**Title:** Preterm birth during the COVID-19 pandemic: parental experience

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The pandemic arising from the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) known as COVID-19, has had wide reaching primary and secondary health implications ([1](#_ENREF_1)). At the end of March 2020, in order to slow the rate of infection, the United Kingdom (UK) government implemented a strict lockdown including; the closure of schools, workplaces, and restrictions on outdoor movements other than for exercise or essential shopping, which lasted until early June 2020. During this period, the National Health Service (NHS) experienced cessation of many services, whilst others imposed changes to reduce visitors and footfall on hospital sites. This included stringent and restrictive measures as to how women gave birth in addition to how Neonatal Services operated. In April 2020 the British Society of Perinatal Medicine published extensive guidance on reducing the transmission and spread of COVID-19 amongst families and their newborns ([2](#_ENREF_2)). As a result all non-essential maternity care stopped, with in-person appointments changed to telephone or video consultations. Strict social distancing measures were implemented by units around the country by limiting partners of women to attend births (with many women giving birth alone except from the care of health care professionals), as well as reducing parental access to infants, particularly those born preterm or unwell, with only one parent at a time allowed by the cot side and no additional visits from the immediate or extended family. The aim of this study was to explore the experiences, information and support needs, and decision-making of parents with a preterm or unwell neonate during the COVID-19 pandemic.

An online survey was developed as part of a larger study investigating the experiences of children and young adults with serious health conditions and their parents ([3](#_ENREF_3)). The survey opened after the end of the first UK national lockdown (01/07/2020 -01/09/2020) a URL link to the survey was distributed, using snowball sampling, through the national charity, Baby Life Support System (Bliss) and the Neonatal Unit, Princess Anne Hospital, Southampton via through their social media. The survey was also open to all parents who were able to access it via a URL link. The study was approved by the University of Southampton and NHS Health Research Authority Research Ethics Committees (Ethics Number IRAS nr. 282176).

The survey contained four sections with an open text box on Experiences, Information, Decision Making and Support needs. Each section started with a free text box for comments, with simple introductory questions: Experiences ‘Can you tell us about your experiences and views on the virus in relation to your baby/babies?’; Information: ‘Can you tell us where you get information on the virus and what other information you might need?’; Decisions: ‘Can you tell us how you make decisions about looking after your baby/babies in relation to the virus?’, Support: ‘What additional support would you like, at home or in hospital, in relation to the virus?’.

One hundred and seven participants completed the survey. 103 (96%) were mothers and four (4%) were fathers. The median (IQR) parental age was 29.5 years (28-34) with 50% of preterm infants born before 33 weeks gestation. Thematic content analysis was conducted on the free text data and was informed by a three-stage coding process ([4](#_ENREF_4)). In stage 1, an initial sample of 226 comments was open coded into broad comment categories by two researchers (NC and LM) and used to develop a framework. Disagreements over coding placement were resolved by a third researcher (ASD). For stage 2, this best-fit framework was used to refine the dataset further and finally, during stage 3, overarching themes were developed. As there was considerable overlap in the rich data within the sections, the total number of comments did not match the number of participants. A total of 226 comments were coded. Experiences (n=58 comments), Information (n=58 comments), Decisions (n=48 comments), Support (n=39 comments), Other (n=23 comments).

Thematic content analysis identified three overarching themes: **1) *Virus****:* with a sub-theme of risk of infection; **2) *Impact of restrictions****:* with a sub-theme of i) loneliness, ii) missed experiences and iii) psychological impact on maternal bonding, **3) *Information and support needs*:** with a sub-theme of i) information on preterm infants vulnerability and ii) mental health and well-being (Table S1 summarises these themes and sub-themes, together with illustrative comments for each one).

Many parents felt there was a significant psychological and emotional impact due to COVID-19 restrictions on the birthing experience and afterwards and on their neonatal intensive care journey. Findings from the SHARE studies exploring the views of parents of children with cancer, and parents of children with congenital heart disease found that parents were worried about the virus in the context of their child’s disease condition ([3](#_ENREF_3)). This is a similar finding to parents views in the preterm population. However, parents within the preterm survey reported additional concerns about their face being covered by a mask, and the subsequent ability to bond with their baby. Parents were also concerned about their baby being unable to distinguish their voice, smell and touch from that of a health care worker caring for their baby.

