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Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study

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ABSTRACT

Objective: To obtain the views of bereaved parents about their interactions with healthcare staff when their baby died just before or during labour.

Design: Qualitative in-depth interview study, following an earlier national survey. All interviews took place during 2011, either face-to-face or on the telephone. Data analysis was informed by the constant comparative technique from grounded theory.

Setting: Every National Health Service (NHS) region in the UK was represented.

Participants: Bereaved parents who had completed an e-questionnaire, via the website of Sands (Stillbirth and Neonatal Death Society). Of the 304 survey respondents who gave provisional consent, 29 families were approached to take part, based on maximum variation sampling and data saturation.

Results: 22 families (n=25) participated. Births took place between 2002 and 2010. Specific practices were identified that were particularly helpful to the parents. Respondents talked about their interactions with hospital staff as having profound effects on their capacity to cope, both during labour and in the longer term. The data generated three key themes: 'enduring and multiple loss': 'making ir retrievable moments precious'; and the 'best care possible to the worst imaginable'. The overall synthesis of findings is encapsulated in the meta-theme 'One chance to get it right.' This pertains to the parents and family themselves, clinical and support staff who care for them directly, and the NHS organisations that indirectly provide the resources and governance procedures that may (or may not) foster a caring ethos.

Conclusions: Positive memories and outcomes following stillbirth depend as much on genuinely caring staff attitudes and behaviours as on high-quality clinical procedures. All staff who encounter parents in this situation need to see each meeting as their one chance to get it right.

INTRODUCTION

In the UK, around 4000 babies are stillborn every year,¹ with the worldwide burden estimated at almost 3 000 000 per annum.² No expectant parent is prepared for the shock of a diagnosis of fetal death in utero, or of giving

ARTICLE SUMMARY

Article focus

- Investigation of parents' views of interactions with hospital staff when their baby died just before or during birth.
- Identification of policies, procedures and practices that bereaved parents viewed as helpful or detrimental to their experience of having a child that was stillborn.

Key messages

- Everyone involved (parents, clinicians, support staff) has 'only one chance to get it right' at the time a baby is stillborn.
- Parental recovery from the experience of stillbirth can be influenced as much by staff attitude and caring behaviours as by high-quality clinical procedures.

Strengths and limitations of this study

- The study design facilitated purposive maximum variation sampling of a national cohort of bereaved mothers and fathers.
- Limitations concern generalisability, population self-identification (from an earlier national e-survey) and the inclusion of few participants from non-white, British backgrounds.

birth to a stillborn child, and for the profound grief that follows. Stillbirth has been described as a *paradoxical coalescence of life and death*,³ and the trauma of this experience is associated with increased incidence of anxiety, depression and post-traumatic stress disorder.⁴⁻⁶ Owing to the social stigma associated with stillbirth,⁷ it is an isolating event leaving mothers more dependent on their own psychological and emotional resources and on those that care for them.³ The burden on staff is demonstrated internationally in studies of maternity professionals who report that caring for families experiencing a stillbirth is a stressful aspect of their work.⁸⁻¹⁰ Recently, the Lancet stillbirth series emphasised the unique status of stillbirth and added that grief may be exacerbated by social stigma, marginalisation and by the standard of care provided for parents.¹¹

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The importance of good-quality care is emphasised in international guidelines for the management of stillbirth from the Royal College of Obstetricians and Gynaecologists in the UK, the American College of Obstetricians and Gynecologists, and the Perinatal Society of Australia and New Zealand.¹²⁻¹⁴

In high-income countries, research into the prevention and clinical management of stillbirth, such as determining investigations that are most useful to define the cause of stillbirth, has increased in recent years.¹⁵ However, this needs to be accompanied by studies that describe parents' experiences so that the quality of care can be improved. Previous qualitative research has investigated the experience of induction of labour, the role of caregivers and the experiences of women accessing bereavement support after stillbirth.¹⁶⁻¹⁸ Very recently, two studies have examined the experiences of parents in the USA¹⁹ and Sweden.²⁰ To date, there have been no in-depth studies from a UK-wide sample of bereaved parents. To understand more about the experience of stillbirth in the UK, Sands (the Stillbirth and Neonatal Death Society) has funded a programme of work in this area.^{10 21} The objective of this study was to obtain the views of bereaved parents about their interactions with hospital staff when their baby died just before or during labour.

