

BMJ Open ‘This is time we’ll never get back’: a qualitative study of mothers’ experiences of care associated with neonatal death

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ABSTRACT

Aims To explore the perceptions and experience of women whose baby died in the neonatal period about their care in the perinatal period, on delivery suite, in the neonatal unit and afterwards, expressed in their own words.

Design Secondary analysis of the Listening to Parents study, using thematic analysis based on the open text responses from a postal survey of parents whose baby died in the neonatal period in England. Women were asked about care during the pregnancy, labour and birth, around the time the baby died and about neonatal care. Women whose pregnancy was terminated for fetal abnormality were excluded from this analysis.

Results Completed questionnaires were received from 249 mothers of whom most (78%) responded with open text. Overarching themes identified were ‘the importance of proximity’, ‘recognition of role and identity as a parent’ and ‘the experience of care’ and subthemes included ‘hours and moments’, ‘barriers to contact’, ‘being able to parent, even for a short time’, ‘missed opportunities’, ‘being heard’ and ‘sensitive and responsive care’.

Conclusion The findings identify what is most important for mothers in experiencing the life and death of a baby as a newborn. Physical contact with the baby was paramount, as was being treated as a mother and a parent and being able to function as such. The way in which healthcare staff behaved and how their babies were cared for was critical to how mothers felt supported and enabled at this time. If all women whose babies die in the neonatal period after birth are to receive the responsive care they need, greater understanding of the primary need for closeness and proximity, for active recognition of their parental role and staff awareness of the limited time window available is essential.

INTRODUCTION

The death of a child at any age is an overwhelming experience for parents whether or not the death is expected.^{1–3} In the perinatal period, the provision of clinical care is generally the primary concern of health-care providers, however, the way in which it is provided and experienced has a potential for impact on parental mental health and well-being, confidence and self-esteem.^{4–6}

Strengths and limitations of this study

- This study focused on mothers whose baby had died as a newborn, in contrast to most studies of women’s experience of childbirth which involve only those with surviving infants.
- An unbiased population-based sample of women in England who registered a neonatal death were contacted 6–9 months after the birth, with an overall response rate of 30%.
- Key demographic characteristics of participants were identified by participants and the Office for National Statistics using birth and death registration data.
- This is a qualitative study providing considerable insights about the needs of a group less commonly a focus of research.
- While individual interviews could have provided a richer picture, the responses of nearly 200 women enable a greater weight to be given to the voices of a diverse group of mothers about this major life event.

Complicated grief, anxiety, depression and post-traumatic stress symptoms have been documented following the death of a baby.^{7 8} Future plans, partner relationships and psychological coping and functioning may be adversely affected in the immediate and longer term not just by the events themselves, but by the quality of the care delivered.^{9 10}

Qualitative and quantitative research on parents’ experience of neonatal care describes it as a ‘roller-coaster’ with mothers and fathers experiencing both joy and grief,^{11–13} empowerment and powerlessness.¹⁰ Some parents experience difficulty in seeing their baby in neonatal care for practical and psychological reasons, fearing they will become emotionally involved and anticipating greater grief if the baby should then die.¹⁰ When babies are admitted for neonatal care the degree of prematurity and how sick their baby is can affect how mothers approach their newborn

infant, make contact with the baby and their feelings of parental attachment.^{13 14} The need for effective family centred neonatal care in which contact is supported has been long identified^{15 16} and is now embodied in the standards of the National Bereavement Care Pathway (NBCP) (2017)^{17 18} covering perinatal loss of all kinds, with guidance for healthcare provider organisations and healthcare professionals using the best evidence to date and including a component on care following death in the neonatal period.¹⁷

The healthcare system and other organisations providing support to parents aim to promote family-centred care such that families whose baby is in hospital can get to know their baby and better cope with the stress, anxiety and altered parenting roles.¹⁶ If a baby is very sick and if a baby dies, skilled healthcare professionals need to be available to provide care, information and support.^{8 19}

Parents whose babies have died in the neonatal period are rarely the main and separate focus of studies, their experience has more commonly been examined in conjunction with that following late miscarriage and stillbirth. This study in England used qualitative methods with the objective of exploring and better understanding the views of this group alone, with the objective of identifying what mattered to them both before and after their baby died, focusing on care during labour and birth, immediate postnatal and neonatal unit (NNU) care.

