



Listening to Parents

after stillbirth or the death
of their baby after birth



Katie and Tim Johnston and their daughter Emily Rose, who was stillborn on 10th May 2011



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of their baby after birth

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2014

First published in April 2014 by the
Policy Research Unit in Maternal Health and Care
National Perinatal Epidemiology Unit
Nuffield Department of Population Health
University of Oxford
Old Road Campus
Oxford OX3 7LF

Printed by Hunts - Paper & Pixels, Oxford



Andrew and Sarah Malm with their son Rudy, who died shortly after he was born at 36 weeks

Acknowledgements

Our particular thanks go to the women and their families who completed the survey, but we would also like to acknowledge all those women who were invited to take part. Although we did as much as we could to lessen the impact of taking part in the survey, we recognise that it will have brought back painful memories and taken courage to respond. We are very grateful to all the mothers, fathers and partners who have told us about their loss.

Special thanks are also due to the ten bereaved mothers who helped us develop the questionnaire and study materials by filling in the questionnaire and talking through that experience with us. Charlotte Bevan, Janet Scott, Sue Hale and Judith Schott at Sands; Farrah Pradhan and Carmel Barrett at Bliss; and our colleagues at the National Perinatal Epidemiology Unit (NPEU), Jenny Kurinczuk and Marian Knight, helped enormously in developing the survey materials. We are also grateful to Emma Haines, the NPEU design team and the NPEU reception staff for their contributions to the survey and especially thankful for the support and advice provided throughout by Patrick Wilcockson and the helpline staff at Sands.

We are grateful to Mark Gautrey and other staff at the Office for National Statistics in Titchfield who worked on drawing the sample and managing the mailings.

Finally, we would like to thank Katie and Tim Johnston, Andrew and Sarah Malm, and Peter Brady for allowing us to use their photos in this report and Simon and Chloe Baker for the use of their photo in the publicity for the report launch day.

This is an independent report from a study which is funded by the Policy Research programme in the Department of Health. The views expressed are not necessarily those of the Department.



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Executive summary

In 2012 in England 3,558 babies were stillborn and a further 1,990 babies died in the neonatal period. Previous national surveys of women's experience of maternity care have excluded women whose baby has died.

Separate questionnaires were sent to an unbiased national sample of women who registered a stillbirth or a neonatal death in two three-month periods in 2012–13. Completed questionnaires were received from 720 women in all: 473 mothers of a stillborn baby and 248 mothers whose baby died in the neonatal period (including one woman who had both a stillborn baby and a baby who died as a newborn); a response rate of 30%.

Younger women, those living in more disadvantaged areas and those born outside the UK were under-represented, although 16% of respondents came from Black and Minority Ethnic groups, 19% of mothers were born outside the UK and 10% indicated that they were single parents.

The questions addressed in this report focused on the recent experiences of parents who had a stillborn baby or a baby who died as a newborn, their maternity care and key areas of concern. The report has separate sections relating to the experience of parents of stillborn babies and parents of babies who died in the neonatal period. Within the first of these, one sub-section covers parents' experience where their baby's death occurred prior to labour, and another sub-section where this occurred during labour. In the section where the focus is on neonatal deaths, sub-sections cover parents' experience where their baby was or was not admitted to a neonatal unit.

Key findings

Women whose baby was stillborn

- A total of 473 women whose baby was stillborn completed the survey.

During pregnancy

- Just over half of all the women who had a stillbirth had problems with their pregnancies. Most of these women had additional specialist care and, overall, about a fifth had at least one hospital admission.

Women whose baby died before labour

- More than four-fifths of stillbirths occurred before labour started. Of those who knew when their baby had died, three-quarters reported that it was in the few days before birth.
- About two-thirds of women felt that something was wrong before their baby died, mostly due to a change in the pattern of their baby's movement. Most of these women contacted a health professional within the next 24 hours. Although women reported positively on their care in pregnancy overall, at this point when they felt something was wrong, they were more critical and only 57% of women felt listened to or that their concerns were taken seriously. Almost all women who had concerns went to hospital to be checked.
- About half the women were told by a consultant on labour ward that their baby had died. Women generally recalled being treated well, with kindness, sensitivity and respect at this time, but around 30% did not feel listened to or felt listened to only 'to some extent' at this point, that their concerns were not always taken seriously or did not feel wholly informed about what was happening. Less than half felt involved in decision-making and confident about the decisions made at this time.
- Women were given various options regarding delivery once it was confirmed that their baby had died. Most women had the option of going home to prepare for the birth, and to have labour induced within 24–48 hours. Eight percent of women were offered a caesarean section.
- Almost all women went on to have a labour, with most having a vaginal birth (85%). Pethidine or another opiate was used by half the women and a quarter had an epidural for pain relief.

- During labour nearly half the women were cared for by only one or two midwives. While most recalled being cared for with kindness and respect, being listened to, and spoken to in a way they could understand, at least one in five felt this did not happen, or only 'to some extent'.
- A total of 20% of women reported that they or their partner were left alone and worried at some time during labour or shortly afterwards.
- Almost all partners were present for the labour, for the birth itself and after the birth.

Women whose baby died during labour

- A total of 56 women in our sample had a baby who died during labour. In this group, nearly half of parents had thought that something was wrong during the labour, mainly as a consequence of bleeding, fetal heart rate abnormalities, changes in their baby's movement, the pain they experienced, and concern among the health professionals providing care.
- Over 40% of these women had a caesarean birth, most commonly as a consequence of unforeseen problems during labour, mostly with a general anaesthetic. Pethidine or similar medication was used for pain relief by 28% and an epidural by 38%.
- Most of these women had three or more midwives caring for them during labour and birth and four out of five women had not met any of these midwives previously.
- Effective communication with staff during labour and birth was difficult: a quarter of women felt that staff communicated poorly, almost half did not always feel listened to and around 10% reported rarely or never having trust or confidence in the staff caring for them during labour and birth.
- One-fifth of women and their partners were left alone and worried at some time during labour.
- Most partners in this group were present for the labour, when they were told their baby had died, for the birth itself, and almost all after the birth.

Postnatal care following a stillbirth

- For most women their hospital stay following a stillbirth was around one day and three-quarters felt that their length of stay was about right.
- Most women had either a single room or a bereavement room or suite on labour ward (87%), although less than half said that this was away from crying babies and labouring women. Most reported that their partner could stay (83%), that they could be with their baby (81%) and that family and friends could visit (81%).
- Almost all women and their partners were able to see their baby, hold them and felt able to spend time with their baby; there were very few who did not have the opportunity to do this.
- Interpersonal care from staff was generally very good, with around 90% or more of women being treated as an individual, with respect and kindness, and being given the care they needed.
- Women did not always receive the information they needed; a third were not given information about managing breast milk production and a quarter did not receive information about counselling services.
- After leaving hospital, most women (86%) had the name and contact number of a midwife. A total of 90% were visited at home by a midwife, a few did not want to see a midwife and 4% were not offered a visit. Some continuity of care was reported for two-thirds of women who saw a midwife after discharge home. Care at this point was variable, with some staff clearly being uncomfortable about calling or visiting.

Overall experience of care

- Overall, women who had a stillborn baby were most positive about their care in labour and most critical about their care in pregnancy.

Fathers' and partners' experience of care

- Most fathers and partners considered that staff communicated well with them throughout pregnancy, birth and afterwards. However, a third or more did not feel listened to or only 'to some extent' and did not always feel that their concerns were taken seriously or that their needs were acknowledged.

Women whose baby died after birth

- A total of 248 women whose baby died as a newborn completed the survey.

During pregnancy

- More than three-quarters of the women had health problems either at booking or later in their pregnancy and more than a third were admitted to hospital.
- Before labour, 69% of this group of women had concerns about their baby, mainly relating to prematurity.
- Most women were positive about their experience of care in pregnancy, although more than one in four reported not being listened to by midwives and medical staff.

During labour and birth

- Three-quarters of women suspected that something was wrong while they were in labour or before their baby was born, some because they just felt things were not right, others because of bleeding or pain.
- Two-thirds of women had a normal vaginal birth, 10% had a caesarean section prior to labour and 19% had a caesarean section in labour due to unforeseen problems.
- More than half of the women reported that three or more midwives looked after them during labour and delivery and four out of five had not met any of these midwives before.
- Three-quarters of these women felt that the midwives communicated well at this time and while 58% always had confidence and trust in the staff, 13% felt this only rarely or never.
- During labour, between 50% and 60% of women felt listened to, that their concerns were taken seriously and that they were informed about what was happening, although about 10% did not feel this way at all. Larger proportions did not feel they had a part in decision-making (28%) or did not feel fully confident in the decisions made (47%) at this time.
- A third of women reported that they or their partner were left alone and worried at some time during labour and/or after the birth.

Women whose babies died without being admitted to neonatal care

- Around one-third, that is 84 of the 256 babies who died in the neonatal period, died soon after the birth without being admitted to a neonatal unit. Most of these babies died within 24 hours of birth and half within an hour. Almost all died on the labour ward or in the operating theatre and a very small number died elsewhere.
- Three-quarters of these babies were born at <32 weeks' gestation and some were born with a diagnosed congenital anomaly.
- Three-quarters of these women had a normal vaginal birth and 18% had a caesarean section.
- A total of 80% of women considered that staff communicated with them well during labour, although one in five considered that communication was poor at this time.
- A small number of women reported never or rarely having confidence and trust in staff providing care, although around two-thirds of this group always had confidence and trust in the maternity staff.
- Most women and their partners in this situation were not left alone at a time when it worried them, although 22% said this happened during labour and 16% afterwards.

- Most women were present when their baby died and almost all subsequently saw, held and spent time with their baby, many in the bereavement room provided.
- Most women were able to stay in a single room (92%), although for more than a third of women (37%) this was not away from other new mothers and babies and only 63% of women could have their partner stay with them.

Care in the neonatal unit

- Two-thirds of babies who died as a newborn were admitted to a neonatal unit (NNU). The most common reason for admission was prematurity, often with associated breathing problems.
- Only about a third of women reported having met neonatal staff prior to their baby's admission.
- About a third of babies spent less than 24 hours in the NNU, about a third stayed for 1–6 days, and about a third stayed for a week or more prior to death.
- Most women and their partners were able to see and touch their babies within the first few days in the NNU and almost all saw or touched their baby at some point before he or she died.
- While their baby was in the NNU, more than two-thirds of women reported that equipment and procedures were always explained by staff, and three-quarters that their baby's problems and treatment plan were always discussed.
- Nearly half of the mothers of babies who spent time in a neonatal unit were able to change their baby's nappy, and over a third were able to cuddle their baby and clean their baby's face or hands, although some babies were too sick for this to be possible.
- Most mothers felt well supported by staff at this time and included in their baby's care, however, 20–30% of women felt that this happened only sometimes, rarely or never.
- A quarter of parents were not offered help with funeral arrangements (25%) and some were not given information about counselling services (21%).

Postnatal care in hospital and at home

- The median length of postnatal stay for women whose baby died as a newborn was 2 days, ranging from less than 12 hours to 28 days. Most women considered their length of stay about right.
- Almost all women stayed in a private or single room, on either the labour ward or a postnatal ward. However, for around half this was within earshot of healthy babies, where their partner couldn't stay with them, or too far from their baby.
- In general, women reported that during their postnatal stay staff treated them well, although this was not always the case.
- Following hospital discharge, three-quarters of women had the name and contact details of a midwife and saw a midwife. A small proportion (7%) were not offered a midwife visit.

Overall experience of care

- Satisfaction was highest for care in the NNU followed by care for labour and birth. However, a quarter of women were dissatisfied with their pregnancy care and one in five were not satisfied with their care during labour and birth, with their postnatal care, and care after their baby had died.

Fathers' and partners' experience of care

- Around three-quarters of fathers or partners considered that staff had communicated well with them throughout pregnancy, childbirth and subsequently.
- Almost all fathers or partners were able to see their baby before he or she died (92%), and some held their baby (72%), although this was not always possible as their baby was too poorly.
- Most fathers or partners were present for discussions when there were concerns about their baby and when their baby died (88%).

- Around 40% of fathers or partners felt that they were not considered or only 'to some extent' with regard to being informed and involved in decision-making and that their own needs were not always acknowledged.

Understanding why babies died

- Most parents reported being asked to consent to a post mortem, but substantial numbers were not asked because a post mortem was considered unnecessary or because it was ordered by a coroner.
- Around two-thirds of parents of a stillborn baby and just over half of parents whose baby died after birth reported that they were given written information about the post mortem.
- More than 70% of parents in both groups felt informed enough and had sufficient time to make a choice in relation to post mortem.
- Among parents who had a stillborn baby, half agreed to a full post mortem examination; of those whose baby died in the neonatal period, a quarter agreed to a full post mortem.
- Parents' reasons for not agreeing to a post mortem were mainly that they didn't want their baby examined and that they already knew the cause of death.
- Almost all of the parents of a stillborn baby (92%) and slightly fewer (84%) of parents whose baby died after birth met with a consultant at least once to talk over their baby's death.
- Less than half of bereaved parents found out the results of the post mortem within 8 weeks and 30% had to wait for more than 12 weeks.
- Most parents were given a cause or explanation for their baby's death, although more than a quarter of stillbirths were described as 'unexplained'. Where a cause for stillbirth was identified this was most commonly placental problems; the most common cause of neonatal deaths was prematurity.

Parental support and wellbeing

- For women and their partners, they found most support following the death of their baby from each other and from close family and friends.
- Health professionals were also important sources of support, particularly staff who had been involved in their own and their baby's care at this time or previously.
- More women than men used a greater variety of types of support, which included counsellors and bereavement midwives.
- Some fathers did not talk to anyone.

Paternity or compassionate leave

- About two-thirds of the fathers or partners who experienced a stillbirth or neonatal death were reported to have taken paternity or compassionate leave.
- Of those who did take leave, the median duration of both types of leave was 10 days.

Parental health and wellbeing

- Almost half the women reported not having a postnatal check with their GP 4–8 weeks after the birth, usually because this was not offered.
- At the time of the survey (around 9 months after their baby's death) few women and their partners described themselves as in poor physical health, although some were currently experiencing poor mental health.
- Nearly a third of women whose baby was stillborn reported suffering from depression and a quarter from anxiety; similarly, among the women whose baby died after birth a quarter of women reported suffering from depression and a similar percentage from anxiety at the time of the survey.
- The mental health of both groups of fathers was also poor at this time, with more than one in ten reporting anxiety, depression or both.

Conclusion

The findings of the study reflect the generally good care provided, but they also show that substantial proportions of bereaved parents do not always receive the best care. The findings also reflect variability between services and the care provided by individual health professionals to individual women and their partners. There is a need to fully implement policy and to practise what is recognised as high quality care for parents who have experienced the death of a baby, in order to avoid some of the unacceptable experiences described by some parents taking part in this survey.

1: Introduction

1.1 Background

National surveys of maternity care carried out in recent years have described the care women receive and women's views on and experiences of that care, but have explicitly excluded women whose baby has died.¹⁻³ In 2012 in England 3,558 babies were stillborn and a further 1,990 babies died in the neonatal period.^{4, 5} Around one in 150 pregnancies ends in the stillbirth or death of a baby in the neonatal period, making the death of a baby at or around the time of birth the most common form of mortality in early life.

Describing parents' perspectives on their care is important because it provides information for maternity care professionals and policy makers seeking to make improvements to the care and services they provide. National surveys of parents' experience can therefore provide a benchmark of current practice and a baseline for measuring change and improvements. Improving parents' experiences of maternity care is a key element of government policy,^{6, 7} underpinned by the principle that the best care is defined by the health and social needs of the woman and her family. More fundamentally however, good care meets the needs of people as individuals, including their needs for support, information and reassurance.

All parents are affected by the quality of care they receive in pregnancy, around the birth of their baby and in the postnatal period. In particular, for parents whose baby dies, the impact of the care they receive at these times and when their baby dies can have profound short and long term effects on their wellbeing, their ability to care for others and their contact with health services in the future.⁸⁻¹⁵ Moreover, some aspects of care can **only** be assessed by asking bereaved parents themselves, for example, whether they were treated with kindness or respect, whether they felt they were given the information and explanations they needed and whether they felt supported and cared for. National users' groups such as Sands (the stillbirth and neonatal death charity) and Bliss (a leading charity working to improve care for sick and preterm babies) work directly to support bereaved parents and have developed good practice guidelines.¹⁶⁻¹⁸ Other relevant guidelines and quality standards have also been produced by NICE, NHS England and by a range of professional organisations.¹⁹⁻²³ Based on all available guidance, Sands has developed auditable standards of care²⁴ for health care professionals looking after women and their partners around the death of their baby. The Sands 17 principles of care are also widely recognised as the benchmark for good practice.²⁵ Surveys of NHS trusts and hospitals have assessed the extent to which services for bereaved parents are provided in different units or health regions, and whether staff feel appropriately trained and prepared to provide support for parents.^{26, 27} There have been surveys of specific areas of care such as discussion of perinatal post mortem,²⁸ but there is no good quality national evidence on parents' experience of their care.

The aim of this survey was therefore to explore and describe the maternity care experiences of women, and their partners, who had a stillborn baby or whose baby died in the neonatal period.

1.2 The questions we aimed to address

The questions addressed by this report were:

- i. What is current clinical practice in the provision of care for parents who have a stillborn baby or a baby who dies in the neonatal period?
- ii. What are the key areas of concern relating to their care for parents who have had a stillborn baby or whose baby has died in the neonatal period?

1.3 This report

Being asked to take part in this study and taking the time to go back over events and complete the questionnaire was demanding for women and their families; nevertheless the insights, views and voices of all those who responded by telephone, email, letter and by returning a questionnaire, are critical and are reflected in this report which focuses on the care that parents received and their experience of services.

Throughout the report relevant standards and guidelines based on research studies, expert groups and users' views are used to contextualise the study findings. Extracts from women's responses to open questions in the survey are also provided to highlight and illustrate the results.

2: Survey methods and response

2.1 Survey method

The study used a postal survey design with an initial contact letter followed several weeks later by the questionnaire and a reminder. A collaborative group, with representatives from Sands and Bliss were involved in all aspects of the study design and management in order to ensure that the perspective of parents was considered throughout. Two separate questionnaires were used, one for women who had a stillborn baby and another for women whose baby died as a newborn, so that the questionnaires addressed appropriate issues for each group. Parents who had more than one baby who died were able to fill in a questionnaire for each baby if they wished. Questions covered pregnancy, labour and birth, and the postnatal period, as well as neonatal care (if appropriate) and care at the time of their baby's death. Questions were mostly structured, but allowed for longer open text responses where appropriate. Before being used in the survey, both questionnaires were tested in interviews with parents who had experienced a stillbirth or the death of their baby as a newborn and revised to take account of their comments.

The Office for National Statistics (ONS) identified samples of women (excluding those aged under 16 years) who registered a stillbirth or neonatal death between 1st January and 31st March 2012 and between 1st June and 31st August 2012. These women were sent an introductory letter and study information between six and nine months after the death of their baby; the letters were sent by ONS. Three weeks later a further letter, questionnaire and information leaflet were sent to each woman by ONS. Questionnaires were returned to the National Perinatal Epidemiology Unit (NPEU). A reminder letter and a further copy of the questionnaire were sent to women who had not responded after a further four weeks. No personal identifying information was provided to the study staff at the NPEU by ONS.

2.2 The women who were surveyed and their babies

The Appendix gives a detailed breakdown of the women included in the survey and a comparison between those who responded to the questionnaire and those who did not. Overall, completed questionnaires were received from 473 mothers of a stillborn baby and 248 mothers whose baby died in the neonatal period, (including one woman who had both a stillborn baby and a baby who died as a newborn), representing a response rate of 30%. On average, women completed the questionnaire 9 months after their baby died.

More than half of the babies who died were premature (23% of stillbirths and 55% of babies who died in the neonatal period were born at 28 weeks' gestation or less), but significant numbers of babies were full term when they died (43% of stillbirths and 29% of neonatal deaths). More than half of the neonatal deaths occurred within the first 24 hours after birth. Babies in multiple pregnancies are at significantly greater risk of stillbirth and death in the neonatal period and there were 76 mothers (of 89 babies who died) who had a multiple birth (12% of the sample); 28 women who had a stillborn baby and 48 whose baby died as a newborn. Of the stillborn multiples, 30 were twins (3 pairs of whom both died) and there was one triplet baby who was stillborn. Of the multiples who died as a newborn, 55 were twins (11 pairs of whom both died) and there was one triplet baby who died in the neonatal period. In addition one woman taking part in the survey had twins, one of whom was stillborn and the other who died as a newborn. The experience of these women is included within the relevant sections, both numerically and in the comments that women made.

The women taking part were mostly in their 30s and had completed full-time education aged 19 years or older, reflecting a difference between those who responded and those who did not. For 59% of mothers of stillborn babies and 52% of mothers of babies who died in the neonatal period, this was their first baby. A total of 10% of women were single mothers at the time of the survey and three women with same sex partners responded to the survey.

Table 2 in the Appendix shows a comparison between the women who responded and those who did not. From this it is clear that study respondents were significantly more likely to be born in the UK, aged in their 30s, and to live in less deprived areas compared with women who did not respond to the survey.

3: Parents whose baby was stillborn

3.1 The women and their babies

A total of 473 women whose baby died before birth were participants in the study. Twenty-eight were expecting more than one baby. Among this group of women 417 had babies who died before labour and 56 had babies who died during labour and birth. The pregnancy care of all these women is described in section 3.2, after which the care of women whose babies who died before and during labour are described separately in sections 3.3 and 3.4. Experience of postnatal care in hospital, at home and overall for all women and their partners whose babies died before birth are described in the later sections of this chapter.