METHODS

The study used an interpretative qualitative methodology, based on in-depth interviews, conducted either face-to-face or on the telephone. Each interview was transcribed verbatim.

Sample

The sample was recruited from respondents to our earlier quantitative survey (see Consolidated criteria for Reporting Qualitative studies (COREQ) participant selection flow diagram/figure 1).²¹ This was an e-questionnaire, advertised through the website of Sands. In all, 760 parents completed the survey, 460 of whom lived in the UK and had experienced the interuterine death or stillbirth of a baby at 24-42 weeks' gestation, between 2000 and 2010. A total of 304 respondents accepted in principle the invitation to discuss their experiences of care in further detail. A sampling frame was derived on the basis of purposive maximum variation sampling.²² Letters and telephone calls were used to inform families about the study, and to invite their participation. Up to three attempts were made to contact them.

Data collection

Interviewees were conducted in person or by telephone, according to participant preference. All parents were given study information leaflets and provided written consent to participate. Interviews were audio-recorded. The same opening and closing questions were used in all interviews:

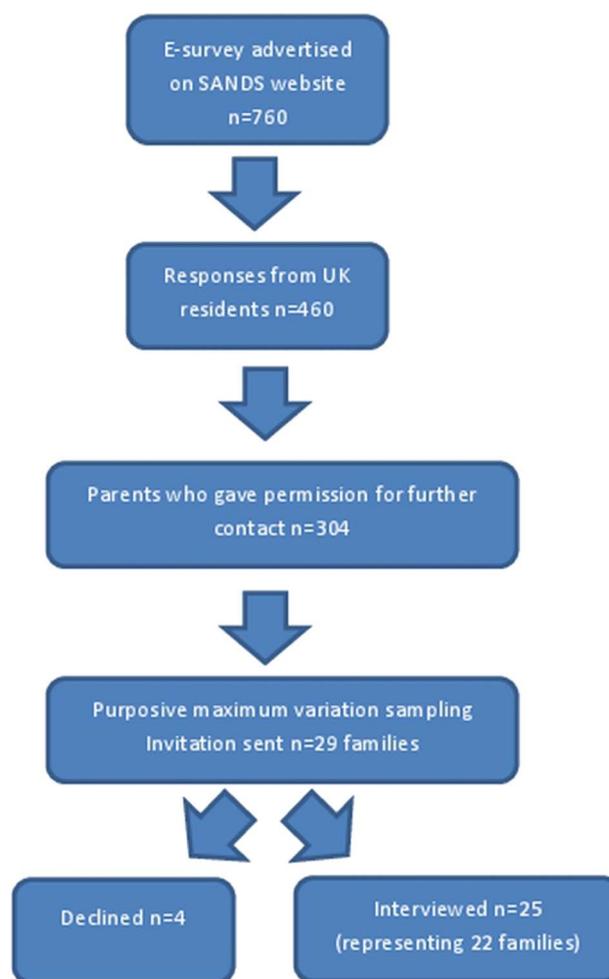


Figure 1 Consolidated criteria for Reporting Qualitative studies (COREQ) participant selection flow diagram.

Tell me the story of what happened when your baby, (Name), was born.ⁱ

and

What advice would you give to doctors and midwives who care for people who have stillbirths in the future?

Data analysis

The study adopted the inductive technique of constant comparative analysis from grounded theory. Sampling continued until the emerging thematic structure appeared to be saturated. To maximise rigour, three authors (ES, AEH and SD) read and re-read the interview transcripts individually, and then agreement was reached on the emerging themes and subthemes in discussion. These discussions provided a locus for debate about potentially disconfirming data, evidence that the study was nearing theoretical saturation and generation of the metatheme, three key themes and ten subtheme (table 2). MAXQDA software was used for data management.

ⁱAll names in this paper have been changed to provide anonymity to the participants.

