

Invisible people: A story of fertility treatment and loss during the pandemic

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Abstract

This account of fertility treatment during the pandemic weaves autobiographical narrative with empirical evidence to show how infertility and loss is experienced by women in the modern workplace. It charts my experience of fertility treatment during the lockdown of 2020 and draws on recent studies to highlight the psychological impact of infertility, the impact it has on work and career, and the stark absence of workplace support. By offering an in-depth portrayal of fertility treatment, I hope to not only to raise awareness about the experience but also explore the interaction between infertility, health, and work, and how this has changed—for better and worse—during lockdown.

KEYWORDS

fertility treatment, infertility, reproduction

1 | INTRODUCTION

I could have been good at homeschooling, I think. My mum used to work in a school and would have made a great teacher. I learned a lot from her. I would have apologized for my slow response to emails and explained how tough it is juggling homeschooling with work and joked about how the rest of my time is spent emptying and refilling the dishwasher. The challenges of homeschooling and closed nurseries defined the first lockdown for many people in the UK, but sadly not for me.

Me and my partner started fertility treatment at the beginning of 2020 after unsuccessfully trying to get pregnant naturally for three years. Like many other womxn and families going through fertility treatment, our Covid story is largely untold. A few media articles have cropped up and Woman's Hour eventually did a short piece on the

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closure of fertility clinics, but the story of infertility, fertility treatment and loss is somewhat absent from the ongoing Covid media circus.

As the end of the year approaches and we reflect back on what 2020 has brought us, I want to tell our story as it is one shared by so many invisible people. Some of the lucky ones will now be getting excited about their baby's first Christmas or happily enjoying sobriety because they are finally pregnant; but many more of us are approaching the end of the year with sadness and trepidation, pinning our hopes on improving fortunes in 2021.

This article is an autobiographical account of my own experience but will no doubt resonate with many others as it highlights the uncomfortable relationship between infertility, fertility treatment, and the way we work. I use the terms infertility and fertility treatment throughout the article, but they do mean different things as infertility does not necessarily lead to fertility treatment. Infertility is defined by the World Health Organization as "the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse" (WHO, 2018) and many of those who experience infertility do not necessarily undergo fertility treatment. Similarly, fertility treatment means much more than just IVF (assisted conception) as it also includes treatment involving medication or surgery.

I also use the terminology of woman, women and womxn, interchangeably to acknowledge that it is not only cis-women who experience the pain of infertility and fertility treatment. Neither is it something that purely affects couples as more and more women (as it is predominantly women) face social infertility (Baldwin, 2019) and turn to assisted reproductive technology (ART) to support their fertility or start a family. Couples also includes same-sex couples who now account for 6% of all treatments which the Human Fertilization and Embryology Authority (HFEA) describe as a "significant increase" in recent years (HFEA, 2019).

This part of my story starts in March 2020, the month that saw the spread of Covid-19 across Europe and the first national lockdown in the UK. This article charts the following 6 months of fertility treatment and the inter-connecting relationship between the IVF process, academic work, and a international pandemic. As my story is yet to reach its conclusion, I end the article with some closing thoughts on what needs to change to support womxn like me in the workplace and how we can all help to make these difficult journeys more visible and better understood.

2 | MARCH

My own fertility treatment began during the advent of lockdown in the UK. As the street quietened and everyone stayed home, I tried to turn my attention inward and focus on what I was about to do to my body. The first phase of IVF is to switch off the reproductive system, effectively simulating the menopause, before firing it back up again into an overstimulated state. This is why this stage is colloquially referred to as "stimming." For most womxn, a typical monthly cycle sees one egg mature for ovulation but this month my body produced over 30 and I was uncomfortably swollen. It is a cruel irony that fertility treatment mimics pregnancy, making you hormonal and fat.

Working from home due to lockdown made it much easier to hide what I was going through. I could more easily attend the long list of appointments by blocking out unidentified time in my calendar. I would often work from my bed after these appointments as I needed comfort to process the gravitas of what was happening to me. Some days the overwhelm of fertility treatment, Covid and a considerably large dose of sex hormones got too much and hours were lost to anxiety fatigue, but being at home meant I could manage these feelings without question. Or at least attempt to.