3.2 During pregnancy

We asked structured questions about pregnancy care, problems that may have been identified and how parents became aware or were told about these.

For some women whose baby was stillborn their pregnancies were problematic and there were concerns that arose at different points during their pregnancy (10% at booking and 55% later in pregnancy). These included concerns about placental problems (30%), fetal growth (14%) and high blood pressure or pre-eclampsia (12%). A small proportion of babies with congenital anomalies were identified (8%). Response to a comparable question in the 2010 National Maternity Survey³ indicated that overall 24% had such pregnancy-related problems. Many of the women about whom there were pregnancy concerns received additional or specialist care (59%). Overall, one in five women whose baby was stillborn had at least one antenatal admission to hospital not related to induction or planned caesarean section (20%), little different from the 19% responding to the 2010 National Maternity Survey³.

Women were also asked about access to maternity services and experience of care during their pregnancy before their baby died. On average most had contacted a health professional about their pregnancy by 6 weeks' gestation and had their booking appointment by 9 weeks. Almost all women had their booking appointment by 18 weeks (99%) and had a pregnancy dating scan and an anomaly scan (98% and 99% respectively). These figures are similar to or slightly higher than those reported in the 2010 National Maternity Survey which excluded women whose babies had died during pregnancy or in the three months after birth.³

Most (between 85% and 89%) felt treated well, with kindness and respect and that they were spoken to in a way they could understand both by midwives and medical staff (Figure 3.1). Smaller proportions of women felt their concerns were listened to (71% and 72%) by the health professionals caring for them.

I had perfectly wonderful, excellent care. There is not one concern or regret in my heart or mind that anything should or could have been done better or different.

I am lucky enough to have a small town Midwifery Practice. It's old-fashioned social care and brilliant.

I felt I wasn't listened to about my headaches and other problems, and could never get hold of my midwife even when I was told she would contact me.

I saw at least four different midwives during the later stages of my pregnancy and at several different venues. It was impossible to build relationships or feel confident enough to 'chat' through 'silly concerns'.

The Specialist Midwife that I had during my pregnancy was amazing, always there for me and very friendly.

Don't think they took my concerns seriously enough when I said (a week before death) that baby was moving too much and I was itching. Perhaps more could have been done? I was disappointed I saw different doctors every time I went to the hospital.

On many occasions I told [midwife] baby didn't move/kick as much as previous babies and she said it was because I was a busy working mum and didn't notice it.

I noticed less movement the day before my 32 week scan... to check on low lying placenta. Expressed my concern to sonographer who confirmed heartbeat present and told lack of movement was due to baby changing position. In clinic afterwards was reassured everything was ok.

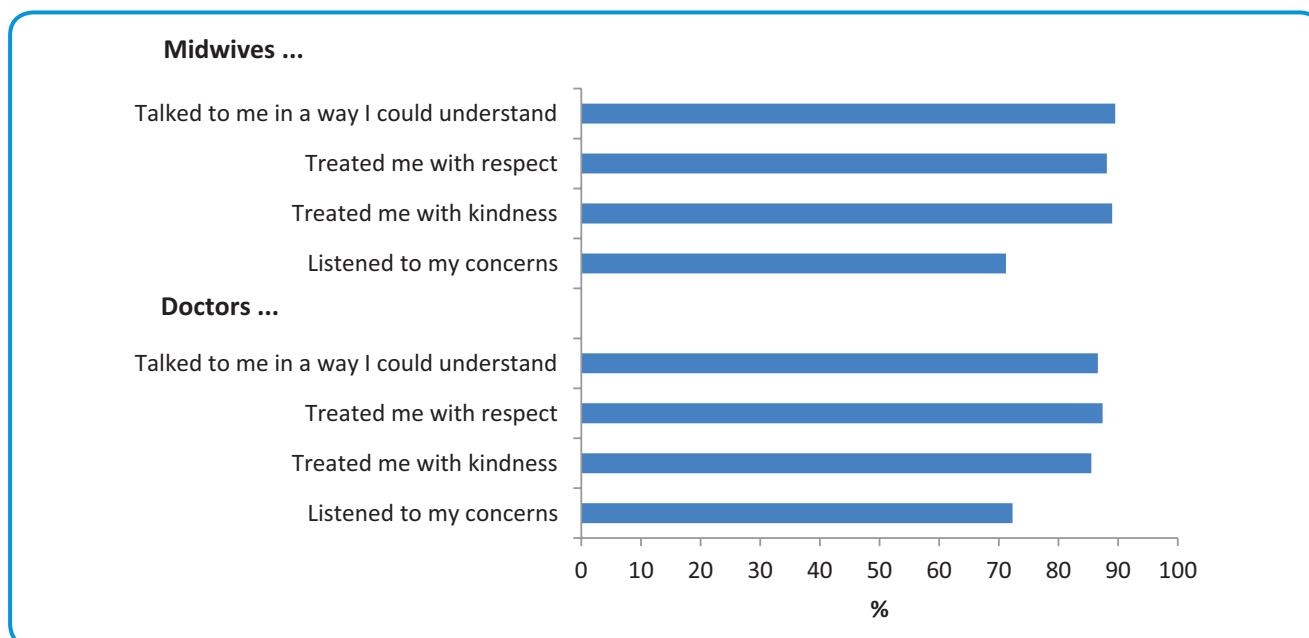


Figure 3.1 Views of care from health professionals during pregnancy in women whose baby was stillborn

3.3 Parents whose baby died before labour

The circumstances of a baby's death can affect parents markedly and around a quarter of parents (24%) were either unsure or did not report the timing. Of those who were more sure, a quarter reported that their baby had died a week or more before birth (25%), nearly half (45%) a few days before birth, a total of 18% reported that their baby had died the day before, and for another 12% this had taken place a few hours before their baby was born. For a small group of women (12% of the women whose baby was stillborn), their baby died during labour and birth.

Parents were asked whether they or their partner had suspected something was wrong before their baby died. Around two-thirds of parents of babies who were stillborn before labour felt that something was wrong before their baby died. Many parents just felt things weren't right (46%) and some women mentioned specific symptoms such as pain (15%) or bleeding (11%), and the concern of midwives or doctors about their baby's condition (25%). However, for most women and partners, recognition that something was wrong was associated with changes in their baby's normal pattern of movement (72%).

Parents were then asked about raising their concerns, the responses of the health professionals contacted and what happened next. A third of women reported contacting a midwife or doctor straight away when they thought something was wrong, with a further 46% contacting someone within 24 hours (Figure 3.2).

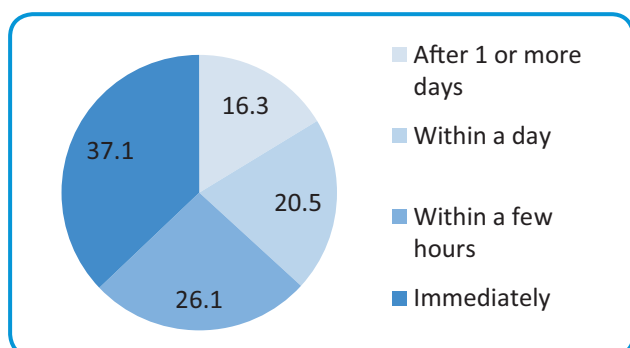


Figure 3.2 The proportion (%) of women, whose baby was stillborn, who contacted a doctor or midwife at different times after they thought something was wrong with their baby

When I came to the hospital knowing there was something wrong for the 2nd time in three days I felt the nurse was shunning what I was saying to her. I had an anterior placenta and when I told her that my baby hadn't moved in over 24 hours her words were "Of course you won't, you have an anterior placenta". I knew this information, but had felt my baby move a lot during pregnancy.

We had 2 trips to hospital in the last month with concern the baby wasn't moving and this was followed up with a biophysical profile. However, we feel we were reassured too much (e.g. given reasons for lack of movement - lots of fluid, baby moved down, anterior placenta) which made me relax about it too much.

Parents' experiences of contacting someone when they were concerned about their baby were varied: three-quarters of parents felt able to contact the health professional they needed (74%), less than two-thirds felt informed about what was happening (61%), only just over half felt listened to at this time (57%) and that their concerns were taken seriously (57%) and smaller proportions felt they had a part in the decision-making that followed (45%) and confident about the decisions made (39%) (Figure 3.3).

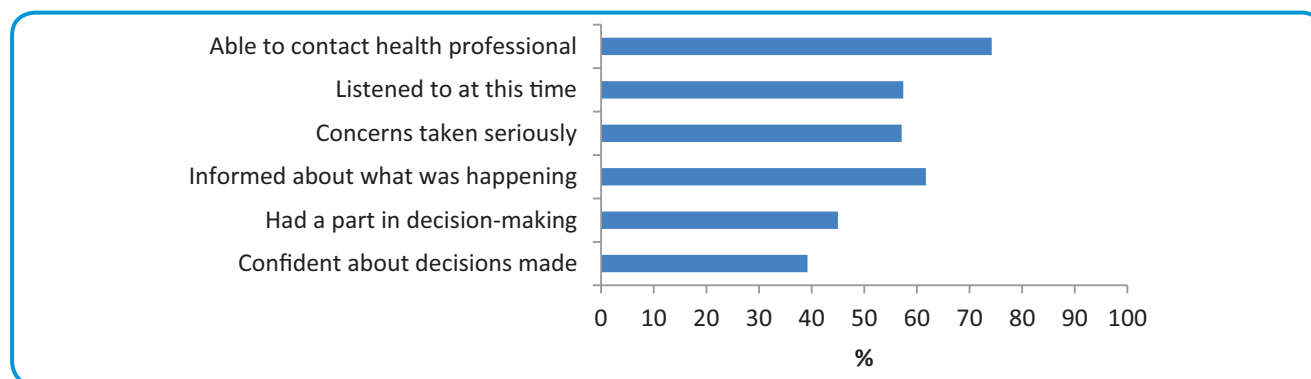


Figure 3.3 How women, whose baby was stillborn, felt about the responses of staff when they expressed concerns about their baby

At this point most women (94%) who had concerns and reported them went to a hospital and had checks either on their baby, including ultrasound scans, electronic fetal monitoring and measurement of placental blood flow, or on themselves, including blood and urine tests. A few women reported only being told to stay at home and rest, to contact their GP or the hospital again in a few hours (6%).

Parent bereavement support groups report that the way parents are told news about their baby's death is critical and can have a profound impact on the way parents view the quality of care they receive. For all the women in the survey and their partners the possible death of their baby was a shock; the way this news was given and how their baby's death was confirmed were extremely important aspects of their experience of care.

The way in which women and their partners were told that their baby had died varied, largely reflecting their individual circumstances and needs, but also the skills and background of the health professionals involved. While most partners were present when women were told that their baby had died (77%), not all couples were given the news together and some were single women. Some parents were unsure about the type of health professional who informed them or confirmed the death of their baby (8%).

The midwives were all amazing. They dealt with our grief and confusion in a very comforting way. The doctor who told us that our son's heart had stopped was the only person who was very short and abrupt ... his initial words still ring in my ears.

First the student midwife checked the heartbeat, then midwife, then the resident doctor and he said to me, "There is no movement." I was shocked. At that time I was on my own, my husband was on [his] way [to] hospital, and they just told to me. I think they should have waited for my husband to come and then informed me.

Doctor said there doesn't seem to be a heartbeat and asked if I know what that means?! Why did she have to make me go through the hardship of telling her that my baby is dead, is this an exam / test? I think she should have gently explained it herself.

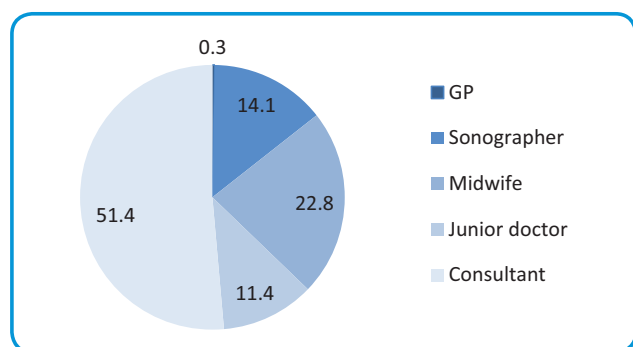


Figure 3.4 The proportion (%) of women, whose baby was stillborn, who were told that their baby had died by different types of health professional

Of those who were able to say, around half were told by senior medical staff (51%), followed by midwives (23%), staff carrying out the sonography (14%) and more junior medical staff for a smaller number of parents (11%) (Figure 3.4).

Most parents of babies who died before labour were on the labour ward when they were told that their baby had died (39%), with smaller proportions in a pregnancy day assessment unit (27%) or in an antenatal clinic (18%) when their baby's death was confirmed. Other places included the ultrasound department, triage, the intensive care unit, the operating theatre and at home.

The ultrasound department [should have] a separate waiting area, away from other pregnant women, for parents who are waiting to confirm an abnormality or an intrauterine fetal death.

Sands Audit Tool for maternity services²⁴

What was particularly distressing at the time was having to leave the scanning department and pass other expectant parents through the waiting room. To this day I struggle with flash backs of this time.

The ultrasound scan was done where all the antenatal scans have been carried out - in the Women's Clinic. After being told my baby had died, I walked back ... to the Labour Ward which meant walking through waiting rooms and along corridors seeing other patients while I was crying constantly.

The staff were really helpful and supportive but it was hard to walk through the waiting room to the exit where all the pregnant women were waiting for their dating and anomaly scans.

Women were asked about the quality of care before labour and how they were treated by staff at this time. High proportions recalled being treated with kindness, with sensitivity and respect, although 1 in 10 or more did not report this as their experience (Figure 3.5). Over two-thirds felt listened to, that their concerns were taken seriously and informed about what was happening at this time.

Doctors, midwives and hospital staff were extremely gentle with us and all decisions made were without pressure. It was helpful to be able to go to the "SANDS room" and talk things through with the doctors.

I was given plenty of time to let me think about all the decisions and help in making them. Lots of opportunity to ask questions, but I didn't know what I needed to know as I was in deep shock.



Figure 3.5 How women whose baby died before labour felt about their care around the time they were told their baby had died

Parents [should] always [be] given enough time... to reflect upon the information and their options, and to seek additional information and advice if they wish to, before they make their choices.

Sands Audit Tool for maternity services²⁴

They did everything to make 100% sure my baby had died before telling me. Having a Bereavement Midwife throughout the experience helped.

I felt too many professionals were in the room. I couldn't take in what was being said to me. There was a Consultant, two midwives, a junior doctor, and a sister, and myself and partner.

A large number of women said they did not feel listened to or only listened to 'to some extent' (31%). They reported a similar experience in relation to their concerns being taken seriously (30%) and feeling informed (28%). More than half felt they did not or only 'to some extent' had a part in the decision-making (43%) or had confidence in the decisions made (55%) and only 44% had confidence in the decisions made about their care around the time they found out that their baby had died. Some women described delays between becoming aware that something was wrong and having the death of their baby confirmed, referring to medical or more senior staff being

required and needing access to scanning equipment.

How labour and birth are planned and managed are critical aspects of parents' experiences with the potential to impact in multiple ways, both in the short and longer term.^{16, 17, 29}

Parents [should] always [be] offered time and opportunities to discuss and plan the birth and how they would like it handled.

Sands Audit Tool for maternity services¹⁵

Parents were asked about the range of options for their delivery care which were given to them following the confirmation of their baby's death. A small number of women were already in labour. Of those who were not, many were told they could go home and prepare for the birth and that labour could be induced within 24–48 hours (Figure 3.6). Others were told that labour could be induced straight away or that it was possible to wait for labour to begin naturally. For a small proportion of women caesarean section was an option. For a small number of women expecting twins where one baby had died, the pregnancy continued.

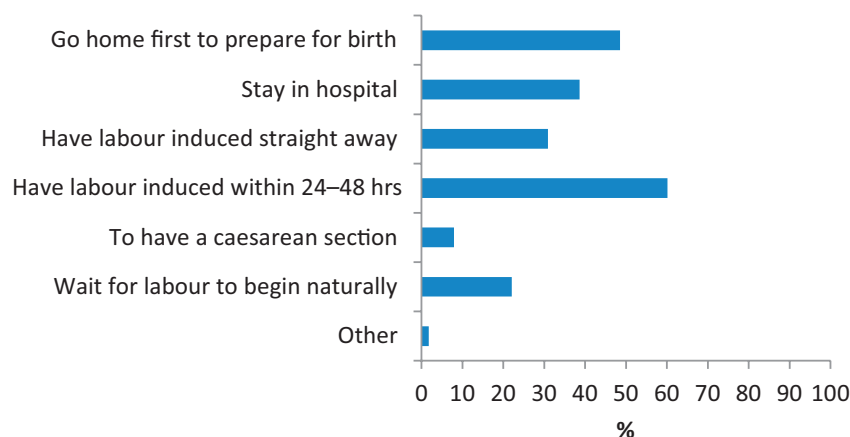


Figure 3.6 The options for labour and birth for women who were not already in labour and whose baby died before labour

Almost all women with a baby who died before labour and birth went on to labour (92%), with most having a vaginal birth (85%) and smaller proportions having an instrumental vaginal delivery (4%) or caesarean section birth (11%). Of women who laboured, 50% had pethidine or similar medication for pain relief, 23% had an epidural, and 15% stated in 'other' that they had been given morphine. For just over a third of this group of women (38%), caesarean birth involved having a general anaesthetic.

We had to wait what seemed like a long time to be visited by a doctor who could operate the ultrasound and confirm the death.

When the midwife did CTG and couldn't find heart beat she said that they would have to do ultrasound scan and that have to be done by a doctor. We had to wait for a doctor for almost 3 hours and they didn't do anything to speed it up.

The midwife and doctor team that we saw at the hospital at this time were very good. We were told about what would happen next (medically) and given information and leaflets ... which we read before returning to the hospital for the birth.

To be honest it all seemed a bit of a blur after we were told. It felt as though I was being bombarded with so much information and making decisions all at once within a few minutes.

I was also told a Doctor would visit me to explain my options but instead my midwife came with a tablet, told me to take it and come back in 2 days. I was sent home with no information or leaflets ... I had no idea what I had been given or any effects.

Although the medical care was excellent, we really felt that there was a lack in emotional support. No one to talk to. I so desperately wanted and needed to talk to somebody, a professional, about what we were going through, and the decisions we had to make.

Appropriate and continuous support in labour can make a difference to women's wellbeing and experience of care. Women were asked about the number of midwives who had looked after them during labour and the birth of their baby and if they had met any of the midwives before. They were also asked about the quality of their interpersonal care, as reflected in how the staff communicated and if they were listened to, informed and able to take part in decisions made over the course of their labour.

Every woman [should have] an experienced midwife who looks after her throughout her labour and birth.

Sands Audit Tool for maternity services²⁴

Just over 40% of women had one or two midwives looking after them during labour, but most were looked after by three or more midwives (Figure 3.7). This was more common with longer labours; the proportion of women being cared for by 5 or more midwives increased steadily with the duration of labour from 8% of women who laboured for less than 4 hours to 26% of women whose labour exceeded 12 hours. Most women (81%) had not met any of the midwives caring for them before. Most partners were present for the labour (90%), for the birth itself (89%) and almost all after the birth (96%).

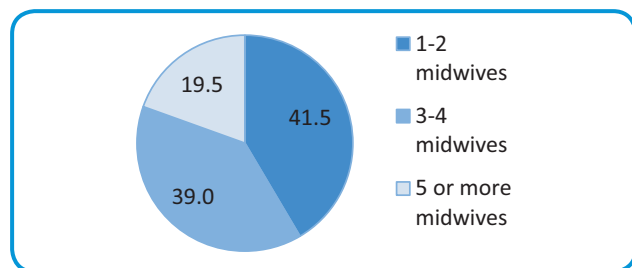


Figure 3.7 The proportion (%) of women, whose baby died before labour, having different numbers of midwives caring for them during labour and birth

I was also told a doctor would visit me to explain my options but instead my midwife came with a tablet, told me to take it and come back in 2 days. I was sent home with no information or leaflets ... I had no idea what I had been given or any effects.

I felt like strangers around me became more like family. Their grief was obvious and a comfort to me. I felt like a person not their job ... They watched my reactions carefully and behaved accordingly.

Midwife who administered tablet to induce labour said she hoped to meet us under happier circumstances in future. Whilst I know she meant well ... we knew we would not try again. Offering a 'happy' ending is not always the answer, better to just acknowledge that it is deeply sad and don't know what to say.

All members of staff, without exception, could not have supported me in any other way possible. As this was our first child we were completely at their mercy, their professionalism throughout this most emotional ordeal was fantastic.

Looking back I don't think the hospital staff could have done anything differently. I was unsure of my decisions but that was only because my world had caved in and I couldn't think properly.

Most women felt that staff communicated very well or fairly well (90%) and that many staff were aware of women's vulnerabilities at this difficult time. Around two-thirds reported always having confidence and trust in the staff caring for them at this time (71%), but communication could have been better for some women in most respects (Figure 3.8).

