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DOI:

[10.1186/s12884-024-06685-8](https://doi.org/10.1186/s12884-024-06685-8)

Document Version

Publisher's PDF, also known as Version of record

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Peterson, L., Bridle, L., Dasgupta, T., Easter, A., Ghobrial, S., Ishlek, I., Magee, L., Mansfield, A., Panayotidis, I., Rosen O'Sullivan, H., Shangaris, P., Banerjee, A., & Silverio, S. A. (2024). Oscillating autonomy: A grounded theory study of women's experiences of COVID-19 infection during pregnancy, labour and birth, and the early postnatal period. *BMC Pregnancy and Childbirth*, 24(1), 1-14. Article 511. <https://doi.org/10.1186/s12884-024-06685-8>

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RESEARCH

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Oscillating autonomy: a grounded theory study of women's experiences of COVID-19 infection during pregnancy, labour and birth, and the early postnatal period

Lili Peterson¹ , Laura Bridle² , Tisha Dasgupta³ , Abigail Easter³ , Stephanos Ghobrial⁴ , Irem Ishlek⁵ , Laura A. Magee^{3,6} , Amanda Mansfield⁷ , Ismini Panayotidis⁸ , Hannah Rosen O'Sullivan^{3,9} , Panicos Shangaris^{3,9} , Anita Banerjee^{3,9†} and Sergio A. Silverio^{3,6*†}

Abstract

Background Testing positive for COVID-19 was associated with higher rates of detrimental psycho-social and physical health outcomes. The COVID-19 pandemic caused unprecedented disruption to everyday life. This included major reconfiguration of maternal, child, and perinatal mental health and care services and provision. This study aimed to investigate the experiences of those who tested positive for COVID-19 during pregnancy, labour and birth, or the early postnatal period.

Methods National on-line recruitment from across the United Kingdom resulted in sixteen mothers being invited to qualitative semi-structured interviews to understand the experiences of mothers who had been infected by COVID-19 during pregnancy, labour and birth, or the early postnatal period. Interviews were conducted, recorded, and transcribed using video-conferencing software. A Grounded Theory approach was used to analyse the data gathered pertaining to women's experiences of their positive COVID-19 diagnosis during pregnancy, labour and birth, or the early postnatal period.

Results The theory of 'Oscillating Autonomy – Losing and Seeking to Regain Control by Striving for Agency' was developed, comprising three main themes: 'Anxious Anticipation: The fear of infection was worse than COVID-19 itself'; 'Fluctuating Agency: What changed when COVID-19 took control'; and 'Reclaiming Control: Seeking reassurance during COVID-19 positivity'. Testing positive for COVID-19 whilst pregnant, during labour or birth, or in the early postnatal period was associated with a perceived loss of control. Those who were able to regain that control felt more secure in their situation.

Conclusions Support was paramount to manage increased vulnerability, as was reassurance achieved by information seeking and positive action including increased health monitoring and COVID-19 vaccination.

Keywords COVID-19, Perinatal period, Pregnancy, Childbirth, Postnatal, SARS-CoV-2

[†]Anita Banerjee and Sergio A. Silverio share joint senior authorship of this manuscript.

*Correspondence:

Sergio A. Silverio

Sergio.Silverio@kcl.ac.uk

Full list of author information is available at the end of the article



Background

Pregnancy, labour and birth, and the early postnatal period are monumental lifecourse transitions in any woman's life and care *should* and usually *does* reflect this. The novel coronavirus – SARS-CoV-2 or 'COVID-19' – caused unprecedented disruption to everyday life [17]. This included major reconfiguration of maternal, child, and perinatal mental health and care services and provision [4, 10, 25, 42, 43, 49] and, detrimental health outcomes, in general (i.e., higher rates of intervention [19]), and for those who tested COVID-19 positive during pregnancy (i.e., higher rates of stillbirth, pre-eclampsia, and preterm birth [50]). Given the pandemic status of COVID-19, the media (both press and social) was regularly reporting on the situation, and very quickly most people found themselves or someone they knew with a COVID-19 positive diagnosis. Women were made very aware of the dangers of contracting COVID-19 during pregnancy, given that national health guidance was being constantly updated and issued, and was highly publicised in the media [27].

Evidence from studies across the world demonstrates the negative effects of COVID-19 infection on perinatal women's physical and mental health as well as the associated restrictions to daily life producing negative outcomes. For example, pregnant women in Turkey were seen to have high levels of fear and anxiety during the pandemic [35], whilst those whose pregnancy and birth were affected by associated lockdowns were seen to have higher rates of depression and lower rates of maternal bonding [37]. In Italy, where COVID-19 first took hold in Europe, and where an enormous amount of fear amongst the perinatal population has been reported in relation to COVID-19 and lockdown experiences [15, 40]; women who tested positive for COVID-19 during pregnancy or their labour and birth were found to have higher rates of postnatal depression compared to those who did not, suggesting it was having the infection itself which was affecting perinatal mental health [5]. Also, they had more health-related anxieties, higher rates of separation from their new-borns (due to infection control measures instituted by healthcare systems), and lower rates of breastfeeding [5].

A cross-sectional study performed in Ireland, Norway, Switzerland, The Netherlands, and the United Kingdom [UK] between June and July 2020, found the prevalence of depression and anxiety in pregnant women to be as high as 15% and 11%, respectively [7]. Data reported from the UK, found significantly higher rates of depression and anxiety (i.e., approximately 40% and 30%, respectively, [7]). Also, mothers in the UK and up to twelve weeks postnatal had rates

of clinically-relevant depression and anxiety (43% and 61%, respectively) which were much higher than population estimates (16% and 14%, respectively) [12].

In a study reviewing the psychosocial experiences of new mothers in London during COVID-19 [36], findings offered potential explanations for increased maternal distress. These included – the uncertainty about how maternity services were to change, a reduction in the number of physical appointments offered and, exclusion of partners at antenatal appointments and during labour and/or birth.