Many commentators have warned that a whole swathe of society will suffer from mental health conditions due to the isolation and anxiety that the pandemic created and that the effect will be compounded for those who already struggle with their mental health. Those of us muddling through infertility and fertility treatment almost certainly fall into that category. The impact of infertility on mental health has been well documented and one seminal study found the psychological effects of infertility and fertility treatment are comparable to that of a cancer diagnosis (Domar et al., 1993). More recently, a large-scale study carried out by Middlesex University and funded by *Fertility Network UK* found that feelings of sadness, frustration, and worry were ubiquitous amongst women respondents with as many as 42% having suicidal thoughts at some point during their experience of infertility

(Payne & van den Akker, 2016). The trauma of infertility is being more widely recognized in the fertility community and support is improving but it is almost always privately funded and often informally accessed—I found my infertility counselor through social media—and 75% of respondents to Payne and van den Akker's (2016) survey said they would have accessed counseling services if they were free.

3 | APRIL

I was sedated for egg collection which was the first operation I had ever had. This meant I needed a few days off work but I covered that with sick leave. Because of the large number of eggs I produced, I was diagnosed with mild ovarian hyperstimulation syndrome (OHSS) during my recovery, which left me more bloated and uncomfortable than before. I was fortunate to have only mild OHSS as more serious cases can require hospitalization as a result of fluid on the lungs. After a couple of days off to recover, I took to working quietly in bed as it was more comfortable to lie down.

Only a few days after this procedure, fertility clinics closed under the advice of the HFEA and as with every other business, there was no indication of when they might reopen. More waiting and uncertainty. I was physically and emotionally exhausted by this time and felt like I was living a dystopian reality—scientists were artificially creating life whilst an animal borne virus threatened to wipe out humanity. Life felt so surreal. As the medication gradually left my body and we got used to life at home, we were better able to cope with the anxiety of waiting for the clinics to reopen. Infertility and fertility treatment is all about waiting.

4 | MAY

Clinics are reopening again. In the end, they were only closed for about 6 weeks as a precaution until the virus was better understood and society could adapt. All the worry I had about months lost was unfounded. We were nervous though and uncertain about venturing back into a clinical environment after all the horror that we had seen in the hospitals. We had been hiding away until now and were anxious about what the outside world had to hold. I also did not feel like I had enough time to mentally prepare for what came next—all the drugs but also the possibility of actually getting pregnant. Media pieces circulating at the time were lamenting how risky it is to be pregnant and how awful it is for mothers and newborns. Uncertainty won over desperation this time and we waited another month.

5 | JUNE

My partner was not allowed to join me for any of the preparatory appointments at the clinic. I went in, got scanned, and came out again. It did not feel exciting anymore and there was no romanticism about it whatsoever. Preparation for the frozen embryo transfer meant a return to the synthetic hormone medication. This time, there was more and I felt the effects immediately. First, estrogen three times a day—thrice the dose of what is recommended for HRT patients—then a week of injections that stung like a fresh insect bite every time. Then there was the progesterone to take three times a day, 5–6 h apart. Every few hours, I was taking medication in one form or other, a visceral reminder that none of this was natural. I was once again grateful for lockdown at this point as I could do all this at home. Previously, I had been traveling around the country conducting focus groups at universities and presenting research findings at fancy venues in the capital, not to mention my regular commute onto campus three times a week. This made managing such a well-calibrated medication schedule much easier. The regime had no mercy and on social media you can find many stories of hurried injections in train toilets and awkward exits from boardroom meetings.

Thankfully, my partner was able to attend the embryo transfer so at least he was actually in the room whilst I was being impregnated. When the nurse asked if we had anything nice planned for the rest of the day, we said we were just going back to work, at home, the same as any other day. I could not really focus on work the rest of that day though. As far as I was concerned I was, what is known in the fertility community as, PUPO—pregnant until proven otherwise. Although I had to wait eleven long days until we would know for sure. This was the furthest we had ever got.

Time behaves strangely when you are trying to conceive. There is so much waiting which only intensifies when you start any sort of fertility treatment. Anyone who has been trying to get pregnant for a while is familiar with the “two week wait”—the length of time it takes after ovulation to find out if you have managed to get pregnant. An online search for the “two week wait,” or TWW as it is commonly referred to, will offer thousands of results on how to “survive.” Suggestions typically involve distracting yourself by keeping busy—lose yourself in your work for a while, get creative and crafty, exercise, spend time with friends and family. Good advice but mostly futile during lockdown. As Bourdieu (2000, pp. 224–228) says, “Waiting is one of the privileged ways of experiencing the effect of power” whereby powerlessness, “makes one conscious of the passage of time.”

During my own TWW, as little was known about the effect of the virus on pregnant women I was advised to self-isolate if possible and do things that would help me relax. I was one of the fortunate ones. The weather was balmy so I mostly attended to my garden and allotment. I do not remember much else about that time other than hot days and hot sleepless nights. The time passed eventually though as it always does.