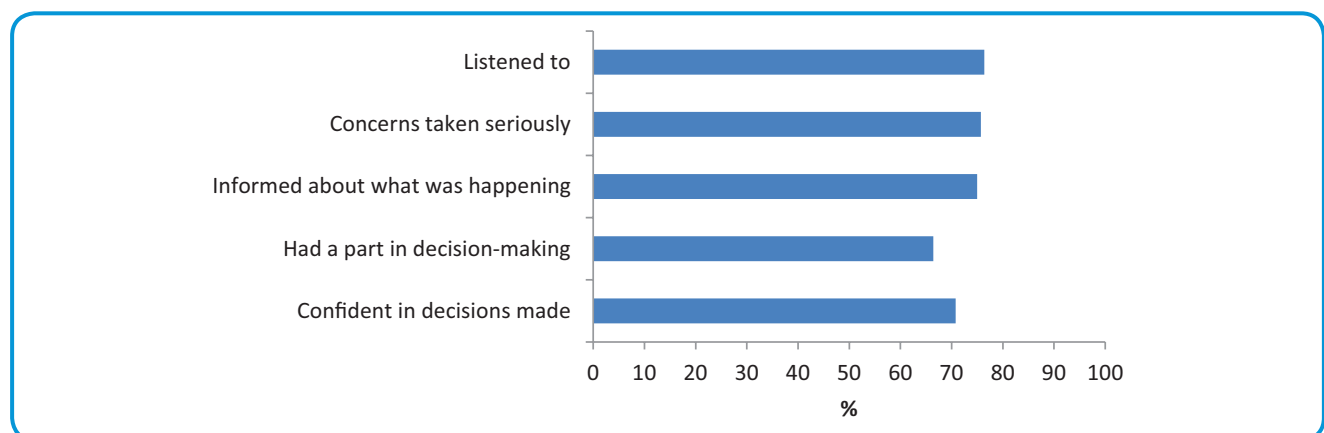


Figure 3.8 How women whose baby died before labour felt about their care during labour and birth

Parents were also asked about their experience of interpersonal care provided by medical and midwifery staff (Figure 3.9). Their responses were largely positive, particularly so about the midwives who cared for them.

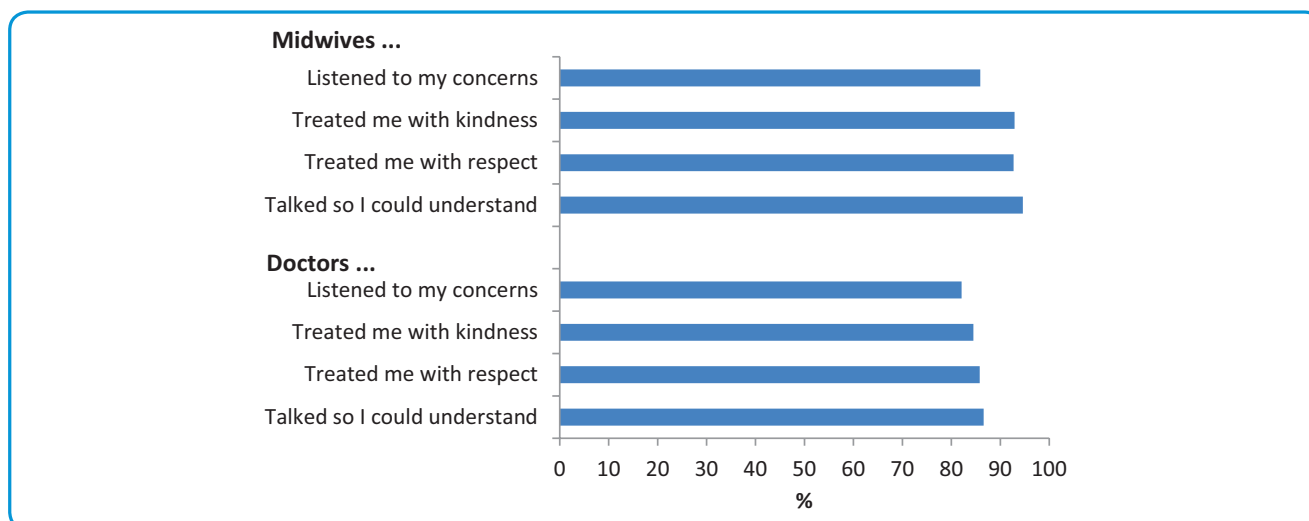


Figure 3.9 Views of care from health professionals during labour and birth in women whose baby died before labour

All staff [should be] able to give the mother sensitive and supportive care during labour and the birth, and to deliver and handle the baby sensitively.

Sands Audit Tool for maternity services²⁴

Given the option to choose from a list of words to describe the staff who cared for them in labour, the words chosen were mostly positive including 'kind', 'supportive', 'considerate', 'warm' and 'sensitive'. Few women selected negative terms: 'rushed' (11%), 'insensitive' (7%), and 'bossy' (5%). Extra words most often added by women to describe staff included 'caring', 'amazing', 'empathetic', 'professional', and 'understanding'.

Women were asked if during their labour and birth or shortly afterwards they and their partner were left alone by staff at a time when it worried them; four out of five (79%) indicated that this had not happened at all. However, this was not the experience of some women and their partners, with 16% reporting this happening during labour and 10% reporting being left alone and worried afterwards.

3.4 Parents whose baby died during labour

Most babies who are stillborn die before labour, but some babies die during labour. Among the women who took part in our survey, 56 had babies who died during labour. Two of these women gave birth to stillborn twins.

Nearly half of the parents in this group (41%) thought that something was wrong during labour. At this point they identified similar concerns to those of women whose baby died before labour: about their baby's movement (42%), with bleeding (29%) and with pain (46%) and concern among the health professionals providing care (38%). With electronic fetal monitoring during labour for this group there was also concern about abnormal heart rate patterns (33%) and the implications of these.

I was kept waiting in the waiting room for hours, I was completely neglected left to my own devices, the hospital failed to check me, because they were busy.

The midwives were generally sensitive, thoughtful and made sure I understood what was happening ... My only concern was that I was left alone once my labour was progressing and as I give birth very quickly this made me more anxious.

We were ushered very quickly into another area and left alone. At this point I was very anxious.

What I found horrible is that shortly after delivery we were left alone and I hadn't decided yet when / where / if I wanted to see my baby.

When contractions had started but I wasn't yet dilated, we got the impression that the traces weren't right ... when [we] asked, our questions were skirted around. With hindsight they didn't tell us of their concerns.

I felt really isolated, "strapped" to the bed, quite removed from the situation. This may have been meds, or the fact I was lying down. I felt that all words were positioned to go over me, like when you don't want a child to hear.

I felt the midwives were caring and respectful towards my husband and I, however we were aware they were discussing things without involving us. It was clear there was something going wrong which they didn't want to mention, and we were in no state to discuss circumstances having contractions every 2-3 minutes.

Half of these women had a normal vaginal birth (49%), a small proportion had an instrumental delivery (10%) and a relatively large proportion (41%) had a caesarean birth, most commonly as a consequence of unforeseen problems during labour, mostly (75%) with a general anaesthetic. Pethidine was used for pain relief by 28% and an epidural by 38%. Women whose baby died during labour, who were more likely to have had unforeseen problems, typically had more midwifery staff caring for them. More than two-thirds had three or more midwives caring for them during labour (69%), with some women having five or more (38%), possibly reflecting length of labour, but also an urgent need for intervention and care (Figure 3.10). Perhaps more importantly, most women in this situation (84%) had not met any of the midwives caring for them before.

I was left alone apart from a student midwife. When my baby's heartbeat stopped being detected the midwife ... did not know what to do. She kept leaving the room to ask other members of staff ... The senior midwife responded - tried to pick up my baby's heartbeat with a sonicaid, could not and left ... she said she was needed elsewhere. I knew my baby had died by this point and nobody helped us.

I didn't discover my son had died until he had been delivered - after my daughter was born. I had received conflicting information prior to the emergency caesarean as to whether his heart beat was present.

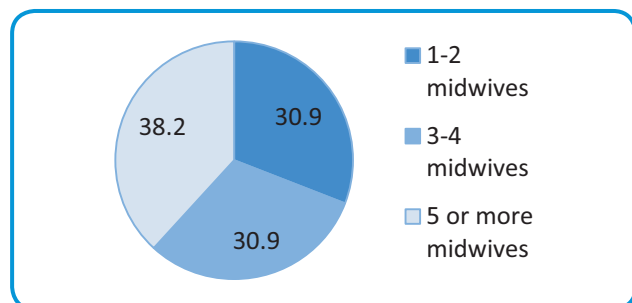


Figure 3.10 The proportion (%) of women, whose baby died during labour, having different numbers of midwives caring for them during labour and birth

For some women whose baby died during labour effective communication with staff at this time was difficult: a quarter of women felt staff communicated poorly (24%) and some reported rarely or never having trust or confidence in the staff caring for them during labour and delivery (14%). The uncertainty and difficulties inherent in their situation for parents and the staff providing clinical care and support are reflected in the way they felt communication was handled, with up to half of the women whose baby died during labour and birth not always feeling listened to (43%) or that their concerns were always taken seriously at this important time (41%) (Figure 3.11). They also felt less engaged with the decision-making or confident in the decisions made.

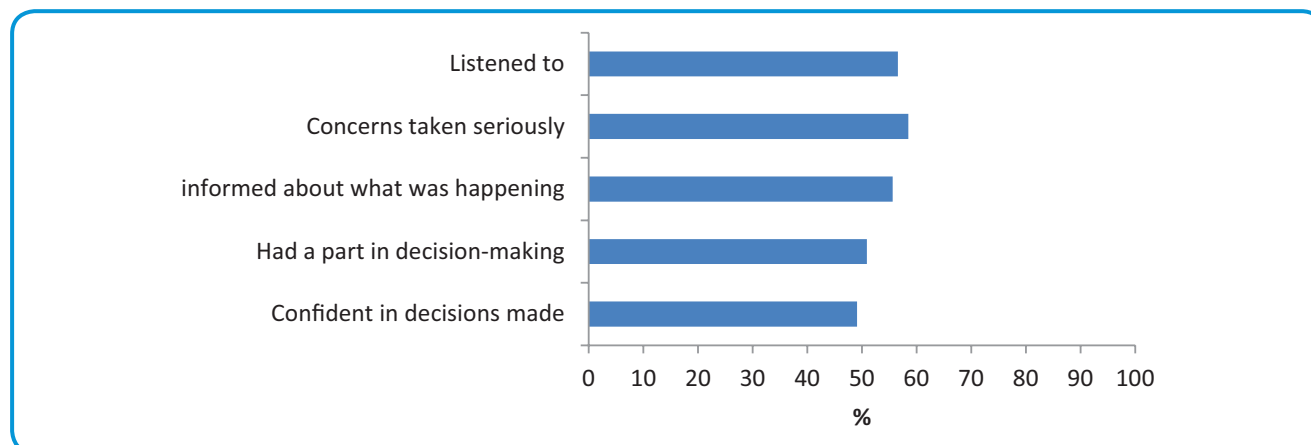


Figure 3.11 How women whose baby died during labour felt about their care during labour and birth

Mothers whose babies died during labour and birth were more critical of their care than those whose babies died before labour. Choosing from a list of words, fewer women, although quite large proportions, chose positive terms 'kind' (73%), 'supportive' (68%) and 'sensitive' (64%) and more women were likely to describe staff as 'rushed' (27%), 'insensitive' (18%), 'rude' (14%) and 'condescending' (16%).

While two-thirds of women and their partners in this group were not left alone by the staff at any time when it worried them, over a quarter (27%) were left alone and worried during labour and birth and 11% in the immediate period after birth.

Women were also asked about the care provided by the two main groups of health professionals caring for them during labour and birth. Midwives and medical staff were perceived to have behaved in a generally similar way although women were slightly more critical of the medical staff caring for them (Figure 3.12).

It was awful. We were left on our own for 1 hour before the Consultant actually told us he had died. I was lying in a pool of my own blood from the episiotomy and 3rd degree tear I sustained ... None of the staff would stay in the room with us. It was chaotic, nobody knew what was going on and nobody took charge.

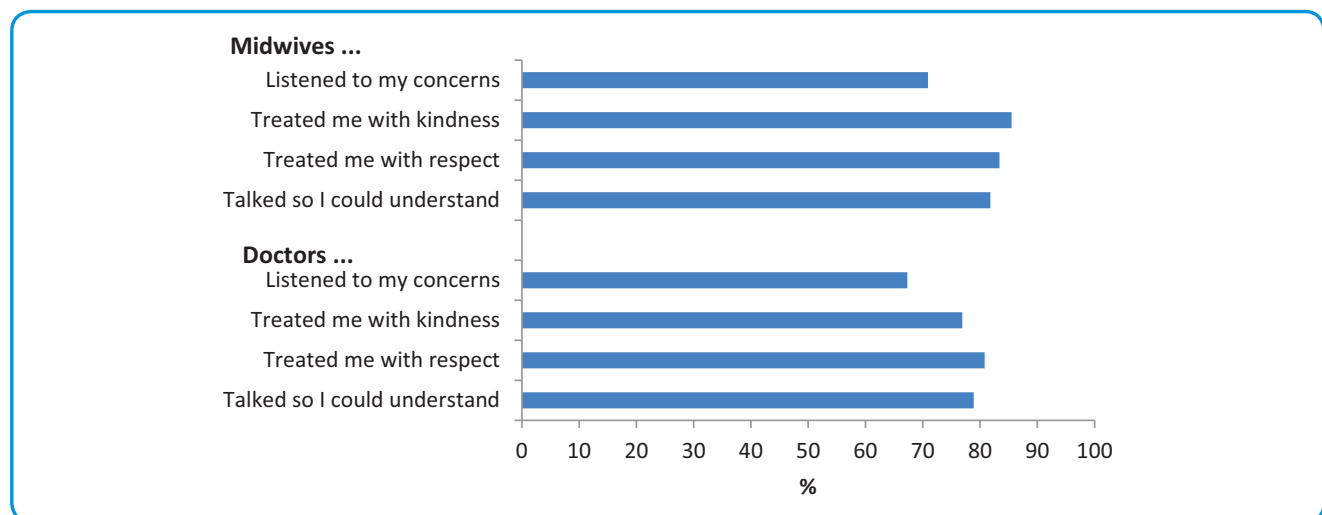


Figure 3.12 Views of care from health professionals during labour and birth in women whose baby died during labour

A specific question was asked about how this group of women were treated by staff around the time they were told that their baby had died. Most women felt they were treated with kindness (82%), sensitivity (85%) and respect (84%) at this time. The difficulties that staff experience in giving parents this news were evident in women's comments.

Most partners in this group were present for the labour (90%), when they were told their baby had died (93%), for the birth itself (82%) and almost all after the birth (98%). Partners were less commonly present at the birth for these women because of the high proportion of women having an emergency caesarean section under general anaesthetic.

The quality of care in labour and around the time that their baby died mattered enormously to parents, even when they were aware that staff were very busy and preoccupied, and responses in their own words reflect this.

It all happened very quick and took the room by shock. That was why the doctor [found] it hard to tell us. He literally died within 5 minutes of being checked! Very strong heartbeat, then nothing.

Consultants, midwives missed things, and did not explain what was happening. During caesarean I was so scared, shouting out asking if baby was ok and no one talked to me!

I was transferred by ambulance to a different hospital. My husband... had to follow in his car. I was sent ... for an emergency c-section but it was too late. This was when I was told baby had died, before my husband arrived. I then had to tell him myself.

The midwives were supportive but the Consultant ... wouldn't explain what was happening ... I had to raise my voice to get her to tell me that my baby had died no-one used the words died - "No fetal heartbeat" are the words that were used.

I remember the silence. I asked "the baby?" and the Registrar said "I'm so sorry, she died". That was all I could take in and I was very grateful that the details were given later.

3.5 Postnatal care in hospital and at home

Postnatal hospital stays were relatively short for women who had experienced a stillbirth either before or during labour at an average of 1.8 days (median 1 day), ranging from less than a day to 42 days). Most women felt that their length of stay was about right (74%).

Until they go home, all parents [should] always [be] cared for in a dedicated room... where they cannot hear other babies....[where] the mother's partner or companion can stay overnight [and where] other family members [can] visit.

Sands Audit Tool for maternity services²⁴

Half stayed in a single room (50%) and half in a bereavement room or suite (54%), a small number used both. The room or suite was mostly on the labour ward (75%). They were asked about where they stayed at this time and how close it was to other babies and labouring women. Less than half said that this was 'away from crying babies' (48%) and 'away from women in labour' (45%). Most reported that it was where their partner could stay (83%), where they could be with their baby (81%) and where family and friends could visit (81%).

All staff [should be] able to offer parents opportunities to see and hold their baby and to create memories.

Sands Audit Tool for maternity services²⁴

Parents were asked about seeing, holding and spending time with their baby at this point. Most women were able to see their baby (93%), hold them (84%) and felt able to spend time with their baby (89%). A few women were not able to do this or did not wish to and very small numbers of women were not offered the opportunity to see (0.4%) or hold (2%) their baby.

Similar proportions of partners were able to see their baby (92%), hold them (82%) and very few were not offered the opportunity of doing so (0.7% seeing, 3% holding). Partners were slightly more likely than mothers to choose not to see (7%) or not to hold (16%) their baby. Around two-thirds of parents (67%) said that family members saw their baby.

Women were also asked about the quality of their maternity unit postnatal care and a range of information and support that would be expected to be available from the hospital for parents in this situation. Around 90% of the women responding reported good interpersonal care at this time, being treated as an individual (89%), with respect (93%) and kindness (93%) and being given the care they needed (88%) while in hospital (Figure 3.13).

I wasn't offered anywhere else to go and I could hear labouring women and crying babies.

I was put into a family room which was perfect except [for] the fact that all I could hear was crying babies which distressed me even more than I already was.

The bereavement suite was on delivery ward but sound proofed. All facilities in room so I did not need to leave.

I am forever grateful to the midwife who encouraged me to hold our daughter post delivery, without her encouragement I wouldn't have felt strong enough.

I could have been better prepared for how my baby would look after he was born. I was so scared ... I didn't know if I could hold him ... I needed to be given time ... I felt that someone was going to swoop in at any moment and take him away to the morgue. I would have loved more time.

The midwife who delivered my baby had not experienced a stillbirth and did not invite me to hold my baby - a simple thing - but I dared not ask at the time. Luckily, at the funeral directors, I asked and got to properly hold him.

They took great care to dress baby so we could hold her even though she weighed only 350g.

I feel that I should have been offered the chance to bathe and dress my baby. I think someone from Bereavement Services should have come sometime after the birth to talk through these things that you need to do but can't think for yourself or don't know enough about them to ask.

The hospital have a specific bereavement room ... we could spend as much time as we wanted with our baby.

We were perfectly cared for and didn't want to leave and return to all the extra pain awaiting us in the "real world" (such as an empty car seat and nursery and people who didn't know what had happened or how fragile we were and sometimes still are.) Our care was so excellent and well-thought-out (taking photos, which seemed a bad idea at first but are now priceless treasures, for example), that we realized we were benefitting from many other parents' grief.

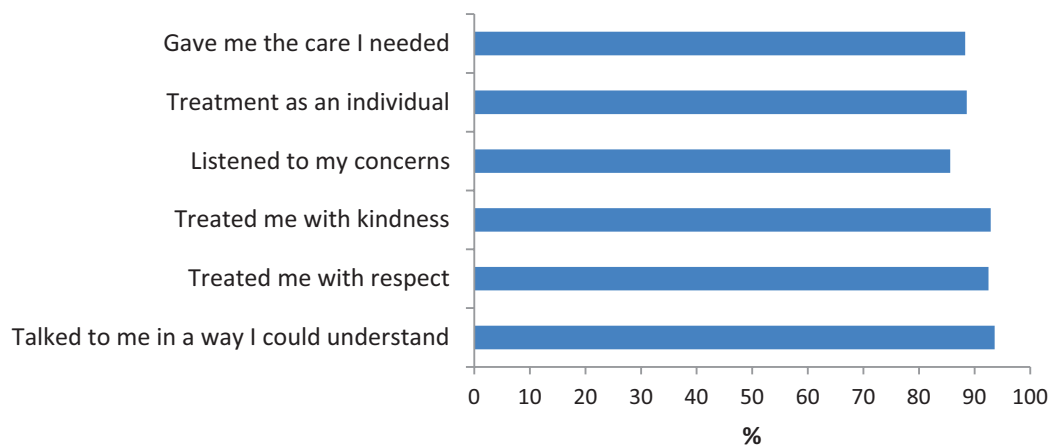


Figure 3.13 How women whose baby was stillborn felt about their postnatal care in hospital

All staff [should be] able to give the parents verbal information about the funeral arrangements that the hospital offers [and] good written back-up information about the funeral options available to them.

All parents whose baby dies [should be] given written details of national and local sources of support and organisations such as Sands, Bliss ...

Sands Audit Tool for maternity services²⁴

A range of information, help and support was available in the hospital for many families (Figure 3.14). Notably, one-third of women (33%) reported that they were not given advice about managing breast milk production and one-quarter (26%) were not given information about counselling services. For most parents there was a quiet room in which they could be with their baby (87%), help with funeral arrangements (85%) and a blessing or religious ceremony (83%), although for one in ten or more this type of support was not available. Some parents were not given written information about stillbirth (11%) or information about support groups (7%).

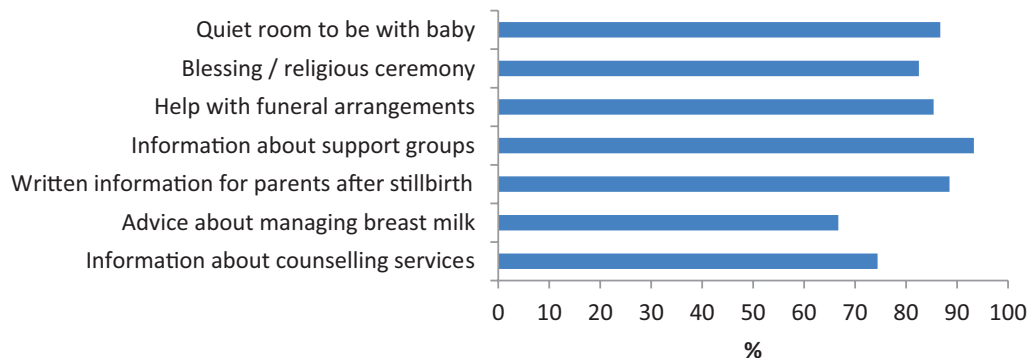


Figure 3.14 The proportion (%) of women, whose baby was stillborn, who were offered different kinds of information and support in hospital after stillbirth

Women were asked if, after leaving hospital, they had the name and telephone number of a midwife they could contact and about actual postnatal contacts with a midwife and their GP or family doctor. Having left hospital most women (86%) had the name and telephone number of a midwife they could contact. However, while some were uncertain on this point, others (8%) reported that they did not have this information.