METHODS

The study used data collected in the Listening to Parents study²⁰ with survey methodology and overall design similar to that used in National Maternity Surveys.²¹ The Office for National Statistics (ONS) identified all women aged 16 years and over in England who registered a stillbirth or neonatal death in two 3-month periods, avoiding mailing during holiday periods, birthdays and anniversaries. All the women, including 893 whose baby had died as a newborn, were sent an initial letter, followed by a further letter, information sheet with details of support services from Sands, Bliss and other organisations and a questionnaire between 6 and 9 months after the stillbirth or neonatal death.²⁰ An information sheet in 18 non-English languages gave a freephone number for getting help in completing the questionnaire, through an interpreter if required. After 4 weeks, a reminder was sent to non-respondents. Women could call or email at any time and opt out of the study. Return of a blank questionnaire was treated as opting out. The research described here focuses on mothers' experiences associated with neonatal death, defined in the UK as a death within the first 28 days after birth. In the UK almost all maternity care is provided by the National Health Service which is free at the point of use.

The questionnaire included space for free-text responses at the end of each section and at the end of the survey.²⁰ The exact wording of the open questions was: 'Is there anything else you would like to say about your

antenatal care?'; '...your care during labour and the birth of your baby?'; '...your baby's stay in neonatal care?'; '... your postnatal care in hospital'; and '...about your postnatal care after your discharge home?' There was also an open question at the end of the questionnaire 'If there is anything else you would like to tell us about your care while you were pregnant or since your baby died, please add your comments here:'

Structured closed-end questions were used to ask about maternal sociodemographic characteristics and the ONS provided information about women's marital status, age group, and Index of Multiple Deprivation in quintiles, an area based measure of deprivation based on income, employment, health and disability.²²

Patient and public involvement

The original research proposal and plan was developed directly in association with the stillbirth and neonatal death charity Sands and the baby charity Bliss. Parents who had experienced stillbirth or neonatal death were consulted informally and then as members of the Listening to Parents advisory group. The survey instrument was piloted with 10 individual bereaved mothers who advised on the content and research process. Patients were not involved in the recruitment and conduct of the national study which was organised by NPEU and separately run by ONS. The completed report was published on the NPEU website and made available to parents and families via the two participating charities, peer-review publications and has been used in working with parents and training health professionals in the field.

Qualitative analysis

Women whose pregnancy was terminated due to fetal abnormality incompatible with life were excluded from this analysis as their experience involved rather different processes and care. Open-text material was analysed, coding themes as they arose using a thematic content analytical approach: familiarisation with the data; generation of initial codes; searching for themes, identifying and reviewing themes, defining and naming themes.²³ This occurred in an iterative process, with the data set and identified themes being visited repeatedly. The analysis was essentially data driven, with an emphasis on new emerging and anticipated themes. Two researchers independently coded themes and subthemes as they arose and differences in coding and interpretation were resolved in review and discussion. Deviant cases which ran counter to the dominant themes were sought. The third author (CB), a patient and public involvement representative, then reviewed, discussed and agreed the themes identified with the other authors. This role was key in confirming the themes presented. Possible biases arising from being white female researchers with children is acknowledged.

RESULTS

Completed questionnaires were received from 249 of 840 mothers of babies who had died in the neonatal period,

Table 1 Maternal and infant characteristics (n=194 mothers)

	No	%
Maternal age (years) (n=194)		
16–19	5	2.58
20–24	24	12.37
25–29	49	25.26
30–34	60	30.93
35–39	48	24.74
40 or >	7	3.61
Parity (n=193)		
Primips	92	47.92
Multips	101	52.08
Ethnic group (n=192)		
White	155	80.71
Mixed	3	1.56
Asian	21	10.94
Black	11	5.73
Other	2	1.04
Index of multiple deprivation (n=177)		
1 (most deprived)	38	21.47
2	38	21.47
3	29	16.38
4	34	19.21
5 (least deprived)	38	21.47
Multiple pregnancy (n=194)		
Singleton	159	81.96
Twins/triplets	35	18.04
NNU admissions (n=191)		
Not admitted to NNU	69	36.13
Admitted to NNU	122	63.87

NNU, neonatal unit.

including 13 mothers who experienced the death of two or more infants, representing a response rate of 30%. Some babies died in on the labour ward (n=84, 34%), though two-thirds (66%) were admitted for neonatal care.

