysis is located within, and coding and theme development are driven by, the data content” (Braun & Clarke, 2021a, p. 58). This approach is appropriate when researchers are interested in “the experiences, perspectives, and meanings of the participants” (Braun & Clarke, 2021a, p. 134). Through this process I produced additional codes including “Key People,” “Rabbit Hole” and “Visibility.” Then I shifted to coding deductively, for example, I coded for “Delegating,” “Critically Assessing,” “Making Evidence” and “Contextualising” based on the work of (Perrotta & Hamper, 2023). See Appendix B for the final list of codes. Then, I reviewed all transcripts again in a different order, as recommend by Braun and Clarke (2021a), so that I could develop and review themes, as part of phase four of RTA. I engaged in phases five and six simultaneously; over the course of writing up my findings, I refined and named my themes, selecting a few to share.

Ethics

I received ethical approval for this study from the Departmental Research Ethics Committee, indicating that it complied with the university’s policies and guidance (See Appendix C). After this I made one amendment to expand my inclusion criteria to include individuals that were considering fertility treatment for any reason. Following data analysis, all data will remain on the University of Oxford OneDrive for three years.

To ensure voluntary informed consent, I sent information and consent forms to all participants (see Appendix D), detailing what kind of questions would be asked, along with data protection and confidentiality information. The form also disclosed my own infertility, which may have affected who agreed to participate. I provided multiple opportunities to ask questions and withdraw from the study. While the participants were not at risk of significant harm, it can be upsetting to discuss infertility as it is a sensitive topic, so I focused on relevant details required to address the research questions. During interviews, I aimed to decrease issues of asymmetric power relations that can arise because the interviewer determines the rules of interaction (Anyan, 2013). I did so by creating a safe environment for participants by leveraging my experience as a leader of a support group and various counselling training. Further, I built rapport and shared my journey to put participants at ease. Many participants ended the interview saying they enjoyed having the space to share and someone to listen; some even commented that they found it cathartic.

Limitations

This study is slightly limited by being cross-sectional and researcher led. Ideally, I would have conducted a longitudinal participatory action study (Fals Borda, 2005), however, that was not possible because of limitations on the scope and timeframe of this project. The analysis is not generalisable to other populations, though this was not intended as this study aimed to be situated within a specific context. I did not have a second coder for this study but RTA does not value interrater reliability, rather it is intended for only a single researcher to be working on the data (Braun & Clarke, 2021a).

Many participants identified with majority positions or held privilege status, such as white ethnicity, high education, heteronormative relationships, and high income, for example. This is common of research in infertility and specific targeting is often necessary to reach people with other types of identities (Jain, 2006; Lemoine et al., 2021). I also found that information sources people used were correlated with how they had heard about my study, so I shared my study on different platforms, but I was not able to recruit from each one. Also, many participants were finished with their fertility journeys, having had children. As Sykes et al. (2020) suggested, it was unlikely that my study reached anyone in the initial stages of searching for information related to infertility. Given that many participants were finished with their journey and spoke retroactively about their experiences, I had to reconsider the questions I could ask and the detail I could expect, so their stories should be considered interpretive accounts, not objective records (Greil, 2002).

I did not have any participants who identified as infertile but were not interested in pursuing treatment. This means that my participants situated themselves within the biomedical definitions of infertility (Greil et al., 2010). Additionally, no one volunteered that had undergone treatment and then chose to live without children. Infertility and childlessness are stigmatised and talking about them is emotionally draining. It can take time to be prepared to share, so it may be easier to do so when a fertility journey has come to happy resolution. Those that end their journeys without children likely want to move on, leaving the communities that I recruited from, thus not learning about my project. I chose not to actively pursue people who were childless because of infertility, as people may choose to be silent to protect themselves. Therefore, I believe that many studies about infertility will reflect incomplete pictures, as it is not easy, and perhaps not ethical, to reach people at every different stage of a fertility journey.

Despite these limitations these data offer rich insights into lived experiences of individuals who had or wanted to engage with fertility treatment for a broad range of infertility diagnoses. As this dataset includes some male perspectives, it allows for analysis of gender imbalances, barriers to informed decision making, and patient-centred care within a couple accessing fertility treatment in the United Kingdom. Given my positionality as a patient of a U.K. fertility clinic, the data provide me with a broader understanding of experiences. Therefore, this dataset is rich and unique.

Chapter 5: Findings

This chapter details the findings of this study that address the research questions. For the purposes of confidentiality, no identifying information has been included. Gender neutral pronouns have been used except for when the participant's gender is relevant to the analysis.

Study participants told moving stories of distress caused by infertility and fertility treatment. Fertility and infertility were not subjects taught in their schools, and participants detailed struggles they had in learning and seeking information. Many participants initially thought that conceiving would be easy and dealt with identity crises when they learned otherwise. All participants engaged in OHISB to learn about infertility, and many implied it was their main source of information, as numerous offline infertility supports moved online during the COVID-19 pandemic and have not returned to in person formats. In fact, most participants were unable to specify individual sources as the internet is so expansive, interconnected, and comprehensive. Additionally, participants used the verb "google" to imply all types of OHISB and did not mention other search engines. Participants googled to understand complex terms and diagnoses, to research clinics, to learn about treatment options, and to buy medications. Many visited NHS and HFEA websites but continued to seek further support through a mix of internet forums, social media, ebooks, blogs, scientific journals, virtual support groups, and online therapy. Some participants reported seeking stories that mirrored theirs to gain a more experiential understanding of what was to come.

Most participants also detailed their shift from NHS funded care to private care. Women sought information online about why they might not have conceived after trying to for many months and when they should see their GPs. Then, when under public care, participants were at the mercy of the system, and they often had to advocate to be tested. Once under the care of a fertility clinic, many participants were at first glad to defer decision making to experts, feeling a sense of relief to not need to worry about trying to conceive. However, lack of communication led many participants to feel confused and distrustful, driving them to google for clarification and advice. If treatment did not work, participants had to engage in more research and become more involved in deciding next steps. Most sought out private treatment which operates under different rules than funded treatment; patients can self-refer, there are no wait lists, and few limitations to treatment. Private clinics often view patients as consumers and defer most decisions to them. If, after many rounds, treatment did not work, then participants were left to wrestle with the decision of stopping without support from the clinic. All participants demonstrated agency and self-efficacy, searching for what they needed and advocating for themselves; however, poor care and communication with health care practitioners meant the burden of learning fell disproportionately to the couple. Googling was a coping mechanism for participants, but they struggled with lack of consensus in the field and getting caught down rabbit holes. Finally, within the couple, women were responsible for both learning about infertility and making decisions about treatment, another example of a gender imbalance in this realm.

The Burden of Learning is on the Couple

Participants described many instances of poor communication from practitioners and how they turned to Google for answers, meaning they learned about infertility mostly online. When good communication was reported, it was usually with private specialists that participants specifically sought for extra support. What follows are four different ways practitioners push patients to google.

GPs are Resistant Gatekeepers

Most participants arrived at their first GP appointment with a list of questions they had gathered from their online research, of which many would go unanswered. Some participants explained how their GPs acted as gatekeepers to investigations, but once tests were done, GPs did not always explain results:

> the GP said, ‘it's come back normal’ and then I googled and was on forums to find out what was normal and what wasn't normal, and I don't think I even understood whether it was normal or not. I don't know. I got some numbers on a bit of paper that really didn't mean much to me.

