

# Experiences of the quality of care of women with near-miss maternal morbidities in the UK

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We undertook a qualitative interview study of women's and their partners' experiences of severe pregnancy complications. Across the care pathway, women identified a number of examples of good practice that made an important difference to their recovery. There were some areas where women felt the quality of care could be improved, for example during points of transition between higher level and routine care or from hospital to the community.

Longer-term support and counselling were felt to be particularly valuable, and yet not always universally available. These results emphasise the importance of integrated quality care across the whole patient pathway.

**Keywords** Experiences of care, near miss, quality, severe maternal morbidity.

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## Introduction

It is increasingly recognised that patient experiences are important drivers to improving the quality of health care.<sup>1</sup> As part of a funded national research programme in the UK, focusing on severe 'near-miss' maternal morbidity, we sought to investigate women's and their partners' experiences of severe complications of pregnancy, with the aim of providing an information resource for women and their partners<sup>2</sup> and teaching and learning materials for health professionals,<sup>3</sup> and hence to drive improvements in care.

We conducted interviews with 35 women, all of whom had experienced a severe life-threatening complication in pregnancy (thrombosis or thromboembolism, hypertensive disorders of pregnancy, haemorrhage, amniotic fluid embolism or sepsis) and 11 of their partners. We aimed for a maximum variation sample and continued interviews until thematic saturation was reached. One of the researchers (LH) conducted the interviews either in the participants' own homes, or in a venue of their choice. Interviews were video- or audio-recorded and fully transcribed. We undertook analysis of the transcribed interviews using an interpretive approach to thematic analysis.<sup>4,5</sup>

Across the care pathway, women and their partners identified a number of straightforward examples of good practice that made an important difference to how they experienced and recovered from these severe morbidities (Box 1).

## Key messages for care

### In the emergency

Women's experiences of the emergency varied greatly. Women and their partners understood that during the emergency, the focus of medical staff was to save the lives of the mother and baby. However, a number of them gave us examples of thoughtfulness from professional staff that made a real difference to how they felt at the time.

*'As soon as the wheels on the trolley hit the ground, then there was sirens and an awful lot of people, and running down the corridor...and they put the Doppler on my tummy which was, I'm so glad they did that, because then they made a point of really saying to me, "You can hear that can't you? You can hear him can't you?" I was like, "Yes."'* Jo, who had a placental abruption, was reassured when she heard her baby's heartbeat.

**Box 1.** Key factors that women who experienced a 'near-miss' event associated with good-quality care

**In the emergency**

Small personal touches of reassurance from doctors and midwives. Information and small acts of kindness to reassure fathers/partners during anxious waiting.

**Transfer in the hospital**

Sensitivity to women's emotional and physical needs to ease transfer, for example offering a private room away from other new mothers and babies.

**Access to the baby**

Women want to mother their baby, even when very ill. Finding ways for women who required high dependency or intensive care to visit their baby (or vice versa) was highly valued.

Keeping women in touch with their baby's progress through photos or regular updates, if they could not be with them.

Support to breastfeed, even while in intensive care.

**Follow-up**

Women valued a meeting with doctors to understand more about what had happened. Flexible timing for these meetings was important—some women were ready before others.

The opportunity to see and go through their notes.

Sensitivity about where follow-up meetings took place, for example not returning to the antenatal clinic.

**Communication and understanding**

Good communication with health professionals during the emergency helped women and families understand what was happening.

Good communication afterwards helped women make sense of the experience.

**Post natal support**

Support from their primary care team after discharge, as women recovered and tried to get back to normal life.

Some women and partners experienced long-lasting mental health impacts. Counselling, where offered, was helpful.

Small personal touches from doctors and midwives could make a big difference to how women coped.

*'They'd stemmed the bleeding and, and it was like, right, the consultant, he was very sweet actually. He took my hand, and he said, "You're going to be okay. You don't need to worry. You're going to be fine." And [er] I think he did the same to my husband actually.'* Natalie, who had a severe postpartum haemorrhage.

