



## Parents' experiences and satisfaction with care during very preterm birth

Alexandra Sawyer is Research Fellow at the Centre for Health Research, University of Brighton. Susan Ayers is Lead, Centre for Maternal and Child Health Research, City University London.

Being aware of the needs of parents whose babies are born very preterm, and involving them in their care, are critical if we are to support them properly at such a potentially distressing time, say Alexandra Sawyer and Susan Ayers.

As part of the 'Improving quality of care and outcome at very preterm birth' NIHR programme grant, we wanted to address gaps in the field by exploring in-depth the experiences of parents having a very preterm baby, including parents' experiences and satisfaction with care during the birth, parents' first moments with their baby, and parents' experiences on the Neonatal Intensive Care Unit (NICU). We also wanted to develop a questionnaire specifically for parents of babies born premature to explore their experiences and satisfaction with care during birth. This article summarises the key findings from these two studies in our work package.

“It was just heart-wrenching to see him like that and it was just like, part of me did think is it worth it, is he gonna pull through?”

## Interviews with parents

The first phase of our work was to interview parents to explore in-depth their experiences of having a very preterm baby (less than 32 weeks gestation). We spoke to 32 mothers and seven fathers about their experiences during birth; their very first experiences with their baby; and their care during labour and birth.

### Parents' initial experiences of the birth of their very preterm baby and their first experience of NICU

Parents had difficulty remembering parts of the birth and reported experiencing a rollercoaster of emotions.<sup>1</sup> Individual differences in emotions were most apparent before parents saw their baby in NICU, when they reported either being nervous and fearful or eager and excited. Parents' first impressions were that NICU was overpowering, especially for those who had not visited before or who saw their baby there for the very first time. However, being able to touch and hold the baby in NICU was important in triggering or strengthening the bond between parents and their baby.

*“It was just heart-wrenching to see him like that and it was just like, part of me did think is it worth it, is he gonna pull through and you think, am I putting him through a lot of pain to, to see him like that it was just really really really hard... you just don't know how you're feeling from one minute to the next, one minute you want to cry, next minute you want to scream.”*  
(Mother)

*“All the monitors and the buzzes and the screens and doctors milling about and you know, nothing quite prepares you for it, and I don't think, I don't think you can prepare for it until it happens basically, you can tell someone until you're blue in the face what it's like but actually until you're in, till that's your children or child, um so it wasn't scary as such, it was just overwhelming.”* (Mother)

### Parents' views and experiences of the care for their very premature baby on NICU

Parents' experiences of care in the NICU was not one of the original aims of the interviews. However, as all parents spoke spontaneously and at length about this we recognised the importance of exploring parents' experiences of NICU separately.<sup>2</sup> Three areas were identified that were particularly important in determining parents' satisfaction with neonatal care:

- Parents' involvement, including looking after their own baby, challenges of expressing breast milk, and easy access to the unit.
- Staff competence and efficiency including communication, experience and confidence, and information provision.
- Interpersonal relationships with staff including emotional support, reassurance and encouragement, and being made to feel like an individual.

*“Because you come in one day, say the day before, especially there was a guy there that, he promoted to hold her, literally whenever we was in, either of us, he would say, ‘Hold her, it’s the best thing you could do’. And then you’d come in the next day thinking ‘oh yes, I get to hold her’. And you have a different nurse that says, ‘no, no you’ve held her this week, you don’t need to hold her for the rest of the week’. So it would be very... and then you’d almost feel devastated that you couldn’t do that.” (Mother)*

*“They’re constantly talking to them, when they’re changing them and so on – ‘hello love,’ they talk to them... It’s not the case of just cleaning and feeding them. You’re talking to my baby, you’re making my baby reassured.” (Father)*

*“And I think they were really, you know, explained everything. Every time we went to the incubator, whoever the nurse was on looking after her, you know, always explained how she’d been doing, how she’d been... they talked... it was really lovely.” (Mother)*

### **Parents’ experiences and satisfaction with care during very preterm birth**

Overall parents’ experiences of care during very preterm birth were positive.<sup>3</sup> Several areas of care were particularly important to parents:

- The professionalism of the staff (such as providing information and explanations, appearing calm, appearing confident and in control, and listening to the woman).
- Empathy shown by the staff (such as being supportive and giving encouragement and reassurance).
- Involvement of the father during the birth.
- The birth environment (e.g. radio playing during the birth).

*“So we actually go down into the operating theatre and again the anaesthesiologist was there and talking to [us] as she said ‘I will stay with you the whole time’... and she talked us through everything that was happening and for both of us that was just outstanding, absolutely.” (Mother)*

*“The midwives were incredible, so during the birth we had this amazingly lovely kind of West African um midwife who was, oh just love, like lovely, so nice, so supportive and caring and empathetic and everything that you could possibly want and just really supportive and, so the birth process itself actually, in the scheme of things was relatively easy thing then to go to because I felt very supportive... and she was so lovely.” (Mother)*

Although many of these areas of care have also been identified as important to parents whose babies are born full term, two factors unique to preterm birth were identified. These were the importance of staff appearing calm during the birth, and staff taking control during the birth. Although parents were overall positive about the care, two areas emerged where parents felt things could have been improved. First, some women described being in

labour or very close to giving birth, and the staff either not believing them or not appearing to be listening to what they were saying. Second, some fathers described feeling marginalised during the birth.