Participants often needed to advocate quite intensely to be referred to fertility clinics or prescribed medication and were surprised how resistant their GPs were. Meanwhile, some even had to teach their GP: “I had to educate him on what the World Health Organization sperm parameter stuff was, and I just done that from my own research online.” Participants also reported that GPs did not always know rules for referral to a fertility specialist or to receive funding, adding to participants’ stress as treatment was delayed and they had to search for this information themselves.

Lack of Practitioner Care

A few participants noted that clinic information sessions and websites were informative, others felt that clinics were just trying to push patients into IVF before considering other options. Once they entered fertility clinics, many participants complained that staff did not provide crucial information, as one explained:

> I don't remember there being a lot of time… to process to then ask a question, it's sort of 'this that the other, any questions at the end? No. OK. Well let me know if you got any' and then that's it, you're off again.

Poor care and communication led to a lack of trust so that the participants felt they needed to research on their own, with some feeling the need to verify everything a practitioner said. Many participants noted that cost was a concern for seeking information from practitioners. When asked what advice they would give to others about learning about infertility, one participant said: "don't speak to doctors too much because they cost a lot, that's half the issue." Participants were disappointed that private clinics did not provide a better level of care than NHS clinics. One participant recounted their reaction when a practitioner at a private clinic was late:

> She said to me 'I'm very busy' and I said, 'I'm a chief executive!' … your time isn't worth more than mine… You're rushed because you're trying to make a profit and you're not an NHS understaff clinic. You've chosen your profit margin and that's why.

Thus, regardless of public or private care, participants felt practitioners did not give them enough time to learn about infertility to then make informed decisions.

Confusing Mixed Messages

Participants reported being frustrated by how often practitioners had contradicting stances on fertility issues. It was frequently left to female participants to decide how to move forward, requiring them to research their options independently. One reported a specific conundrum:

> You've got a medical director at the clinic who is like the biggest guy in fertility, with the top immunologist in the U.K. contradicting each other. This is why you can't trust anyone. So, I was like, right, I'm doing my own research then, I'll take your information, then I'll make my own decision.

Male participants specifically felt that not enough attention was paid to men's issues. They did not receive clear information from clinics. One stated:

> I spoke to a consultant, he was saying that 'I advise my clients not to drink,' but then another doctor was like 'you can drink but drink moderately,' but he's like, 'don't drink because it affects you completely. Even one sip of alcohol, the stats show it.'

Thus, participants felt it was their responsibility to research and decide how to proceed, as there was not clear, unequivocal direction from practitioners.

Lack of Holistic Understanding

Participants often reported concerns with practitioners not having holistic knowledge of causes, comorbidities, and complications. Some participants explained specific past events had harmed their fertility but practitioners treating them at the time had not warned them, leaving the participants to research on their own to make sense of what had happened. For example,

> When I had the mumps, they were just treating the fever and that was it. There was no aftercare... it's not like I had a bad leg or something. My testicles had swollen up to the stretching point. It's not a leap to think that could have an effect on fertility. And I'm not a medical professional!

Additionally, multiple participants reported comorbidities that affected their fertility journeys and explained they felt let down that practitioners were not able to handle the complexities.

> Even fertility doctors should be way more clued up about all the different conditions and everything else than they are because they're just not really, and the whole process just sends you down an IVF route. It doesn't matter what your problem is, they don't care about that… it shouldn't be that way, but definitely because it is that way, the Internet is like the, the go between, I guess.

Participants also complained that, when they experienced complications from treatment, emergency doctors would not know enough about fertility treatments. Participants needed to advocate to get scanned for suspected miscarriage or would have to explain treatment side effects while in pain. Again, patients and their partners needed to learn on their own to understand their bodies or to navigate the system.

Benefits of OHISB

This study supports previous research findings that OHISB has some benefits for people with infertility. Below are two benefits reported by study participants.

Googling to Cope

Googling can be a coping mechanism for people with infertility, where they seek support and stories that mirror theirs. Just the act of reading information can be calming, for example, one participant said: “it's good to preoccupy yourself with science sometimes.” One male participant, when asked if OHISB was helpful, said:

> If I didn't look… mentally it would affect me more because there would be no outlet, cause I would just be frustrated with myself, like ‘there's no information, there's nothing for me. Like what do I, where do I seek the help? What do I do?’ like so it was great having that information, even just like an Instagram post or someone talking about, it was great to have that.

Many participants echoed these sentiments, stating that seeking information was soothing or helpful. One participant had gone even farther by collating information that made them feel good:

> I have a Google Doc ‘literature for sanity’, and it's whenever I'm having an absolute meltdown and I want to just go and reassure myself that everything will be OK, instead of going to like search for success stories, I'd be like find me a study that says DNA fragmentation doesn't really impact miscarriage rates... ignore the ones that say it does... I know it's not perfect, but it makes me feel good.

Googling is Empowering

Unsurprisingly, given previous research, OHISB can also be empowering. Female participants found that searching for information enabled them to make their own decisions and challenge practitioners. Two women said:

> The information would give me power… Doctors have all the power, you know, they are physically opening up your bodies and poking you around… It gives you that small bit of power back to question and feel like it's a partnership between a doctor and a patient rather than ‘you are just another plug in a wheel, and you would just do what I say.’
>
> Because I've done my own reading, I've learnt to make my own decisions about things, which feels like it's a bit against the grain because I do want to trust the medical profession, overall, but, I think you do have to trust your gut in this, then otherwise you’re just pushed through this conveyor belt of IVF all the time… that's how it made me feel empowered.

However, female participants were not only seeking medical information, they also sought personal stories to either understand on an emotional level what they were about to undertake, or to feel less alone. Reading about others online helped one female participant reconceptualise her struggles:

> I learned that it's not personal, it's not me… It's not because I haven't been clear enough or polite enough or found the right clinic. It is just the industry and its people's understanding of infertility and people's understanding women's bodies and so I'm not special, it's a theme.

Thus, online health information seeking behaviour was often helpful, encouraging participants to engage with practitioners and to better understand the experience of infertility. While male participants engaged in OHISB, they did not report feeling empowered by it.

Challenges of OHISB

Participants detailed many difficulties with seeking information about infertility and fertility treatment online that harmed their ability to learn. In fact, OHISB can be a considerable burden for couples who are already experiencing distress from infertility and fertility treatment. Below are three factors that make OHISB burdensome for couples.

Lack of Consensus and Detail

Participants complained that despite the vastness of the internet, it did not provide either the right information or clear answers to their queries. Institutional websites are missing a lot of crucial information. For example, at the time of writing, the NHS website does not have a page on adenomyosis[3]. One participant noted a lack of pictures; most websites rely on illustrations which are not clear enough. Many complained that it is not clear how to access NHS funding for fertility treatment. Others stated that more intersectional, inclusive, and interconnected information was needed. When looking at biomedical research, participants understood the limits of science, as this participant stated: "There are no real answers to this and just because one "experiment"… had X results, doesn't mean that it will always be like that." However, participants reported information online about infertility was not pitched at the right level, but rather "was either like really advanced and specific or really general, like 'eggs are harvested' and you're like 'but how'?" Another participant said that the information is not wrong but too simplified and explained: "it's always really difficult when you simplify something because you can almost change the meaning of it." This lack of consensus is so frustrating that, when asked about advice for others looking to learn about infertility online, another participant answered: "don't do it. You don't learn anything… You're gonna spiral out of control, and nothing is right, and nothing is wrong and you're not actually gonna know what the hell is going on with your body."