*'The gynaecologist was there...who was delivering her and she sort of rubbed my cheek and said, "I'll make sure you're okay." [um] I was okay. Actually it was really important, because with [my first daughter] I didn't believe that she was my baby at all, because I'd never seen her born, and I was completely traumatised from it. Whereas this was a lot worse and I wasn't [traumatised].'* Naomi, who had a uterine rupture.

Fathers were often left wondering what was happening to their wife/partner while staff were fighting to save her

life. We were given examples of small acts of kindness that helped them cope during the anxious waiting period.

*'One of the doctors had come in and told me that everything was okay. ... He brought back my digital camera so I got to have a look at a couple of photos of our boy on the back of the camera.'* Michael, whose son was delivered early after his wife developed HELLP (haemolysis, elevated liver enzymes and low platelet count) syndrome.

**Transfer in the hospital**

Being transferred out of surgery or critical care to the post-natal ward was often a difficult time for women.

*'But I just feel that when, when you're a woman who has given birth, but has these other complications it's like you're an, an anomaly. You don't fit anywhere within the system. ... So there was no setting whereby I could be given the care I needed, yet with the ability to see my new baby.'* Paula, who had an amniotic fluid embolism.

*'She left me to get on with everything at that point. But I remember saying to my husband, "I think they think I've just had an emergency caesarean, but it's been so much more than that. And it's going to take a long time to get over". ... So I begged to get out as soon as possible.'* Debbie, who had a uterine rupture.

There were important examples given where the sensitivity of staff eased the transfer. Several women described being offered their own room for a night or two, so that they could have more privacy as they started to recover from their critical illness.

**Access to their baby**

Even when very ill, women wanted to be a mother to their new baby. Many women faced challenges in seeing their baby, and it would be helpful to develop protocols ahead of time for women who require high dependency or intensive care to facilitate the baby being allowed to visit the mother or vice versa.

Where it was not possible for women to see or be with their baby, they really appreciated being kept in touch with the baby's progress through photos, regular verbal or written updates such as a diary of the baby's day or direct contact with the paediatrician when the baby was ill.

Missing a baby's 'firsts' was something women really noticed; if at all possible they wanted to be there for important milestones such as the first feed. Women were sometimes in intensive care units for several days, still critically ill and separated from their newborn babies. Even when women were not in intensive care, some women we spoke to, while very keen to breastfeed, found that they did not feel strong enough or were in too much pain. Several

women found expressing milk stressful. Sometimes women who were in intensive care were supported by staff and able to establish breastfeeding. A combination of breastfeeding, expressing milk and supplementing with bottle feeding made this possible, but it was often a struggle.

### Follow-up

Some women wanted to meet with doctors to understand better what had happened during the emergency, to piece together the missing bits of their experience. Others found it helpful to go through their notes.

*'I was provided with my intensive care notes by the intensive care department and then I applied to receive my notes from the hospital. ... I just wanted to try and fill in some of the gaps, for my, my reference. ... It was definitely helpful to have the notes, to refer back to them.'* Karen, who had a postpartum haemorrhage and hysterectomy.

Women who had a follow-up review at the hospital found this a positive experience to help their understanding and recovery. Where follow-up was not offered women felt abandoned and were left with questions.

Women noted a number of things that were particularly helpful elements of the follow-up review: seeing and talking through their notes, answering questions about future pregnancies, sensitivity about the place where the review was conducted (returning to the antenatal clinic or labour ward or even hospital could be upsetting), and flexible timing of the follow-up review (some women were not ready for this until several months or even years after the event).

The follow-up programme with intensive care unit staff that some women were involved with was considered a good model. The models of intensive care follow-up varied, including follow-up visits by the intensive care outreach team, usually nurse-led, while the women were still in hospital, and for some women, the offer of an appointment at a consultant-led follow-up clinic after hospital discharge.