Midwife stayed 10 minutes, had never met us before and was clearly uncomfortable.

There wasn't much postnatal care. Midwife visited me twice and it felt like she didn't want to be there. She also offered several times that I can see different midwife.

We felt like we had been abandoned somewhat. A midwife I had never met came to check my physical health a few days after leaving hospital. A few weeks later a health visitor visited for 10 minutes, which I felt was not enough.

Most women were visited at home by a midwife (90%), a small proportion visited a midwife in a clinic (2%), and others did not want to see a midwife (4%), but some women were not offered a midwife visit at all (4%). Relatively few women were visited by their GP (8%). Those who were visited by a midwife also indicated whether they had met them before. Just less than half of those who were visited were seen by more than one midwife (47%) and almost two-thirds had met some or all of the midwives who visited them before their baby had died (65%). Women's comments suggest that care at this point was rather variable in quality; women were aware of the discomfort of some health professionals and some expressed a wish to have their need for postnatal care recognised.

Once home, the number of times that women were seen during the postnatal period varied considerably: while the average (median) number of contacts was two, a few women saw their midwife every week or so for some months. The timing of the last contact with midwifery care also varied, with a third of women (32%) seeing their midwife for the last time four weeks or more after their baby was stillborn. While for most women they felt that they saw a midwife as much as they wanted, one in five women would still like to have seen their midwife more (22%). These were primarily women who saw a midwife only for the first few days. Women were asked about their relationship with the midwives they saw at home: of those who were visited at home, over half the women responding (62%) indicated that they always had confidence and trust in the midwives visiting them, a quarter (26%) sometimes, and just over one in ten (12%) said that they rarely or never had confidence and trust in the midwives who they saw at this time. Some women commented that continuity of care, carrying on from relationships made during pregnancy or labour and birth was also important and that some health professionals responded to this.

3.6 Overall experience of care

Women were asked about their overall view of the different phases of their care (Figure 3.15).

Their perceptions were most negative in relation to pregnancy, although approaching two-thirds (63%) were satisfied or very satisfied with their care at this time.

I feel quite let down, my midwife was lovely and gave me lots of information, but I had no-one else check to see if I was ok, to talk to me, to check me over. I didn't see a doctor or a health visitor and as lovely as my midwife was I only saw her a couple of times.

It would have been good to have had the opportunity to see my regular midwife, prior to the stillbirth, one last time as she is the person I had built a relationship with.

Support worker telephoned once, she said she would send a Midwife to see me who I had never met. I said I wanted to see the midwife who was at the delivery so she called me direct and I saw her at the maternity unit.

It was only the bereavement midwife that I met once before my baby was born and then after she was stillborn. The other midwives were new and changing all the time, I didn't like this it meant explaining my story to each midwife knowing the outcome of the pregnancy.

Our GP just popped in to see us at home to offer all their sympathy and support. Again we couldn't have asked for better care.

Overall the care I have received was very good but during the pregnancy from 20 weeks me and my partner felt we weren't dealt with in a sensitive manner when we needed to be. We felt like when consultant explained the problems he didn't take into consideration she was our baby. This was very distressing and hurtful at the time when we were going through a very difficult pregnancy.

The care during labour was great and even for the following few days. I was promised a follow up a few months later by local and [name] hospital but never received this.

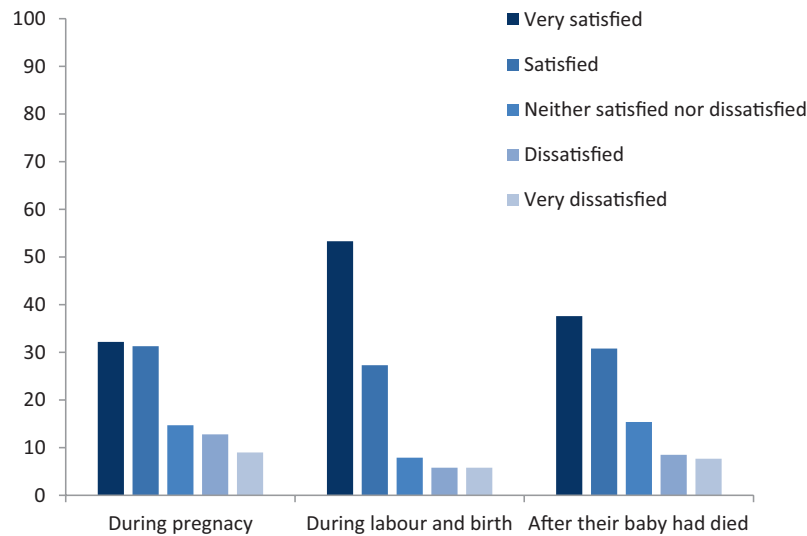


Figure 3.15 Overall satisfaction with care provided during pregnancy, labour and birth and after their baby had died for women whose baby was stillborn

Women were slightly more positive about their postnatal care, with 69% satisfied, and care during labour and birth was perceived most positively, with more than three-quarters (80%) of this group being satisfied. Nevertheless some women, ranging from 12% to 22%, were dissatisfied with the care received at different points across their care pathway.

3.7 Fathers' and partners' experience of care

Women who experienced stillbirth were asked about their partners' experience of care and interaction with the health professionals providing care. Doctors and midwives were thought to have communicated very or quite well with most partners during pregnancy (77%), labour and birth (85%) and after their baby was born (83%).

In general fathers and partners who had experienced the stillbirth of their baby were positive about the way they were treated (Figure 3.16).

Every single question I asked was answered honestly and truthfully and the care I received was excellent. Throughout my pregnancy and during the birth I cannot find any fault in the hospital or its staff and am very grateful to them all at the difficult time I was experiencing. Until something like this happens to you, you do not realise how common it is and feel that overall I could not have been in better hands.

Overall, despite the horrifying fact that you have lost a child, my experience of pregnancy, labour, delivery, birth and aftercare has been positive. I have some wonderful mementos of my child and she was made to feel like she was as important as a baby who was alive and that was the most important thing for me.

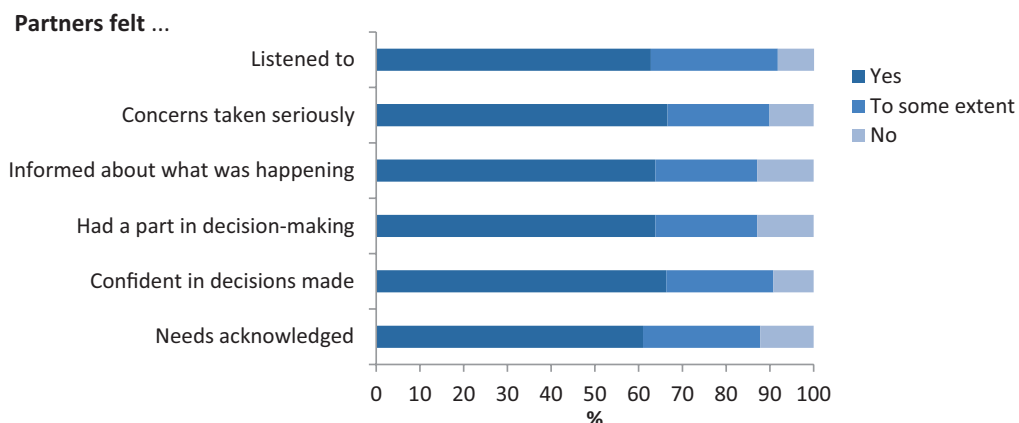


Figure 3.16 The experience of care and interaction with health professionals in fathers and partners whose baby was stillborn

However, a third or more did not feel listened to or only 'to some extent' (37%) and did not always feel that their concerns were taken seriously (33%) or their needs acknowledged (39%). With regard to decision-making in what was a difficult and changing set of circumstances, similar percentages of fathers and partners did not always feel part of what was happening: 36% did not always feel fully informed, 36% felt that they did not always have a sufficient part in decision-making and 34% were not entirely confident about the decisions made.

Women frequently referred to the presence of their partner and his active role as supporter and advocate, particularly in the context of being given bad news, in relation to labour and being together with their baby. One father responded himself, enabling us to appreciate how partner presence and experience may be taken for granted.

My husband repeatedly tried to get attention and was told 'I was not the only woman in labour'! Minutes later I delivered!

When I told the midwife I wanted to push she left the room to get another midwife. I delivered my son while she was out of the room and my husband had to go get help. This was the only time he felt unsupported.

One midwife was a bit blasé about taking the tablet to stop my milk coming in but my husband explained to her that she had upset me and she apologised and understood the situation and was lovely about it after that.

Such a traumatic loss, naturally focus concentrates on the mother. A father's loss isn't understood, as mainly they have that mantle of being strong and dealing with the initial fall out of calls, communication ... Even after a time an understanding of what a father goes through isn't really broached, it's rather like primer applied to a wall, which eventually is painted over.

3.8 Summary

In summary, parents of stillborn babies were generally positive about the care they received, especially care in labour and at birth. However, they sometimes didn't feel listened to or that their concerns were taken seriously. This was particularly the case in the antenatal period when they felt that something was wrong and when their baby's death was confirmed. Most stillborn babies died before labour, but for those women whose baby died during labour, many felt that communication was poor, that they had little confidence or trust in the staff, and didn't feel listened to or that their concerns were taken seriously. Postnatal care in hospital was recalled positively by most, but many women were in rooms close to healthy newborn babies or labouring women, which was distressing. While many fathers and partners felt they were treated well, for some, their needs and perspective could have been better acknowledged.

4: Parents whose baby died after birth

4.1 The women and their babies

Of the women taking part in the survey, 248 had a baby who died as a newborn; sections 4.2 and 4.3 of this report address the pregnancy and birth care experienced by these women. Section 4.4 reports on the experience of the 84 women whose baby died soon after birth, but who were not admitted to a neonatal unit, and section 4.5 focuses on the experiences of women whose baby was admitted to a neonatal unit.

4.2 During pregnancy

Women were asked about access to and use of maternity services. Like the women whose babies were stillborn, the majority of women whose babies died as newborns had contacted a health professional about their pregnancy by 7 weeks' gestation (median 7 weeks) and had their booking appointment by 10 weeks (median 10 weeks). While 68% had booked for their pregnancy care by 10 weeks' gestation, 99% had done so by 18 weeks. Almost all had a pregnancy dating scan and an anomaly scan (97% and 95% respectively). These figures are similar or slightly higher than those reported in the 2010 National Maternity Survey.³

A small proportion of women (16%) whose baby died after birth had health problems identified at booking, most commonly asthma. However, more than two-thirds of women (70%) developed further problems during their pregnancy, either with their own, or their baby's health. This principally included placental problems, i.e. bleeding, low-lying placenta and other placental problems, which occurred in 40% of women, but also included threatened preterm labour (21%), concerns about their baby's growth (16%) and congenital anomalies (15%). More than a third of women (39%) were admitted to hospital at least once in pregnancy (excluding admissions for induction or elective caesarean section), most commonly for bleeding (21%). Women were also asked if they had concerns about their baby before labour and birth. More than two-thirds (69%) said they did have concerns, most commonly about their baby being preterm, often associated with premature rupture of the membranes.

Women were asked about their experience of care from midwives and medical staff during pregnancy (Figure 4.1). Most felt that midwives and doctors treated them well while providing their antenatal care, although with both staff groups more than a quarter of women (29%) felt that their worries and concerns had not been listened to.

I called to say about pains and was told that I can't expect a pregnancy without discomfort. A day or two before I went into early labour I ... expressed concerns to which I was told pains and back ache is normal. On the day I gave birth I called ... and was explaining my symptoms ... she said it was ok as long as it didn't get worse. It was nothing to worry about.

I felt my consultant was too busy to care. Consultant simply said if you lose it you lose it. Nothing you can do. Very insensitive. Not enough staff, not enough time. Midwives were great but were so busy ...

When we had our 32 week scan, our appointment was at the end of the day. The scan was terrifying. Our world fell apart, yet there was no one available ... other than a midwife from pre-natal diagnosis who couldn't tell us anything. We waited around for ages ... We were sent home knowing our baby had something massively wrong, but [with no] idea if anything could be done.

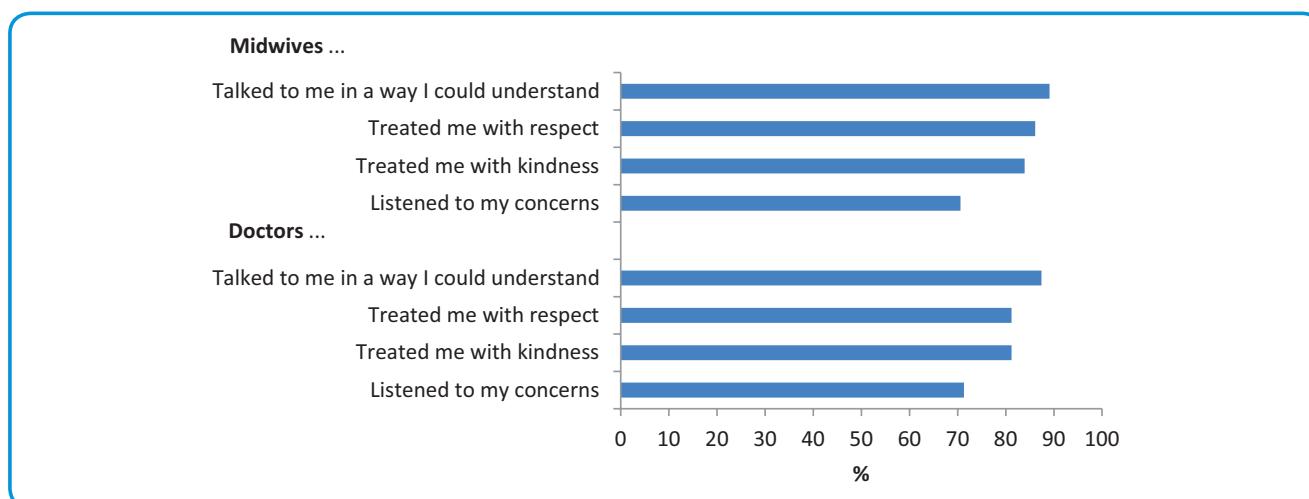


Figure 4.1 Views of care from health professionals during pregnancy in women whose baby died as a newborn

4.3 Labour and birth

Three-quarters of women suspected that something was wrong while they were in labour or before their baby was born. Some reported that they just felt that things were not right (31%), but others were prompted by symptoms of bleeding (32%) or pain (31%). Some of these women also said that their labour was preterm.

About 10% of women had a caesarean section before labour started, and 62% had a normal vaginal birth, similar proportions to those reported for an unselected population of women in a recent national survey.³⁰ However, 19% of women had a caesarean section due to unforeseen problems, somewhat higher than in the national survey referred to, and only 6% of women had instrumental vaginal deliveries (forceps or ventouse) compared to 14% nationally.³⁰ A third of caesarean sections were carried out under general anaesthetic. The most common reasons for caesarean section were that their baby was 'distressed' (43%) and that there were concerns about the mother's health (27%).

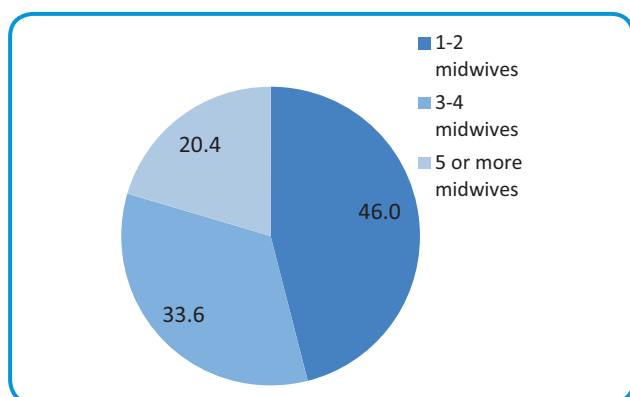


Figure 4.2 The proportion (%) of women, whose baby died as a newborn, having different numbers of midwives caring for them during labour and birth

Associated with type of delivery, more than half of the women (54%) reported that three or more midwives looked after them during labour and delivery (Figure 4.2). Most women (79%) had not met any of these midwives before, but three-quarters (75%) felt that the midwives communicated very or quite well at this time. While most women always had confidence and trust in the staff (58%),

The care I received during labour was excellent. I was obviously very emotional and the midwives were outstanding. The midwife who delivered our baby remained on shift for additional time to ensure it was her who delivered.

The doctors involved in the delivery were constantly talking to me. It all happened very quickly but I was updated all the time.

I feel that we were extremely well looked after during the whole time. It was the worst time of our whole lives, but all of the staff who looked after us were exceptionally professional and amazing.

Wasn't informed how worried they were with heart tracing - thought everything was ok until rushed for C-section. Would have better to have been informed ASAP.

I was pushed to make a decision about if I wanted to resuscitate my babies by one of the paediatricians ... she was pretty much telling me that should any of my babies survive its highly likely they would be very disabled.

a significant number felt this only sometimes (29%), rarely (4%) or never (9%).

Women were asked about their overall views of care at this time. They were more critical about their care during labour than about their pregnancy care. During labour, although most felt listened to (60%), that their concerns were taken seriously (58%) and that they were informed about what was happening (61%), quite large numbers did not express this view or did so only 'to some extent'. Their views about having a part in decision-making and feeling confident in the decisions made were also less positive, with 28% feeling they did not have a part in decisions and 17% saying they were not confident in the decisions made (Figure 4.3).

I felt that I could have been informed better of what was happening and why ... because of my age I wasn't cared for (emotionally) as much as someone older would have.

It did feel that decisions were made very quickly with little opportunity to formulate and ask questions. Between the births of each twin I wasn't sure what to expect as the Consultant and Obstetric team seemed to rush out very quickly.

The midwives read our birthplan and ensured all we had hoped for could happen; details such as [my husband] announcing she was a girl. We felt as much in charge as possible, whilst being reassured that they were monitoring everything well. We had a calm and peaceful labour as we had hoped for, only possible with the midwives' support.

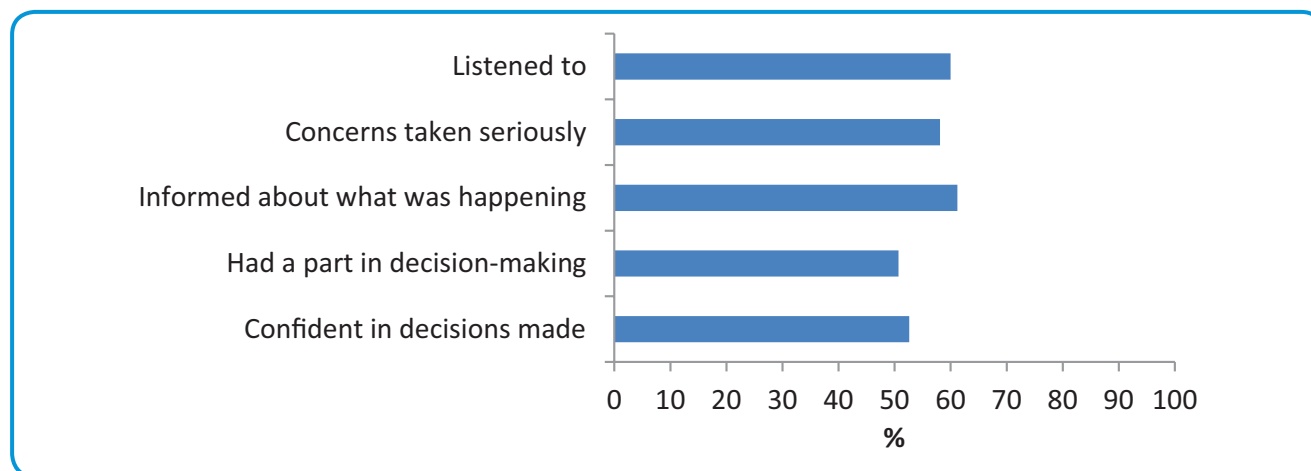


Figure 4.3 How women whose baby died as a newborn felt about their care during labour and birth

Parents were also asked about their experience of the care provided by the different types of staff caring for them in labour. Their responses were broadly positive with regard to medical and midwifery staff, but parents were slightly less likely to feel that their concerns were listened to compared with feeling that they were treated with kindness or respect or that they were talked to in a way they could understand (Figure 4.4).