Thoughts of lack of support and loneliness were vocalised by new mothers in a separate study [20]. It was also found that COVID-19 had been experienced as a prenatal trauma, leading to an amplification of vulnerability to mental health symptomatology and lower levels of foetal attachment amongst pregnant women [13]. Pregnant women also experienced a loss of choice and autonomy during the COVID-19 pandemic, being informed they cannot have their desired birth plan, sometimes with very short notice [43]. There is also a feeling of lack of control and powerlessness with delayed appointments, changed or disrupted [21, 38]. Similarly, new mothers felt a lack of independence postnatally due to lockdown measures restricting them from leaving the home [20].

The aim of this study was to examine the psychosocial experiences of women in the UK who tested positive for COVID-19 during their pregnancy, labour and birth, or the early postnatal period, to inform a richer understanding of these experiences and how to improve care if and when another health system shock arises.

Statement of significance

Problem or Issue

The COVID-19 pandemic completely changed the landscape of how antepartum, intrapartum, and postpartum care was delivered, and whilst much has been written about the perinatal experiences during the pandemic, less has been written about the psycho-social impact for women of a positive COVID-19 diagnosis during pregnancy, labour and birth, and the postnatal period.

What is Already Known

Globally, women have reported high levels of dissatisfaction with their maternity care during the COVID-19 pandemic and in the UK especially, maternity services had been completely reconfigured in order to reduce infection transmission to pregnant, birthing, and postnatal women. Perinatal women have also reported higher rates of mental health issues related to the pandemic.

Statement of significance

What this Paper Adds This study found that loss of control and lack of support available to perinatal women was a key feature in them feeling vulnerable during pregnancy, labour and birth, and the early postnatal period during the COVID-19 pandemic. Those who were able to regain control by effective support networks, vaccination, and high quality information, felt more secure in their situation.

Participants, ethics, and methods

Study design

We designed a qualitative [39], Grounded Theory [16, 45] study, employing semi-structured interviews [33] with the aim of understanding the experiences of mothers who had a positive COVID-19 diagnosis during pregnancy, labour and birth, or up to six weeks postnatal. Guidance for qualitative research into sensitive topics was followed [46]. A critical realist ontological approach was adopted, thereby enabling an empathic, but critical understanding of the participants experiences [1]. This was coupled with an objectivist epistemology where the interviewer and analyst are objective outsiders [1]. This approach assumes participants recount their lived reality in interviews, whereby accounts may not be *true*, but is their *lived truth*, and that these subjective versions of reality are more important than objective facts, and in and of themselves bring us closer to the truth through knowledge acquisition [28]. With regard to our positionality, we engaged a critically empathic reflexive judgement towards our participants and their data, whereby we accept certain acts are value-laden, however, some acts are performed due to social pressures and in-line with societal norms. Our own position within the data is somewhat more complex as we represent a large collaborative who co-authored the manuscript, including a medically-trained Public Health Master’s student [LP] who was supervised by an Obstetric Physician [AB], a Psychologist [SAS], and a Perinatal Mental Health Midwife [LB]; and then worked

with Junior Doctors [SG, II, IP, HRO’S], and others with expertise in Public Health Inequalities [TD], Perinatal Psychology [AE], Obstetric Medicine [LAM], Obstetrics [PS], and Midwifery in Ambulance Services [AM].

Ethics

Ethical approval was sought from and granted by the King’s College London Research Ethics Committee (3 October 2022; ref:- LRS/DP-21/22–22282). Participants were provided with an information sheet which contained details of privacy, confidentiality, and data usage and storage. They were then asked to provide informed consent by signing an electronic consent form before participating. All participants were reassured their participation was voluntary, they could withdraw at any point during the study, their data would be anonymised during transcription, and their transcript would be assigned a unique code.

Recruitment

Recruitment of participants ($N=16$) for semi-structured interviews took place in the UK between October and November 2022, according to set inclusion and exclusion criteria (see Table 1) and using these mechanisms: (i) e-mails to participants of another study where they had agreed to be re-contacted by other researchers working on similar research ($n=13$); (ii) national social media advertisement of study posters ($n=2$); and (iii) participant snowballing ($n=1$). The other study through which recruitment took place, was a study focused on post-pandemic maternity care planning in the UK (RESILIENT; [29]). This study was over-subscribed with potential participants interested in being interviewed, therefore we purposively sampled those who had stated they were happy to be contacted about future projects and were known to have had a COVID-19 positive diagnosis during pregnancy or postnatally ($n=169$), inviting all to interview and recruiting those who replied positively ($n=13$).

Table 1 Inclusion and exclusion criteria

Inclusion	Exclusion
Given birth in the United Kingdom	Did not give birth in the United Kingdom
COVID-19 positive test result during pregnancy, labour and birth, and/or the first six weeks post-partum	Did not have a COVID-19 positive test result during pregnancy, labour and birth, and/or in the first six weeks post-partum
Given birth during the COVID-19 Pandemic	Baby has passed away since delivery
Given birth within the 24 months prior to the date of interview	Under the age of 18 years
	Are still in hospital due to ill-health or whose baby is still in hospital
	Has learning difficulties or severe mental health issues
	Those who cannot converse in English

COVID-19 vaccines were first rolled-out in the UK after December 2020. Although not asked directly, fifteen participants disclosed their vaccination status spontaneously. Six women were vaccinated prior to pregnancy (including one who had been discouraged from pregnancy to ensure vaccination); one woman tested positive with COVID-19 for the first time and was vaccinated around the time of conception; and two women were vaccinated during their pregnancy. Six women were vaccinated after pregnancy (including one woman was recommended to wait until after pregnancy to be vaccinated and three for whom vaccination would not have been available due to giving birth between December 2020 and January 2021). Other pandemic-related factors are listed in Table 2.