### Communication and understanding

Understanding what was happening during the emergency, or what had happened after the event, was very important to the women who experienced a near-miss, and their partners and families. It helped deal with anxieties during the emergency, and coming to terms with events afterwards.

Good communication with health professionals, during the emergency or afterwards, helped women and their partners to understand what was happening to them, and make sense of the experience afterwards.

Alex and Kerry's contrasting experiences illustrate the importance of good communication and understanding. They were both diagnosed with grade four placenta praevia. The information they received and their subsequent understanding was very different. Alex was kept in hospital for

8 weeks until her baby was delivered at 34 weeks. She said the way doctors explained her condition, and its risks, was excellent. It was like a 'drip feeding process' which enabled her to process little things at a time. When she was interviewed 3 months later, she was recovering well and had not felt the need for counselling. In contrast, Kerry, felt that doctors did not explain the risks to her and when she started to haemorrhage in hospital at 28 weeks of pregnancy, she was terrified. She later developed panic attacks, mostly focused around bleeding to death. She had counselling and was on medication.

### Postnatal support

The support that women were offered after they were discharged from hospital varied greatly. Women who were given support by their general practitioners in the community valued it as they recovered and tried to get back to normal life.

*'He visited me every day when I got out of hospital. Here at the house. He's just been amazing. ... He's gone beyond the call of duty, without a doubt. Well they all have at the surgery actually.'* Lisa, who had a haemorrhage and hysterectomy.

Many said that counselling was very helpful.

*'I felt like I wanted to see a counsellor because there were things that I was feeling that I didn't want to say to my family and friends because I felt like I put them through so much already.'* Alison, who had a haemorrhage and hysterectomy.

Many women reported that they would have welcomed more support in the wider community. They felt that they could not attend normal mother and toddler groups as their experiences were so extreme. Access to parent's groups where other women had similarly 'abnormal' birth experiences, as well as general practitioner and health visitor support for first-time mothers to help with feelings of isolation would be valued.

### Long-lasting effects

Some women appeared resilient and their near-miss experience did not seem to have a long-lasting effect on them or their families. But there were mothers and fathers in our study who reported mental health impacts that required long-term management. Some did not seek help for long-term mental health issues; actively offering counselling may therefore be beneficial.

*'Before the anniversary [son's first birthday], that's when I really panicked, because I just thought, well what am I going to do? I don't know what I'm... It's weird, it's like I was in, in prison in my head. ... Straight after [the*

near-miss], you are in shock and I think it takes up to 6 months really for [it to sink in]...

So I went to the doctors and I just said, 'I, I need some help.' ... It was just the feeling inside me. I just wanted it to just stop. I just didn't want to be here. I wanted to be here, but I didn't, just didn't want to be this person, this, this cage that I was in, and so I went to the doctors and I told them everything and they were just like, we need to get you to see somebody and... I ended up having to go through it all again and process it all and it really helped.' Anna, who had septicaemia and hysterectomy.

## Conclusions

Studies of women's experiences provide an important additional perspective on quality care that cannot be provided by numbers alone.<sup>6</sup> This study of the experiences of both women and their partners revealed a number of important examples of high-quality care that helped to improve the outcomes of severe pregnancy complications. In addition, it highlighted a number of areas where women felt the quality of care could be improved, for example during points of transition between higher level and routine care or from hospital to the community. Longer-term support and counselling were felt to be particularly valuable, and yet not always universally available. Other studies in both high<sup>7,8</sup> and low-income<sup>9,10</sup> settings have identified similar themes, and emphasise the importance of integrated quality care across the whole patient pathway in order to improve the outcomes from severe pregnancy complications.

## Disclosure of interests

None to declare.

## Contribution to authorship

All authors (LH, LL, MK) contributed to the conception and design of the study, analysis of the data, drafting the article and final approval of the version to be published. LH conducted the interviews.

## Details of ethics approval

Ethics committee approval was given for this study by the Berkshire Ethics Committee, 09/H0505/66. All participants gave informed consent before taking part and have given written consent to their interview data being included in publications.

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