Reflexive accounting

A participant, a midwife and academic, believed that services for parents experiencing stillbirth had improved greatly over the last two decades^{23 24}. She anticipated that the study would indicate some gaps in service provision. Another participant, a social scientist, specialises in research with families. She had no previous experience of working with maternity services, and approached the research with a high degree of openness. A participant, who is a medical sociologist with over 10 years experience in maternity research, hoped that greater recognition and understanding of parents' perspectives would provide a catalyst for change. An obstetrician believed that there were significant gaps in care, particularly for psychological support and preparing parents for discharge from hospital. He also believed that clinical care, such as the choice to have investigations to determine a cause for stillbirth, can be positively associated with parents' recovery from grief.

The project started after approval by the research ethics committee of the University of Manchester (ref 09392).

RESULTS

In all, 29 families were approached. Twenty-two families are represented in the study, including 25 respondents. Nineteen mothers were interviewed separately, and, in three instances, the mother and the father were interviewed together. For eight interviews, the aforementioned social scientist travelled to interview the family face-to-face. Fourteen families preferred a telephone interview. [Table 1](#) provides additional information about the participants' demographics and circumstances of the stillbirth.

Interviews lasted between 42 min and 1 h and 59 min.

FINDINGS

[Table 2](#) gives the thematic structure of the findings. This is summarised by the metatheme of 'One chance to get it right'. To a greater or lesser extent, all of the transcripts conveyed this core imperative. Three themes underpinned this synthesis: Parent experiences (*enduring and multiple loss*); parent needs (*making irretrievable moments precious*) and (lack of) care in the caring (*the best care possible to the worst imaginable*). The subthemes and codes for each of these themes are presented in [table 2](#).

Parents' experiences (enduring and multiple loss)

In each of the interviews, parents gave a powerful sense of overwhelming loss of what might have been. This was felt not only in relation to the baby as a physical presence, but also the loss of joy, of celebration, of parenthood and, in some cases, of their sense of self. In some cases, this was enduring; it affected their relationships, capacity to work and ability to trust others. This is evident in the data presented in [box 1](#). As reported in previous studies of stillbirth,^{25 26} parents struggled with feelings of guilt and blame, regret, fear and grief. In some cases, the pressure to make decisions, at a time when they felt completely psychologically incapacitated, and the perceived inability of professionals to notice their state of mind or to respond to their needs and requests led respondents to experience intense frustration, sometimes expressed in angry and aggressive behaviours. Ten parents remarked that no matter how hard they tried, they could not seem to absorb the information that midwives, doctors and administrators shared. This led to a feeling of psychological distance from the events that were happening, from family and friends, and from the staff who were active in those events. Being parted from their child exacerbated this sense of being distant and apart.

Table 1 Location and year of stillbirth and mothers' demographics (n=22)

Region	n	Religion	n	Mother's age at time of stillbirth	n	Mother's pregnancy history at stillbirth	n	Mother's previous childbirth experience	n	Year of stillbirth	n	Gestation at time of stillbirth	n
East Anglia	2	No religion	5	18–24	2	1st Pregnancy	12	0 Births	15	2002	1	24–27	2
London	5	Christian	14	25–29	6	2nd Pregnancy	6	1 Birth	3	2003	1	28–31	0
Midlands	3	Other	3	30–34	3	3rd Pregnancy	4	2 Births	4	2004	0	32–35	7
N Ireland	2			35–39	8					2005	3	36–39	7
NE England	3			40–44	3					2006	1	40–42	6
NW England	2									2007	5		
Scotland	1									2008	2		
SE England	2									2009	4		
SW England	1									2010	6		
Wales	1												