Participants were aged between 29 and 42 years old. All were employed or in full-time education, although some were employed part-time or on maternity leave at the time of the study. All participants, bar two had given birth within two weeks of their due date. Of the two who did not, one gave birth to twins two and half weeks early and another had an emergency caesarean-section at six months gestation. Only one participant had a home birth, with all other women giving birth in hospital, with almost half via a caesarean-section. Women included in the study, had received a COVID-19 positive diagnosis at varying points during the perinatal period, between conception to one-week postnatal. Of note, were participant 7 (who had COVID-19 at 28-weeks and underwent an emergency caesarean section); and participant 12 (who had COVID-19 at 8-weeks, after which she suffered from debilitating long-COVID and had a vaginal birth). Full demographics are in Table 3.

Data collection

The interview schedule (see Appendix 1) was developed by the research team and adapted after consultation

with key stakeholders (e.g., lay members, clinicians, and policy makers). The interview began with information gathering on demographics, followed by questions on the beginning of the pregnancy, the experiences women had of their maternity care, and then end of the pregnancy; before specific questions were asked about women's COVID-19 infection, the postpartum period; and ended with final reflections on care, maternity services, and the pandemic. Interviews were semi-structured [33], to allow for similar questions to be asked of all questions, but enough flexibility in the schedule in order to respond to individuals' stories. All participants were interviewed using Microsoft Teams [LP, SAS], whereby audio was recorded and automatically transcribed, which were then manually checked for accuracy against the recording. Memo notes were made during and immediately after each interview about the most pertinent points of each participant's interview.

Data analysis

Grounded Theory Analysis [16], appropriate for cross-disciplinary health research [45], see Table 4), was utilised. The rationale was that the research group was a large inter-disciplinary team, and our interest was in finding out how a specific population (perinatal women) experienced a specific phenomenon (COVID-19 infection) in a specific context (UK pandemic circumstances and maternity care). Coding of data pertaining to women's experiences of their positive COVID-19 diagnosis during pregnancy, labour and birth, or the early postnatal period was undertaken 'by hand' using Microsoft Word (LP, SAS). Coding was first done sentence-by-sentence whereby each sentence was coded using a verbatim word or phrase to summarize the sentence; after which focused coding was undertaken, providing more conceptual codes to larger sections of the coded data. Analysis was consultative with regular meetings between analysts [45],

Table 2 Pandemic-related factors

Characteristic ^a	Respondents (N = 16)	Participant ID Number
<i>Year of the Pandemic in which Women Gave Birth</i>		
Year 1 (March 2020 – February 2021)	4	6, 7, 8, 14
Year 2 (March 2021 – February 2022)	7	1, 3, 4, 9, 12, 13, 16
Year 3 (March 2022 – February 2023)	5	2, 5, 10, 11, 15
<i>Time of COVID-19 positivity^b</i>		
At conception	1	1
Pregnancy (Antepartum)	11	1, 2, 3, 4, 5, 9, 10, 11, 12, 14, 15
Labour and Birth (Intrapartum)	3	7, 8, 16
First Six Weeks after Birth (Postpartum)	2	6, 13

^a Only categories for which we had participants were included in this table

^b One participant was COVID-19 positive twice – once at conception and once during pregnancy

Table 3 Full demographics

Characteristic ^a	Respondents (N = 16)
<i>Age of participant (Mean = 36 years)</i>	
25–30	2
31–34	4
35–40	8
41–45	2
<i>Marital status</i>	
Married	12
Co-habiting	4
<i>Parity</i>	
1	8
2	6
3	2
<i>Ethnicity</i>	
Black	1
Mixed	3
White British	10
White Other	2
<i>Faith</i>	
Buddhist	1
Jewish	1
Christian	6
No faith	8
<i>Geographical spread</i>	
London	8
East Midlands	2
East of England	2
North East	1
South East	1
Scotland	1
Wales	1
<i>Pregnancy management</i>	
Midwifery-led	6
Consultant-led	6
Midwifery and Consultant mix	4
<i>Mode of birth</i>	
Vaginal ^b	9
Elective Caesarean Section	4
Emergency Caesarean Section	3

^a Only categories for which we had participants were included in this table

^b Included one woman who gave birth to twins

which also facilitated the generation of super-categories, final themes, and the overarching theory. Constant comparison between new transcripts and previously-analysed ones, as well as consultation with memo notes made at the point of interview, allowed for a highly reflexive and consultative analysis. Recruitment ceased when there was data saturation (whereby no new concepts emerged

from additional data) reached at twelve participants; and theoretical saturation (where there was enough data to support each emergent theme) was reached after sixteen interviews.

Results

The analysis comprised of three main themes: ‘The fear of infection was worse than COVID-19 itself’; ‘What changed when COVID-19 took control’; and ‘Seeking reassurance during COVID-19 positivity’. Themes are supported by the most eloquent and illustrative quotations, preceded by each participant’s unique number. Supplementary quotations can be found in Table 5.

Anxious Anticipation: The fear of infection was worse than COVID-19 itself

This theme describes participants’ anticipatory anxiety about contracting COVID-19, the precautions they had taken to prevent infection, and their experience when they actually contracted COVID-19. After infection, the majority of participants felt that the previous fear of infection had been worse than the physical symptoms of the infection itself. Firstly, the anticipation of hypothetically contracting COVID-19 was anxiety-provoking for many participants:

P11: Having had COVID, I don’t really... think it affected me, it was beforehand. It was the worry and they’re being extra cautious that sort of meant that I was stuck at home during my pregnancy.

P5: I was terrified about getting COVID and anything else infectious, to be honest.

Due to this fear, many described the precautions they had taken to avoid infection. Participants describe losing their ‘freedom’ as a result of avoiding social situations and leaving the home, burdening themselves to avoid child-care, as well as delaying pregnancy to await vaccination.

P4: And like there were COVID outbreaks in his nursery, like three times in December [2020]. And we were like, right. So, for my last trimester, is it sensible to take him out of nursery ‘cause in our lives, like the one main risk of us getting COVID is nursery. So, we had arranged for my dad to look after <Child’s name> so that he didn’t have to go to nursery for the last three months of my pregnancy.