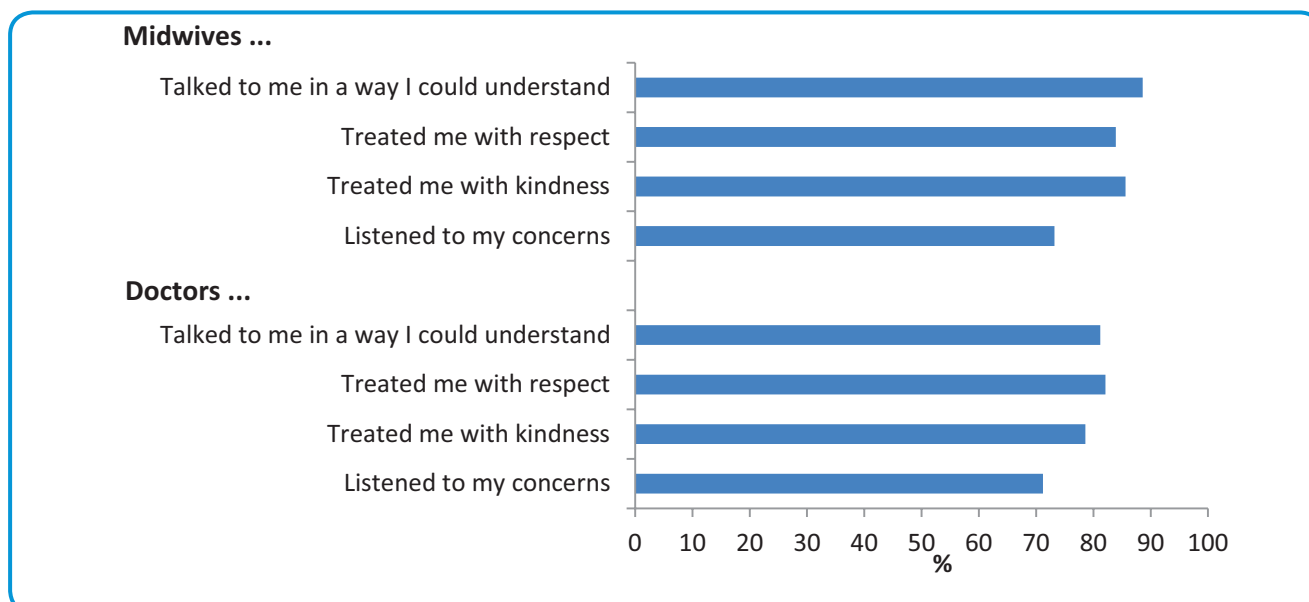


Figure 4.4 Views of care from health professionals during labour and birth in women whose baby died as a newborn

Choosing from a list of words provided, women described how they were looked after during labour and birth. Half or more described the staff who cared for them as ‘supportive’ (67%), ‘warm’ (53%), ‘sensitive’ (51%), ‘considerate’ (50%) and ‘informative’ (39%). The most common negative terms used were ‘rushed’ (30%), ‘insensitive’ (18%) and ‘inconsiderate’ (12%). Women also added their own words; the most often used were ‘compassionate’, ‘amazing’, ‘professional’, ‘friendly’, although a range of negative terms was also used, including ‘uncaring’, ‘unsupportive’ and ‘complacent’.

We also asked women if during labour and birth or shortly afterwards they or their partner were left alone at a time when it worried them. Most women (62%) were not left alone at such a time, but a quarter (26%) reported being left alone and worried during labour and 20% reported being left alone and worried shortly after birth.

The first midwife's attitude and 'bedside manner' was a bit rude and abrupt as if she didn't have enough time to spend with us.

Everything was happening so fast and decisions were being made without explanations. I was not made to feel relaxed and reassured due to all the rush.

I was cared for by an amazing midwife who was wonderfully warm and supportive. The Registrars ... were the ones who were insensitive and on one occasion rude. Consultants were very kind but I didn't always feel that they knew what they were doing.

My only general concern was the Midwife kept leaving the room when I knew my baby was coming and would need immediate care when born, this left me feeling even more scared than I already was.

During the early stages (when my waters had only just broken and I wasn't in established labour) I was given very little attention because they were busy. Only when things ... started to go wrong did I get the full attention of the staff.

My husband was left on his own on Delivery Suite with no communication from staff for an hour while I was in surgery.

4.4 Women whose babies were not admitted to a neonatal unit

Just over one-third (36%) of the 84 babies who died in the neonatal period died without being admitted to a neonatal unit. Most of these babies (90%) died within 24 hours of birth and half within an hour. Almost all died on the labour ward or in the operating theatre, with a small number dying at home. A high proportion were very preterm, 75% being born at less than 32 weeks' gestation and 61% at less than 25 weeks. Some were born with a diagnosed congenital anomaly so were not expected to live for very long after birth; for others their baby's death was unexpected, often as a result of complications arising during labour and birth. The parents of all these babies had a limited, but valued opportunity to spend time with their baby.

While they were in labour most women and their partners in this group (75%) had suspected that something was wrong, with symptoms of bleeding and pain and concern about prematurity being key issues. Most of the women had a normal vaginal birth (77%) with smaller numbers being assisted by forceps (5%) or having a caesarean section (18%).

During their labour most of these women (80%) felt that staff communicated with them well about their care. A high proportion had confidence and trust in the staff caring for them (88%), although some (12%) had rarely or never felt this way. While many felt informed (66%), listened to at this time (65%) and that their concerns were taken seriously (58%), one in ten felt that this was not the case (10%) and more felt they had no part in the decision-making at all (29%). Their interpersonal care from midwives was very good with more than 90% feeling they were talked to in a way they could understand and treated with respect and kindness. More than 80% of women experienced similar good interpersonal care from medical staff.

While most women and their partners in this situation were not left alone at a time when it worried them either during labour or afterwards (71%), one in five (22%) said this happened during labour and 16% experienced this after the birth.

For a proportion of these babies life support was withheld or withdrawn (34%); many women reported not being involved in the decision-making at this time.

Most women were present when their baby died (83%) and almost all subsequently saw (96%), held (91%), and spent time with their baby (95%), many in the bereavement room provided (96%). Some women were able to have their family come and see their baby too (81%). Most women were able to stay in a single room (93%), although for more than a third of women this was not away from other new mothers and babies (37%) and only 63% of women

My labour happened very quickly - I was fully dilated two hours after the pain started. Everything was done to stop the labour ... but to no avail. I was informed from the very beginning that the baby may not survive so was able to prepare myself. I couldn't have wished for more understanding and caring midwives.

All the staff were kind and they acted quickly to get baby out. [They] knew how ill she would be and had all the equipment ready to help to get her to breathe. They tried for 28 minutes and I felt they did all they could have.

The midwives were amazing. It was the worst experience of my life ... with the best care. They really understood the feelings I had - I'll forever be grateful to the handful of women I'd never met before who got me through the birth and death of my son.

Numerous people worked on my baby for about an hour after he was born. They tried very hard but there was nothing that could have been done to save him. Even when I was taken into recovery, they still came to us to discuss what was happening. I feel they did everything they could for my husband and me and our baby.

Amazing, I knew my baby wouldn't survive. The staff informed me of [the] decisions we would have to make beforehand so we weren't so rushed or shocked when we had to make them.

The whole labour was rushed - I was too 'spaced out' to understand fully what was going on. The neonatal staff (doctors) did not want to put our son in an incubator to prolong life ... I think they should give every born breathing baby a chance.

Baby received no neonatal care. At 23 weeks they would not try to prolong his life. Baby died after one hour. Very distressing.

The Bereavement Midwife organised for [baby's name] to stay with us in a cold cot so I could be a proud mom for a few hours - very precious memories. I got to hold her, kiss her, put a nappy on and show her to interested midwives / doctors and also to my family who came to visit their granddaughter/niece.

could have their partner stay with them. A small number of women said that they did not wish to stay and left hospital relatively quickly.

Being cared for in a hospital which had the facilities for parents to be together and stay overnight if they wished, to be with their baby, but away from other babies and families, and for their family to be able to visit, was critical for many parents who responded in their own words.

We were in a private room ... for the delivery of [baby's name]. Our midwife was the best we could ask for. Everyone knew what lay ahead and she [and] the paediatricians made everything comfortable and as best as possible for our situation. We got to spend 4 hours with our baby boy ... He cried, was clothed, drank some milk and gave us wonderful joy before we had to say goodbye. The staff that night were such a blessing to us and we are very grateful.

I wasn't happy about staying in a postnatal ward. It was painful to watch other mothers with their babies, it was unbearable to hear the cries of other babies.

4.5 Care in the neonatal unit

Two-thirds of babies who died as a newborn were admitted to a neonatal unit (NNU), with a total of 149 babies of 147 mothers receiving care in this environment. The most common reason for admission was prematurity (60%), often with associated breathing problems. Only about a third of women (35%) reported having met neonatal staff prior to their baby's admission. Just over a quarter of babies were transferred between units in different hospitals (29%), usually to access specialist facilities.

Nearly a third of babies spent less than 24 hours in the NNU (29%), 41% stayed for 1-6 days, and about a third stayed for a week or more (30%). However, it should be emphasised that these were all babies who died within the first 28 days after they were born.

Parents of babies receiving specialist neonatal care [should be] encouraged and supported to be involved in planning and providing care for their baby, and regular communication with clinical staff [should] occur throughout the care pathway.

NICE specialist neonatal care quality standard¹⁹

The care from the professionals on the neonatal unit was wonderful. They made sure we understood everything - they would always check we were ok even though they were extremely busy. We were included in most consultations about our baby. They were all considerate, kind, caring and professional whilst working very hard.

As devastating and unexpected as losing our daughter was, we are so thankful that we [had] time with her before and after her death and that family members were with us. The care [from] all the neonatal staff before and after she died was second to none. One of the nurses who had looked after [baby] looked after myself and my husband and helped us bath her and dress her which meant so much to us. We were also given a memory box containing teddies, frames for her hand and foot prints and a box for a locket of her. We cannot put into words what this box means to us. The meetings we had with the paediatric consultant were both upsetting and helpful and everyone we dealt with [was] sympathetic, knowledgeable, kind and understanding.

The Neonatal staff were amazing. Very informative and supportive ... They provided details for a nearby charity offering accommodation and facilitated this.

We asked women about the kinds of care they were able to give to their baby while in the neonatal unit. Some, but not all women were able to see (52%) and touch (19%) their baby at birth; by the end of the first day most had been able to see (96%) and touch (81%) their baby. Almost all saw or touched their baby at some point before he or she died. For 20% of women their baby was too unwell to be held and a very small number of women reported that they did not want to hold their baby. Most partners saw their baby (92%) and, like mothers, were also less likely to have held their baby (72%). A small number of women reported that their partner was not offered the possibility of seeing (4%) or holding their baby (18%) or else they felt they could not or did not want to do so.

Parents [should be] informed, guided and supported, so they understand their baby's care processes and feel confident in caring for them.

The Bliss Baby Charter Standards¹⁸

We also asked whether women felt that equipment, procedures and care and treatment plans were explained and discussed with parents. Most women reported that equipment (67%) and procedures (69%) were always explained by staff, and that their baby's problems and treatment plan were always discussed (76%). Less than ten per cent said these things were rarely or never explained or discussed (Figure 4.5). Nearly half of the mothers of babies who spent time in a neonatal unit were able to change their baby's nappy (44%), and over a third were able to cuddle their baby (39%) and clean their baby's face or hands (39%). The relatively low number of women able to care for their babies reflects the fact that many of these babies were very ill.

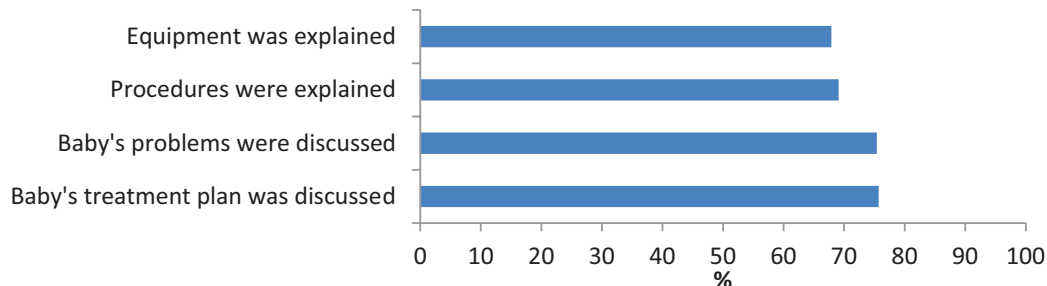


Figure 4.5 The proportion (%) of women who felt that equipment, procedures, problems and treatment were 'always' discussed while their baby was in a neonatal unit

We asked women about aspects of the quality of the support and information they received and their feelings about their involvement in their baby's care in the NNU. Most mothers felt well supported by staff (77%), that they were always able to see their baby when they wanted (80%), and were always given the information they needed (73%). Most also felt that neonatal staff responded to their needs as parents: that staff were always aware of their needs (74%), that they were always included in care (65%) and always involved in decisions about care (67%) (Figure 4.6). Small numbers of women, around 6%, felt that they were rarely or never supported by staff, not able to see their baby when they wished and that staff were not aware of their needs as parents. Slightly higher numbers felt rarely or never involved in decision-making about their baby (15%) or rarely or never included in their baby's care (14%).

At the shift change the new Specialist was a locum. He was very rude. Even if I asked him a question, he would reply to my partner. It felt that being female he would not speak to me. He was reluctant to talk to us or explain the treatments they were carrying out.

The Neonatal Nurses rarely discussed anything with me... Sometimes the nurses (some) would look down on me, treat me like I had ruined their shifts by giving them a very sick child.

Care from the Nurses was very variable. Some were great - very competent and good at explaining what they were doing to anxious parents. But others were rushed, seemed stressed and made us feel as if we were not welcome, and this upset us as we didn't want to make things any worse but we also really wanted to spend time with our little baby daughter.

I just wished my twins could have had cots next to each other. It would have made such a difference to us.

All the staff were incredible - they were so sensitive and helpful; most importantly, they were so lovely with our daughter, we felt she was getting the best care possible from good people. They ensured we had as much time with her and holding her, as was possible; they took photos which are invaluable and compiled a memory box - all things that wouldn't have occurred to us in our shock. They treated her as if she was the most important person in the world, which of course, she is to us, and we did appreciate their approach.

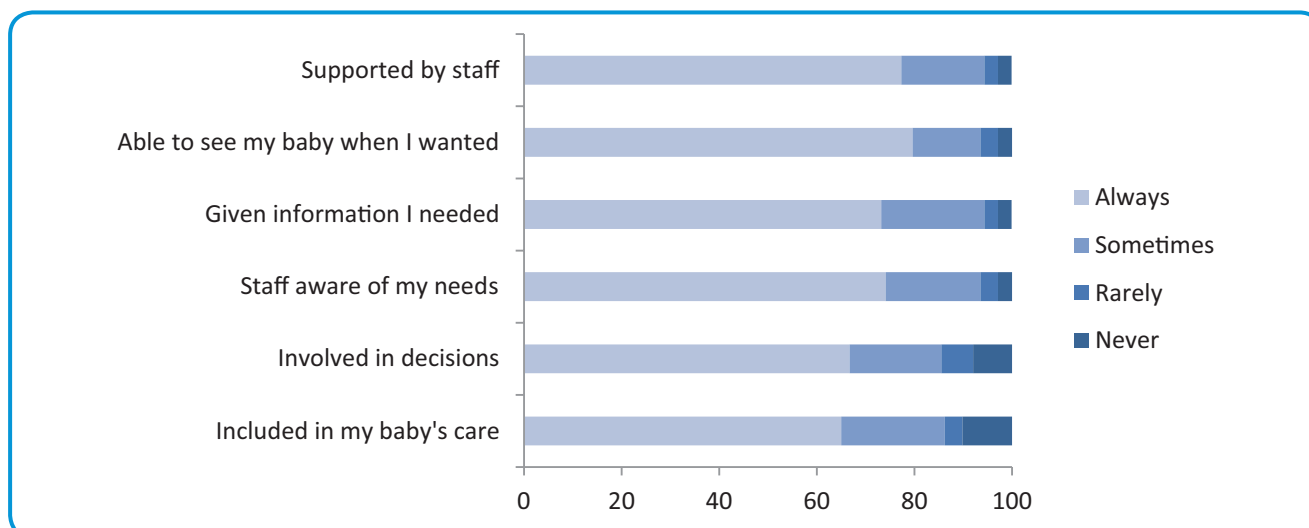


Figure 4.6 Women's perceptions of support, information and involvement while their baby was in the neonatal unit

End of life/palliative care decisions [should be] made following discussion between parents and senior/suitably trained clinicians.

The Bliss Baby Charter Standards¹⁸

The situation for parents whose baby was very preterm or had major abnormalities not compatible with life was very difficult; many parents were aware that time with their baby was very limited. About three-quarters of babies died as a result of life support being withdrawn; nearly two-thirds of their mothers (61%) reported that they were involved in the decision to withdraw life support and a further 26% felt involved 'to some extent'.

4.6 Care when their baby died

Most mothers (85%) reported that they were with their baby when he or she died. After their baby had died, almost all mothers saw their baby (95%), held their baby (91%) and felt able to spend time with their baby (93%). Less than 6% chose not to spend time with their baby and a very small number were not able to because they were unwell themselves. Three-quarters of parents (74%) reported that family members also saw their baby. Staff were usually described as being very good at making it possible for parents to spend time with their baby and at preparing parents for this, but some women's comments were less positive.

All staff [should be] able to offer parents opportunities to see and hold their baby and to create memories.

Sands Audit Tool for maternity services²⁴

The midwives / nurses at [the] Special Care Unit where my baby was admitted were very supportive ... We were involved in all decisions. We were given plenty of time to consult our family and friends. After my baby's death I was given the opportunity to cuddle, bath and dress my baby. We were given a quiet room where our family and friends [could] see our baby. We were offered bereavement services and help in arranging funeral services.

We weren't made aware of the condition that she would be in when we visited her, so it was a shock to see her and incredibly upsetting, so much so that we could only stay a couple of minutes. I wish we were warned and spent some time with her. I never even had the opportunity to touch her.

I was very happy with the care and support and information I received. They left us alone with our child for quality time but were always on hand. They suggested taking photos, getting hand and foot prints etc. which we are grateful for now.

Most women reported that while in hospital they were offered a quiet room in which to spend time with their baby (93%), a blessing or religious ceremony (84%), written information for parents after the death of a baby (86%) and information about support groups (87%) (Figure 4.7). Slightly smaller percentages reported being offered help with funeral arrangements (75%) or information about counselling services (79%).

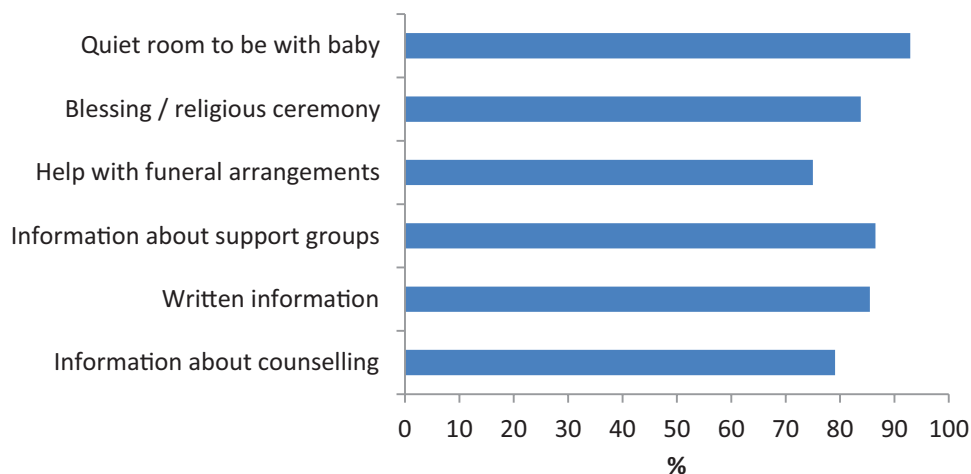


Figure 4.7 Proportion (%) of women whose baby died as a newborn in hospital who were offered different kinds of help or information after their baby's death

4.7 Postnatal care in hospital and at home

Postnatal care for women in hospital after the birth varied. The average (median) length of stay was 2 days, ranging from less than 12 hours to 28 days. Just under two-thirds of women (62%) felt that they stayed for about the right amount of time and 13% felt that their postnatal stay was too short. Almost all women (92%) stayed in a private or single room, on either the labour ward (47%) or a postnatal ward (42%), with small proportions elsewhere, including the antenatal ward or in a high dependency or intensive care unit. However, for many women this was within earshot of healthy crying babies (52%), where their partner couldn't stay with them (47%), or too far from the NNU (55%).

In general, women reported that during their postnatal stay staff talked to them in a way they could understand (87%) and treated them with respect (82%) and kindness (85%) (Figure 4.8). Slightly smaller percentages of women felt that staff listened to their concerns at this time (75%), treated them as an individual (79%), and gave them the care they needed (77%).

More effort should be given in supporting new mothers with a critically ill baby. Staff are too busy to listen to my concerns and too quick to tell you off.

The staff in the Neonatal Unit were very good and informative. However, it was hard being on the postnatal ward in a family room as you saw lots of new mums and heard crying babies.

Staff were great, but hardly saw anyone. They were too busy through no fault of their own. I just wanted to get out of there. One midwife stayed behind 4 hours after her shift to complete my paperwork.

I was informed by the consultant that I could stay in the postnatal ward so I was close to my babies, but the senior midwife discharged me regardless even though I asked ... I needed to be close to my babies, not a 20 minute journey away.