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Table 2 Thematic structure

Metatheme: one chance to get it right

Theme 1 Parents experiences; <i>enduring and multiple loss</i>	Theme 2 Parent needs: <i>making irretrievable moments precious</i>	Theme 3 (Lack of) care in the caring: <i>the best care possible to the worst imaginable</i>
Beyond distress: <i>Bowled over by the horror...</i>	<i>Premonition</i> <i>Horrible journey of discovery</i> inability to protect <i>Wounded emotionally</i> Blame, guilt, regret, grief, fear, silence abandonment <i>Unexpectedness</i> pressure (to make decisions); being driven to anger	Memories to last forever: <i>A lifetime of memories in a few hours</i>
Separation and loss: <i>I was just lost, really lost...</i>	Can't talk to people Different from previous experience Distant from staff (geographically/needs) Parted from child	Importance of memories Time to process Options: changing choices over time ('I wish...') Need for staff to direct as well as suggest
What could have been: <i>he was just perfect...</i>	Incredible rush of love Peace of mind / coping Altruism/answers for us and for others	<i>Caritas:</i> <i>A generalised human love for each other in bad times...</i>
Wider Impacts: <i>there is just too much of me missing...</i>	<i>Loss of capacity to trust (self, professionals) to manage job, family, mental health</i> <i>Feeling sorry for others/responsible for their sadness</i> Family tragedy	<i>It's the small things...</i> Giving time, care for father of the baby Emotional engagement, caring touch, hugs, seeing the baby as a loved child
		<i>Guidance</i> Managing expectations, being flexible, guidance, protection (exhibit/receive), experience <i>Planning for the future</i> Need to care for partner/baby's siblings Aftercare/counselling SB prevention/awareness Space for bereaved parents
		Casual inhumanity: <i>'everything you can imagine they shouldn't do, they did'</i>
		<i>Lacking:</i> Time (time delay), respect, competence, engagement, empathy, consistent and comprehensible treatment <i>Denying:</i> Medicalising grief, concerns dismissed, discouragement of investigations, inadequate science / research, broken promises / trust
		Positive caring in the care: <i>'they hold a special place in our lives'</i>
		<i>Being:</i> Emotionally intelligent, experienced, intuitive, humane, <i>Giving:</i> Reassurance, support, advocacy, information, normality back
		<i>Providing:</i> Continuity of care, personal connection / relationship, good communication (to parents, to fellow professionals).
		Necessary knowledge: <i>The truth..... is hard and cold</i>
		<i>Needing answers</i> Information Harsh facts

Although distress was predominant in the narratives, parents did also reference positive emotions that they felt. One mother said that when she saw her baby for the first time, she felt 'this incredible rush of love' (Interview 9). Other mothers expressed this feeling of pleasure on meeting the baby that transcended, at least

temporarily, the shock of death. Some of these feelings translated into a keen desire to accept the offer of a postmortem. In general, this was based on two distinct imperatives: to bring peace of mind (and to relieve personal distress and guilt) and to try to make sure this would not happen to others in the future.

Box 1 Parents experiences - enduring and multiple loss

- ▶ "I was just bowled over by the horror." (Interview #14)
- ▶ "We had no concept at the time of what we had to do, what would happen. It's that instant shock. And then you've got the gradual realisation in the hours after that you've got to go home and face everybody. And they're so happy for you, and suddenly they're so... It just doesn't make sense at all. Your whole perspective on the world has changed." (Interview #8)
- ▶ "I've never been so angry." (Interview #10)
- ▶ "They only left him with me for about an hour. Then they just took him away. I was begging them not to take my baby." (Interview #9)
- ▶ "I still wanted to see him. I had been carrying him for eight months. It was exciting to have him... I was just lost, really, really lost. Nothing consoles me. Nothing. I think what impact that's had on my life." (Interview #2)
- ▶ "I understand that it's quite traumatic having a dead body put onto you. But that body comes out warm, and it's still yours, it's still your baby. And it's still something that you have formed a relationship with inside." (Interview #6)
- ▶ "It's as hard being a mother and losing [him], than not being a mother. Because I'm aware of every stage he could be at." (Interview #17)
- ▶ "He was just perfect. Beautiful. I'm still there. I'm still grieving. I'm still struggling. I have to carry on, and it's very hard to carry on. I am torn between two sons now. I want desperately to be with Joshua [stillborn son], but I can't because I've got to be with Callum [second son]. I thought these people [midwives and doctors] know what they are doing. I wish I hadn't thought that now." (Interview #1)
- ▶ "As I held Ruby, I promised her that dying wouldn't be in vain. That I would do everything I could to try and stop somebody else going through the same sort of pain." (Interview #15)
- ▶ "It's too much of a big thing to deal with. And you can't ask your husband because they're dealing with it as well. And you can't really go to your mum, because they've not only lost a grandchild, they know how much it's hurting you." (Interview #13)

Over time, some parents reflected on how their grief had intensified because, as one mother said, 'there is too much of me missing' (Interview 17). For some parents, this extreme sorrow extended beyond the immediate family to grandparents, siblings and cousins. This engendered a sense of responsibility for managing the sadness of others, including friends, at a time when the respondents were also trying to integrate their own distress.