P2: I didn’t want to get pregnant until they’d had both of my vaccinations, so we put off having a child.

This fear and worry could be further exacerbated by past negative experiences, highlighting the perceived fragility of their pregnancy:

Table 4 Grounded Theory Analysis Methodology (adapted from [45])

Study Phase	Brief Description of Data Handling Stages
1. Study design and development	Interview schedule has been produced to facilitate open dialogue with participants
2. Preparing the data	Interviews to be recorded and transcribed
3. Cleaning the data	This involves checking the transcripts for correctness and ensuring all team members are familiarised with the interviews
4. Coding	Firstly, by Open (Sentence-by-Sentence) coding – Involves reviewing interview transcripts line by line and summarizing each line into one or two words Secondly, Focused (Axial) coding – Grouping open together, reducing the total number of codes
5. Theme development	Development of Super Categories (Sub-Themes) – By merging and rearranging focused codes together Creating themes – Through combining of Sub-Themes
6. Theory generation	Consulting with field notes – To ensure there is an answer to queries researcher had Generating theory – Developed by establishing relationships between themes
7. Defence of theory	Within team defence – Analyst must explain and defend their theories to team and consensus met Interpreting theory – By explaining the relationships between the themes, a narrative can be found to explain the theory Framing theory – Establishing the relationship between each theme to one another. Must be framed amongst existing literature to ensure cohesion
8. Writing-up	Demonstrating how the findings have produced said theory, using quotations to support this
9. Testing the theory	On different populations to establish whether this theory 'holds true'

P13: Yeah. Just because I think probably more cautious than if I'd got pregnant sort of without IVE. I think just because I... I was so... We've been trying to conceive for a while, and I think I just didn't... I was really impatient to be pregnant, stay pregnant and not have anything kind of derail that so I just need to really careful.

This worry deepened when the positive test did arrive, citing the media, or stories they had heard displaying horror stories. This made many of the participants feel their vulnerability in the pandemic, knowing that there could be very serious ramifications to both them and their baby:

P4: I do remember just messaging a friend being like. Yeah, like I've seen cases of ladies in the news that have, like, gone into a coma. And they died. And their babies died. Or maybe their babies lived, and they've died. But my baby is, at an age where I know that it's beyond medicines reach to save it. So basically, if my immune system fails now, which I don't think it's going to, but like if it did like, that's me and my baby both dead. And that was quite scary to think.

P16: One of the mums that I looked after her daughter was pregnant during COVID and she was so ill, and she ended up on a ventilator and she was... she had it really bad... So that was all that was going through my mind. And then I think we previous there was a story on the news about a mum who was late in pregnancy, got COVID, had an emergency

C-section and bless her she never woke up.

Then, after the infection, many expressed how lucky they were that it 'was not that bad'. However, they did appreciate that they were extremely fortunate, knowing that others had not fared as well, and justifying their prior fear and worry.

P1: Fairly, asymptomatic. Yeah, so I didn't have an experience which I'm sure some woman did where I was breathless, and I had a high fever. And, you know, I think if that had been the case or if I'd felt seriously ill, I think that would have, that would have been much worse. But... But fortunately, I was. I was OK.

However, for some who were negatively affected by the disease, the opposite sentiment was expressed, and again, explaining and justifying their prior worry and fear:

P7: They kept doing the monitor and then all of a sudden and my husband had come to bring me more things and he had just finished his COVID isolation. I came back positive, so I was still in hospital isolation and all of a sudden, they were saying that the baby's in distress and they need to take him out.

Fluctuating Agency: What changed when COVID-19 took control

This theme describes the practicalities and logistical issues of actually having COVID-19 whilst pregnant. This starts with the symptoms, but also account for the practicalities of the physical toll of being 'sick' whilst pregnant or when having to care for a newborn. It then also