 There are a number of limitations of this work including the small sample size, low number of fathers participating, and those with limited access to the digital survey. Although participants were recruited through charities and support groups of preterm infants, some groups might have been overlooked such as those whose first language is not English or those who do not seek information from Bliss, thus imposing sample bias. Despite these limitations, we believe the qualitative findings of this survey are important particularly with regards to findings ways to address the trauma felt by mothers giving birth alone as well as the psychological impact of missed experiences for partners. It has been reported that parental stress (especially following a NICU admission), is associated with poorer development outcomes in preterm infants ([5](#_ENREF_5)). The cessation or reduction of visitation rights in many NICUs as part of COVID-19 related restrictions are postulated as increasing parental stress associated with an admission. Whilst there is no empiric studies at present, future work will undoubtedly consider the impact of these restrictions on preterm development ([5](#_ENREF_5)). Future work should consider innovative ways to include fathers and the extended family in preterm infant’s journey from birth to home, as well as considering the use of clear visor style face coverings that will allow infants to see their parent’s full face.

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There is no funding associated with this work and the authors have no conflict of interests.

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**Table S1 Preterm: Experiences of Covid-19: Table of themes from 226comments from a total of 107 parent respondents**

|  |  |  |  |
| --- | --- | --- | --- |
| **Theme**  | **Subtheme**  | **Number**  | **Illustrative comments parents** |
| **VIRUS** |
| 1. **Risk of infection**
 | Based on the precautions I can take e.g. whether I can socially distance | 15 | It would be useful to know how at risk my baby is. I've classified him as high risk and shielding but I have not been told this officially. I would like to know a reasonable timeframe to start introducing him into the world a bit. I feel a lot of pressure from family and friends to be able to see him. |
| Own/judgement (what will keep family safe) | 16 | We wanted to leave hospital as soon as possible as felt it risky to be there. We don't take our baby anywhere like shops etc. as don't want to risk her getting it. |
| **IMPACT OF RESTRICTIONS** |
| 1. **Loneliness**
 | Loneliness | 12 | Very lonely time to be pregnant & have a baby in hospital. |
| Attending appointments by themselves/being alone in the hospital | 14 | Worries about fathers bonding with new babies. Fathers not allowed at scans and appointments and asked to leave hospital quickly after birth of child. Effects to both mother and fathers mental health is huge.….. It was very difficult as myself & my partner were not allowed to be in the neonatal unit or even the hospital premises at the same time after I was discharged & my baby remained in neonatal unit. We were repeatedly told we were not allowed to be together & this was so hard as I hadn’t seen my partner from before giving birth, he was unable to attend due to underlying health problems & my Covid test result not back before I gave birth. Giving birth alone in emergency section was horrific as I didn’t know what was going to happen. |
| 1. **Missed experiences**
 | Difficulties in lack of family contact due to restrictions | 14 | My baby was born at the start of lockdown she was put on neonatal care and we found out only 1 of us could visit her per day. My partner was told later that same day he could no longer visit me. It was terrifying being in hospital during such uncertain times and being separated from my partner. Towards the end of her neonatal stay we were asked to wear masks to visit her, our own baby and we couldn't kiss her. I was scared to leave her in hospital at night as I couldn't keep her safe I was scared that she would get sick. I was then scared to bring her home as we had a 5 year old at home and between us visiting the hospital and bringing her home I was terrified that we would contract the virus and bring it into our home. It has also been hard that none of our family can meet her and hold her.The biggest impact the virus had was that my husband and I could not visit the unit together. It is a time we will never get back and I feel we missed out on having time as a family during the first few weeks. |
| Partner missing out due to restrictions/difficulties in partner not being allowed to be there | 34 | The impact of parents wearing masks around the babies all the time and how that could affect the babies ability to bond/recognise their parents from hospital staff. |
| 1. **Psychological impact on maternal bonding**
 | Impact on mental health (being scared/worry/anxious) | 19 | The hardest part was being separated from family, especially my other son as they were not allowed to visit and I couldn't visit anyone either. I also found it difficult not being able to visit my baby with my husband. We had to visit separately and alone. Emotional support was missed greatly. |