6 | JULY

I was pregnant for the first time ever. Really pregnant as the home pregnancy test confirmed it. So many emotions; elation and disbelief mostly. We were one of the lucky ones for whom one go was all it took. All that sadness, stress, time, and money. I did not quite cry but I certainly could not focus on work for the rest of the day, but what else could we do. The disbelief and subsequent worry lasted longer than the elation but the more I said it out loud, to myself and my family, I started to believe and get excited. Really excited.

I was bleeding a bit but the nurse and Dr Google reassured me that this can be perfectly normal but to keep an eye on it. Not the best start but I was pregnant and as the days past I got more used to the idea. The thought always made me smile.

Less than a week later, I was not pregnant anymore. It was early days but it was brutal. The physical pain, the emotions, and the mess. I will never forget how I felt that week. The loss and the confusion, all senses heightened by the medication of course. My partner did not know how to comfort me. The boiler broke down. My stepson was here for the school holidays. It was probably the worst week of my life. The tears have started again as I write this. I stayed with my Mum that week. I did not know if I was having a “normal” miscarriage or whether I was supposed to keep taking all that medication. Because of Covid restrictions, I had to sit alone in the Early Pregnancy Unit waiting for the results of a test to confirm it was all over. So much time waiting and alone.

I felt better after some time away but trying to work was out of the question. I needed more time. The miscarriage brought all the emotions of the past few months crashing down. All the fear and uncertainty the pandemic caused, the isolation of working from home every day, and the exhaustion of trying to maintain a sense of stability, normality and sanity through it all. So I made the decision to tell my research leader what had been going on.

In the UK, employees going through fertility treatment have little legal protection as infertility is not a protected characteristic and there is no statutory right to undergo treatment. Infertility is not recognized as an illness but neither does it fall within the remit of maternity policy. You fall through the cracks. A legislative technicality means that you are considered pregnant after an embryo transfer and therefore any less favorable treatment would be considered discrimination under the Equality Act (2010) (Payne et al., 2019). However, if the pregnancy

does not continue—which is highly likely given the average live birth rate per embryo transferred in IVF is only 23% (HFEA, 2020)—this legal protection ends.

Early pregnancy loss (miscarriage) is not covered by legislation either and may not be explicitly stated in organizational bereavement policies meaning many women may struggle to take the time off they need for physical and mental recovery. In Payne and van den Akker's (2016) study, only 23% of participants said their organization had policy related to fertility treatment and the absence of a policy corresponded with greater emotional distress. The whole process of conception, however it is experienced, is notably absent from equality and employment legislation at all levels and any time off for fertility treatment is often expected to be taken as sickness absence or annual leave. This despite many women needing to take more than a week off work during one treatment cycle alone with the average number of days being as much as 8.74 (Payne & van den Akker, 2016).

The absence of workplace fertility problems is symptomatic of the gendered organization of work (Acker, 1990) as over 70% of working age women in the UK are in some form of employment (ONS, 2020), an estimated one in four pregnancies ending in miscarriage (Tommy's, 2018) and one in seven couples experience infertility (NICE, 2017; NHS, 2020). Given this lack of legal protection, it is no wonder that those with fertility issues are apprehensive about telling their employer what they are going through. In Payne and van den Akker's (2016) study, the majority of women (72%) did disclose treatment to their employer but this was usually only because they needed to arrange or explain ongoing absences. They did this despite feeling concerned about the effect that doing so may have on their careers (Payne et al., 2019).

I am fortunate to work in an all-women team where we openly declare our feminist allegiance and actively work to improve conditions for women at work. Even then I put off telling my colleagues and managers what was happening. I am an early career researcher on a temporary contract at a time when universities are declaring a state of financial emergency. I feel a need to prove my commitment and capability but how can I do that if I am constantly taking time off for appointments, battling exhaustion from ongoing trauma, and hoping to be off on maternity leave soon? It is difficult enough for women to tell their employer they are pregnant let alone admit they are *trying* to get pregnant.

It was a relief when I told people at work. I never told my two (women) PhD supervisors what I was going through a few years earlier although in hindsight I sincerely wish I had. I know I have the support and sympathy of my colleagues but no one really understands what it is like or what I need. Here is the research gap. If this experience has shown me anything, it is that I am one of the lucky ones and there are many women out there who have little or no support. This may be one reason why the Fertility Network UK study found that 13% of women reduced their working hours and 6% left their job entirely due to fertility treatment (Payne & van den Akker, 2016; Payne et al, 2019).