Not all participants responded to the open-text questions but the responses of 194 women (78%) were available for qualitative analysis.

Among women who responded to the survey, mothers whose baby died in the neonatal period were more likely to be white, married, UK-born, older and living in less disadvantaged areas than women with surviving infants participating in the National Maternity Surveys^{21 24} (see table 1 with description of sample responding to open text questions). Half the babies (50.4%) were born at less than 28 weeks’ gestation. While the majority were admitted to an NNU, 61% of those babies not admitted for neonatal care were born at less than 25 weeks’ gestation.

Duration of stay in the NNU was generally quite short, with 51% of babies dying less than 24 hours after they were born. Nearly two-thirds died following withdrawal of life-sustaining interventions.

Qualitative data

Women wrote about both how they remembered feeling at the time and when completing the survey. Their responses thus reflected both their immediate reactions and their longer-term reflections on what had happened to them before and following their baby’s death. Selected extracts from the data set are used to support the analytical narrative that emerged.

We are directly reminded of parents’ needs in these circumstances by the powerful responses they made. The thematic analysis identified three overarching themes: ‘The importance of proximity’, ‘Recognition of role and identity as ‘mother’ and ‘parent’ and ‘The experience of care’ (table 2).

Cross-cutting themes of ‘Communication’ and ‘Time’ are included and shown in the table with the ways in which they were referenced by women, and are evidenced throughout the text, but not described separately in the Results section.

The importance of proximity

The need for touch and physical contact is a key aspect of the powerful attachment to the baby that develops during pregnancy and consolidates at birth and afterwards. Following birth, the primary need that women expressed

Table 2 Overarching themes and subthemes identified in mothers’ responses following neonatal death

Themes	Subthemes	Cross-cutting themes	
The importance of proximity	<ul style="list-style-type: none"> ▶ Counting the hours and minutes ▶ Presence and absence ▶ Barriers to contact 	Time	Communication
Recognition of role and identity as a parent	<ul style="list-style-type: none"> ▶ Being included ▶ Being able to parent, even for a short time ▶ Missed opportunities 	Duration	Effective
The experience of care	<ul style="list-style-type: none"> ▶ ‘Good’ clinical care ▶ Being heard ▶ Sensitive and responsive care 	▶ Of contact	Valued
		▶ Of separation	Appropriate
		▶ Of life	
		Speed	Difficulties
		Delays	Not enough
		Waiting	Unwanted
		Continuity	Inappropriate

in their own words was to be near their baby. Subthemes of 'Counting the hours and minutes', 'Presence and absence' and 'Barriers to contact' were identified.

Mothers repeatedly emphasised an intense need for closeness and physical contact, describing the pain of delays and of their baby being removed from the delivery suite or theatre, even transferred to another hospital. The emotional impact of separation, of being left, was evident in the language used and feelings expressed.

Counting the hours and minutes

Many mothers in framing their experience postbirth wrote specifically about the duration of contact and of separation: '*having to wait to 8 hours*' to see her baby was devastating to a desperate mother who had just given birth. This was an integral element of their narrative in explaining what was most important to them at this time and the associated difficulties.

It would have been nice if I was closer [to NICU]. I was recovering from the section and 3 hours and a long corridor away from him. It took 5 mins to get to him but the longest 5 mins of my life

They valued the little time they had enormously:

...they worked very hard on me and my little boy *Name* and gave me 15 precious hours

I cannot thank them enough for helping to provide 4 precious hours with my daughter.

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.

Our baby was diagnosed with Trisomy 18 at 20 week scan and we chose to proceed with the pregnancy. We didn't know whether our baby would make it to term or be born alive.... We were able to take him home within 4 hours of the birth and spend time until he died, holding him and getting to know him.

Though their baby was very preterm some parents in this situation would have really appreciated close contact, though this was not necessarily anticipated by staff or offered:

Was not told I could do skin-to-skin contact which is a regret. In retrospect no-one was prepared for [Name] to be born alive and for us as parents to cuddle her etc. My husband would have done skin-to-skin if he could.

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.

Immediately following birth mothers in normal circumstances would expect to have contact with their baby. However, following at-risk pregnancies, difficult births

and preterm deliveries, some of their expectations may have been more complex, encompassing both their primary need and an understanding of what was needed for the care of their babies:

They scanned my tummy and instantly told me to push as my daughters depended on it They showed us our daughters before rushing them to Neonatal Intensive Care.