Misinformation is Distressing but Avoidable

Misinformation is a big concern in this space; however, many participants were confident in their ability to avoid it, saying for example: "I know my sources that I kind of look at and I kind of purposely just dismiss anything I think 'oh that's just rubbish'". Some participants found forums and social media useful for hearing lived experience, however, as one participant explained, people in online communities were often:

> picking up on one particular piece of research or one particular paper that supported what they were selling or pushing, or their belief… I was quite conscious that there was people out there just picking up on a thread that they just wanted to peddle. And actually, there's loads of other research out there that would probably say something different.

Participants reported that, while they had developed the skills to navigate misinformation through their journeys, their friends and family had not, which added to their distress. One

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[3] "Adenomyosis is where the tissue that normally lines the womb starts to grow within the muscular wall of the womb" (NHS, 2022).

participant was sent a website by their friend and said:

> It was a f*cking masked Catholic website… it was just full of lies… and misinformation about how bad IVF was and how it's linked to cancer. But it was packaged so professionally, even my very intelligent, well-meaning friends sent to me.

Thus, overall, the lack of consensus was much more distressing to participants than misinformation. While some misinformation was annoying or insulting, participants found it easy to ignore. However, they felt they devoted, and in some cases wasted, a considerable amount of time researching and sifting through the information, often not finding helpful answers.

Overwhelm and Rabbit Holes

OHISB can be overwhelming, one male participant said there were so many links that "unless you know what you're looking for and what questions to ask, you're probably not gonna find what you really need." The female participants reported more intense negative emotions associated with googling than male participants. Many specifically reported going down figurative rabbit holes in search of relevant information and suffering for it: "It got to a point where I was so obsessive that I couldn't stop and my whole life, my whole world, my whole brain, my whole body, everything was IVF, and I couldn't stop. It was damaging." One female participant who usually avoided searching for infertility information online described a challenging time that led her to google:

> Particularly when things weren't going well with that pregnancy a few years ago and I was googling every scenario of every embryo that was growing slowly… I should not have googled anything… But I just felt like I just was clutching at straws with the positive stories… It's when you're desperate… I probably went down a bit too much for rabbit hole then.

Additionally, some participants found specific online communities to be toxic and it was up to them to navigate all the different resources, testing out what worked for them personally. This was an arduous process as it was often not possible to determine the culture of a community before joining. Many participants explained they only found their way through the vast amount of online information thanks to a key individual who signposted them to the right resources. This could have been a stranger on a forum, a nurse with an active Facebook page, or an academic with access to journal articles. However, as noted, friends and family often sent damaging information as well. Therefore, all participants wished it was easier to learn about infertility and seek information online, and women specifically implied it was a major burden that added to the difficult experiences of infertility.

Within Couples the Burden is on the Women

This study supports previous research that women engage in more OHISB than men. Women decide to approach their GP for investigations, and often push for treatment. Women reported leading the decision to seek private care and the men wanted to support their partners. Additionally, women were responsible for learning about infertility and treatment options, collecting and evaluating information which they sometimes communicated back to their male partners.

Infertility is Not Men's Fault

While most of the female participants described feeling hungry for information about infertility and treatment, they reported their male partners did not. When asked if her partner does any research about infertility, one female participant said: "No, he's fine. Nothing wrong with him. His sperm strong." She even emphasised the point by flexing her biceps, and although she laughed, her frustration was clear. Another woman hypothesised that "you're not as invested as you are when it's like your body… maybe if we had male factor[4], it would be different." The implication is that, for these couples, the diagnosis of infertility was held by the women, even when they had a diagnosis of unexplained infertility[5], so their male partners were not involved in learning and seeking information.

Men Research Their Own Bodies

Conversely, the male participants in this study all sought information about infertility online, though they all have male factor infertility (MFI). Having a medical diagnosis themselves may have led them to feeling more involved; some engaged in OHISB to improve their reproductive health, researching diet and exercise plans and specific treatments such as the surgical retrieval of sperm. However, they noted that their female partners did more research, particularly around specifics of treatment, while the male participants focused on their own diagnoses. One male participant said:

> I've learned in this process that women are more attentive to this sort of subject than men… she was more involved and wanted to know *every*thing that was

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[4] An infertility diagnosis that indicates the biomedical barrier to reproduction lays with the male partner.

[5] An infertility diagnosis that indicates couples have tried to conceive for the required time, but no biomedical barrier has been found with either partner.

> happening… and she's feeding me this sort of information 'OK, don't do this or don't do that.'

This suggests that, within the couples in this study, the women also took on the burden of educating their male partners. But these men may be exceptions as they are all active in the infertility community, sharing their stories and advocating for others. Moreover, all but one were finished with their fertility journeys and reported having come to terms with their diagnoses. One of the few female participants with a partner with MFI reported that during treatment:

> I used to say to him, 'why aren't you involved, why aren't we a team in this?' And it was only when we went to couples counselling, did she say, 'you know, this is 99% of men. Get over it. Just get on with it if that's what you want to do.'

This suggests that in most couples, the woman is more involved in pursuing treatment and overall information. One male participant described a recent event where he was advertising a FNUK support group for men:

> I had a few couples come up to me and asked me about the support group and you could see it was the [female] partner that was doing the talking. It was the man sorta stood behind, 'Oh there she goes'… 'oh I don't wanna be here. I don't wanna ask.' … they just wanted to go and hide under a desk… it's not a representation of they're not wanting to. It's just feeling comfortable and dealing with all their internal emotions wherever they're going through.

Men might not feel comfortable engaging with infertility information or seeking support because of the stigma of male infertility.

Lack of Information for Men

On the other hand, there is not enough relevant information for men available. Even the female participants complained they couldn't find useful information worth relaying to their partners, or that resources were designed for women specifically and were too "pink" and "cutesy." There has been progress in recent years, however, much of that is thanks to a small group of dedicated men, like those quoted in this study, who are keen to improve things for those coming behind them:

> There's been a massive change in like the last 10 years, from basically, there's been nothing for men, there are now companies and individuals talking out about it, which is making it a lot more accessible, and men are becoming more aware of it… We're on the right track. It's gone from nothing, say low, and we're now kind of medium.

Therefore, more information is needed, from credible sources, that is dedicated to men dealing with infertility.

Chapter 6: Discussion

In the previous chapter, I found that in a situation involving a couple and practitioners, for a variety of reasons, women were responsible for most of the learning and decision making along their journeys. This chapter connects my findings to past literature, first by exploring why, even though OHISB can be empowering, it is also a major burden for fertility patients and does not fully support informed decision making. People's choices are not made in a vacuum, rather they are situated within societal structures and messages (Ginsburg & Rapp, 1995). Therefore, I then situate the lived experiences of study participants within U.K.'s socio-cultural context, examining the neoliberal and patriarchal influences on fertility care and OHISB.

