

Sands survey of maternity and neonatal care

Introduction

In the spring of 2019, Sands canvassed the views and experiences of parents to find out about their experiences of care maternity and neonatal settings. We shared the survey on Sands social media platforms and through partner organisations. Questions looked at their perceptions of safety and of the quality of care received.

The findings set out below are from people whose baby had died in 2018 or 2019 (is a subset of 345, out of 1,640 people who responded to the survey).

Almost all the respondents were women, ranging from under 16 to over 42 years old. The overwhelming majority were white and from a mid to a lower income bracket.

Summary of key findings

- Women are not receiving continuity of carer from pregnancy into labour
- A third of parents felt unable to raise concerns they had about their baby, or if they did raise them, they did not feel their concerns were taken seriously
- Many women are getting different messages about what care they need from different staff
- Low risk at booking does not mean no risk, with only 35% of the women whose baby died in this survey 36% considered high risk from the start
- 40% of women were concerned about the level of care they received in pregnancy, feeling that the right tests and monitoring were not carried out in a timely way
- The time taken to receive the post mortem report remains unacceptably long, with parents suffering the consequences of long waits to understand more about why their baby died.
- Too many parents are not aware of hospital reviews, and did not know if their baby's care had been investigated.
- The majority women (70%) were satisfied everything possible had been done for their baby around their birth.

1. Antenatal care

Continuity of midwifery care

During pregnancy:

- 70% of women were looked after by between 1-3 midwives
- 17% were looked after by between 4-6 midwives
- 10% were looked after by more than seven different midwives

The numbers of midwives looking after each respondent in labour and birth were similar to the numbers for pregnancy. However, more than 80% of women had not met any of the midwives who looked after them in labour, before their labour began. Only 4% had already met all the labour midwives who cared for them.

Relationships with midwives:

- 60% of women felt they had a positive relationship with one or more of the midwives they saw regularly
- 28% of women felt they did not see any of the same midwives regularly
- 9% of women felt they did not have a positive relationship with any of the midwives who cared for them

Sixty percent of women felt that during pregnancy, labour and birth, the clinical staff were familiar with their notes and communicated well with each other. Twenty five percent of women did not feel this.

Quality and consistency of care

Around 70% of women did not feel rushed in antenatal appointments. Similarly, 70% felt that they were informed and involved in decisions about their care.

A third of women said that the different staff caring for them had different opinions about what care they needed. Only half of respondents disagreed with this statement.

The majority of women felt that the staff looking after them treated them with respect, dignity, kindness and sensitivity. Fifteen percent did not feel this.

Information and concerns

Over 70% of women said they had all the information they needed in pregnancy about tests, diet, exercise and choices about birth.

Fewer women felt they had the information they needed about pregnancy risks, with only half reporting they had enough information about the signs to look out for that something might be wrong with their baby in the womb.

When asked about worried about their baby:

- 57% of women had worries about their baby while they were pregnant
- 15% of women had worried about their baby during labour

- 37% of women had no worries at any time before the baby died

Of those who had concerns about their baby:

- 70% felt able to raise these concerns with health care professionals
- Only 48% of women felt their concerns were taken seriously or acted on

Of those who felt unable to raise their concerns, we asked why this was the case:

- 43% said they were not confident about the seriousness of their concerns, and so did not report them
- 20% said they were worried that they annoy staff if they raised concerns, and this would affect their care, or that they felt that they would not be listened to
- 20% felt staff were too busy for them to feel able to raise concerns

2. Risk assessment

Risk profile

- 55% of respondents were considered low risk at the start of their pregnancy
- 36% said they were considered high risk from the start

Yet all these pregnancies ended with the death of the baby, highlighting that low risk does not mean no risk.

Care during pregnancy

When asked if they felt they had the right level of care throughout their pregnancy:

- 56% said they did
- 40% did not agree

In addition, 41% of women felt they did not have the right tests or monitoring during the pregnancy. Thirty seven percent of women felt tests were not undertaken in a timely way.

More than two out of three women felt the staff caring for them had the right skills and knowledge, but a quarter said they did not.

Care during labour and birth

Asked if all the necessary equipment and facilities were available during delivery, 80% said yes, with 15% disagreeing.

Seventy percent of women felt that healthcare staff were able to pick up concerns quickly and act on them, as well as feeling that staff had enough time to give them the care they needed. Twenty percent felt this was not the case.

Eighty percent of women felt happy that the staff caring for them had the right skills and knowledge, and were able to deal with an emergency; but around one in seven did not.

When asked if they felt everything possible was done for them and their baby:

- under half said yes for care during pregnancy
- three quarters said yes for care during labour and birth

This suggests that a significant number of parents feel that their care was lacking in some way.

3. Post mortem and reviews

Post mortem

The vast majority (92%) of women were asked whether they wanted to consent to a post mortem on their baby.

More than 80% felt they had all the information they needed to make this decision, that the information was easy to understand, and that staff helping them with the decision were appropriately skilled and qualified.

Nevertheless around 15% did not agree this was the case for them. This represents a relatively small but troubling number of parents who did not feel they had the right support in making this very difficult decision.

Of our respondents, half agreed to a full post mortem, and just over a quarter agreed to a post mortem on the placenta only.

We asked respondents how long it took the post mortem report to come back:

- 7% had the results within 4 weeks
- 22% had the results within 8 weeks
- 30% had results within 12 weeks
- 17 had results within 16 weeks
- 8% waited more than 5 months

Reviewing a death

- Half of respondents did not know whether the hospital had reviewed their baby's death
- 12% knew that a review was carried out, but had not been invited to take part
- Only 22% said the review included their perspective of what happened
- 14% said there was no review of care at all

Of those who were not invited to take part in a review of their baby's care, 72% said they would have liked their perspective to be part of a review. Only 9% said they would not.

Once the review was completed, around one in three felt well informed about and satisfied with the findings. Twenty seven percent did not feel they were informed about the findings and 23% did not feel satisfied.

Strikingly, a third to a half of parents did not know if they were 'well informed' or 'satisfied' with the findings or not. This suggests that many parents do not feel party to that stage of the review and that communication with parents is lacking in many cases.

The vast majority of parents want the chance to say what they think happened and to be taken seriously in reviews of their baby's death.

4. Neonatal Care

We asked where the respondent's baby had died. Thirty six percent of deaths took place in a neonatal unit.

Of these neonatal babies:

- just over half were looked after by a neonatologist immediately after they were born
- 8% were looked after by a neonatologist very soon after birth
- 26% said there was no neonatologist at the birth
- 20% said no neonatologist looked after their baby at all.

We asked respondents about their and their baby's care at birth and before any neonatal admission:

- 70% of respondents felt confident that everything possible was done for their baby at this time (that staff had the right skills and knowledge, were prepared to deal with an emergency and that the right equipment was on hand).
- 21% felt this was not the case (with 23% disagreeing that the right equipment was on hand and 18% questioning if staff had the right skills and were prepared).

Almost all babies were admitted to neonatal care were in intensive care. Half the respondents felt the level of care was right for their baby throughout. Sixteen percent felt the level of care was right for only some of their baby's care, and, another 16% felt it was not right.

We asked about the care their baby received while they were alive, whether there were enough staff with the right knowledge to give the baby the right care, and, about how staff communicated with them. We also asked if parents felt involved in their baby's care, able to talk to staff about any concerns and if their concerns were taken seriously. Overall, 60-70% of responses to each of these questions were positive and 20-25% were not.