In the long term, respondents reported adverse effects on their ability to manage their jobs, their family life and their own mental health. This was rooted in a loss of faith in their personal capacity to function effectively in life. Where the care received was felt to be inadequate, there was also a persistent lack of faith in healthcare professionals, even in areas unrelated to maternity care.

Parents' needs: making those irretrievable moments precious

Parents talked movingly of the fact that losing their baby was a loss of a whole lifetime of the parenting they

would have done and of the child that would have been. Quotes illustrative of this data are presented in box 2. They show how a loss of any of those memories, or of the mementos that might crystallise them, such as photographs, locks of hair, handprints and footprints, was devastating. The quality of memories was the anchor point for a good or a bad experience, with long-term and, often, unexpected consequences. Ensuring good memories and the collection of meaningful physical mementos was one of the most important things staff could do to help parents to deal with their situation. Good memories were also formed by regular and individualised updates and information as the pregnancy and labour progressed, if the death of the baby was known about before the birth; as much time as possible for parents to make decisions and choices; skilled, competent and consistent care; careful, respectful handling of the baby once it was born; and attention to detail in every communication to ensure that each encounter was as positive as possible.

Box 2 Making irretrievable moments precious

- ▶ "They [hospital staff] talked to me with respect. They treated the baby with respect. I wasn't just a woman giving birth. I was a woman who was giving birth under horrific circumstances." (Interview #1)
- ▶ "You don't know at the time, that the little time you've got with the baby is going to be so important... We definitely didn't want a post-mortem. The idea of that tiny body being cut open." (Interview #8).
- ▶ "You've got to cram a lifetime of memories into a few hours." (Interview #16).
- ▶ "Professionals must realise this is the only time parents are going to spend with their child." (Interview #13)
- ▶ "You need someone to tell you what your options are because you have no idea what's coming." (Interview #12)
- ▶ "I wish someone had said to me in those first few hours. Even if you don't want to see her now, you can see her in an hour or two. Or in a day or so... I was left to believe because I said I wasn't ready to see her, that was final. (Interview #21)
- ▶ "Even though she wasn't breathing and she didn't open her eyes, she [the midwife] still said you've got a beautiful baby girl. It just meant the world." (Interview #15)
- ▶ "We met Zoe. She looked beautiful and perfect in every way." (Interview #10)
- ▶ "We were so scared, we never did, we never sort of unwrapped her. So we never had that chance to unwrap her and look at her hands. And it's something I bitterly regret. That we never did there and then." (Interview #7)
- ▶ "Because he looked so perfect, I was just willing him to cry." (Interview #2)
- ▶ "Just before I went into delivery, they started talking about a post-mortem. We were discouraged by the midwives who were telling us that it was a pointless activity. It was prolonging the agony before you could actually say goodbye to your baby. But I know I would have made a different decision today if I had been talked to in the right way and explained about how it could help." (Interview #11)

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Of the 25 participants in this study, 23 spontaneously talked about holding their baby. Only two women had to be directly asked the probe question, 'Did you hold (your baby)'? (see interview schedule appendix 1). Mothers recounted a desire to hold the baby, although from person to person, there were varying preferences for the timing of this. This is an area where some parents felt that healthcare staff could be more assertive. These findings contrast with the recommendation, based on the findings of Hughes *et al*,²⁷ that 'carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed'.¹² For some of the respondents in our study, their early rejection of the offer of seeing and holding their baby led to profound regret later, when the opportunity to do so had gone forever.

Where parents encountered genuine, authentic caring (*caritas*), it provided a sense of being protected from the raw horror of what had happened to them around the time of birth. When professionals seized the only opportunity they would have to communicate information about the stillbirth, and used it to provide emotional support to the bereaved parents, this was seen as genuinely caring. Often, this was enacted in the small gestures made by professionals that authenticated their sympathetic engagement. Additionally, parents placed a very high value on professionals who overtly acknowledged their baby's existence as a much loved child. Small gestures that featured strongly in parents memories included a hand to hold, hugs and caring touch, staff that sat next to them, and sustained eye contact. Parents were generally very touched by the moist eyes and apparent upset shown by professionals of all types, ranging from community midwives to hospital midwives, general practitioners to obstetric consultants, sonographers to chaplains.