OHISB is Insufficient for Informed Decision Making and is Burdensome

While participants reported they googled as a coping mechanism and learning about infertility empowered them to question practitioners and make decisions, they also reported many downsides. They described navigating misinformation, inconsistencies, and rabbit holes, which took considerable time and skill. Additionally, many participants sought answers that did not exist. Brahic and Nauta (2023) said the success of IVF hides how little is known about conceiving, even to the point of obviating the need to understand. However, it is difficult to resolve controversies because of the challenges of running Randomised Control Trials, considered to be the gold standard methodology in medical studies (Perrotta & Geampana, 2021). Therefore, there is little consensus in the field. Moreover, private fertility clinics can recommend treatment that is not well evidenced, and they often disagree on what is best, meaning participants had to use online information to decide for themselves. Thus, for participants, OHISB was a burden that did not always lead them to feeling prepared and informed for treatment.

My findings also suggest existing research is not well translated or communicated to the public, so participants needed to search for a lot of information to gain a good understanding. Past research has found that a lot of information online is confusing (English et al., 2021; Mehr et al., 2020) or that patients find biomedical terms intimidating (Greil et al., 2010), but my study suggests that the information which organisations publish may be too basic. The lack of detail is partly explained by knowledge translation guidelines to present information at the average reading level (e.g., Corcoran & Ahmad, 2016). Participants immediately turned to Google for more information because official sources explain the basic treatment procedures and give advice like "do not smoke." Many organisations also focus on the most common conditions and tend to see patients as static individuals with only one problem, so they do not provide information for various stages or for complex patients with comorbidities. Therefore, these gaps lead participants to research independently, but they might not find the answers they need.

There are many misconceptions about fertility that practitioners are unable to combat. Given previous research, it was surprising that study participants reported that misinformation online is easy to avoid. Sykes et al. (2020) found that people with infertility struggle to judge the credibility of online sources and (Chu et al., 2017) found it was difficult for people to evaluate their ability to spot misinformation. My contrary findings may be explained by bias from many in my participant group being highly educated, though similar bias appears in most studies about infertility (e.g., Grace et al., 2023) or my participants overestimating their ability to identify misinformation. Additionally, our lives are becoming increasingly digital so general online health literacy may be rising. The COVID-19 pandemic brought a lot of discussion about misinformation (Abbasi, 2022), which may have heightened the participants' awareness and skills to identify it. However, it was difficult for the women to avoid descending into rabbit holes, which Prescott and Mackie (2017) found to be a struggle for pregnant women as well. The authors discovered that online information tends towards "horror stories" which increased women's anxiety. Participants in this study reported obsessively searching, particularly when fertility treatment did not work or they were experiencing complications, adding to their distress. Thus, searching online was often upsetting for participants; what started as a coping mechanism became a toxic spiral of searching for more information.

The Burden is on the Couple Because of Neoliberal Policies and Perspectives

Like in Daniluk (2001), study participants felt they were on an assembly line in fertility clinics and the burden of learning was on them. I argue that this burden is inappropriately placed on couples thanks to neoliberal policies and perspectives that are pervasive in the U.K., which, as mentioned, affect the fertility industry. The neoliberalist influence on reproduction is most strongly seen in messaging about third party reproduction, which commodifies gametes and wombs, and egg freezing, which commodifies youth. However, it also appears in more routine fertility treatment and is relevant to my findings of heterosexual couples with infertility.

The NHS is affected by neoliberal policies, which have had a substantial impact on fertility care. When study participants accessed the NHS for fertility testing and treatment, they discovered most health practitioners are siloed by specialty, which fragments care

(Leinster, 2014). Thus, participants felt practitioners were not equipped to handle complicated concerns, such as infertility related to thyroid problems. Leinster (2014) says more generalists are needed for patient-centred care so that people can be treated as whole beings. Additionally, the NHS is fragmented by geography, leading to the "postcode lottery"; only a few areas in the U.K. offer the fertility treatment laid out in the NICE guidelines (NICE, 2013). Moreover, each area has unique eligibility criteria to receive funding (Hamper & Perrotta, 2023). Like Wingert et al. (2005), I found that participants started seeking information online because they perceived that they had a problem and then did not receive adequate information from their GPs. The NHS is underfunded and overwhelmed (Alderwick, 2022), so it is not surprising that participants felt their GPs did not have enough time to deal with their concerns. However, it was unique in this dataset that participants' GPs were often reluctant to refer to specialists, and that patients needed to simultaneously advocate and educate, both about medical issues and funding requirements. Combined with insufficient funding for treatment, this situation indicates a lack of state support for people with infertility.

Like many other industries, COVID-19 has accelerated privatisation of fertility treatment. The number of funded cycles decreased over the pandemic and has not returned to pre-pandemic levels, with only 24% of cycles being funded in England in 2021 (HFEA, 2023). Unfortunately, most NHS clinics have long wait times, leading patients who are otherwise eligible for funding to seek private care over concerns about decreasing fertility. They can expect to pay over £5000 for each cycle, not including medication, thus Kinloch (2018) explains that there is no perfect option for people with infertility, describing the situation as "damned if they do (pay) and damned if they don't" (p. 214). The high price leads patients to enter private clinics expecting a higher level of care than what is on offer at an NHS clinic. However, participants did not always receive that, complaining that private clinics were just as busy as public ones. As one participant suggested, the clinics chose their profit margins over care, meaning they do not take the time to educate patients. Instead, study participants needed to educate themselves to be able to navigate the system.

The neoliberal focus on self-sufficiency ignores unequal societal structures (Hamilton, 2016), which affects who can access fertility treatment. In the U.K. fertility industry, only the wealthy or self-sufficient can seek treatment, as the skills, time, and dedication needed to learn about infertility and navigate misinformation is a considerable barrier. In the US, the government argues that it has a duty to protect mothers from having to make choices, as they might not be able to make informed decisions (Craven, 2007). This is a paternalistic view, though, as discussed, becoming informed about fertility treatment is difficult. Moreover, taking on so much burden to learn personally, removes responsibility to educate from the state and practitioners, which could harm those who cannot do similar research. Likewise, fertility clinics may feel absolved of educating patients as charities, such as FNUK, can pick up the burden, as neoliberalism obligates volunteering to mask the withdrawal of public services (Hyatt, 2001). When I started this study, I expected to focus solely on improving online resources for those in my community. However, just as Craven (2007) found the focus on choice and consumer rights negatively impacted cross class organising for midwifery care, a focus only on improving online information for individuals to access could negatively impact attempts to improve fertility care for everyone. Neoliberalism calls for individuals to make do with less as opposed to refusing to accept less and questioning the sources of precarity. Therefore, this analysis highlights the need to focus on broader structures to enact social change in this space.