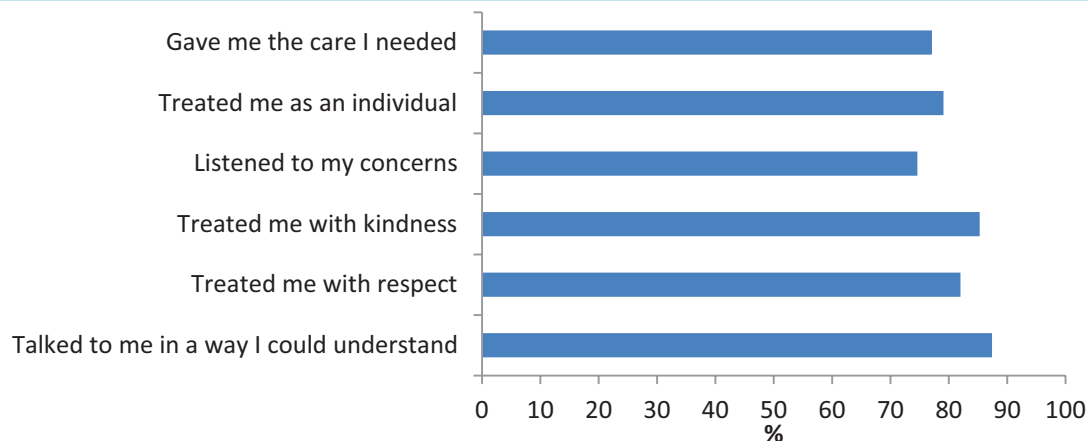


Figure 4.8 How women whose baby died as a newborn felt about their postnatal care in hospital

Having left hospital, just over three-quarters of women (77%) had the name and phone number of a midwife they could contact, but almost one in five (19%) said they did not. Once home, 73% of women reported being visited at home by a midwife and 4% saw a midwife in a clinic. Small numbers did not see a midwife because they were not offered a visit (7%), because they were staying away from home to be near their baby in hospital (5%) or because they did not want a visit (5%). One in ten (10%) women reported being visited at home by their GP. Of those who were visited at home by a midwife, less than half (45%) were visited by more than one midwife and just over half (53%) had met some or all of the midwives who visited them.

Seeing a midwife was just a reminder of what you have lost so I did not like seeing a midwife. So I tried to see the midwife as little as possible.

Almost overwhelmed with support - Bereavement Midwife, Health Visitors etc. All a bit much, wanted to be left alone, just wanted to get physical problems sorted.

Due to baby dying on a Thursday and the midwife due to come on Friday, the midwife didn't know he died. Apart from that midwives [were] excellent and offered lots of support.

The number and timing of postnatal visits from midwives varied considerably. The average (median) number of visits was two, but women reported up to 20 visits. For a third of women the last home visit by a midwife took place within one week after the birth of their baby, a further third had their last home visit 2-3 weeks after the birth, and a third saw their midwife for the last time four weeks or later after the birth. Most women (70%) saw a midwife as much as they wanted to after the birth, although a quarter would have preferred to see a midwife more often and a few women did not want to see a midwife at all.

4.8 Overall experience of care

Figure 4.9 below shows overall satisfaction with each stage of care.

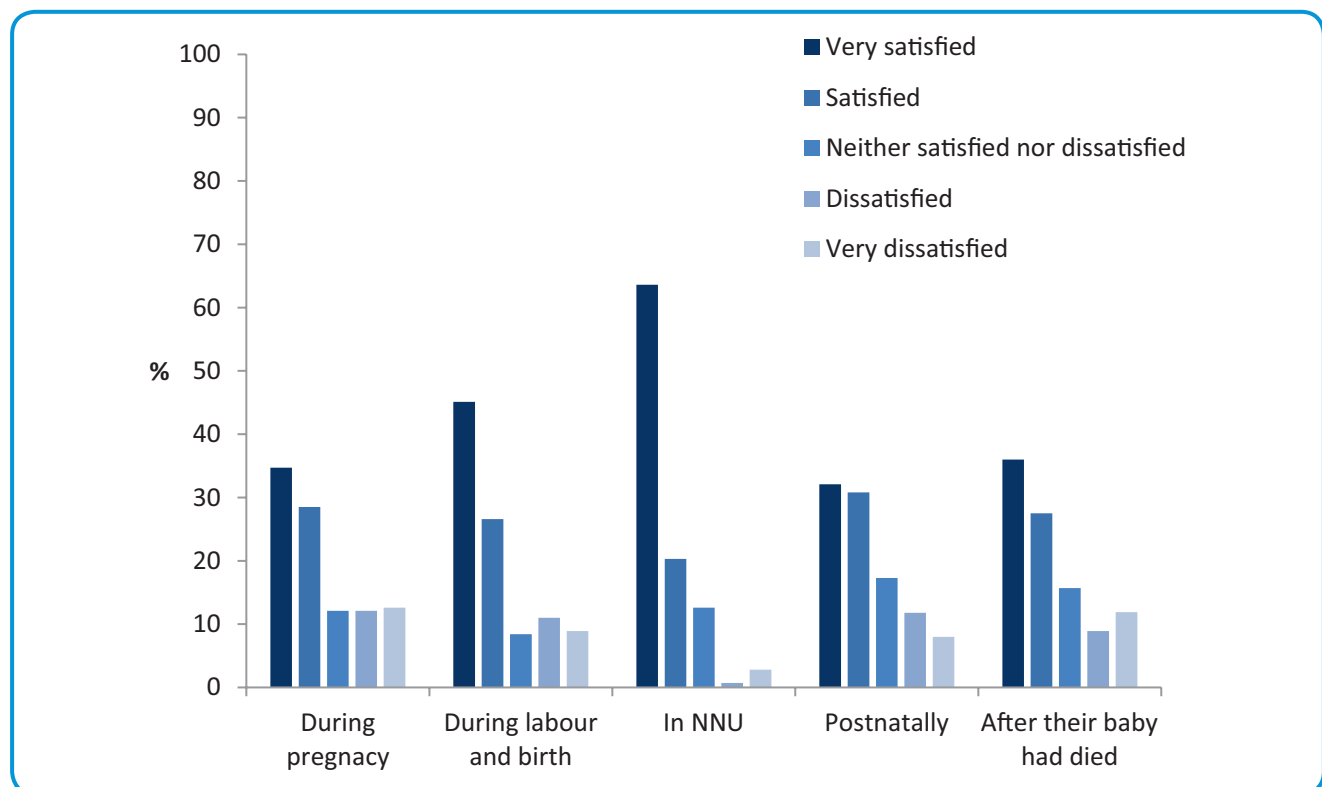


Figure 4.9 Overall satisfaction with the different stages of care for women whose baby died as a newborn

Satisfaction was highest for care in the NNU, although not all babies were admitted for neonatal care. Next most highly rated was labour and birth care. However, one in five women were dissatisfied with their care during labour and birth (20%), with their postnatal care (20%) and care after their baby had died (21%) and slightly more were dissatisfied with their pregnancy care (25%). This differs from the pattern seen in the National Maternity Survey where most criticism was directed at postnatal care.^{2, 3}

4.9 Fathers' and partners' experience of care

Women whose baby died as a newborn were also asked about their partners' experience of care and interaction with health professionals. Three-quarters or more of fathers and partners considered that staff communicated with them 'very well' or 'quite well' throughout pregnancy (80%), during the birth (74%), after the birth (80%), when their baby was sick (81%) and when their baby died (89%). Where women had a partner, most had been present for one or more antenatal checks (70%) and pregnancy ultrasounds (92%). Fewer were present for the labour (79%) and birth (76%), mostly due to unforeseen events or problems in relation to their partner and their baby. Most partners were present for discussions when there were concerns about their baby and when their baby died (88%).

Almost all fathers and partners (92%) were able to see their baby before he or she died and a smaller percentage held their baby at this time (72%), although in nearly a fifth of cases their baby was too poorly to be held.

In general around 60% of fathers and partners felt listened to, that their concerns were taken seriously, they were kept informed, had a part in decision-making, felt confident in the decisions made, and their needs were acknowledged (Figure 4.10). Significant proportions, however, felt this only 'to some extent' (25% to 34%) or not at all (8% to 14%). The importance of partners was recognised by staff, although not always immediately.

My husband was able to stay with me the whole time. A bed was provided for him in my room as it took two days before my labour actually started.

I was not listened to by any midwife re: pain, waters breaking and from 14.50 - 16.45 I received no care until my husband physically went to get a midwife, by then my babies [heart rate] had dropped and I went in to have C-Section.

They told my husband baby was receiving advanced resuscitation..., then to be given the baby born alive to hold. All this occurred in the room where placental abruption occurred - blood soaked towels still on floor ... Not the best environment for him.

The doctors explained there was a lot of people in the room because my baby would need special care ... They ... rang my partner. They waited outside the hospital and showed him straight to where I was.

I got left on my own all the time and my partner got kicked out ... after birth on postnatal ward at 5.30 a.m.

Had difficulty with my partner being allowed to sleep with me in maternity ward. Was only after a few hours they gave us a shared room.

The hospital was brilliant, because of the situation I was kept away from other women and babies. I was moved the following day to a parents' room on the Neonatal Unit and my partner was able to stay.

Partners felt...

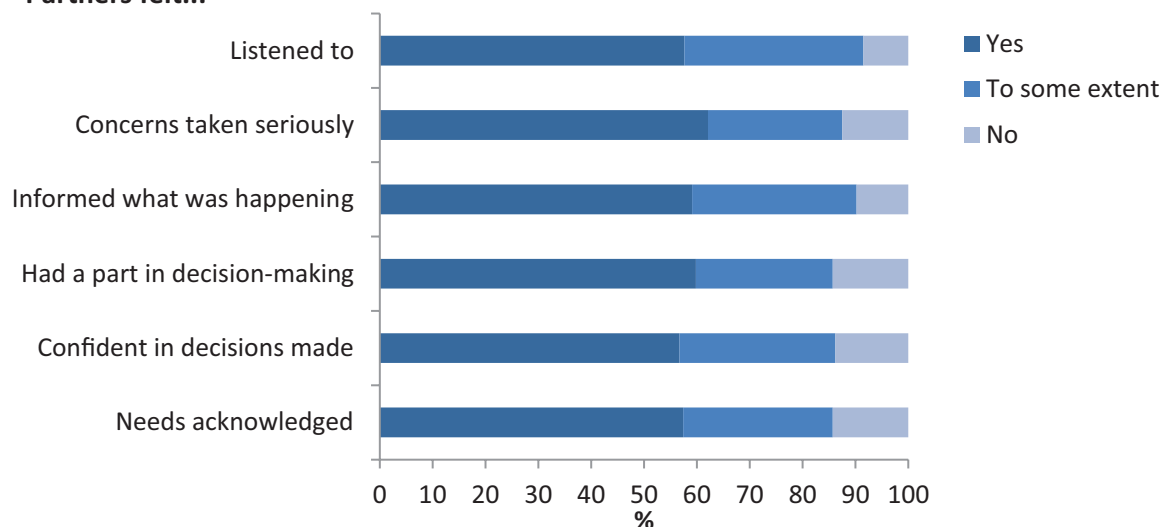


Figure 4.10 The experience of care and interaction with health professionals in fathers and partners whose baby died as a newborn

4.10 Summary

Most babies who died in the neonatal period were very premature, which is reflected in the concerns that women expressed going into labour. In general, care in labour and at birth was recalled favourably, although a third of women were left alone at a time when it worried them either in labour or immediately after the birth. About a third of babies died without being admitted to neonatal care, most within 24 hours of birth. Only a third of women whose baby was admitted to neonatal care had met any of the neonatal staff before, but they were very positive in their recollections of care at this time; staff were very supportive, treatment was discussed and explanations provided to almost all women. However, women whose baby was in neonatal care sometimes said that they needed to be closer to the unit, that their partner could not stay with them, and that proximity to healthy mothers and babies was also an issue.

5: Understanding why babies died

A post mortem examination is the best available investigation for finding causes and explanations for a baby's death and to guide care in a subsequent pregnancy, although it may not be conclusive in all cases. We asked about consent for post mortem examinations, reasons for not having a post mortem and the timing of post mortem results. We also asked about what parents were told about the causes of and explanations for their baby's death and whether they were able to ask all the questions they wanted to.

5.1 Post mortem examinations

All parents whose baby dies [should be] offered a post mortem examination.

Sands Audit Tool for maternity services²⁴

All parents [should be] given written back-up information about post mortems that is specifically suitable for a perinatal death.

Sands Audit Tool for maternity services²⁴

Some parents (12% of parents of a stillborn baby and 39% of parents whose baby died after birth) reported that they were not asked about post mortem because a post mortem was not necessary or because a post mortem was ordered by the coroner (4% of parents whose baby died after birth). Otherwise, most parents said that they were asked to consent to a post mortem, but 5% in both groups said that they were not asked.

We also asked parents about the information they were given about the post mortem examination and how they felt about the decision-making process. Around two-thirds (68%) of parents of a stillborn baby and just over half (55%) of parents whose baby died after birth reported that they were given written information about the post mortem, with the rest saying they did not receive written information

or were unsure (around 8% in both groups). The proportion of parents of a stillborn baby reporting being given written information is higher than that reported in a previous survey of parents' experience of the post mortem consent process.²⁸ Higher percentages said that they felt informed enough to make a choice about post mortem (85% of parents of a stillborn baby and 74% of parents whose baby died after birth) and that they had enough time to make a decision (82% of parents of a stillborn baby and 70% of parents whose baby died after birth).

Among parents who had a stillborn baby 49% agreed to a full post mortem examination, 4% had a partial post mortem and a further 3% had a placental examination only. Of those whose baby died in the neonatal period 23% agreed to a full post mortem; a further 2% had a partial post mortem and 7% a placental examination. Taking into account those who said that they were not offered a post mortem, this suggests that around 30% of parents in both groups decided not to have a post mortem examination of their baby, a lower percentage than that reported in a previous survey of parents of stillborn babies.²⁸ Parents who did not have a post mortem carried out were asked about their reasons for not having a post mortem and were free to give more than one reason. Most did not want to have their baby's body examined, but large numbers also said that they did not need to have a post mortem, either because they knew why their baby had died or because they didn't think that a post mortem would give them an answer (Figure 5.1).

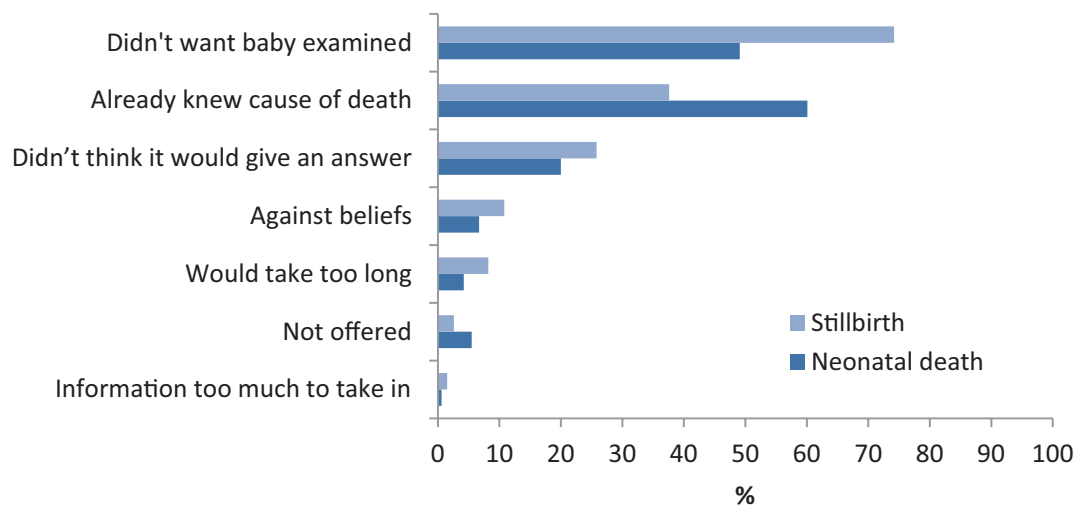


Figure 5.1 Reasons given by parents who chose not to have a post mortem examination after stillbirth or the death of their baby as a newborn

60% of final reports for routine post mortem examination will be issued... within 42 days of examination and 90% should be issued within 56 days.

NHS England Commissioning Standard²²

Less than half of bereaved parents reported that they found out the results of the post mortem within 8 weeks, more than 30% had to wait for more than 12 weeks and of these around half indicated in free text that they waited for 16 weeks or more (Figure 5.2).

The post mortem was the most traumatic ... we were told by the consultant that it would take 2 weeks. Fourteen weeks later we finally got the results and in between that time I felt like I couldn't move on as I was constantly waiting.

The post mortem results took a very long time. If we had been told from the beginning 20 weeks instead of 6-8 weeks we may have made a different decision. Waiting so long meant moving forward with our lives was very hard ... we were continuously worrying about the results. It was very stressful.

It was important for me to have a post mortem because I wanted to know what had happened and if there was going to be any implication for the surviving twin. The wait for the results was one of the hardest parts.

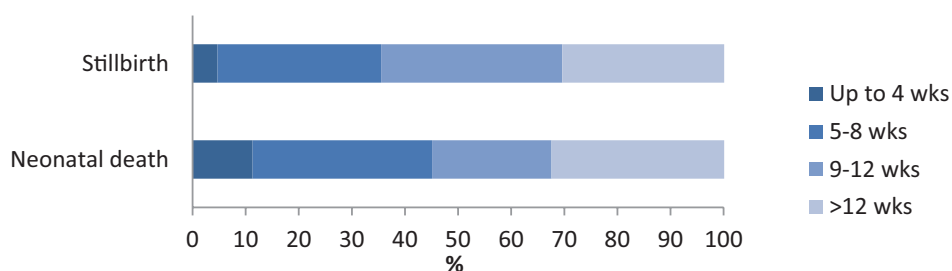


Figure 5.2 Waiting time until post mortem results for parents whose baby was stillborn or who died as a newborn

5.2 Causes and explanations

All parents who have consented to a post mortem [should be] able to discuss the results with a senior member of staff within twelve weeks of the birth.

Sands Audit Tool for maternity services²⁴

The registrar at the hospital spent 1½ hours explaining the results to us and we appreciated that.

[We have] not been seen by [doctors] to answer questions. We had to chase up the post mortem report and we received it after 8 months [with] no professional explanation to us.

At the time of completing the survey, 92% of parents of a stillborn baby and 84% of parents whose baby died after birth reported that they had met with a consultant at least once to talk about their baby's death. Of those who had a post mortem, similar percentages of parents received the results of the post mortem in a meeting with a consultant. Over 90% of parents reported that they had felt able to ask at least some questions (Figure 5.3).

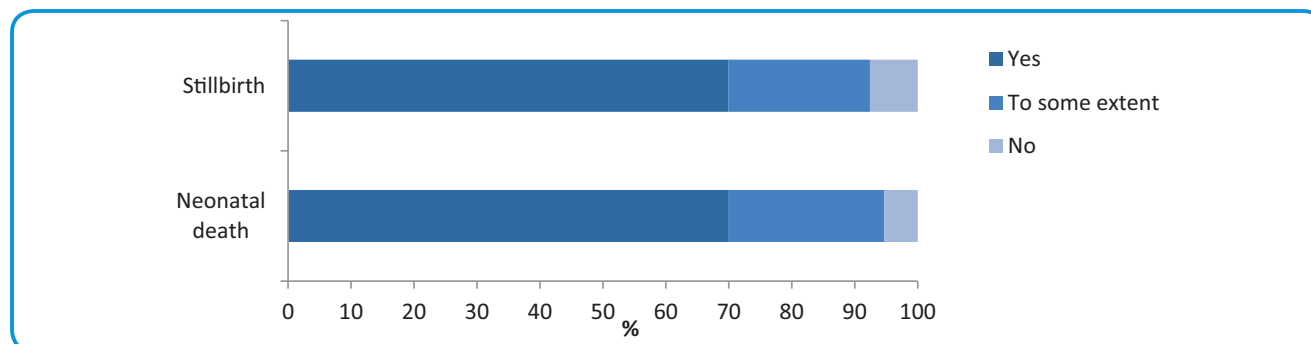


Figure 5.3: Parents' reports of whether they were able to ask all the questions they wanted after their baby was stillborn or died as a newborn

We also asked whether parents felt they had been given a cause or explanation for their baby's death. Overall 94% of parents of a stillborn baby and 88% of parents whose baby died after birth said that they had been given some kind of explanation for their baby's death, although included in these were the 29% of parents who reported that their baby's death was an 'unexplained stillbirth' (Figure 5.4).

The letter from the hospital inviting us to an appointment with the consultant after the stillbirth of our baby started with 'I am writing to offer you a follow-up appointment to discuss care in future pregnancies'. I found this quite distressing ... I wanted to understand why my baby had died and the thought of future pregnancies was not appropriate. At this first meeting the consultant had not prepared ahead ... was not familiar with the cause of death and ... could only offer to find out some more information for a second meeting. We had a second and a third meeting ... and felt we had to ask a lot of questions in order to get some reasonable answers.