My C-section went from planned for the weekend to rush me into Theatre immediately. The Anaesthetist Reg and Consultant were supportive and understood why I desperately wanted a spinal (so whatever time my daughter survived for I could get to meet her) and facilitated this.

Time and recognition of time limits was thus constantly referred to and was critical in the way mothers described their experience.

Presence and absence

The suddenness of the absence of their babies after admission to an NNU and sometimes, transfer, is salient in women's descriptions of their need as new mothers, their situation, the key features they mention and the language used about how they felt:

I just wanted to be moved to where my baby was, but instead I had to stay in a room with an empty cot.

While separated, new mothers needed to know how their baby was doing, feeling helpless in this context, they were completely reliant on staff providing information:

When Doctors took my baby after delivery I had to wait 5 hours before I saw her which was understandable, but no one came to give me an update.

Not all mothers with very sick or very preterm babies and those who were unwell themselves had an opportunity to see or hold their baby at all until decisions for withdrawal of interventions were enacted:

I never saw my baby till they turned the machines off while she was in my arms.

Baby was transferred to a different hospital the day it was born and I was not transferred there until a few hours before the baby's death as I required blood transfusions.

The psychological impact of separation was marked:

...she was taken to another hospital as she was so ill. I was supposed to be put in Intensive Care but as it was over New Year there weren't enough staff to look after me so I stayed in the Labour Ward in a room by myself with an empty cot ... I only saw her a brief moment in an incubator, then not again for 4 days... knowing my baby was critical and I couldn't get to her it was very distressing.

The absence of their baby in the maternity unit where they had given birth and the associated postnatal area contrasted painfully for many mothers:

All I could hear from my room was mothers with newborns. Leaving and returning to my room was stressful and traumatic as mothers were leaving with their babies, people with congratulation balloons etc.

Being moved to a ward where there were lots of mothers and babies was very distressing as I felt I was looked at by them as I was clearly not pregnant, with no baby.

While some mothers were cared for separately, being placed on a ward with other mothers and babies was common for those whose baby died after birth:

I felt very isolated on the ward. I shared a room with 4 other women who had their babies by their bedside and I was the only one without my baby. They were getting all the attention from Doctors, Midwives and other Specialist and no one came to my cubicle. It was depressing, and I couldn't wait to get out of there or wait for the time I could visit my baby in the Neonatal Unit.

Being without their baby, left alone and then confronted with other apparently healthy mothers and their healthy newborn babies was really difficult for this group of mothers. They were conscious of their own emotional response in this situation in which the absence of their own baby was marked by both an empty cot and the visual and auditory presence of pairs of mothers and babies together. At the same time awareness of being viewed differently in the regard of other mothers was uncomfortably evident.

Barriers to contact

Feeling very short of time and just wanting to be nearby or in the NNU with their babies was emphasised. A need to be unequivocally understood in this respect was clearly expressed. The separateness and isolation felt by mothers in this situation was exacerbated by misunderstandings, infantilisation—being 'allowed' or 'told'—and the disconnect between the practical clinical care and the provision of emotional care and support that included helping them to see and have some contact with their babies.

I felt like I was encouraged to sleep/eat too forcefully when frankly I just wanted to be beside my poorly baby.

When parents want to go to NICU after having a baby they should be able to, not convinced to stay on ward or be told to wait for wheelchair for 4 hours.

Some members of staff should tell you it is ok to cuddle your baby...—even hand you baby if they can see you are unsure.

I didn't feel that the staff on the postnatal ward fully understood how I felt about being away from my

baby. I think the communication could have [been] improved between NICU and postnatal ward.

Around the time the baby died a continuing need for closeness was emphasised whether in delivery suite or after admission to the NNU. What was important was to have the maximum contact time as a family, to be with their newborn as much as possible and for as long as they wished, though this did not happen for all parents.

Recognition of needs and identity as a mother and parent

Being involved in care, holding their baby, feeding, changing a nappy, carrying out 'cares' were seen as key responsibilities by parents, essential to their role and sense of self at this time and later. They also wanted, and to some extent expected, external recognition of their role as parents.