Upon the diagnosis of their stillbirth, parents found themselves facing the unknown. They needed guidance from professionals to navigate the unforeseen circumstances of their child's birth. Although parents had no power to decide about the ultimate outcome of the birth, they appreciated being able to make incremental choices about the process. For instance, in cases of antepartum death, some mothers appreciated being able to influence the timing of induction of labour and where they would wait for labour to start. Parents also highlighted their need for guidance about what would occur after the birth of their baby and some appreciated having options on procedures such as the father cutting the cord or washing and dressing the baby.

Women who had an antenatal diagnosis that their baby had died reported that they had a strong desire for information relating to what was likely to happen during their labour and birth, at each stage of induction, labour and delivery. They needed professionals to be forthcoming when describing the likely physical deterioration of the baby by the time of the birth, and those

who reported being well informed about this seemed to be less alarmed when deterioration had indeed occurred. Conversely, in cases where parents were not aware of the physical deterioration they would observe, they were very upset when they noticed unexpected changes in their baby's appearance.

Fifteen parents expressed a strong drive to find out why their baby died. Ten of these had had a post-mortem. Most emphasised the importance of discussions and accurate information about maternal and child blood tests, placental investigations, postmortem examination and any other tests that could be conducted. Some parents voiced a clear sense of frustration and injustice at having their decisions influenced by insufficient or inaccurate information provided by professionals. Respondents also reported a need for healthcare providers to pay attention to their specific postpartum information needs, in terms of advice on physical issues that they would face postpartum, such as lactation suppression, and in terms of practical steps, such as how to register the baby's birth and how to arrange for a funeral. Some of this information was hard to hear and even harder to assimilate. Despite this, in general, parents believed that they coped better when professionals were forthcoming with candid information during the hospital stay, as long as this was given to them at an appropriate time, and in ways that were tailored to their specific capacity to understand and respond to it.

(Lack of) Care in the caring: the worst care imaginable to the best possible

This subtheme is summed up by two concepts: *lacking* and *denying*. The first concept relates to a passive gap in resources, skills, attitudes and behaviours. The second encapsulates active practices that disrupted or damaged the recovery of parents. From the moment of diagnosis through to postnatal care, parents were extremely sensitive to the messages that professionals sent out through both verbal and non-verbal communication, and through caring, indifferent, or, at the extreme, hostile behaviours. When these messages were poorly communicated or inconsistent or led parents to question clinical judgement or skill, their sense of loss was augmented. Parents reported frustration in relation to confused information about appointments, and miscommunication about when they should arrive at the hospital for induction of labour. They recounted distress related to their vicinity to other expectant (often labouring) women and new mothers in the hospital. For example, one woman said, 'When I was readmitted they put me on the postnatal ward and everything you can imagine they shouldn't do, they did' (Interview 9). Some respondents expressed shock at the minimal regard for their needs and emotions shown by caregivers. The distress this caused remained evident in their accounts many years after the event (box 3).

Box 3 Lack of Care in the caring: The best care possible to the worse imaginable

- ▶ "It was really sad it wasn't a live birth because everyone was just so great. Just very, very caring staff." (Interview #6)
- ▶ "She [the midwife] made me feel incredibly proud. A natural reaction after just giving birth is re-living the birth and wanting to talk about the birth experience. It sounds odd, but because I'd had such a good birth, I felt that I could behave like a normal mother. I could talk about that experience as a normal labour to close family. That was really important to acknowledge Zoe in a way." (Interview #10)
- ▶ "The delivery was just awful from beginning to end. They almost treated me like '*The Woman With The Dead Baby*' [mother's emphasis]. There was no sympathy. When I asked to see a doctor, this particular doctor came in and said 'we're very busy.' And his exact words, I'll never forget them 'Well, with all due respect, your baby's dead already.' Which was just the most awful thing you could say." (Interview #9)
- ▶ "She gave me a book, a parenting book. And she said "this is the only thing I can give you. The information is at the back and I didn't have time to print it." It was all about new parents." (Interview #22)
- ▶ "All the medical staff that were meant to care, just didn't seem to care." (Interview #7)
- ▶ "We asked for hospital notes and they came addressed to Eve. I did e-mail them and said I can't phone you because I can't tell you what you've done. You've addressed my notes to my daughter who's died." (Interview #2)
- ▶ "The way she [midwife] spoke to me, I cannot think of a word to describe it. I mean, my mum was there, but it was like having another mum." (Interview #16).
- ▶ "She said to me they were putting him in the sluice room because it was cold. And I thought 'O Jesus, if he's lying..' At one stage in the night I wanted to go and get him." (Interview #17)
- ▶ "I was so worried about having to walk in there [delivery area] and say who I was. I didn't have to. I walked through the door and she [her midwife] looked at me and she know it was me... She was so friendly and so honest. She holds a special place in our lives." (Interview #19)