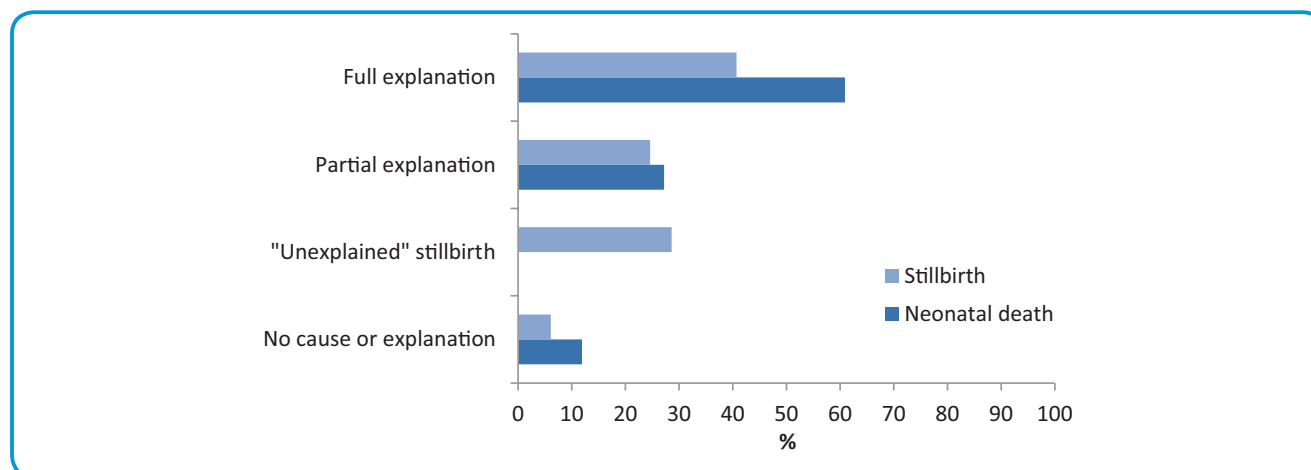


Figure 5.4: Parents' reports of the explanation they received for their baby's death

The causes or explanations that parents reported for their baby's death are presented in Figure 5.5. Parents were able to give more than one cause and those whose baby died as a newborn often gave two or more causes for death, e.g. prematurity, infection and breathing problems or withdrawal of life support in combination with other causes. In contrast, parents of babies who were stillborn more commonly gave just one cause or explanation, although some indicated that growth restriction and placental problems were the cause of their baby's death. The most common responses for parents whose baby was stillborn were that their baby's death was "unexplained" (34%) or that it was caused by placental problems (26%). Prematurity (52%) and congenital anomalies (26%) were the most common responses for parents whose baby died as a newborn.

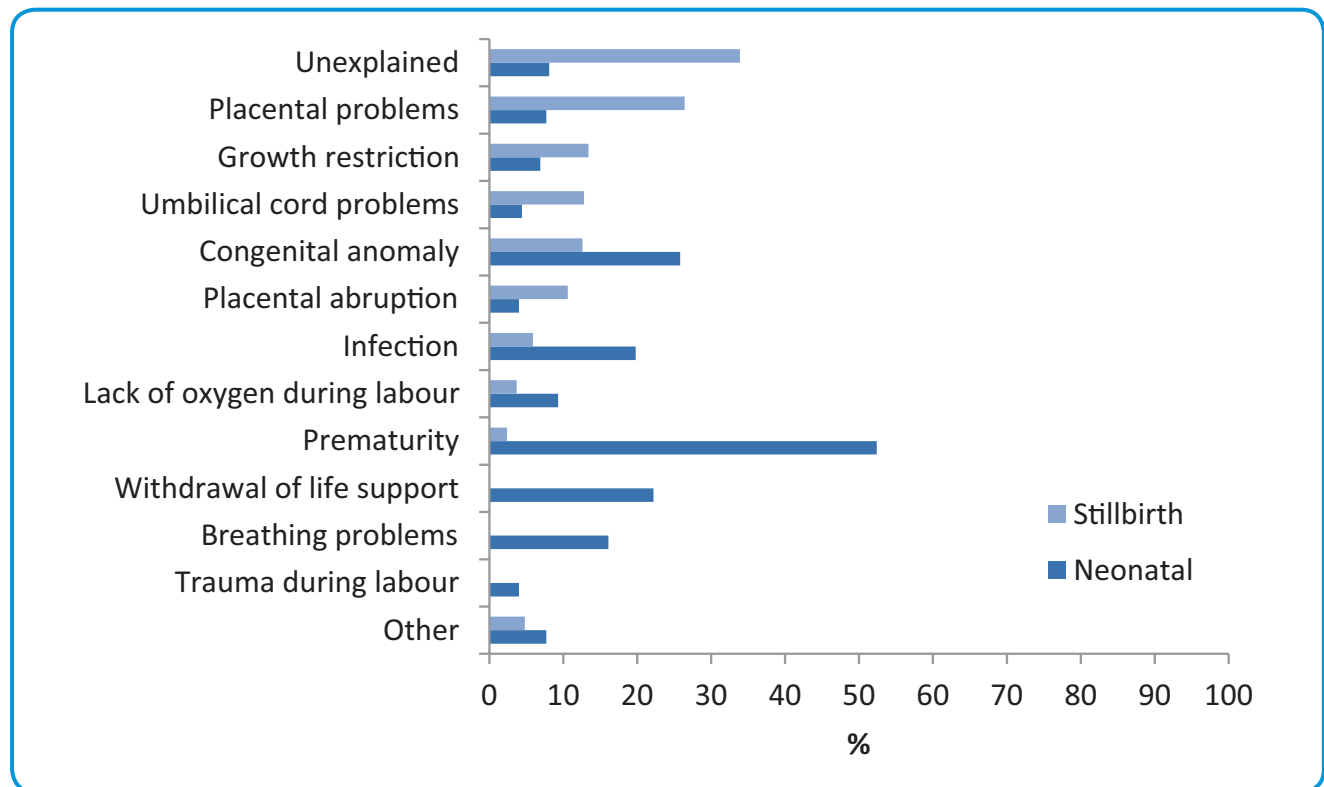


Figure 5.5 Parents' reports of the causes or explanations for their baby's death

5.3 Summary

Among parents who had a stillborn baby half agreed to a full post mortem examination; however, of those whose baby died in the neonatal period only a quarter agreed to a full post mortem. This reflects the high proportion of babies who died due to prematurity where a post mortem was considered unnecessary. Most parents felt informed enough and had sufficient time to make a choice regarding post mortem, but between 10% and 25% did not feel this way. The main reasons that women gave for not having a post mortem were that they didn't want their baby examined and that they already knew the cause of death. Most parents reported that they found out the results of the post mortem within 12 weeks, but a third of both groups had to wait longer than this. A quarter of stillbirths were described as 'unexplained'.

6: Parental support and wellbeing

6.1 Going home and handover of care

Women were not asked directly about discharge from hospital and communication between hospital midwives and community midwives and health visitors providing care after women went home. However, in response to open questions about their postnatal care some women reported that the information about their baby had not been handed over to community health services, including midwives, health visitors and GPs, causing increased distress. Others focused on the gap in care between services, particularly in relation to a need for support.

The unit... [should] always ensure that the mother's GP and community midwife are accurately informed of what has happened within one working day... following a stillbirth [or] a neonatal death in the maternity unit.

Sands Audit Tool for maternity services²⁴

The day my baby died I came home and got a call from Health Visitor the next day. She clearly didn't know the situation and just thought baby and mother were home and she wanted to visit. She was very apologetic but it was something I didn't want to speak to a stranger about.

I feel that the care and support I received in hospital was not continued after I left hospital, it was as if I fell between a 'gap'. The midwives and healthcare workers were not in contact as I didn't have a healthy baby ... The bereavement midwife only contacted me 2½ months after the birth when I was preparing to return to work. I really could have done with her support earlier as she proved to be very caring and understanding ... There was definitely no clear care plan for me after leaving hospital. I had to figure out what needed to be done in order to arrange the funeral, and to pick up support with my GP.

6.2 Support for parents

The psychological impact of stillbirth and neonatal death on parents is profound.^{16, 17} Both practical and psychological support is needed from close family members, friends, health professionals and others. We asked women about their own and their partner's experience of support, who they had talked to about what had happened, their feelings and about their main sources of support (Figure 6.1).

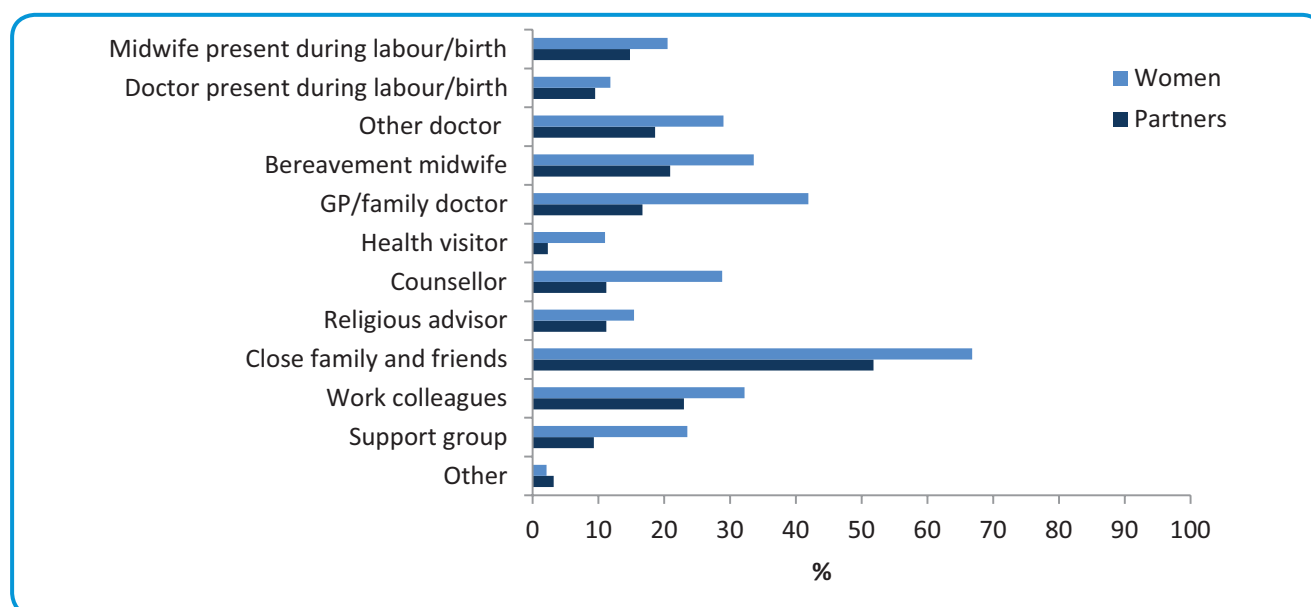


Figure 6.1 Health professionals and others to whom parents talked after their baby was stillborn

For women who experienced a stillbirth, close family and friends were the major source of support; health professionals present at the birth were also important as were other health professionals with specialist knowledge or experience or those previously known to the couple. The GP or family

What I really needed was someone to talk to. It is incredible how common this problem is. I do feel there is very little support available for people, both women and their partners.

doctor was listed by nearly half of the women responding on this point (42%) and a smaller proportion of their partners (17%). While nearly three-quarters of women (72%) had talked to a health professional of some kind about their stillbirth and how they felt, less than half of their partners (47%) did so.

Compared with their partners, women were twice as likely to have talked to a counsellor of some kind (29% compared with 11%), more likely to have used a support group (24% compared with 9%) and to have talked to a bereavement or other midwife (34% compared with 21%). Work colleagues were important for some women and their partners, as was religious support and advice for some couples. A small number of couples reported not talking to any of those listed or did not identify any helpful source of support.

We waited over 3 months to see a NHS counsellor, who when we did get to see her, was on the labour ward, we had to sign a disclaimer, then she said, "So tell me all about it then" and it was truly awful, I was terribly upset and it made my partner very cross, when it had taken a lot to get him to attend in the first place.

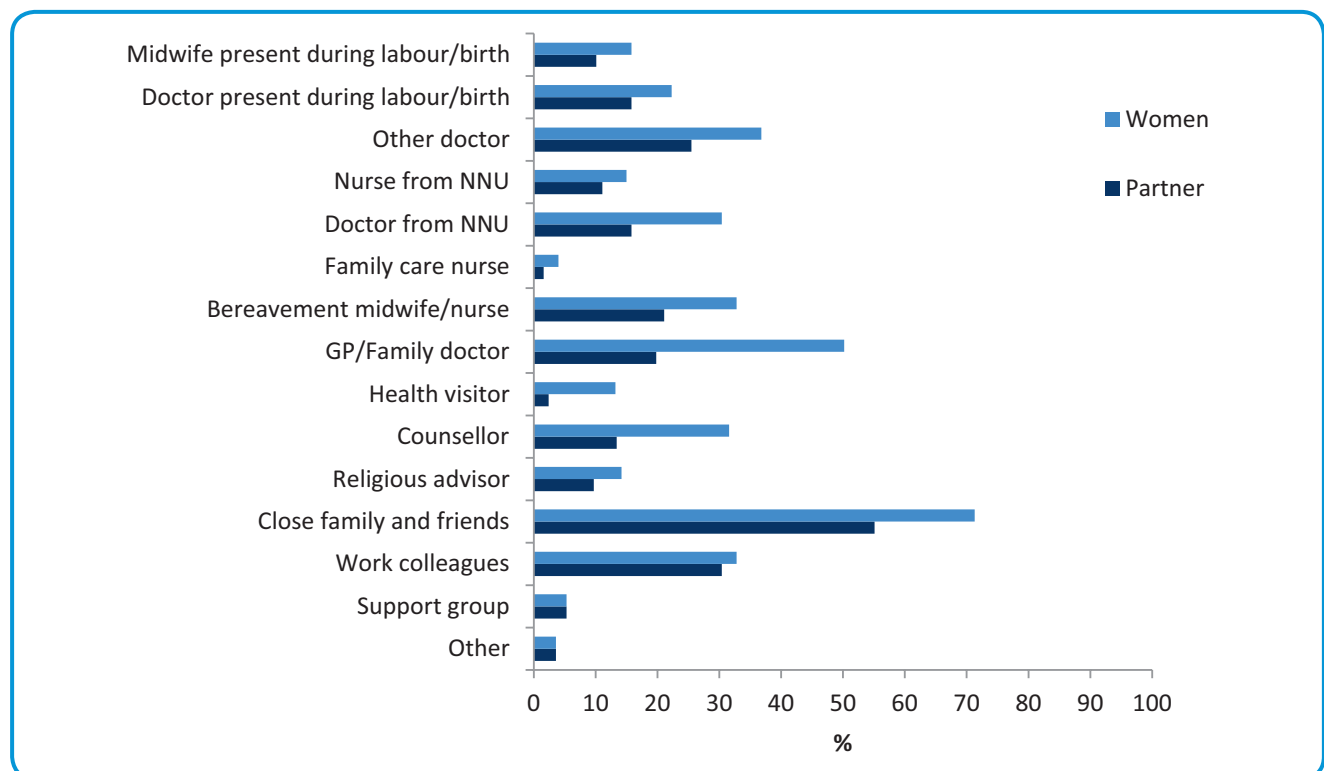


Figure 6.2 Health professionals and others to whom parents talked after the death of their baby as a newborn

The experience of support for parents whose baby died after birth was largely similar to those who experienced a stillbirth, with an emphasis on close family and friends (71% and 55% respectively for women and their partners) (Figure 6.2). Overall, like the women whose babies died before birth, many had talked to one or more health professionals (78%) since their baby's death about what happened, although again partners were much less likely to have done so (56%).

Over half the women (50%) talked to their GP about their baby's death as well as to a range of health professionals who had cared for them and their baby. Use of a counsellor was similar in both groups, with a third of women and half their partners talking to a counsellor. Again, compared

I have had no offer of counselling or anything from the hospital, it has been down to my husband to comfort me and get me through this tragic time.

Neither me nor my partner were offered any professional counselling and I believe this was an integral part of my recovery and so should be offered to all parents finding themselves in this situation. I also believe it should be offered, not be down to the individual to seek it out ... I was offered anti-depressants by my doctor but I declined as I wasn't depressed, but going through a bereavement. My partner feels that he wasn't offered any help at all ... In short I believe that both parents who have been through a situation such as this should be offered the help of and encouraged to use the help of a counsellor and it should be free and available on the NHS.

with their partners, women were more likely have talked to all the groups listed, and, as with those parents experiencing a stillbirth, a third or more of parents whose baby died after birth had talked to work colleagues. Fewer parents in this group reported using a support group or helpline. Again a small number indicated that they had not talked to anyone about their baby's death.

We asked women to say who had been their most helpful source of support. Responses were diverse, but for both groups the most frequently mentioned person was their partner, followed by their family (Figure 6.3 and Figure 6.4). Women's responses included: "Each other"; "Friends and family and Facebook support groups"; "Seeing bereavement midwife at the hospital"; "Family and friends and more importantly our 5 year old" and "Doctors, midwife, friends, family and co-workers".

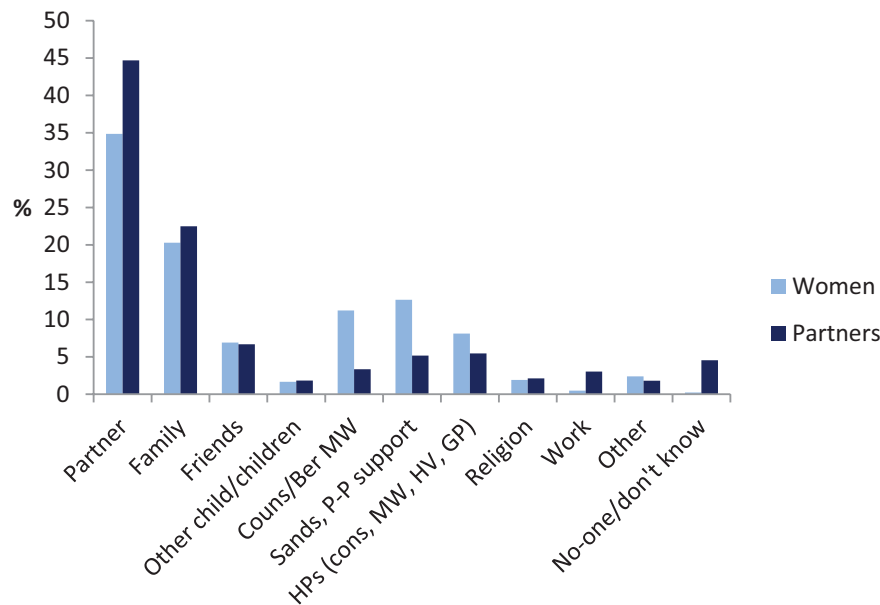


Figure 6.3 Most helpful source of support for parents whose baby was stillborn

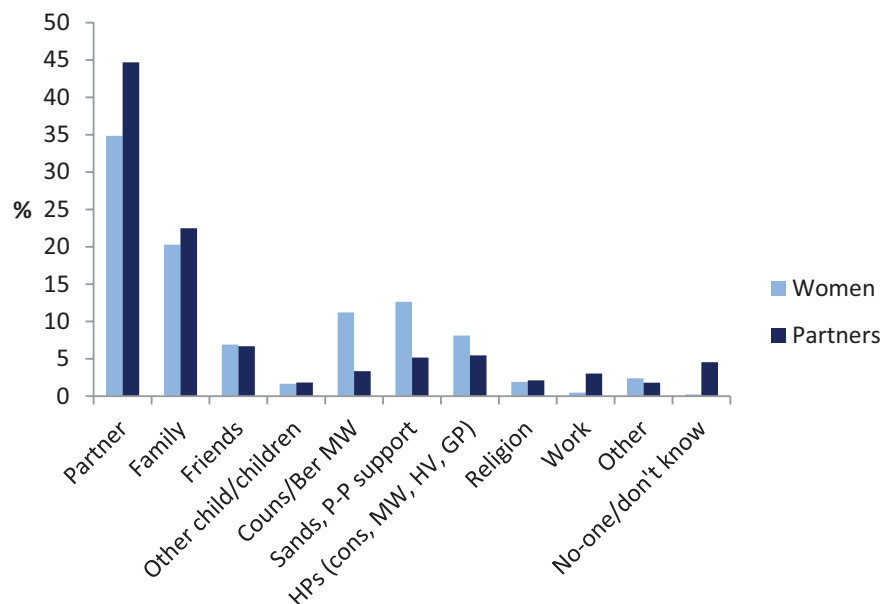


Figure 6.4 Most helpful source of support for parents whose baby died as a newborn

More women in both groups of parents used a wider range of types of support compared with their partners. Compared with women whose baby died in the neonatal period a smaller proportion of women who experienced a stillbirth reported that their partner was their main source of support. For both groups of bereaved parents, bereavement

The care I received [from] doctors and midwives was faultless ... They were extremely considerate and allowed many family members to be with me during the night after our son passed away. I will be forever grateful.

midwives and counsellors and parent-to-parent support (either direct or online) were the main sources of support for one in ten women, although less so for their partners. In response to this question some women said that their partner was not able to talk to anyone, for example: “My partner won’t talk about it”; “He has not sought support (typical male)”; and “My partner has blocked her death out”.

In the comments that women added, family support was identified as important for many couples, as was the couple relationship itself. The burden and impact on families was also recognised and a need for direct one-to-one support from outside the family in the form of counselling was mentioned by many women. Others described their need for parent groups and the benefit of the implicit shared understanding that these brought.

We have been offered so much support from the NHS but we feel we didn’t need it; we have such a strong family and supportive friends that talking to them has helped. The relationship I have with my husband is so strong we talk about what happened and our little boy all the time.

I would like to attend a group or see a counsellor about things from time to time as it does upset my nan or mum if I talk about it. They are getting better but it’s just hard when they are upset I feel I’m having to support them, who can support me?

I also feel that there isn’t enough free help to parents who lost a baby. We had no one in our local area that we could see ... Whilst I appreciate there are ‘free’ helplines etc. a parent who is grieving doesn’t want to call up someone and talk/cry over the phone. They need human contact.

There needs to be more groups for mothers and fathers set up by mothers and fathers because only they truly know how you feel and the processes you go through when you have lost a baby.

6.3 Paternity and compassionate leave

Women were asked if their husband or partner had been able to take paternity, parental or compassionate leave and how much time they had been able to take.

Only 59% of the fathers or partners who experienced a stillbirth were reported to have taken paternity or parental leave and 65% took compassionate leave. Of note, 8% of those fathers or partners whose baby was stillborn took neither type of leave. A slightly higher proportion (67%) of the fathers or partners whose baby died after birth, took compassionate leave, but only half (51%) took paternity leave, and 5% said they had taken neither compassionate nor paternity leave. Of those who did take leave, the duration of both types of leave was on average (median) 10 days. The duration of leave for fathers or partners after stillbirth ranged from 1 to 140 days, paternity and compassionate leave after neonatal death ranged from 1 to 70 days.