Table 5 Supplementary quotations

Anxious Anticipation: The fear of infection was worse than the disease	Fluctuating Agency: What changed when COVID-19 took control	Reclaiming Control: Seeking reassurance during COVID-19 positivity
<p>P1: I don't think the having of the COVID affects it particularly, I think it did add a level of complexity and it added a level of anxiety, you know, in the at the very beginning when the baby is just forming and it's a fetus you think got anything in your you know it's so vulnerable and anything could tip it into not being viable</p> <p>P9: It definitely worried me because you do think of that you my head always goes to the worst case scenario is like is this it? Is that it? Have I you know- Has my husband put us all at risk and that's it I'm going to die</p> <p>P9: And I think I was very lucky. You know, things worked out well for me. I so you know, it was whilst it wasn't a great situation. I look at the positive that you know it wasn't horrendous. It was, yeah, it wasn't great, but it wasn't horrendous</p> <p>P11: Umm, I was really upset because I felt like I'd taken so much care not to get COVID that I didn't go. I didn't really see anyone. Everywhere I went. I wore a mask. Uh, yeah, I was really. I was really upset and annoyed with myself. I mean, the fact that our daughter was still going to nursery was that was necessary in order for us both to work. We couldn't have her at home</p> <p>P12: You know, if I hadn't of been pregnant when I had COVID, I probably would have recovered a lot quicker because it's just not the ideal way to get better by having a baby</p> <p>P13: I think having ADHD gives you brain fog and memory loss and stuff like that. And I was like, I'm not. I don't wanna have. I know what that's like and I don't want it to be any worse than it is</p> <p>P15: It felt like second trimester was quite a lucky if you had to have it. Probably not a bad time to have it so I ran that past a doctor who was scanning me and she said "yes"</p> <p>P16: OK, baby's coming. I'm by myself. I'm terrified. I've never had an operation before, so I've never had an anaesthetic</p>	<p>P1: I phoned up and I, you know, so I phoned up and I said I need to come in. I phoned the sort of switch I think I need to come in. I'm COVID positive and they said OK give us, you know, give us half an hour or I can't remember how long. It wasn't very long, and they were like well, we'll set up a room for you so you know I went in. I wore a mask and in the waiting room I was shown into a room that they sanitized, and a midwife came in and full PPE and she put the monitor and did the monitoring and then I left. It was exactly the same experience</p> <p>P4: And my breathing was slightly felt, a bit restricted and. I mean, I was pregnant, so maybe that's part of it as well</p> <p>P7: And I talked to my husband, but he couldn't see me. I was still in COVID isolation, and there was no clear protocol when you tested positive in the hospital. How long?</p> <p>P7: Yeah. I just think that's really wrong and that was probably the most traumatic thing about all of this is just the fact that we were separated, and I couldn't see him</p> <p>P9: A chest infection and then I got tonsillitis. I just felt like I got a lot of illnesses from being run down and I never really got could shift them until I'd had the baby. And so that's why I think I was sort of like I'm done. I just want this baby out now</p> <p>P10: I don't know if I was tired anyway, so I don't know who I was and I was achy anyway. My back was sore. I was tired, so I don't know if it was pregnancy or COVID, but I didn't feel extra affected by anything though</p> <p>P12: I didn't really have that many symptoms and the main thing was that the fatigue just was getting worse, and we didn't really know whether it was pregnancy related or COVID related and but when we got into the second trimester, my midwife said, like you really should be feeling better by now. And she said, I don't think this is pregnancy related. I think it's COVID</p> <p>P15: Just this cough and then a long time after I had a kind of. That, like feeling of your like, needing to clear your throat that took months to go</p>	<p>P2: They originally said, you know, don't even try and get pregnant for two months after you've been vaccinated and that you couldn't get vaccinated if you were pregnant or if you were breastfeeding. And so I think. Then they changed all of that, but I think that information left quite a legacy</p> <p>P5: They sent me a pulse ox, so I was checking that and my heart rate and that all stayed very normal. So that was nice</p> <p>P6: I guess because being a doctor and because my husband's a paediatrician, we knew that the data that was about children and babies especially that they tended to be fine. So that was a huge relief. I think it had been, you know, something like a flu that affected kids, it would have been a very, very different matter</p> <p>P6: But they came round anyway. They came around to the house. They just put their PPE on. And the kind of FFP3 masks and and were great and didn't make any fuss about it. They just wore the right PPE and protected themselves</p> <p>P11: But the community midwives they came around and dropped off the monitor and everything. And then they said basically said I sort of left to it. I was told if you feel worse, call us. I was told that someone would call me sort of midway through the week and check how I was doing, but no one did</p> <p>P16: I cannot fault the consultant led team and the people that did my caesarean at all. They were insane. It was like I didn't have COVID. It was like I was a human again, like I had a mask on everything. They had PPE on. But it was just, yeah, it was. Amazing</p>

explores the logistics of being ‘infectious’ and still needing to navigate health care as well as wanting to be looked after, and be with, their partner and children. Firstly, the symptoms, which, as with anybody with COVID-19, can be very unpleasant:

P3: *I'd say the worst in the first day was the worst symptoms, and it was almost like I was kind of cycling through all the different symptoms. So, at first, I had a sore throat and then it went on to a cough and then it went into a cold and... And then second day onwards, it just got less and less. So, I say from about after about three days, I felt completely normal. But I carried on testing positive for ten days.*

However, many described how it took a very long time to recover from this difficult illness, taking a physical toll on their body, as well as developing long COVID-19 following an acute infection.

P2: *Then I got COVID, and we didn't get better from having COVID for... Uhm, a good couple of months as well. So, it was like had kind of been ill maybe from about week six to probably. I don't know about twenty weeks. So, then I was like much less fit than I would have been going on through pregnancy.*

Some participants described being unable to differentiate COVID-19 symptoms from being pregnancy-related symptoms due to the overlapping features, such as shortness-of-breath. This also meant more serious obstetric conditions were dismissed as assumed to be COVID-19.

P13: *Also, it was quite hard to discern between. What was COVID and what was postpartum like I've had, like really massive sweats and I know that that's a postpartum thing, but it can also be a COVID thing.*

P16: *I was asymptomatic from COVID. I had no symptoms from COVID, but my sepsis symptoms got put down to COVID all day for the whole day, I was left and it [medical review] wasn't until they [midwives] changed in the evening.*

There was also the logistics of navigating the British healthcare system while COVID-19 positive. Some had positive experiences and voiced their gratitude for the services adapting to their situation, whilst others found those providing care within the healthcare system were unsure of what to do:

P13: *There was a health visitor who had to do a prick test on <Baby's Name> and she just came in like full PPE. While we had COVID and and still COVID. Which I think is really like brave with her.*

P7: *They weren't really sure where to put me. They spent some time in the parking lot figuring, you know, then they took me to regular A&E.*

Participants also discussed the futility of some of the COVID-19 testing, the results of which were often delayed, so positive results were not known until much of their care had been provided. They described the worry they had about the unknown result as well as the retrospective worry to the staff and other patients they could have potentially infected:

P10: *Hopefully the nurses, and everything were OK because they obviously go on and see other people, so hopefully they will have their mask on...*

P8: *As soon as they did the test. A) it's not comfortable to do the test particularly; and B) you're like 'ohh gosh now I'm thinking about the fact that I might have COVID, I don't know'. I'm going through this whole labour going. Oh God, I can't breathe too heavy on these people. In case I've got COVID, which obviously are breathing quite hard in labour, and you think, but none of them knew and then they've all gone around their day, gone home. The next morning, have no idea whether I had COVID or not.*

COVID-19 also impacted the connectivity participants had with their partner. This being separated from one's partner in hospital due to COVID-19 positivity or getting to spend more time, and having more support due to shared isolation:

P14: *But then they said if I test positive on arrival, then <partner's name> would be a close contact and he would have to go home because he would be a close contact of so. And so, we found that all very confusing and actually we didn't get good information.*

P6: *It meant like on the plus side and like in a way it did me a favour because it meant that my husband had to stay home for 10 more days. And so, he was kind of a week into his parental leave at that stage.*

Finally, there were issues with logistics regarding child-care. Firstly, pregnant women and new mothers having to care for other older children as well as themselves and their newborns at the same time as being unwell.