The importance of proximity and closeness was emphasised repeatedly in women's construction of their own parenting and role as mothers. Wanting to be near their baby, to be located close by, to see and hold their baby and easily gain access to where the baby was being cared for, were key elements. They were quite explicit about staff recognition of their need to be helped or supported as parents in being with and caring for their baby. Not having this experience was extremely painful and continued to be so. Subthemes of 'Being included', 'Being able to parent, even for a short time' and 'Missed opportunities' were identified.

BEING INCLUDED

Being given choices and explanations, asked about what they would like and informed about what was possible in relation to their baby's care before their baby's death was emphasised:

I will never forget that I never got to feed or dress my son before he died! ... When we were told we had to take life support away no one explained what was going to happen. We sent our parents away, they should have been involved we didn't realise they could be part of it! As no one explained. The nurses helped us bath our son because he was still under life support. Had they explained we would have asked them to leave and would have wanted to bath our son on our own! Also we would have wanted our parents to be able to hold their grandson!

Staff are good but some nurses are not very supportive. I wanted to hold my little baby girl as she wanted my touch and warmth but they did not let me hold her. For which I am still very upset and when first time she put on dress she was looking very cute. I requested the photograph but the ladies in charge kept telling the other will come and take one for you. I am very upset no one gave me one because no one took one. And when she was dead they said now you can hold your baby and have her dead photographs.

Both of these mothers had wished to be treated inclusively in order to fulfil their caring maternal role in a positive way, preferably supported by their family. This involved being informed and taking care of their baby to the extent that was possible, with their parental role appreciated and respected in the care environment.

Other mothers described a different, more positive experience:

They left us alone with our child for quality time but were always on hand.

The family suite at the hospital was perfect—quiet and secluded, and allowed my husband to stay by my side, and family to visit. It was a place for us to stay with our baby for as long as we wished.

We were not given a time limit, we were allowed to decide how long we wanted to spend with our son [Name]. We were supported to hold him.

Being able to parent, even for a short time

To have their role and identity as a parent recognised by hospital staff was vital, as was feeling they had agency and had functioned as a parent while being an advocate for their baby and providing some care. Having done the right thing as a mother was important and whether they had been enabled to do so or not was stressed in the responses. To have had the right care provided for their baby and, where possible, to have had a role in that care was emphasised. Part of being able to parent a sick baby involved making choices and having some degree of control in a situation that was largely not manageable from a shocked parent's perspective due to their baby's clinical condition, the care required and support needed.

Being able to parent in these difficult circumstances necessitated their role being anticipated by staff, being asked, informed and directly involved in contact and care in the delivery suite and the NNU. This required access, information, flexibility and a sensitive awareness of parents' needs where pregnancies, babies and mothers were at risk and death was possible, even likely:

Our only problem with him was that they didn't tell us for 4 hours that my baby was having serious problems. Neither baby's father nor my mother were allowed in. This is time we'll never get back.

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.

... they were so lovely with our daughter... They ensured we had as much time with her and holding her, as was possible... 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.

Being asked what they would prefer, told about what was possible, being involved and supported in this was

important, especially prior to the death of their baby and in the period that followed:

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. The advice on when to do comfort holding etc varied from person to person—it would have been better if we'd had consistent advice.'

Greeting and saying goodbye to their baby was critical for parents, and for staff to have facilitated and supported this was hugely valued:

I think it also helped that *Baby's name* was actually born alive, even though he only lived for 10-15 mins, it felt like we actually got a proper chance to say hello, and tell him how much we love him and to say goodbye. It also made everything seem more natural, and just feel lucky we got to see a glimpse of *Baby's name* alive, ...but he died in our arms, which if you are going to die, that's the best place to die in the arms of the people who love you the most in the world.

Our daughter was removed from the NICU and from her life support mechanisms (at our decision) at eight hours old. She lived for another forty hours; during this time... she was with us on the postnatal ward—with a NICU nurse when required... under neonatal care, but not in the ward and preferring not to have help unless we called for it and they gave us the maximum time we could have together, as a family.

Missed opportunities

A key component of fulfilling their role effectively as a parent was having had their baby cared for in the best and most appropriate way possible. Where they felt the service fell short they were critical. They thus wrote about missed opportunities and significant time points and events as they perceived them associated with the birth and afterwards, relating to contact and acknowledgement of their role as a mother and parent:

We did feel that the gaps between updates on his critical condition were too long. We often had to ask Midwives on recovery unit to chase neonatal unit. When we were called to the SCBU I waited for my husband who had gone for fresh air. When we got there we were told our baby wasn't going to make it and he was brought to me. But I could have got there earlier and been with him for longer at the end if the staff had encouraged me to go and not wait... All these little things count so much when looking back on it all.