Gill and Orgad (2018) argue that neoliberal solutions to precarity are always individual and sometimes technological. Instead of dealing with the causes of infertility or teaching people about infertility, neoliberalism offers a technological fix through fertility treatment and the internet. However, technological fixes often fail and, as with education (Selwyn, 2016), technology is not always good for reproductive health. This study adds more nuance to past research on OHISB, as study participants described how learning about infertility online helped them cope and exercise agency, demonstrating a desire for autonomy and competency (M. Lee, 2017). However, OHISB can also hide the fact that clinics and the state are not doing enough to educate people. Clinics may assume that patients come in having researched the treatment options or assume that they do not need to explain how to self-administer medication because patients can google it. While it is likely not done from malice, stereotypes of those seeking fertility care being highly educated and committed to the process mean that clinics might not reflect on whether they are providing enough information. Instead, they may just trust that patients will find out what they need themselves, thus pushing the responsibility to the couples. Clinics also do not recognise the downsides of OHISB other than exposure to misinformation, such as the feeling of being overwhelmed or getting stuck in rabbit holes. Thus, technology will not solve all problems that arise in fertility care, as such solutions are too narrow and individualistic and given the sociocultural conditions they are generally doomed to fail.

The NHS and U.K. fertility industry construct choice in a neoliberal fashion, focusing on individual decisions based on facts and ignoring the emotional and social complexities involved. It also implies practitioners offer the “right choice” regardless of patient preference. However, study participants noted that practitioners often did not have the “right” information nor did they offer meaningful “choices”. Instead, information was inconsistent and partial. Questioning facts can be seen as resisting the experts and lack of compliance with medical care. Adams (2007) explained that even a patient taking time to decide if she would take medicine that would make her infertile, led her to be pathologised and sent for cognitive behaviour therapy to reframe her resistance as a choice of when to start medication. She argued that the focus on choice, “supposedly installed to increase autonomy, actually functions to decrease it” (Adams, 2007, p. 331). Having the choice to engage with treatment at all is crucial. Sundby (1999) said that infertility is traumatic but that undergoing medical treatment induces more suffering, and both cultural norms and the medical establishment push people towards ever more intensified interventions. Thus, decision making regarding fertility treatment is complicated and study participants felt burdened by this responsibility.

Unfortunately, I found that practitioners mentioned in this study across the fertility industry in the U.K. do not have time to develop relationships with their patients, to gain their trust, elicit and answer questions, and allay fears, all of which is necessary for patient-centred care. Practitioners are often only able to see patients for a brief period, learning about them from scanning their patient notes. Thus, they may only see one view of the patient; a static problem to be fixed with resources available (Hinton et al., 2012). GPs may be reluctant to refer patients to resource intensive tests and treatments, instead suggesting patients keep trying unassisted. Some study participants reported needing to advocate to be referred and experiencing considerable resistance from their GPs. Conversely, fertility specialists only see patients with fertility concerns, so they may over-suggest that patients seek out invasive treatment, often without explaining all the terms, risks, and consequences to patients. Study participants also reported that they were unprepared for their first treatment cycles. Thus, informed decision making is often used to describe the process of informing patients of a narrow range of biomedical options, not actually considering patient values or offering nonmedical alternatives (Joseph-Williams et al., 2014). Meanwhile, societal messaging suggests that fertility treatment, while sometimes difficult, is “successful.” For example, TV shows about infertility always have happy endings (Daniluk, 2001) and clinic websites report “success rates” without appropriate contextual information (Wilkinson et al., 2017). Combined with the lack of public education about infertility, people may start treatment without learning much from experts. Instead, my findings suggest their knowledge comes from what they can learn alone and online, and then they generally have to make decisions independently.

The Burden is on the Woman Because of Patriarchy

The U.K. also has a long patriarchal and pronatalist history that has led to reductionist views of gendered bodies and has affected how people learn about infertility. Historically, the blame for infertility was placed on women, either thanks to past choices or faulty biology (Sandelowski, 1990b). Even when the infertility diagnosis sits only with the male partner, men may deflect stigma by blaming their female partners (Throsby & Gill, 2004). Given the stigma around MFI, little is known about men's reproductive health, which further entrenches these issues.

Infertility is considered a disruption to heteronormative narratives that men and women marry and reproduce (Kinloch, 2018). It is assumed that all women will have children, so making choices about fertility treatment is further complicated when those who deviate from the norm are criticised (Throsby, 2002a). Undergoing fertility treatment is a way to fulfil the pronatalist imperative but treatment is also judged for being unnatural. When treatment works, patients are held up as either winners of the lottery (de Lacey, 2002) or being rewarded for perseverance (Kinloch, 2018). Conversely, when treatment does not work, patients are either labelled as losers (de Lacey, 2002) or are judged for going too far down the route of technological intervention (Kinloch, 2018). This creates another kind of stratified reproduction, where some parents and patients are deemed more socially valid than others. In pregnancy, women are expected to demonstrate that they would make fit mothers by engaging with prenatal treatment, learning about what is best for baby, and buying the right items (Song et al., 2012). Thus, it is not surprising that the women in my study willingly took on the responsibility of learning about infertility to, as Throsby (2014) explains, demonstrate that they deserve treatment by engaging the right amount with technology to be informed and have a miracle child. This balancing act is another burden for women.

Additionally, patriarchal notions have resulted in men's reproductive health being ignored. Fertility is considered inherently female, and men are cast in the supporting role by fertility clinics, which further stigmatises male infertility (Kinloch, 2018). Thus, women in this study shouldered both the physical burden of treatment and the emotional and educational burdens, while the men reported feeling overlooked. However, it is possible that men do not engage in OHISB because there is not enough information available for men. Croissant

(2014) asks if nonknowledge is intentionally or unconsciously created. I argue that, regarding infertility, it is both. The gender binary has led researchers to unintentionally focus on female bodies when asking questions about reproduction. For example, Martin (1991) explained that more is known about the physiology of eggs than sperm, despite requisite technology being available to study both. Furthermore, research is often curtailed by cultural scripts, even new research tends to anthropomorphise cells based on gender stereotypes and supports the idea that the male body is standard (Almeling, 2020).

Unsurprisingly, men in this study reported how little research they could find about methods to improve their reproductive health. Nonknowledge is intentional when authors frame concerns and advice about male infertility in hypotheticals. Almeling (2020) suggests authors write in this way to avoid hurting men’s masculinity and to reassure men that they do not need to be concerned with their virility. This was evidenced in the female participants who reported their male partners did not engage in OHISB because there was nothing wrong with them. Such nonknowledge extends to understanding lived experiences of those with male infertility; men are rarely represented in social science studies of infertility. Moreover, Kinloch (2018) found that when male infertility is discussed, it is done so scientifically and described as a public health risk. This distances individuals from the diagnosis, which is beneficial for not apportioning blame, but negative in that it does not encourage men to shoulder responsibility in treatment or in learning about infertility. Therefore, it was not surprising to find that men are less involved in OHISB about infertility. Men tend to do less OHISB in general, and their general healthcare is supervised by their female partners (Coles et al., 2010). Additionally, as study participants noted, men might not feel comfortable with their emotions regarding infertility. Men have fewer social supports than women (Courtenay, 2000) and often do not feel welcome in most communities for those with infertility, though this is partly explained by the fact that women started the support spaces. The male support group in the FNUK is helping to change that, though many men may still not feel comfortable enough to attend.