*“The only kind of downside to it, was I kept saying to her, all my family have very quick labours... I kept saying to her I need to push I need to push and she said I’ve only checked you half an hour ago, you’re only 3cm... and she went I’m just popping out the room... and at that point I just pushed and her head popped out, and no one was in the room apart from me and my partner.” (Mother)*

*“He found it very awkward...When they were being born he just sat out there, wasn’t really able to participate... So he felt like a spare part... when we were rushed to the surgical unit... there were so many people in the room, he felt he didn’t know where to stand. He didn’t want to get in the way. He knew he needed to get there... let everyone get on with their job. But he felt in the way.” (Mother)*

## Development of the Preterm Birth Experience and Satisfaction Scale (P-BESS)

---

In the second study of our work package we wanted to develop a questionnaire that could be used to measure parents’ experiences and satisfaction with care during preterm birth. Previous questionnaires were not developed specifically for preterm birth and our qualitative research showed important differences between preterm and full-term birth. We developed the P-BESS on the basis of the interviews with parents, a review of the literature for appropriate measures, and discussion with relevant experts. We sent the questionnaire to parents of preterm babies and received responses from 145 women and 85 partners. We used these to refine the questionnaire using psychometrics to ensure it was reliable and valid. The final version of the P-BESS consists of 17-questions which measure three aspects of care (*Staff Professionalism and Empathy, Information and Explanations, Confidence in Staff*). A fourth subscale can also be added to assess Partner Involvement for women whose partners attended the birth. Individual questions can either be summed to produce a total score, or factors of care can be looked at individually. A total score may be useful to compare across hospitals and differing practices, whereas individual aspects of the care environment can be evaluated using the separate subscales.<sup>4</sup>

## Most useful lessons learned

---

- Our recommendations for family-centred care include recognising critical steps for parents during the care pathway and being aware of their needs, the emotional impact, and individual differences in responses.<sup>5</sup> Our research shows the birth of the baby is one critical step and that family-centred care should extend, wherever possible, to the birth of the baby. Initial care of the baby by the bedside is one way where family-centred care during the birth can be achieved.

Feeding, changing and holding their baby help parents connect with their baby, and take on the role and identity of being a parent.

- The impact of parents' first experiences with NICU varies between individuals. The buffering effect of prenatal visits to NICU, alongside the regret expressed by parents who did not take up this opportunity, suggests all parents should be encouraged to visit NICU before birth if possible.
- Involvement in the care of their baby is extremely important to parents. Therefore it is important that staff in NICUs facilitate parent participation as much as possible. Feeding, changing and holding their baby help parents connect with their baby, and take on the role and identity of being a parent.<sup>6,7</sup>
- During birth the provision of information and explanations to parents, and offering caring and emotional support, are extremely important to parents. Our research findings suggest that women should be listened to more, especially when telling staff they are in labour or feel close to giving birth.
- It is clear that we need to involve fathers more, particularly during the birth. Involvement of the father during preterm birth is important as it can facilitate father-infant attachment<sup>8</sup> and fathers can be an additional source of support to the mother during the birth.

## References

1. Arnold L, Sawyer A, Rabe H, et al. Parents' first moments with their very preterm babies: a qualitative study. *BMJ Open* 2013;3:e002487.
2. Russell G, Sawyer A, Rabe H, et al. Parents' views on care of their premature babies in neonatal intensive care units: A qualitative study. *BMC Pediatrics* 2014;14:230.
3. Sawyer A, Rabe H, Abbott J, et al. Parents' experiences and satisfaction with care during the birth of their very preterm baby: A qualitative study. *Brit J Obstet Gynaecol* 2013;120:637–43.
4. Sawyer A, Rabe H, Abbott J, et al. Measuring parents' experiences and satisfaction with care during very preterm birth: A questionnaire development study. *Brit J Obstet Gynaecol* 2014;121:1294-301.
5. Staniszewska S, Brett J, Redshaw M, et al. The POPPY study: developing a model of family-centred care for neonatal units. *Worldviews Evid Based Nurs* 2012;9:243–55.
6. Lupton D, and Fenwick J. 'They've forgotten that I'm the mum': constructing and practicing motherhood in special care nurseries. *Soc Sci Med* 2001;53:1011–21.
7. Nykvist KH, & Engvall G. Parents as their infant's primary caregivers in a neonatal intensive care unit. *J Pediatr Nurs* 2009;24:153–63.
8. Brandao S, and Figueiredo B. Fathers' emotional involvement with the neonate: impact of the umbilical cord cutting experience. *J Adv Nurs* 2012;68:2730-9.