P9: *So, we weren't allowed to send our [older] child to nursery, so we were trying to balance being ill, working from home with the child... with having a child at home.*

P13: *At the beginning, I started feeding when I was feeding her or like when we were holding her, we'd wear a mask. And then after a while, we kind of stopped because we were just like. Uh, just because masking is like, not super pleasant.*

There was also separation of the parent from the newborn in the hospital (when admitted to the neonatal unit) due to infection. This caused great distress and prolonged emotional trauma from the event.

P7: *After like the 10 days or whatever we were allowed to start visiting him initially only while he was still in isolation. So, it will it in ten days after he was born, he was still in isolation, so we were allowed one at a time. With full PPE. Like special surgical mask, you know, goggles, gown, gloves. Couldn't even touch him properly.*

Reclaiming Control: Seeking reassurance during COVID-19 positivity

This final theme explores what contributed to participants feeling better or worse about their situation. This ranged from medical attention or medical equipment (such as pulse oximeters), the information they heard, and also comfort and support from friends, family, or any other source. It also describes, what did not bring participants comfort and events which heightened their concern. Participants described the feeling of relief and solace that they gained from access to self-monitoring via medical devices. This helped to inform them that they and their babies were well and coping with COVID-19:

P9: *They're in a big like hazmat suit, and while she was testing me like oxygen levels and all sorts of things, she was testing me, and then she let me take the oximeter away with me. And she said if your levels drop below 95%, you go straight to hospital. And so, I felt really quite reassured that I had then this oximeter that I was measuring my oxygen at various points throughout the day*

P10: *They had scanned the babies; they've been listening to their heartbeats and everything. Anyway, I knew they were fine*

Within this study, although not directly asked, many women provided their vaccination status. Those who were pregnant later on in the pandemic expressed their comfort in knowing they were vaccinated and therefore their increased security in their pregnancy, something they perhaps would not have had earlier on.

P3: *I guess actually I feel because having had COVID and being pregnant and I feel very grateful for hav-*

ing had the vaccine and being fully boosted. That's one thing. And also, I feel like it's a less now had it, it's less of a kind of scary unknown virus. It's more if you're fully vaccinated and you're young and healthy, then you're probably going to be OK.

P2: *Then I suppose the information I knew was that actually if you get COVID while, you're pregnant, you're much higher risk. But I didn't worry about that because I was already vaccinated, and I had it in early pregnancy.*

Others explained that they had researched, or knew, the risks and the potential effects of COVID-19 on themselves and their baby. With this they were satisfied that the risk of harm was very small, and therefore, did not need to worry too much:

P1: *I was nervous about the effect on the baby, but I also had done a lot of, you know, research and thinking and..... I was fairly confident that this wouldn't affect the baby in any other, you know, in, in any way... there was no evidence that it was, you know, it was not like Zika or something like that.*

P15: *I feel fortunate that my that this happened, you know, several years after COVID began, so there's more... More knowledge, or at least absence of evidence of very severe adversity from this.*

Others, looked at the potential benefits having COVID-19 could bring to their new-born:

P8: *But I sort of thought, well, if he's got antibodies from me, that's maybe a good thing because it hasn't affected me, but I've had it. Therefore, is he being born with a bit of natural immunity to it? And that's a superpower!*

However, many were not reassured by the services they received. Feeling that there was over the top worry from the medical providers or, conversely, feeling abandoned by services:

P4: *How have we gone from: 'You're probably fine' to. 'You're calling me an ambulance'? But then, like, of course they do that thing like... Yeah, but you don't know if your babies suffering and then you're like, OK, so I don't wanna kill my baby because I refused to have a paramedic come out. But like, that's literally the only time there's ever been an ambulance sent for me or anybody in my household. I felt ridiculous.*

P11: *It was sort of like... I was sort of given the stuff and like off you go, we're not really that bothered about you. And we've got more important things to.*

Finally, whilst support did not always reassure the women that everything was going to be okay, many expressed the gratitude and comfort of that external support to help get through the ordeal.

P7: She like sent me a breast pump and you know, like disposable underwear and snacks at the hospital and some other women started collecting baby, like premature baby clothes. And someone else got books. So there and there was a little group where I could message. So, there was some support.

Discussion

Summary of main findings

We conducted a Grounded Theory analysis of interviews with sixteen women who had COVID-19 during pregnancy, labour and birth, or the early postnatal period. This allowed for development of the theory: ‘Oscillating Autonomy – Losing and Seeking to Regain Control by Striving for Agency’.

The theory was derived from three emergent themes. The first of these was: ‘Anxious Anticipation: The fear of infection was worse than COVID-19 itself’, which reflects how mothers feared contracting COVID-19 and their emerging concern when they did, despite often contracting it with no ill-effects or minimal long-term complications following illness. The second theme: ‘Fluctuating Agency: What changed when COVID-19 took control’ illustrated how women coped with the fundamentals of having COVID-19, both in being unwell as well as the logistics of being infectious. Finally, the theme: ‘Reclaiming Control: Seeking reassurance during COVID-19 positivity’ demonstrated what elements of positive action such as information seeking, vaccination, health monitoring, and seeking support – helped women cope with their situation and feel reassured, or conversely, what did not assist in making their perinatal experiences more agentic.