Adams (2007) argued that women should have access to information they need to make choices and the time to do so, with the support of practitioners even if they disagree with the final decision. Additionally, Daniluk (2001) found that, in Canada, treatment decisions were not equally shared within a couple; women pursued treatment and men often “capitulated” to their partners. My findings support this, and I add that men should also be given enough information and support so that they can engage in decision making regarding infertility and share the burden with their partner.

Chapter 7: Conclusion

This study aimed to address the following research questions:

- How do people with infertility in the U.K. learn about infertility and fertility treatment to make decisions?
- What role does the internet play in this learning?
- How is this learning influenced by local policy, perspectives, and institutions?
- What improvements could be made to better support those with infertility?

In summary, study participants mostly learned about infertility and fertility treatment independently and online which was a considerable burden. They were not taught about reproductive health in school or by general healthcare practitioners, so they turned to Google to seek answers. These findings are situated in a neoliberal context, meaning there is a focus on profit over care and on solutions that are individual and technological. I argue that, just as fertility treatment is positioned as a technological fix to infertility (Kinloch, 2018), clinics see googling as a technological solution for creating informed patients. Therefore, GPs and fertility clinic practitioners mentioned by study participants did not educate, and instead expected participants to search for information independently, pushing the responsibility of learning to the couples.

Thus, all participants engaged in OHISB which was sometimes empowering and often burdensome. More regulation within the fertility industry is needed so that the burden does not fall only to couples. Many female participants got stuck in rabbit holes of information or struggled to find the right support; thus, I propose that online resources should be improved. Given historical gender imbalances, when men sought information online, it was mostly about their own bodies because of MFI diagnoses. Some reported feeling overwhelmed by the quantity and inconsistency of information, but the men found it easy to stop OHISB. However, the female participants generally reported their male partners did not engage in OHISB at all as they did not view infertility as their problem. Consequently, the burden to learn about infertility and fertility treatment fell more heavily on the women in couples. Women also reported needing to educate their male partners about the process of IVF or educate GPs about funding requirements. I propose that clinics should instead improve their communication and institute truly shared decision making between the triad of the person undergoing treatment, their partner, and practitioners. Just as in education, where Google should not replace teachers (Ideland, 2021), Google should not replace practitioners in the fertility industry. Additionally, the fertility industry should be more heavily regulated to ensure patient-centred care is being provided and people with infertility are being appropriately supported. The remainder of this chapter will address the final research question in more detail.

More Industry Regulation is Needed

From this work, I conclude that one way to curtail the negative effects of neoliberalism on the NHS and fertility industry is to increase regulation and state support. These findings are reinforced by the literature with, for example, Hamilton (2016) having said that the focus on individual mothers’ responsibility for their child’s health, instead of the broader social structure, enables the withdrawal of state services. This is analogous to how women are blamed for their infertility because of past choices, for poor response to treatment, and for health outcomes of children born from treatment. Thus, the U.K. government does not deem it necessary to fund treatment for all individuals with infertility. Hamilton (2016) argued that neoliberal governments limit support for mothering, instead privatising maternal responsibility and increasing intensive mothering, and I argue this extends to preconception care and infertility. The lack of public/state support for those who cannot conceive leads individuals to seek private treatment and information, which means only those with money and skill can do so. Hamilton (2016) also argued the focus on individual consumers making the right decisions for their children occludes social determinants for health. Another example is that research on breast cancer usually frames “personal choice” as decisions about lifestyle, which can lead to victim blaming and distract from structural risk factors such as pollution (Adams, 2007). Likewise, the focus on individual women seeking fertility care can occlude broader causes for infertility. On this point, I must agree with early feminists; biomedicine should not focus solely on overcoming infertility through technology but also explore prevention (Thompson, 2002). Change needs to occur in both what research is conducted and how information about infertility is translated, disseminated, and taught. Additionally, more regulation that deals with social and environmental determinants of infertility may reduce both incidence and distress for all people who are interested in conceiving.

Increased regulation and state support could also improve fertility care for those that need it. My findings suggest that across the NHS and fertility clinics, practitioners should receive more holistic training, both during initial training and as professional development. This would help enable practitioners to see patients as whole beings whose comorbidities influence each other and who experience complex situations that require particular care. More actors should be responsible for discussing family planning; not only should fertility be taught in schools, but it should also be addressed in regular GP appointments. However, my data suggest this needs to be done for both genders in a way that reduces stigma and neutrally provides information about all family planning options, such as living childfree. This could go hand in hand with mandating fertility testing by, for example, women having their ovaries examined along with cervical screenings. Some study participants were surprised that they had to advocate to be investigated for infertility and felt their reproductive health was ignored by the NHS. The government should ensure citizens are holistically cared for. Additionally, all patients deserve both more time with practitioners and patient-centred care. In fertility clinics, this could be accomplished by limiting the number of patients a doctor can treat, or by hiring more staff for education roles. Funding agencies could also mandate that more research focus on or include men. Ideally, the government would end the postcode lottery for fertility treatment funding, but if that is not possible, the government could clarify the approval process to make it easier for GPs and patients to learn.

Resources Should be Improved so OHISB is Less Burdensome

Based on my findings and past research, I suggest that online infertility resources should be improved. Study participants found it difficult to find reliable and relevant information, thus, organisations should create more targeted resources (Shamlou et al., 2022), for example, ones focused on ovarian failure (Jones et al., 2020) or tailored to stages in the fertility treatment process (Tuil et al., 2009). Resources should be collaboratively created by fertility practitioners and patients to fit their needs (Brochu et al., 2019; Haagen et al., 2003; Jones et al., 2020; Lemoine et al., 2021). Based on my findings regarding misinformation, I suggest organisations could provide a library of resources and discussion forums that are closely monitored and frequently updated by practitioners, in agreement with Jia at el. (2021). Study participants wanted to see more detailed information about infertility online, including causes, testing, and treatment, which is well supported by past research (Jones et al., 2020; Kahlor & Mackert, 2009; Lemoine et al., 2021). Contrary to other past research, my findings suggest online information is too basic. Lemoine et al. (2021) suggested sites should start with basic, but not patronising, information and offer the option to “read more” with higher complexity. Some studies found that patients want more graphics and videos (Grace et al., 2023; Rauprich et al., 2011), though participants in this study specifically requested real images over cartoons and fewer pictures of babies on infertility related websites.

These findings also suggest that online resources should be more diverse. Men in particular could benefit from more targeted resources or support spaces. To reduce some of the effects of patriarchal influences on the fertility industry, men's reproductive health should be discussed with more clarity and without hypotheticals. Direct advice on how men can improve their health should be provided. Online support spaces could encourage men to engage with learning about infertility and participating in the treatment process. Websites could be designed either with men in mind or to be gender neutral. Study participants also noted that many websites for infertility and journal articles had offensive or exclusionary language, such as using heteronormative terms, so website creators should work to use more inclusive language. Shifting the conversation and creating more inclusive spaces would reduce the harms caused by patriarchy.

In general, the study participants wished for a "one stop shop" for all, run by a neutral third party, with FAQs, references, and sign posting to further information where relevant. However, it is also crucial to recognise that online resources do not replace in person support and guidance (Brochu et al., 2019).