| Emotional impact of NICU journey during COVID | 5 | Having a severely premature baby is hard enough at any time. But our NICU journey has been completely hindered by this virus threat. Imagine not being able to see your baby with the mother and father together. Imagine having to sit through upsetting, emotional and difficult talks with nurses and consultants whilst alone without the support of your partner because hospital policies won't allow parents in together. Imagine having already suffered a stillborn baby previously and now having your new baby and its living sibling not ever allowed to meet until baby is discharged. Imagine your 12 week old baby having NEVER FULLY SEEN YOUR FACE!! Because you have to wear a mask. Imagine having to go through that scenario for 16-20 weeks. I don’t have to imagine it- that's my life. My 2 children have never met and it's been nearly 13 weeks. Schools are closed, there is no childcare available and children are not allowed to be on the neonatal ward. I am torn in half as a mother- having to currently choose who needs my time more. I am so repulsed and incredibly angry about the virus. Whilst lockdown is easing and people are throwing caution and travelling around the country- the hospital restrictions are only getting harder because it's now more of a threat! I haven't been able to have a 6 week postpartum check-up, no way of getting help for my mental health because my gp surgery won’t let anyone in to see a doctor. No outside agency is allowed in neonatal so there is no support from anyone for me as a mum watching her baby fight for her life. I feel because of this virus and our NICU circumstances that I as a mother have been brushed aside. |
| Impact of restrictions when seeing baby in NICU (wearing masks, time limit, unable to see baby as a couple, no other family members allowed, not able to speak to other parents, siblings unable to bond with baby, changes to breastfeeding schedule) | 44 | No consistency between hospitals regarding guidelines, rules were changed part way through the duration of our time on the unit. No real consideration as to the impact on restrictions to parents and the impact on the mental health of the mothers. Skin to skin not really possible as PPE restrictions didn’t allow you to touch your child with bare hands. No kisses allowed due to face masks. Baby can’t see your face.Initially my partner and I had to visit our daughter in the NICU separately making it feel very lonely during this emotional time. This has since changed however we are required to wear masks at all times. I can completely understand the reasons for this, however we cannot kiss our daughter and she is unable to see our faces in full. Our visits are restricted to two a day for two hours. |
| Positive view of support from hospital (incl. home support) | 6 | Giving birth for me during the pandemic wasn't too stressful, I had to go to an alternative hospital within the same trust but I was possibly going there anyway in case my baby needed the extra care. My husband could be with me for the birth then got sent home. We spent 3 weeks in neonatal, couldn't have any visitors including my husband which made things very difficult. My baby had to be treated as a suspected covid case and isolated because he had a runny nose and went into high flow oxygen for a short time. That was extremely stressful, especially being alone in hospital. They messed up the sample and the test had to be redone, I was asked to store my breast milk in a separate fridge from the others mums which made me feel a bit alienated. Luckily it eventually all came back clear and we went back to 'normal'. Obviously we all had to wear PPE in the nurseries so things felt a bit impersonal but the staff were amazing and very supportive. They were like my family while I was in there. My husband was finally allowed to visit just before we were discharged.  |
|  | Difficulties in lack of family contact due to restrictions | 14 | Gave birth alone, and then didn’t see my husband or oldest daughter until we were discharged home 2 and a half weeks after birth. Understand the precautions the hospital has to take to ensure babies safety, but was mentally very hard. Very grateful to be allowed to stay at the hospital and with my baby throughout her stay.….Covid meant that my husband and I weren't allowed to see our baby at the same time until we got home a week after they were born. I know this is short compared to some people but it had a huge effect on us and my husband didn't really feel like he was a father. Once home we couldn't see any family or friends for support after such a traumatic week. |
| ***Information and support needs***  |
| i) information on preterm infants risk to contracting COVID | Information on risks of baby contracting COVID/how COVID can affect babies | 20 | It would be useful to know how at risk my baby is. I've classified him as high risk and shielding but I have not been told this officially. I would like to know a reasonable timeframe to start introducing him into the world a bit. I feel a lot of pressure from family and friends to be able to see him. |
| Hospital team | 7 | A lot more support from the health visitors. I only had 2 phone calls and wasn't told if I'd have any more or what I'm meant to have had. |
| ii) Health & well being | Physical and emotional support needs | 6 | I think there should be more support, both physically and especially emotionally for parents during this time. Volunteers offering support (Bliss, hospital chaplain etc) are not allowed on the wards at a time where they are probably needed the most. Every parent will be there alone and there is no support available. |