7 | SEPTEMBER

I do not remember much about August. It rained a lot and I slowly started to feel better. We went out a bit more, saw family and friends. The house was quiet again—just us and our sadness. September was the month to pick ourselves and try again. We started to prepare for the next round of treatment. We were feeling positive and emotionally ready but with IVF, there is so much more to prepare than the body and mind. ART is hugely bureaucratic and the amount of paperwork required makes a mortgage application seem infantile in comparison. As well as all the forms to sign there is also the constant administration—GP appointments to attend, fertility clinic appointments to arrange, test results to follow up, emails that need a response, phone calls at any time of the day. Maybe once you have had several cycles all this becomes routine, but I do not want to get to that stage.

Going through fertility treatment is like having a side hustle. A part-time job to chase a dream, where the outcome is uncertain and you have spent your lifetime's savings on it. This is probably another reason why so many women leave their jobs or reduce their hours, there is just so much to do. There is always something to be done,

planned, considered, or dwelled upon. At least being at home meant I was not having whispered calls to the fertility nurse in the university corridors, or trying to hide the patient portal that was open on my laptop screen, or make excuses for why I was dashing off early again. But it did mean that work and fertility treatment became uncomfortably blurred and there was no real escape or distraction. It is so hard to stop it becoming overwhelming.

8 | OCTOBER

I do not want to be writing this article today. I am having to postpone our next cycle because blood tests revealed my thyroid levels are too low. This means the dose of medication I am taking to regulate it is too high. The only reason I am taking medication at all is because thyroid function is one of the standard tests for subfertile couples. Thyroid issues are thought to affect fertility and there is a chance this could be why I miscarried. Or at least they cannot rule it out. So more waiting. Can I directly blame Covid? Not really. Although it took longer than usual to get an appointment at my GP for a rudimentary blood test and everyone now seems to have more work to do than normal. My heart is broken today. But not for the first time, so I pick myself up and get back to editing the report and completing the ethics form. It probably only means waiting a few more months but this keeps happening— just one more month...and another. After years of this, you would think I would be used to the waiting.

That was a tough week. I struggled to focus and work seemed inconsequential. A couple of weeks later and I am feeling much better. The time is passing and I am making a big effort to stay present and work on enjoying the life I am living right now. Sounds so cliché but it is working. My job is great and I am in such a fortunate position for an ECR and have fewer worries about my security than many of my peers. My job is interesting and valuable, just really challenging right now as it is for everybody. I have been working from home for about 7 months and getting used to the new routine but still pining for parts of my old life to return. In 10 days, my cycle starts again and it will be time for another blood test to see if we can try again in November. Counting time in weeks and menstrual cycles again.

When you are working through infertility, you start to see time differently. It is rhythmic and cyclical as the menstrual month comes around again. Each new menstrual month means we can try again. Sadly, whilst we are stuck in this, Mobius loop time keeps moving forward. We age, our friends' families continue to grow, we get closer to the end of our research project and employment contracts. Eventually, these monthly menstrual cycles turn into years as we commiserate infertility anniversaries. It will soon be time for another difficult Christmas. Whilst the majority of those in lockdown are losing track of the days or the month, infertility time keeps ticking and most women going through it can tell you exactly which day of their cycle it is and how many months are left until our next birthday. The ticking body clock metaphor is never far away.

9 | CLOSING THOUGHTS

On paper, I am an ideal and privileged academic—a young white woman with no caring responsibilities, research only contract, and the support of my colleagues to spend time cultivating my academic CV. But as Utoft (2020) explored earlier in the year, this status does not exempt us from struggling with motivation and concentration as so many of us have during lockdown. For me and others in my situation, these struggles with productivity are compounded by the omnipresence of infertility and fertility treatment. Payne and van den Akker (2016) reported that 85% of respondents felt that treatment impacted their work with 35% feeling it had detrimentally affected their career. I do not feel like the ideal academic right now. I should have finished that paper months ago, my career really does depend on it. I could be blogging or Tweeting about my experience of infertility to reach a nonacademic audience, or applying for some Covid-related funding to expand my PhD research on gender and flexible working. I was relieved to read that even the most prolific writers—journalists and authors—were struggling to focus and create during the pandemic but as months tick by how long can we sustain this inertia?

The idea of the “new normal” must have been invented by capitalists to ensure we keep consuming. Rather, as I see it, adopting a new normal is about accepting and adapting. I should know as I have been waiting and living in a similar kind of limbo for years. Accepting and adapting is not always easy but it is easier with support. I am not the only one dealing with sadness and trauma during lockdown. There will be millions of us silently trying to get on with their own version of new normality but wondering why it is not really working.