Clinics Should Improve Communication and Engage in Shared Decision Making

There are many ways communication could be improved between practitioners and patients. My findings and past literature suggest that. during appointments, practitioners should signpost patients early and often to reliable sources to reduce overwhelm with OHSIB (Chu et al., 2017; Haagen et al., 2003; Jia et al., 2021; Kahlor & Mackert, 2009; Marriott et al., 2008). Study participants noted many instances where more information could be easily provided. For example, explanatory information could be included on reports and in patient letters, so that googling is not required for patients to understand what is written. Participants also wished that practitioners were more honest and upfront about the risks and possibilities of treatment. This finding is reflected in Hinton's (2012) work, she found patients appreciated if GPs were honest and "gave realistic assessments of the challenges ahead" (p. e440). Participants were surprised by how much unknown exists in this field but noted that practitioners give the impression of being "all knowing". I argue the discourse of science triumphing over nature that is prevalent in fertility treatment leads patients to believe it is possible to know all. However, when participants began to discover the lack of consensus in the field, it drove some of them to obsession in their search for definitive answers. Practitioners may find honestly discussing the unknowns could help couples and practitioners decide together the best course of action when faced with infertility (Daniluk, 2001).

Another way to combat the influences of patriarchy on the experience of infertility is to purposefully include men at all stages. Most participants noted that men should be included from the beginning, from designing resources with men in mind, to putting the male partner's name on patient files. My findings suggest that clinics should reconceptualise patients in heterosexual couples to be a unit of two people who are being treated together. Male partners should be invited to fertility appointments and asked for their input, so they feel included and to help reduce the burden on women. My findings also suggest there was some variety in the communication that patients prefer; fertility clinics could ask for their preferences (e.g., the mode, the frequency, the level of complexity). Since the burden to make decisions was on the couples throughout treatment, clinics should try to reduce this burden by providing more patient-centred care. For example, clinics should continue to provide support during the last stages of treatment (Tuil et al., 2009), so that patients do not feel the internet is their only source of support. Practitioners also did not adequately help some participants decide when to stop treatment, so, as others have suggested, patients need more information regarding stopping treatment and living child free (Jones et al., 2020; Mounce, 2013).

Finally, my analysis suggests that clinics should shift from a model of informed decision making to shared decision making, so that responsibility to make decisions is more appropriately shared among all parties. The National Institute for Health and Care Excellence defines shared decision making as "a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care" (Carmona et al., 2021). Shared decision making acknowledges that both patients and practitioners have relevant knowledge (Bomhof-Roordink et al., 2019). This would reduce the historical power imbalances between patients and practitioners that have contributed to the current patriarchal medical system. According to NICE, shared decision making should be embedded in organisations and people should be offered resources that encourage them to prepare questions in advance of appointments so they can be actively involved (Carmona et al., 2021). This would help create clinics that facilitate patients to empower themselves (Currie & Wiesenberg, 2003). During appointments, practitioners should create a collaborative atmosphere, which includes informing patients they can participate in decision making and allowing adequate time for them to pose questions. Some participants in this study only became involved in decision making after fertility treatment did not work and may have benefited from being encouraged to participate earlier. The risks and benefits of treatments, and doing nothing, should be discussed in relation to the couple's lives and values, so that patients feel respected and appropriately informed. Verkerk et al. (2022) suggested that allowing patients to reflect and share their values enables the triad of a couple and a practitioner to discuss differing preferences and set expectations for treatment. After appointments, patients should receive a record of decisions made along with more information to help them understand what was agreed, including "links to high quality online resources" (Carmona et al., 2021, p. 2). Changes such as these could reduce the imbalances seen in my findings regarding decision making and reduce the neoliberal focus on individual responsibility for health.

Further Research

This dissertation has contributed to the field of infertility and OHISB studies by adding voices of those with lived experiences of fertility treatment in the U.K. and discussing ways that learning about infertility is a burden. There are many avenues for more research, including expanding this study to be longitudinal, using a mixed methods approach to better understand how people learn about infertility over time, and exploring potential causal links between learning about infertility and treatment or psychological outcomes. Intervention studies could help explore how best to support and educate patients dealing with infertility. The participant group for this study was majority female, highly educated, and reported high online literacy regarding health information, suggesting some findings may be underestimates of how burdensome OHISB for infertility could be for the broader population. Thus, more research is needed to determine how online infertility information could better serve those with infertility who are male, in minority ethnic groups, and with less education. This study could also be repeated with people who pursue fertility treatment for social reasons or who cannot conceive for other known health conditions. As suggested by others, further research could also explore how people who meet the diagnosis criteria but do not identify as infertile (Johnson et al., 2020) or seek treatment (Greil et al., 2010) learn about their fertility. Finally, research about knowledge translation of specific elements of infertility and fertility treatment could be undertaken, for example, exploring how to clearly explain treatment timelines.

Final Thoughts

If any readers are dealing with infertility, participants shared advice specifically for individuals. However, it must be noted that this advice does not replace social change, rather it is immediate support while we work towards substantive change. When you search for information online, set time limits and boundaries for yourself to avoid going into unhelpful rabbit holes. Unfortunately, there is currently a lack of consensus in infertility and sometimes you will not be able to find the answers you are seeking. Advocate for yourself throughout the process and ask questions. Finally, seek supports that work for you.

In conclusion, for study participants, there was little decision making that was truly shared among the triad of the person undergoing treatment, their partner, and practitioners. Instead, the burden to learn and make decisions fell unevenly to the woman, and they relied on OHISB to do so. While learning independently was a coping mechanism and empowering for some participants, it should not be solely their responsibility to educate themselves as it can be burdensome. I argue that these findings are partly the result of neoliberal and patriarchal policies and views in the U.K. that have led to a complex structure which people with infertility must navigate. The fertility industry is mostly privatised and profit driven, and it supports gender imbalances among heterosexual couples that seek fertility treatment. However, change is possible, requiring more regulation and organisational support, as well as improving communication, both in person and online.

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Appendices

Appendix A: Interview Schedule

Journey	What would you like to share with me about your fertility journey?
Diagnosis	Thinking back to when you started thinking about fertility or when you received a diagnosis, how did you go about learning about infertility? Why did you search online?
Explore	How often do you search for medical information related to infertility online? When did you start searching for information online? What do you hope to get out of these internet searches? What methods do you use to search for this information? What search engines do you use? What search terms? How do you decide what to read/watch? What criteria do you use to choose what to read/watch? Are there specific websites or apps you go to often to learn about infertility? What do you like about them? Do you spontaneously see medical information related to infertility online? E.g., shared on social media. Have you visited the HFEA or NHS websites?
Quality	How would you describe the information you find online? Do you find the medical information online helpful? Why or why not? Do you have any struggles finding answers to your questions about infertility online? Do you come across misinformation? Why do you think you find it easy/difficult to search for information?
Other sources	Do you look for information from any other sources? Where else do you see or come in contact with medical information related to infertility? E.g., apps, webinars, books
Partner	What has your partner done in terms of looking for information online? Have you looked at infertility information together?
Influence	How does this information affect your understanding of infertility? How does the information make you feel? Have you talked to your doctor/nurses about the information you have seen online? How do you feel about asking questions to them? How does this information affect your decisions related to infertility and treatment? Have you ever changed your behaviour because of something you saw online? E.g., a complementary treatment, pineapple, McDonald's fries.
Suggestions	Is there anything you would improve about medical information related to infertility online? What advice would you give others who are searching for infertility information online? Why do you think there a lack of information?
Other	Is there anything else about medical information related to infertility online that we haven't covered that you would like to discuss?