We would have liked to bathe her, clothe her, and put a nappy on etc the next day and skin-to-skin immediately, as she was alive for 2 1/2 hours. But this was not offered to us. I asked to dress her and put a nappy on the next day with the bereavement midwife—I wish I had asked to bathe her.

Awareness of time pressure for staff and for parents themselves was evident in these responses, though not all missed opportunities reflected this:

I wish the staff would have said to me do we want a picture taking of me, my fiancée and [Name] as we don't have one of us all together, nor holding him either. Which at the time we didn't think of, this due to being distressed/upset.

The experience of care

In looking back and writing about the perinatal care they had received women described a wide range of issues and situations that were salient for them. The focus here was on what was critical in terms of the quality of care. This was evidenced in the provision of what was perceived as effective clinical care, communication and information giving, and in sensitive interpersonal care, taking account of the needs of women and their partners both before and in association with bereavement. They wrote about the staff and directly about the quality of the care received, identifying how the care provided matched their needs and wishes or not.

'Good' clinical care

Identification of risk during pregnancy, labour and birth for women and care in line with this was a common concern for those who had experienced previous pregnancy losses, those with a multiple pregnancy, women who were admitted for hospital care antenatally and those whose babies were thought to be on the boundary of viability. Communication was a critical issue for these mothers:

My very worried concerns were due to my multiple pregnancy and then complication of early waters breaking. My Consultant lacked in people skills and often left us feeling so distressed by the information she gave us—there is a way to impart difficult information and she didn't have it.

While these women with complex pregnancies recognised that they required skilled clinical care and management, how they were spoken to was a prevailing concern in what they took away from their experience, both negative and positive:

One Consultant sent me away from my 22 week scan and said 'come back at Xmas (25 weeks) for a heart-beat check, but there isn't likely to be one.

Everything was done to stop the labour that could have been done 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.

Doctors respected our wishes of doing what was necessary but not to do invasive procedures that were not necessary. Consultants realised fairly soon that the baby will not breathe on his own. They took him until I was stitched and brought him to us whilst helping him breathe. Our baby passed away in our arms peacefully.

Effective coordination of clinical care was also an integral element of this theme and was reflected in responses about all the phases of the maternity care journey that women took. The disjunction experienced at times between staff groups, individuals and the process of care was directly referred to by some women, though not all.

Our son's condition was diagnosed within an hour of being taken into the NICU. The plan was to transfer him across town to the specialist children's hospital but he deteriorated so rapidly that this did not happen and the Specialist Doctors came to us to perform the intended procedure as a last ditch chance to save him—but he was just too poorly....The staff and the care they gave to our son was exemplary in such a stressful short period of time, and the care and information they gave to us was the best they could do under such pressured circumstances.

Being heard

Listening to women was explicitly identified as key throughout their pathway by women themselves:

No-one listened or explained things to me. Didn't give me the time or facts I needed.

The lady administering the spinal was brilliant. She really listened to me when I was scared and felt awful.

I have never felt so helpless and not listened to in my life. No-one cared that I was in Labour at 24 weeks and didn't know what was happening

Sensitive, responsive care

Women were most critical about aspects of their antenatal and postnatal care. However, in relation to labour and birth, and care in the NNU, many were positive, though some mixed comments were made about the quality of care. One mother suggested that staff should be more aware of parents' anxieties and encourage them not to be afraid to ask questions. Those who clearly felt very well looked after were unequivocal in their praise, but not all had this experience:

Antenatal care concentrated too much on blood sugars and not on the joy of being pregnant or the baby, so my husband and I do not feel like we ever got the chance to be "happy" about being pregnant, especially after years of not being able to conceive... No empathy from medical staff or acknowledgement that

pregnancy was very special because of the difficulties we had had.