Like many of society's taboos, infertility is treated as a very personal and private issue but there are lots of women like me working and campaigning to make it more public and political, often drawing on their own unique experience and expertise to do so. My experience has shaped me and my work, and this article is not just about making infertility visible, it is also a gateway into a new area of research that will use my own expertise to support other women in this situation. I can listen and document their experiences, share findings with the research community, campaign for legislative change, and educate workplaces on the support we need to maintain our jobs and our sanity. As I have shown in this paper, there is some great work out there on the experiences of fertility treatments at work but, if you allow me just one pun to lighten the mood, it is still an embryonic area of study and one that I am only just beginning to explore.

I will repeat again, that one in seven couples in the UK are estimated to experience infertility (NICE, 2017; NHS, 2020) so the likelihood is we will all have a colleague who is struggling, often silently. It is even more likely we have a colleague who has gone through infertility in the past, their stories are just as hidden. We are getting better at talking about pregnancy, maternity, and returning to work after having children (although there are substantial improvements still to be made) but what comes before this is rarely acknowledged.

This is a call to start sharing our stories and exposing our vulnerabilities to help others. It is not easy. It has taken me many months, even years to feel ready to share my experiences and even now I have omitted so much of the raw emotion and pain and the visceral descriptions of what happens to the body. Neither have I discussed the implications of the financial side of fertility treatment—borrowing from family and increasing our debt—as a result of the unfathomably unequal distribution of NHS funding for treatment around the UK. This in itself should be an urgent line of enquiry for sociologists as it means poorer families are routinely excluded from accessing the treatment that some argue they have a human right to obtain (UN, 1995: para 4.1 as cited in Momsen, 2004). Similarly, the intersection of gender, race, and healthcare that means women of color are more likely to experience infertility but less likely to access treatment (Okafor, 2020). These womxn have stories too but we are even less likely to hear them.

I have a platform and privilege, but I may not manage this show of vulnerability again until I am “out the other side,” whatever that looks like for me. I have spent years prioritizing my work—delaying IVF to finish my PhD is just one example—and so now is time to prioritize me. These bigger issues will still be here when I get back.

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REFERENCES

- Acker, J. (1990). Hierarchies, jobs, bodies: A theory of gendered organizations. *Gender & Society*, 4(2), 139–158.
- Baldwin, K. (2019). *Egg freezing, fertility and reproductive choice: Negotiating responsibility, hope and modern motherhood*. Emerald Publishing Limited.
- Bourdieu, P. (2000). *Pascalian meditations*. Stanford University Press.
- Domar, A. D., Zuttermeister, P. C., & Friedman, R. (1993). The psychological impact of infertility: A comparison with patients with other medical conditions. *Journal of Psychosomatic Obstetrics and Gynaecology*, 14, 45–52.
- Equality Act 2010. https://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf
- HFEA. (2019). Fertility treatment 2017: Trends and figures. <https://www.hfea.gov.uk/media/2894/fertility-treatment-2017-trends-and-figures-may-2019.pdf>
- HFEA. (2020). Fertility treatment 2018: Trends and figures. <https://www.hfea.gov.uk/media/3158/fertility-treatment-2018-trends-and-figures.pdf>
- Momsen, J. H. (2004). *Gender and development*. Routledge.

- NHS. (2020). Conditions: Infertility. <https://www.nhs.uk/conditions/Infertility/>
- NICE. (2017). Fertility problems: Assessment and treatment. <https://www.nice.org.uk/guidance/CG156/chapter/Context>
- Okafor, K. A. (2020). *Flipping the script on infertility: Taking back control of life and purpose*. Brown Dog Books.
- ONS. (2020) *Employment in the UK: November 2020*. <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/bulletins/employmentintheuk/november2020>
- Payne, N., Seenan, S., & van den Akker, O. (2019). Experiences and psychological distress of fertility treatment and employment. *Journal of Psychosomatic Obstetrics and Gynecology*, 40(2), 156–165.
- Payne, N., & van den Akker, O. (2016). *Fertility Network UK survey on the impact of fertility problems*. <https://www.nfaw.org.uk/wp-content/uploads/2019/10/SURVEY-RESULTS-Impact-of-Fertility-Problems.pdf>
- Tommy's. (2018). How common is miscarriage? <https://www.tommys.org/pregnancy-information/im-pregnant/early-pregnancy/how-common-miscarriage>
- Utoft, E. H. (2020). 'All the single ladies' as the ideal academic during times of COVID-19?. *Gender, Work & Organization*, 27(5), 778–787.
- World Health Organization (WHO). (2018). International classification of diseases, 11th Revision (ICD-11). Geneva, Switzerland: WHO. <https://www.who.int/classifications/classification-of-diseases>

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