6.4 Parental health and wellbeing

The huge impact of the death of a baby on the physical and psychological health of parents has been well described^{16, 17} and what women wrote in response to the survey reflected this.

With regard to their postnatal health women were asked if they had been given a postnatal check by their GP approximately 4-8 weeks after the birth of their baby. Of those women whose baby was stillborn, only 56% reported such a check. Of those not receiving a check, most (85%) reported not being offered a follow-up appointment of this kind, although a small number had not wanted a postnatal check (9%). The situation was similar for those women whose babies died after birth: more than half had a postnatal check (62%), but of those not having a check, a large proportion (79%) had not been offered one and some women (17%) did not wish to have a check.

I feel as if I should have taken anti-depressants soon after and been given weekly counselling for at least a year instead of six sessions. There was a point three months after when I needed rehab for depression.

Nothing prepared me or warned me for the mental breakdown and severe depression ... since my daughter’s traumatic death. Nothing forewarned me of the destabilising grief, nor the day to day panics, guilt, anger and lack of motivation to function.

Due to my depression I [father] lost my business and possibly now my home as I can’t work due to the trauma - I’m just a recluse. Something needs to improve as I don’t want anyone going through what we did (and still suffering 9 months on).

I had a previous miscarriage ... the loss of my baby has left me with a serious case of depression at 21 and no longer wanting to have children in case this was to happen a third time.

Women were asked about their current health and wellbeing and that of their partner at the time of the survey (Figure 6.5). Some described the effects on their mental health and their need for care and help.

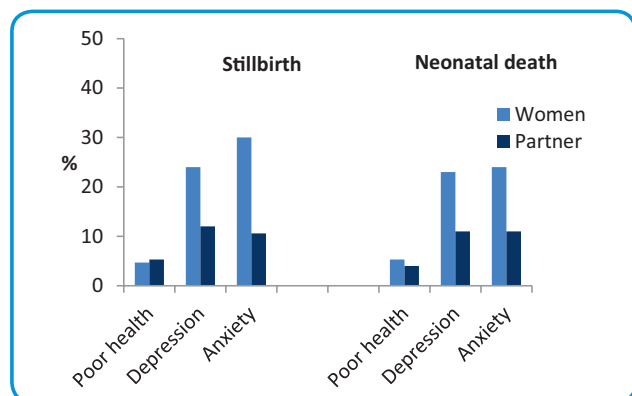


Figure 6.5 Physical and psychological health of women and their partners at the time of the survey

Few differences were evident between the groups, with small proportions of women (5% or less) reporting poor physical health for them and their partners. However, both groups of women experiencing stillbirth and the death of their baby after birth reported high rates of depression (24% in the two groups) and anxiety (30% and 24% respectively) compared with data from the National Maternity Surveys and other studies.³¹⁻³³ Similar patterns were evident for their partners, although depression and anxiety were less likely than for the women.³⁴

6.5 Future plans

Towards the end of the survey questionnaire women were asked about their plans for future pregnancies. Following their recent bereavement over a third (39%) were currently pregnant and slightly more (44%) planned a pregnancy in the future. Just over one in ten women (12%) were not sure about becoming pregnant again and a few women (5%) had decided not to have another baby.

Continuity of care mattered for some women and their partners who said they would appreciate having someone with whom they have previously developed a relationship care for them in a further pregnancy. Trust may have been lost in particular institutions or reinforced by a good experience in what had been difficult circumstances.

Some women made it explicit that they would like other care-providers to be aware of what they have experienced in relation to stillbirth or neonatal death and to take care in labelling and reading their notes and health records. Women who had been through stillbirth or neonatal death reiterated the important point that communication between professional

I was struggling to cope after my baby's death and so I saw my GP who referred me to see a psychiatrist who specialises in mother and infant mental health. She assessed me and said that I needed CBT therapy. I waited 3 months before I received a letter stating that she could not help me as there are no services for women in my position in the area. I felt completely abandoned and alone, not to mention the fact that I was angry that it had taken 3 months for them to tell me this. I was lucky because I managed to access the psychiatrist and CBT therapist through my work. They have diagnosed me with PTSD and depression. I am half way through a course of 16 sessions which are really helping. I have since managed to return to work and can now leave the house without fear of anxiety and panic attacks. I no longer spend every day in bed crying but why was there no help available from the NHS?

I [father] went back to work after 6 weeks post birth and was very focused to succeed in a high pressure performance based environment and I performed well. However after about 3 months my performance began slipping and I lost focus as everything was catching up with me. During our stay in hospital the midwives were invaluable in not only helping [wife] recover but also helping me cope with everything. They understood how I felt and were able to provide emotional support for me and also let me provide some care for [wife], which helped me cope.

I am pregnant again now and it would be useful to see her [bereavement midwife] again now, but I don't think I am allowed or encouraged to do so. Also we thought there would be a 'flag' for our next pregnancy to help staff know what had happened, but there is not, so we find ourselves explaining each time we see someone new.

I can't thank the staff at [hospital] enough. They were all amazing and if I was to become pregnant again, I would definitely go back there!

I would also like to see her [bereavement midwife] now I am pregnant again. Also I would like a 'label' on my notes indicating a previous neonatal death to staff, especially sonographers so that they ... understand what we have already gone through.

Now that I am pregnant again, I have had regular appointments with my consultant, fortnightly growth scans, ... offers of weekly scans ... and the option of going to the midwife to listen to baby's heartbeat whenever we like.

I am 23 weeks pregnant now and being seen by the midwife every 4 weeks and having 2 extra scans at 28 and 34 weeks where I will be given my date for the c section.

groups should be sufficiently effective with further pregnancies so that they do not have to explain their history repeatedly.

Recognition by health professionals that they might be at risk of similar problems in a further pregnancy was something that some women valued. While women appreciated the easier and more frequent access to antenatal care with a subsequent or further pregnancy, they also recognised the importance of this for their own mental health and wellbeing as well as for more medical reasons.

Among those women who were not pregnant at the time of the survey there was an awareness of their own continuing needs for help and support at this time and through a next pregnancy if that occurred.

I've since been told that when I get pregnant again I will be monitored closely and I can contact them whenever I need to. This is a comfort as being pregnant again is what I want but is also something that terrifies me.

As soon as we could we started trying for a baby. I have felt extremely excluded from everyday life and do not feel that I should 'bother' my GP as I have not been 'trying for a baby for long enough'.

Quite a few of my friends were pregnant at the same time and I have been unable to visit them and see their new babies as I have these awful thoughts about how unfair it is that they have healthy babies but I do not.

We did not seek help until we started to try again. We wanted to speak with couples who had had stillbirths previously [for] advice ... [on] trying again and coping with anxiety.

We were told we were fine to start trying straight away for another baby but I wish the advice had been to let my body and mind heal for at least 6 months. Trying and subsequently not getting pregnant has been a negative experience.

6.6 Summary

For both women and men, close family and friends provided the most support around the death of their baby, although health professionals, especially GPs and bereavement midwives, also provided much valued support. Compared to their partners, women whose baby died were much more likely to see a counsellor or someone from a support group and to access a greater variety of types of support. Some men did not talk to anyone. Half of the women in the survey did not have a postnatal check, usually because it was not offered. Poor mental health at the time of the survey, around nine months after their baby's death, was significant with about a third of women and a fifth of men suffering from anxiety and/or depression.

7: Conclusions

7.1 The report

This report is the first to present a national picture of the care experienced by parents of babies who died before birth or as newborns, with responses from 720 women across England. We anticipated that the care and needs of those who had experienced a stillbirth and those whose baby died as a newborn were likely to be different, so women in these two groups were sent different questionnaires. Much of the data for these two groups were then analysed separately. Data were also analysed separately for women whose baby died before labour and those whose baby died during labour; for women whose baby died after birth, separate analyses were carried out for women whose baby died without admission to a neonatal unit and those whose baby was admitted.

Many of the key findings are consistent with previous research in this area^{9, 35–37} and strengthen the evidence for care which is sensitive to parents' needs throughout the care pathway. Echoing previous research, key points where care could be improved in this respect were when parents raise concerns during pregnancy; when their baby died; when causes and explanations for their baby's death were discussed and in the immediate and longer-term period after their baby's death.

7.2 Key findings

- The data returned from women and their partners whose babies had died either before or after birth indicate that the quality of care provided was generally good in what were very difficult circumstances.
- However, for some women there were clearly gaps in care, where women felt their care could have been better managed and facilities could have been better suited to their needs.
- While there were fundamental issues that were common to many women and their partners, in their comments parents also expressed marked individual preferences.
- Women and their partners expressed a need for individualised care, focusing on both their clinical and psychological needs. Individual women's comments illustrate this point well.
- The way in which staff behaved was of great importance. Parents identified the following as critical aspects of care affecting their experience: appropriate and timely response to concerns raised during pregnancy; when and how they were told about the death of their baby; the staff involved; and timely information about any investigations that were carried out and what was known about the cause of their baby's death.
- The physical environment in which care was delivered was also important, particularly when the death of their baby was first identified during labour (if their baby died before birth) and in the hospital after their baby died.
- There is evidence of a clear need for the option for continuing support and counselling for parents after discharge from hospital in the postnatal period.
- The answers to the survey, and in particular women's comments, highlight the need for a responsive care system and pathway which ensures that health professionals listen to parents at every stage: during pregnancy and if parents have concerns about their baby, during periods of difficult decision-making once the death has been confirmed, and in the postnatal period, both immediately afterwards and in the longer term.

7.3 Strengths and limitations

It is a notable strength of this survey that, by using a national sampling frame identified by the Office for National Statistics, all women aged 16 years or more in England whose babies had died during the two sampling periods were given the opportunity to participate. The survey also benefitted from significant involvement from bereaved parents, and users' groups working with bereaved parents, at all stages of its development and management. The results of the survey are limited by the 30% response rate; women born outside the UK, those aged less than 30 and those living in more deprived areas were significantly under-represented. However, completed questionnaires were received from 720 women, from a wide

range of socio-demographic backgrounds, providing a rich data source and reflecting a wide range of individual experiences.

7.4 Looking forward

This report represents a first step in having an up-to-date picture of the experiences of parents whose baby has died before birth or soon afterwards. Further quantitative and qualitative analyses are planned using the data returned on the health and wellbeing outcomes for parents, on the impact of disadvantage in parents' experience of care, on the impact of seeing and holding their baby who had died, and on the experience of specific groups such as those having a multiple pregnancy and birth. There is potential for the survey to be repeated after a suitable interval to assess whether practices have changed.

Holding in mind that the parents in this study have been cared for within a service that must provide for all women, it is also planned to make comparisons with the experience and health outcomes of women whose babies have not died, that is those who have participated in the National Maternity Surveys.³

7.5 Implications for practice and care

The care of parents whose babies have died has been the focus of this study and report. At the same time it is acknowledged that this care takes place within a broader service providing maternity care for all women. For the women themselves and their partners the best care is needed and the health professionals involved recognise this.^{35, 38} While there have been improvements in the past 20 years in care for parents in this situation, the learning that is an integral part of this research study has the potential to facilitate further change in improving their experience.

The following initiatives or improvements could impact on care directly:

- The adoption of policies, procedures and practices to address the psychosocial and practical needs of both women and their partners at the time of their baby's death and afterwards. To include:
 - Management of women's concerns during pregnancy, for example about reduced fetal movement, which is in line with national guidelines.²³
 - Appropriate arrangements for access to ultrasound assessment.
 - Soundproofed rooms in which to labour and be with their baby.
 - Facilities that enable women and their partners to be together.
 - Information in written and other forms for women and their partners about stillbirth, neonatal death and sources of support.
 - A framework of follow-up arrangements to inform and support parents.
 - Funded options for counselling and support in the short and longer term available for women and their partners.
- The consideration of individual care needs along the whole pathway from pre-pregnancy to postnatal care.
- The recognition of the importance of informed choice for parents; the role partners play in supporting each other and the role of close family in providing support, receiving information and helping women and their partners make decisions.
- The development and adoption of policies, at both national and local level, to explicitly recognise the need for appropriate facilities and staff to care for parents of babies who die before birth or as a newborn, that are physically separate from antenatal clinics, labour or postnatal wards.
- The use of toolkits and principles developed by user groups such as Sands and Bliss, which provide a framework for checks on progress and implementation.

More broadly in perinatal services, policy and commissioning there is need for commitment to continue to listen to this group of parents and to monitor their needs and experiences of care.



Peter Brady and his son Jude, who was stillborn on 16th June 2006

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9: Appendix: Methods and response

9.1 Method

9.1.1 Study design

The study used a postal survey design, modelled on that used for the National Maternity Surveys in 2006 and 2010,^{2,3} but with a number of changes to reflect the particular needs of the parents taking part in this survey. This design is the best way to obtain responses from a large, representative sample, but there were challenges involved in seeking information on such a sensitive and potentially distressing topic in this way. User representatives from Sands and Bliss were involved in all aspects of the study design and management in order to ensure that parents' perspectives were considered throughout the study.

9.1.2 Questionnaire development and testing

The questionnaires developed for the 2006 and 2010 national surveys^{2,3} formed the basis of this survey, with some sections removed and others added, informed by the 2009 Sands online survey for parents and discussions with representatives from Sands and Bliss. Two separate questionnaires were used, one for women who had a stillborn baby and another for women whose baby died as a newborn, so that the questionnaires addressed appropriate issues for each group.

Draft questionnaires were developed and the acceptability of these questionnaires, accompanying leaflets and the recruitment process was tested through 'cognitive interviews' with ten women who had a stillborn baby or a baby who died in the neonatal period, identified through the networks of Sands and Bliss. For these interviews, women were asked to complete the questionnaire and comment on the questions, the topics covered, the instructions and on how it felt to complete the questionnaire. The questionnaires and study information were then revised. The surveys included questions relating to pregnancy, labour and birth, and the postnatal period, as well as questions relating to neonatal care (if appropriate) and care at the time of the baby's death, and parental health and wellbeing since the death of their baby. Questions were mostly structured but allowed for longer open text responses where appropriate.

9.1.3 Ethics approval

NHS Research Ethics approval for the study was obtained from National Research Ethics Service Committee South Central – Oxford A on 10th July 2012 (REC Ref. 2/SC/0322).

9.1.4 National survey

The Office for National Statistics (ONS) identified all women (excluding those aged under 16 years) who registered a stillbirth or neonatal death between 1st January and 31st March 2012 or between 1st June and 31st August 2012 in England. These women were sent an introductory letter and study information between six and nine months after the death of their baby, avoiding significant dates such as Christmas and birthdays/anniversaries. Information about the survey was also posted on the websites of Sands and Bliss and on the Sands Facebook page. Three weeks later women received a further letter, a questionnaire, an information leaflet about the study and a leaflet in eighteen languages other than English giving details of how to get help with the questionnaire in different languages. Women had the option to complete and return the questionnaire or to return it uncompleted if they did not wish to take part. A reminder letter and a further copy of the questionnaire were sent to women who had not responded after a further four weeks. All letters and questionnaires were sent by ONS so that the research team did not have the names and contact details of women invited to take part in the survey. Questionnaires were returned to NPEU.

Multiples are more likely to be stillborn or die in the neonatal period than singleton babies. Following advice from women who took part in cognitive interviews, mothers who had more than one baby who died were sent tailored information and sufficient questionnaires so that, if they wished, they were able to complete one questionnaire for each baby.

9.1.5 Support for women invited to take part in the survey

In recognition of the potential for distress and concern caused by the survey we offered women the opportunity to call a Freephone helpline to talk about the survey and also gave information about support services offered by Sands, Bliss and other organisations in the survey information leaflet and on the survey website. In addition, Sands posted information about the survey on their website and on their Facebook page and Sands representatives responded directly to women's concerns raised on the Facebook page. Sands and Bliss helpline staff were also briefed about the survey and responded to calls accordingly.

9.2 The women

9.2.1 Response

In total 2,561 women were invited to take part in the survey, 1,668 who had a stillborn baby and 893 whose baby died as a newborn (Table 1). Questionnaires for 154 women were returned by the Royal Mail as undelivered and 132 women returned blank questionnaires or contacted the research office to say that they did not want to take part. Overall 720 women completed questionnaires, resulting in a 30% useable response rate.

Table 1: Response to the survey

	Stillbirth survey	Neonatal death survey
Questionnaires sent	1,668	893
Questionnaires returned undelivered	154 (assumed to be in proportion to number sent for each survey)	
Effective denominator	1,567	840
Returned blank or phoned/emailed declining to participate	86	46
Returned completed	473	247
Response rate (%)	35.7	34.9
Usable response rate (%)	30.2	29.4

9.2.2 Telephone and email contacts

In total 63 women, or others calling on behalf of women invited to take part in the survey, contacted the research office directly by phone or email. Of these contacts, 39 (62%) were from women not wanting to take part in the survey. Other contacts were from women who wanted to talk or to ask questions about the survey, or to give information about a change of address. Two women called to request help with the questionnaire in their own language and subsequently completed the questionnaire over the phone with the help of an interpreter.

9.2.3 Comparing responders and non-responders

The characteristics of the 720 women who completed a questionnaire (responders) and those 1,687 who did not (non-responders) were provided by ONS and are shown in Table 2 below. There was no difference in response to the survey between the two groups of women invited to take part (those whose baby was stillborn and those whose baby died as a newborn). Compared with those who responded, women who chose not to take part were statistically significantly more likely to have been born outside the UK, to be aged less than 30 and to live in more deprived areas.

Table 2: Characteristics of women who responded and did not respond to the survey

	Responders N=720		Non-responders N=1,687	
	n	%	n	%
When the baby died				
Stillbirth	473	65.7	1,094	64.8
Neonatal death	247	34.3	593	35.2
Country of birth of mother¹				
UK	581	80.7	1,100	65.2
Not UK	139	19.3	587	34.8
Country of birth of father¹				
UK	548	79.2	997	64.7
Non UK	144	20.8	545	35.3
Age group of mother¹				
16-19	32	4.4	107	6.3
20-24	108	15.0	336	19.9
25-29	170	23.6	454	26.9
30-34	236	32.8	422	25.0
35-39	139	19.3	263	15.6
≥40	35	4.9	105	6.2
Age group of father¹				
16-19	8	1.2	40	2.6
20-24	49	7.1	203	13.2
25-29	127	18.4	334	21.7
30-34	211	30.5	374	24.3
35-39	182	26.3	336	21.8
≥40	115	16.6	254	16.5
Index of Multiple Deprivation quintile¹				
1 (most deprived)	166	23.3	625	37.3
2	146	20.5	443	26.4
3	134	18.8	277	16.5
4	139	19.5	184	11.0
5 (least deprived)	127	17.8	147	8.8

¹ Significant difference between responders and non-responders, $p < 0.001$

Note that for some characteristics, numbers do not add up to the total of responders or non-responders because of missing data.

9.2.4 The women who completed the survey

Reflecting the population of women who have a baby who dies during pregnancy or shortly after birth, 6% of the women whose baby was stillborn and 20% of those whose baby died as a newborn had a multiple pregnancy. A high proportion of babies were preterm, but over 40% of the women whose baby was stillborn and 30% of those whose baby died after birth gave birth at or after 37 weeks' gestation. Over 60% of women in both groups were aged 30 years or older, just over half left full-time education aged 19 years or more and 10% of women were single parents. Overall, 13% of the women whose baby was stillborn and 20% of the women whose baby died as a newborn were from a Black and Minority Ethnic background; around a quarter in both groups (23% and 25% respectively) lived in the most deprived areas.

Table 3: Characteristics of the women who took part in the survey

	Stillbirth survey (N=473) ¹		Neonatal death survey (N=248) ¹	
	n	%	n	%
Multiple births				
Singletons	438	94.0	196	80.3
Twins	27	5.8	47	19.3
Triplets	1	0.2	1	0.4
Gestation at birth (weeks)				
≤ 28	108	23.4	129	54.7
29-32	61	13.2	19	8.0
33-36	95	20.6	19	8.0
≥ 37	196	42.7	69	29.2
Age of baby at death (neonatal death survey only)				
< 24 hours	-	-	123	51.9
1-2 days	-	-	29	12.2
3-7 days	-	-	38	16.0
> 1 week	-	-	47	19.8
Maternal age (years)				
16-19	12	2.6	5	2.0
20-24	64	13.7	34	13.9
25-29	100	21.4	57	23.3
30-34	151	32.3	79	32.2
35-39	99	21.2	61	24.9
≥40	41	8.7	9	3.7
Age on leaving full-time education (years)				
≤ 16	77	16.6	50	20.7
17-18	143	30.9	65	27.0
≥ 19 years	242	52.3	126	52.3
Still in FT education	1	0.2	0	0
Partnership status				
Married / with partner	413	90.4	216	90.0
Single mother	44	9.6	24	10.0
Ethnicity				
White	409	87.0	196	80.3
Asian	34	7.2	29	11.9
Black	18	3.8	13	5.3
Mixed / Other	9	1.9	6	2.5
Parity				
Primiparous	276	58.6	127	52.5
Multiparous	195	41.4	115	47.5
Who completed the questionnaire²				
Woman	438	94.0	233	96.7
Husband / partner	100	21.5	35	14.5
Other	15	3.2	9	3.7
Index of Multiple Deprivation quintile				
1 (most deprived)	106	22.6	59	24.7
2	93	19.9	50	20.9
3	89	19.0	45	18.8
4	96	20.5	43	18.0
5 (least deprived)	84	17.9	42	17.6

¹ Includes one woman who had both a stillborn baby and a baby who died as a newborn

² Does not add up to 100% as respondents could give more than one answer