My care, if that's what you can call it, it seemed like they cancelled my care and wasn't bothered

Gratitude for care that was perceived to be responsive to individual needs and differences in the circumstances of women and their families was evident in their replies:

The Midwives were absolutely wonderful throughout my stay in hospital—before the caesarean, during the operation in theatre, after the caesarean and after our son died. They referred me to the OBS and GYNAE counsellor and looked after me post discharge when I attended triage after my BP [blood pressure] spiked again. They treated me away from the women expecting babies and did not put me on the antenatal or postnatal wards.

The hospital allowed both my husband and mum to stay with me during the whole stay and delivery of our daughter. My dad and brother were also allowed to see and hold her. All members of staff we dealt with before, during and after her death were excellent and I couldn't praise them highly enough.

Feeling they were treated as individuals and that health-care staff were sensitive to their needs as mothers, as bereaved parents and as a whole family was crucial in the kind of judgements and views expressed:

All the staff in the Neonatal Unit made my family very comfortable there. I have 2 other children aged 10 and 12 and the staff made sure they spoke to them to and answered any questions they had, they also got them involved in my baby's care too.

Twin 1 was held on day 2 as she passed away, twin 2 was held at nearly 4 wks.... The staff at NICU were fantastic all the way through. They were very in depth on explaining the problems our daughters had. And helped make twin 1's passing special...They also helped support us during her funeral preparation and helped support our children explaining how they could help look after twin 2.

DISCUSSION

This research has focused on the experience of mothers whose baby died in the neonatal period, an event less common and a topic less frequently addressed of itself than that associated with stillbirth, though there are clear commonalities in terms of distress, grief reactions, the need for memories, to be listened to, respected and communicated with clearly at the time and subsequently.⁴ The thematic analysis undertaken has demonstrated the importance of acknowledging and addressing parents' core needs, in this instance those of mothers, to understand what happened, how they felt and how staff behaved in the context of the death of their baby as a newborn in both delivery suite and neonatal care.

The emerging themes of 'the importance of proximity', 'recognition of role and identity as 'mother' and 'parent'', and 'the experience of care' reflect the major psychological issue of maternal-infant attachment which is begun for most parents well before birth.^{14 25} It is not surprising that meeting their baby for the first time is a critical and life-changing experience that is much anticipated and that where there is clinical concern, this is magnified.¹¹ Following the birth, the time spent on delivery suite and for many of the respondents, in the NNU, gave rise to the specific themes powerfully emphasising a desperate wish for proximity, contact and for acknowledgement of a parental identity, and the distress caused by delays and missed opportunities. Separation for variable periods of time is an integral aspect of care when babies are admitted for neonatal care²⁶ and especially when mothers are unwell.²⁷ The pain and distress associated with such separation, sharpened by being on wards with healthy babies' or themselves being in intensive care, was evident in the responses made, with most women being aware that opportunities to be with and to get to know their sick or small newborn were likely to be limited.

Being helped to be a parent in this context was vital from their perspective, even for those whose infants were on the boundary of viability. Supporting and empowering mothers and fathers in having an active role in providing whatever care is possible validates and confirms their role in a fundamental way. The emotional tone, intensity and significance of the experience is evident in the language used. Maximising the opportunities for contact and facilitating involvement both before and following the death of their baby was hugely valued by the women in describing their experience and was emphasised both when it occurred and when it did not. There are some specific commonalities with other qualitative studies, mainly with women following stillbirth, where there is thematic reference to 'physicality' and 'maternal pride'²⁸ and to 'a finite window to interact' and 'acts of parenting'.⁶ However, the presence of a newborn as a live baby and their subsequent death clearly impacts differently on women's experience and perceptions in a way not identified in the literature with the creation of positive emotional memories of their living baby as indicated in the themes identified and examples presented. The separation of new mothers, and indeed parents, and their babies at a critical time, as a function of clinical condition, as with other less extreme parent and baby situations when separation occurs, has the potential to impact on current and longer term health and well-being and relationships.^{3 8 10}

The shock of seeing their baby initially and in neonatal care was mentioned by some of the women in this study. Other qualitative work has highlighted how frightening hospital environments can seem, especially the context of neonatal care.¹⁰ Most significantly, the different facets of the construction of 'the experience of care' that mattered most to this group of mothers were evidenced in what they saw as 'good' clinical care, attitudes that were sensitive to their needs and positive interactive communication that

embodied their individual voices being heard in an essential way.