Appendix B: Codes

- Advice for others
- Change over time
- Comorbidity
- Decisions
    - Clinic Decision
    - Couple Decision
    - Shared Decision
    - Solo Decision
- Dr. Communication
- Empowerment
- Exercise
- Evidence
    - Critically Assessing
    - Delegating
    - Making Evidence
    - Contextualising
- Gender Differences
- Information Quality
- Initial Fertility Knowledge
- Journey
- Key People
- Lack for Men
- Lack of Details
- Lack of Consensus
- Misinformation
- Money
- Own research
    - Apps
    - Book
    - Forum
    - Journal
    - Online
    - Podcasts
    - Support Group
    - TV
- Partner
- Rabbit Hole
- Skill and Personality
- Suggestions for improvement
- Weight and Diet

Appendix C: Research ethics approval

21 February 2023

Dear [redacted]

Research ethics approval

Research title: Self-Efficacy, the Internet and Infertility

Research ethics reference: EDUC_C1A_23_046

The above application has been considered on behalf of the Education Departmental Research Ethics Committee (DREC) in accordance with the University's procedures for ethical approval of all research involving human participants.

I am pleased to confirm that, on the basis of the information provided to the DREC, ethics approval has now been granted for this study.

Please note the following:

Personal data: It is the responsibility of the PI to ensure that all personal data collected during the project is managed in accordance with the University's guidance and legal requirements.

In-person activities: Any data collection involving in-person interactions with participants must have an up-to-date fieldwork risk assessment in place; further guidance is available from the Safety Office's website.

Amendments: Please notify the committee if you intend to make any amendments to the information in your ethics application as submitted at date of this approval, as all changes must receive ethical approval prior to implementation. The amendment form is available on the SSH IDREC webpage.

We welcome feedback on your experience of the ethical review process and suggestions for improvement. Please email any comments to staff.curec@education.ox.ac.uk / student.curec@education.ox.ac.uk or ethics@socsci.ox.ac.uk.

Yours sincerely

Liam Francis Gearon

DREC Chair

Liam Francis Gearon, PhD, FHEA, FRSA, Docent

DEPARTMENT OF EDUCATION UNIVERSITY OF OXFORD

Senior Research Fellow, Harris Manchester College, University of Oxford
Associate Professor, Department of Education, University of Oxford
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Extraordinary Professor, North-West University, South Africa
Visiting Professor, Irish Institute for Catholic Studies, MIC, Limerick, Ireland
Honorary Senior Research Fellow, School of Education, University of Birmingham

Appendix D: Information Sheet and Consent Form

The Self-Efficacy, Internet, and Infertility Project

PARTICIPANT INFORMATION SHEET

Central University Research Ethics Committee Approval Reference: EDUC_C1A_23_046

You are being invited to take part in a research project. We ask that you review the information below and then indicate whether you consent to participating in the research. Ask us if there is anything that is not clear or if you would like more information.

Why is this research being conducted?

The project is being conducted to explore how individuals access medical information about infertility and/or fertility treatments online, their impressions of this information, and how this affects their self-efficacy regarding infertility or fertility treatments.

Why have I been invited to take part?

For this study, we are seeking the participation of those with infertility and/or have a partner with infertility and/or who are considering fertility treatments, between 18 and 50 years of age, and use the Internet to access medical information regarding infertility and/or fertility treatments. Between 5 and 10 participants will be recruited to take part so we can hear from a range of perspectives.

Do I have to take part?

It is up to you to decide whether to take part. You can ask questions about the research before deciding whether to take part. You can withdraw yourself from the research at any time, without giving a reason, and without negative consequences, by advising us of this decision. The deadline by which you can withdraw any information you have contributed is 31/07/2023. If you choose to withdraw, any data that has already been collected about you will be destroyed.

What will happen to me if I take part in the research?

All participation for this project will occur online. You will be sent a short survey and we will schedule at your convenience an hour long 1:1 online interview of approximately. The survey and the interview will cover topics of infertility, fertility treatments, accessing medical information online, and self-efficacy. Some questions may be sensitive in nature, for example, duration of infertility, treatments sought or considered, and how you and/or your partner handle the difficult nature of infertility and/or fertility treatments. You can choose not to answer any questions and only provide the information you feel comfortable with. You may pause the interview or withdraw from the project at any time. With your permission we may reach out to you to clarify parts of our conversation up until 31/07/2023.

What are the possible disadvantages and risks in taking part?

Participating in this project may be upsetting as infertility and fertility treatment are often distressing topics. All research questions have been carefully considered to reduce distress. As the primary researcher has infertility and has pursued fertility treatments, she will be very understanding, accommodating and supportive throughout the project. You will also be provided with mental health resources. You will not be identifiable in the data and in any research outputs and the information you share will not be discussed with others. If you are already known to the primary researcher, be assured that she will not reference any parts of the interview in future interactions without your permission.

Are there any benefits in taking part?

It is hoped that this research will lead to improved medical information regarding infertility online and lead to further research regarding self-efficacy, to the benefit of other individuals with Infertility.

Will the research be published? Could I be identified from any publications or other research outputs?

The findings from the research will be written up in a dissertation, academic publications, conference presentations and websites. You will not be identifiable in any of these outputs. A copy of the dissertation will be deposited both in print and online in the Oxford University Research Archive where it will be publicly available to facilitate its use in future research. If you wish to obtain a copy of the published results, please inform the researcher.

What happens to the data I have provided?

The data you provide will be stored in a password-protected file on University of Oxford secure servers. We will collect your contact information, survey responses and an audio record of the interview, which will be deleted after transcription. Only the research team will have access to the research data. Your data will be stored for 3 years, after which it will be destroyed.

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the research. The University will process your personal data for the purpose of the research outlined above. Further information about your rights with respect to your personal data is available from the University's Information Compliance web site at https://compliance.admin.ox.ac.uk/individual-rights.

Who has reviewed this research?
This research has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee. (Ethics reference: EDUC_C1A_23_046**)**.

Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this research, please contact [redacted] at [redacted] or [redacted] at [redacted] and we will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

The Chair, Social Sciences & Humanities Interdivisional Research Ethics Committee;
Email: ethics@socsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB

PARTICIPANT CONSENT SHEET

	Please initial each box if you agree with the statement
I confirm that I have read and understand the information sheet for the above research. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any point until **31/07/23**, without giving any reason.	☐
I understand who will have access to personal data, how the data will be stored and what will happen to the data at the end of the project.	☐
I understand that I will not be identifiable from any publications or presentations, or websites.	☐
I consent to being audio recorded.	☐
I give permission for you to contact me again to clarify information.	☐
I understand how to raise a concern or make a complaint.	☐
I agree to take part.	☐

______________________ dd / mm / yyyy ______________________

Name of participant Date Signature

______________________ dd / mm / yyyy ______________________

Name of person taking consent Date Signature