The relationship between these themes was such, that the first was a perceived threat and therefore women were apprehensive about the possible loss of perinatal autonomy they might face, although when they were infected, they realised their COVID-19 positivity did not really change the way in which their pregnancy, labour and birth, or the early postnatal period progressed. The second theme spoke to this idea as well, whereby women were having to navigate and negotiate their perinatal autonomy when COVID-19 infection took hold. The final piece of our theory ‘Oscillating Autonomy – Losing and Seeking to Regain Control by Striving for Agency’ was derived from the third theme, which was where most women sought out or were provided with information

and/or reassurance through action (i.e. vaccination, health monitoring, information seeking, and accessing support) to reclaim agency over their perinatal period blighted by COVID-19 infection.

Interpretation of findings

Given considerations about maternal and foetal health in pregnancy, women lose full body ownership; this was demonstrated both before [3] and during the pandemic [2]. Women must ensure the health of themselves and their unborn baby [18], with whom they have an emotional attachment [48]. With this comes a need to keep control of one’s body throughout the stages of pregnancy [41]. The pandemic as a whole has been associated with a societal loss of freedom and autonomy. Rules and regulations were implemented, dictating where a person could go, who they could see and whether they were able to work [51], meaning pregnant women – especially those in the UK NHS system – often struggled to draw upon the social and healthcare professional support they felt they needed [22]. This loss of control extended to maternity services and the women for whom they are offered. For example, women’s antenatal appointments were reduced, cancelled, or moved to a virtual format. Also, there were swift changes in birth plans and loss of postnatal support groups [20, 34, 43].

Our study is unique in evaluating the experiences of women who became positive for COVID-19 in pregnancy. Women reported clinging to this need to protect their baby in this uncontrolled environment and – as has been found in a recent systematic review of perinatal women’s experiences of the pandemic in the UK – found messaging around safety and potential outcomes, confusing and conflicting [9]. They discussed fear of catching COVID-19 and the worry of what harm this could potentially do, to their baby. When they did become unwell, women often tried, but struggled, to separate what was COVID-19 infection and what was normal during pregnancy and particularly, postnatally. However, there were reassurances in these situations. Those who were able to steer through the health care service, despite infectivity, reported more positive feelings. There were also reassurances in information of low risk to pregnancy, and at home or self-monitoring, ensuring child’s safety. Conversely, those who felt they did not have control, sometimes with frightening stories of other’s experiences, being unable to successfully navigate healthcare [36], or those feeling abandoned by services, often displaying much more negative sentiments [14]. Of note, was the reassurance vaccination appeared to provide as well as the decision to be vaccinated being a method of reclaiming a sense of agency over their care, during the otherwise uncertain perinatal period. This is consistent with

public messaging which emphasised from the initial offer of vaccination, that accepting vaccination was a woman's choice [31, 47]. Many participants reported they felt as if they had nothing to regret as they were vaccinated and had done all they could to protect themselves and their newborns from the negative effects of COVID-19, even when they eventually contracted COVID-19 or were afflicted by long-COVID. This is also consistent with other findings from across the UK, which suggested the choice to be vaccinated was not always a straightforward one, but overwhelmingly women of reproductive age opted to have it [30].

Consistent with the published literature [24], is our finding that participants: needed support and to be listened to, were extremely grateful to healthcare services when they received this support, and experienced relief when their partner was with them throughout the experience and despair when separated from their partner. Having a scaffold of support around oneself is extremely helpful [4, 20, 21, 36, 38, 43, 44]. A consistent conclusion is that under no circumstances in the future, should chosen and consented birthing partners be forcibly separated from women and birthing people.

Implications and future directions

With Grounded Theory studies, it is commonplace to reflect on the newly emergent theory being proposed, considering extant theories in the literature. We propose our emergent theory: 'Oscillating Autonomy – Losing and Seeking to Regain Control by Striving for Agency' could be interpreted in light of the literature on post-traumatic growth, which has been described as: "*positive psychological change experienced as a result of the struggle with highly challenging life circumstances*" [6], p.157). In our study, women documented their stories of challenge during their perinatal journeys as they received their COVID-19 positive diagnoses, and how they went about overcoming the circumstances through positive action and reassurance in order to reclaim agency and control during their pregnancy, labour and birth, or early postnatal period. This could act as point of learning for maternity services wanting to deliver personalised and relational care, insofar as we clearly document that the ability to undertake positive advances in care (such as, accessing new preventative medications or vaccinations) or the ability to rectify something during pregnancy (for example, stopping smoking), may allow women to feel more empowered and therefore more positive about their perinatal journey. We therefore recommend maternity staff to work with women to achieve their personalised pregnancy, childbirth, and postnatal goals, in a relational way and that healthcare systems provide resource and allow maternity staff latitude (within the bounds of

clinical safety) to support women to pursue these goals, where safe to do so.

Whilst women in this study did not report their COVID-19 infection as a trauma, it was a notable fear and a significant event. Thus, COVID-19 infection could be seen as a smaller lifecourse rupture in the context of a much wider global pandemic. Women, therefore, were inclined to positively overcome this event, and in a sense, found their own pathways to post-traumatic growth, and future studies should consider both of these conceptual hypotheses when testing this Grounded Theory in the future, by either changing the specific population, phenomenon, or context. Again, this aspect offers an opportunity for reflection and potential change of current maternity care practices. Here we can interpret the pandemic itself being seen as a healthcare failure, or a threat to the pregnancy, labour and birth, or postnatal period, which then may lead to feelings of personal failure (to have the perinatal experience one desired). The ability for healthcare professionals to guide women to overcome perceived or actual failures in the perinatal period and open-up non-judgemental conversations about fears, concerns, and mental wellbeing (see [23]), could act as a catalyst for women and birthing people to be more positive, comfortable and resilient about their perinatal journeys. To do this, maternity healthcare professionals should engage with models of candidacy [11] to allow both women and maternity health care services and providers to continually negotiate care, whilst maintaining its accessibility and safety. In doing so, they should be trained to be able to communicate risk, explain options, and convey why some options may not be available to certain perinatal women without women themselves feeling judged by the subsequent pregnancy, labour and birth, or postnatal period they go onto have or the healthcare professionals who provide care along the way.