Quantitative data were collected in the same project with this population of mothers. The findings have been published separately²⁹ and generally agree with the present paper. While the focus for analysis was different, there was evidence of substantial proportions of women reporting not feeling listened to in labour and postnatally and subsequently, not being able fulfil their role as a parent, providing any basic care before their baby died, although most were able to have family members spend time with them and the baby in the NNU. However, a strength of the qualitative analysis undertaken, based on the individual mothers' own words, created insights and identified needs that were not specifically included in the structured question formats utilised for the quantitative analysis.

A review of support for families after perinatal death³⁰ highlighted the importance of memory creation, seeing, holding, taking photos of the baby, in helping families recover. However, there has also been research suggesting that women who held their deceased baby were at greater risk of PTSD (Post Traumatic Stress Disorder) in a subsequent pregnancy.³¹ Nevertheless, qualitative studies, including the data presented here, indicate that women very much want the opportunity to hold their baby while alive, even if the longer term neonatal outcome is thought to be poor, and to do so afterwards. Thus, it is clear that the narrative is very similar to that put forward in studies of women and families following stillbirth, though for this group the possibility of being with their live newborn and having a parental role, all be it a limited one, is a critical additional phase which allowed mothers to describe and contrast their feelings before and afterwards in their retrospective reports on these really challenging events.

The introduction of the NCBP in the context of perinatal bereavement, particularly those relating to stillbirth and neonatal death^{17 18} aims to improve care by addressing the kind of issues raised by the women in this study in a systematic way, by changing both policy and practice. The standards, guidance and resources for staff are valuable although are not yet adopted by all Trusts^{32 33} or necessarily embodied in care. While the NCBP does not explicitly cover some of the issues and needs identified in this study, the evidence arising from the small-scale evaluation of parent experience so far provides some positive confirmation of the benefits of the pathway³⁴ to which the voices of women in this study add weight, identifying aspects of care that may influence future iterations of the pathway.

This study is limited by the overall response rate of 30% with under-representation of women born outside the UK, those aged less than 30 years, and those living in more deprived areas. Thus, the findings may not be representative of the wider population, though representativeness was not the goal of this qualitative analysis. Nevertheless, the response rate is similar or better than other study response rates on this kind of topic,³⁵

and a large proportion of those responding wrote open text comments. This necessarily retrospective study was carried out relatively soon after the event at between 6 and 9 months afterwards when recall bias may have been less affected than in some studies of stillbirth and neonatal death.^{6 36} It is also argued that such salient major life events as infant death and bereavement are very well remembered.³⁷ Interview data with a small number of mothers could have provided a richer picture of the experience of individual mothers. However, the responses of nearly 200 women allowed us to gain a different perspective, identifying themes for which there was a weight of women's voices following the experience of neonatal death, a topic that is less often a separate focus of concern. Throughout the data set, and in the illustrative extracts used, the emotional tone of the mothers' responses was evident in terms both negative and positive affect. While many mothers 'spoke' for both parents at times, a need for studies explicitly involving fathers as participants, reflecting on their own experience is evident and a limitation of this study.

Continuing to listen to the voices women and parents, asking and hearing about their experience as individuals, finding commonalities and abstracting patterns of meaning, is essential in further developing understanding and the research evidence base for improving care. The implications are clear: the human needs of women and their families both before and following the death of a baby soon after birth need to be absolutely held in mind by those organising and providing care and acted on. It is anticipated that the material presented here will be used formally and informally in training midwives and neonatal staff as occurred with the earlier main study.²⁰

CONCLUSIONS

The findings and themes identified powerfully highlight the pain and distress experienced by women who had a baby survive birth and then die in the neonatal period, making explicit what is particularly important in terms of psychological and interpersonal aspects of care, guiding healthcare staff and the wider family and friends in caring for and supporting parents in this situation. The need for proximity to the baby and support in being a parent, even for a short time are paramount, framed by the shortage of time and the active recognition of the critical role of effective and appropriate communication between parents and health professionals.

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Contributors MR and CB conceived and planned the main study working with the Listening to Parents advisory group. All three authors contributed to the acquisition of the data and all three authors planned the analysis of the open text material that is the basis of this specific study. MR and JH undertook the initial qualitative

analysis, with CB reviewing and agreeing the themes identified and supported by the data. MR and JH were responsible for the initial draft of the manuscript and all three authors actively contributed to the interpretation of the findings, redrafted the final version and agreed the final and revised versions of the paper.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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