Strengths, limitations, and future directions

The strengths of this study include the diversity of participants in this study including their geographical spread, as well as date of delivery and COVID-19 infection spanning across two years' worth of the pandemic. This allows our findings to be broadly generalisable across the UK and allowed us to account for the changing pandemic circumstances over time, rather than limited to dense cities (such as the one in which the study team is based) and/or at just one discreet point during the pandemic. With this, data saturation was reached quickly allowing for a solid theory of a specific population (perinatal women), who had experienced a specific phenomenon (COVID-19 infection), in a specific context (UK pandemic circumstances and maternity care).

Limitations of this study include under-representation of minority ethnic voices, particularly as ethnic minorities have had even more negative experiences with maternity care during the pandemic [26, 38]. Furthermore, all of the women who participated were employed or in education and either married or cohabiting with a partner. It is known that those of a lower socio-economic status suffered more both in terms of health and social factors with both COVID-19 and the lockdown restrictions in the UK [8]. Future research should also take account of other minoritised perinatal groups such as sexual minorities, those who are dis/differently-abled, and those of advanced maternal age [32]. There is also something to be said about how the women in the sample seemed to represent a group who were not overly debilitated by COVID-19 infection, which was not the case for all pregnant women. Hearing the experiences of these specific groups may have produced a different perspective and research with these groups should be prioritised as we plan the pandemic recovery for maternity care.

Conclusion

Women reported a perceived loss of autonomy resulting from testing positive for COVID-19 whilst pregnant, during labour or birth, or in the early postnatal period. However, agency was reclaimed by diverse means, and often through positive action on their part (such as acceptance of the offer of COVID-19 vaccination) and/or receipt of information from trusted sources, like healthcare professionals. The importance of this supportive scaffolding from both partners, trusted sources (such as Government Organisations, The NHS, and the Royal Colleges), as well as from healthcare professionals was evident, and should not be underestimated in future health crises and other health system shocks.

Abbreviations

HCP	Healthcare professional
NHS	National Health Service
SARS-CoV-2 or COVID-19	The novel coronavirus pandemic

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12884-024-06685-8>.

Supplementary Material 1.

Acknowledgements

We would like to extend our thanks to the women who took part in this study and who shared stories of their perinatal experiences, during an unimaginably hard time to navigate pregnancy, childbirth, and the postnatal period. Our thanks are also extended to Prof. J. Sandall (King's College London) for her initial encouragement of the project and input into the study design.

Authors' contributions

Conceptualization: SAS, AB, LB, AM, AE, SG, II, IP, HRO'S, PS. Methodology: SAS, LP. Software: LP, SAS; TD. Validation: SAS, LAM, TD, LB, AB, AE. Formal analysis: LP,

SAS, LB, AB. Investigation: SAS, LP, LB, AB. Resources: AB, SAS, LAM. Data curation: LP, SAS. Writing—Original Draft: LP, SAS. Writing—Review & Editing: SAS, AB, LB, TD, AE, SG, II, LAM, AM, IP, HRO'S, PS. Visualization: LP, SAS. Supervision: AB, SAS, LB. Project administration: SAS, AB.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors, however, members of the research team [SAS, LAM, AE] were supported by King's College London King's Together Rapid COVID-19 Call [ref:- 204823/Z/16/Z]. The King's Together Fund is a Wellcome Trust funded initiative.

Availability of data and materials

The datasets used and/or analysed during the current study are part of a common dataset from The COVID +ve Births Study. The datasets are not publicly available due to the sensitive nature of the interviews, however they are available upon reasonable request from the corresponding author.

Declarations

Ethics approval and consent to participate

Ethical approval was sought from and granted by the King's College London Research Ethics Committee (3 October 2022; ref:- LRS/DP-21/22-22282). All participants provided consent to participate. An interview method was utilised in accordance with relevant guidelines and regulations, with the interview schedule (Appendix 1) having been approved by the Research Ethics Committee. Informed consent was obtained from all study participants electronically either where they completed and signed consent forms as a PDF and returned them to the researcher via e-mail; or where participants printed, manually completed and signed consent forms, and scanned them back to the researcher via e-mail. Where neither electronic method was possible, a verbal informed consent was employed with the researcher recorded a reading of the consent form with replies from the participant confirming consent recorded on an electronic copy of the consent form at the beginning of the interview. All methods of consent were approved by the Research Ethics Committee as pragmatic ways of conducting qualitative research virtually during the COVID-19 pandemic due to traditional 'wet signature' consent not being possible in light of lockdown restrictions. All participants were also made aware of their right to withdraw.

Consent for publication

Not applicable.

Competing interests

AE (King's College London) is currently supported by the National Institute for Health Research Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. SAS (King's College London) is in receipt of a Personal Doctoral Fellowship from the NIHR ARC South London Capacity Building Theme [ref:- NIHR-INF-2170]. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. The other authors do not have any competing interests.

Author details

¹Department of Population Health Sciences, School of Life Course & Population Sciences, King's College London, London, UK. ²HELIX Service, Maternal Mental Health Services, King's College Hospital NHS Foundation Trust, London, UK. ³Department of Women & Children's Health, School of Life Course & Population Sciences, King's College London, London, UK. ⁴General Internal Medicine, Royal Cornwall Hospital, Royal Cornwall Hospitals NHS Trust, Cornwall, UK. ⁵Paediatric Services, Kingston Hospital, Kingston Hospital NHS Foundation Trust, London, UK. ⁶Institute of Women and Children's Health, King's Health Partners, London, UK. ⁷Maternity Advisor, Royal College of Midwives, London, UK. ⁸Maternity Services, Queen's Hospital, Havering and Redbridge University Hospitals NHS Trust, Barking, UK. ⁹Maternity Services, St. Thomas' Hospital, Guy's and St. Thomas' NHS Foundation Trust, London, UK.

Received: 22 March 2024 Accepted: 8 July 2024

Published online: 29 July 2024

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