In stark contrast, other respondents reported excellent, empathic, competent, respectful, humane, skilled and emotionally intelligent care. This was more than just doing a job or a duty—it reverberated forward into the future for the couple, their families and their future mental health. Data in this subtheme reflect some of the caring behaviours previously noted in relation to 'caritas.' The findings coalesced into three key areas: *being*, *providing* and *giving*. Providing and giving centred around the kind of resources that were available (such as continuity of care and time for effective communication) and the elements of the care provided (such as reassurance, support and advocacy). Both of these were underpinned by (and apparently dependent on) the nature of 'being' expressed by the staff. This was a combination of emotional intelligence, skills, experience and the capacity to be intuitive and to respond

humanely to the unique set of circumstances presented by the particular women and partners they encountered.

The emotional warmth and strong interpersonal skills of such professionals had a powerful influence on the parents' experiences. This was especially valued when staff succeeded in giving back to the parents a degree of the joy and pride that had so suddenly been taken from them with the diagnosis of the loss of their baby. Parents viewed professionals' choice to spend time with them as a very supportive behaviour. Respondents reported that such care was given by doctors, midwives, ultrasound staff and, in one case, the hospital chaplain. It tended to be fractal, that is, where it existed, it seemed to exist to a greater or lesser extent in all the staff encountered in that unit by the respondent who reported it. Wherever it was encountered, skilled empathic care was remembered vividly and with profound gratitude. Most importantly, such care permitted parents to maximise their 'one chance to get it right' and to store positive, healing memories that aided their psychosocial recovery.

DISCUSSION

The overarching theme emerging from the narratives of the bereaved parents who were interviewed was that, in the case of a stillborn baby, everyone involved *only has one chance to get it right*. This includes the parents and their family themselves, the professionals and support staff who care for them directly, and the service that indirectly provides the resources, governance procedures and a caring (or uncaring) ethos within which each individual event occurs. Once the hospital experience had passed, respondents in this study spent a great deal of time processing what had happened to them. When care was not delivered well, parents were further distressed, on top of their grief for their child, with unpredictable long-term consequences. However, when this one chance was seized and used to its full capacity, the benefits appeared to be significant and long term. Parents were particularly negative about perceived emotional distance on the part of health professionals. This issue is increasingly relevant now, in the context of a growing international literature around a general failure of care and support in some maternity care settings,²⁸ and there is a national emphasis in the UK on increasing caring behaviours among staff in healthcare provision in general.

As noted in the introduction, the Royal College of Obstetricians and Gynaecologists¹² and the American College of Obstetrics and Gynaecology¹³ have issued new guidance relating to the management of stillbirths. The Royal College of Obstetricians and Gynaecologists guidelines state that 'carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed'.¹³ Our data suggest that, for some parents at least, persuasion might, in fact, be appropriate. Some respondents explicitly praised members of the staff who were directive about seeing and holding their baby, and a few were highly critical when

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staff did not repeatedly offer to facilitate this. These sentiments resonate with the 2010 Sands campaign that led to an amendment to the wording of the National Institute of Clinical Excellence (NICE) guidance in this area,²⁹ a very recently published focus group study including bereaved parents from the USA,¹⁹ and an e-survey of 840 mothers' experiences of seeing and holding their still-born baby in Sweden.²⁰ The latter study reports that mothers felt more natural, comfortable and less frightened if staff supported 'assumptive bonding', where the baby was simply presented to the mother without asking her to choose. We suggest that when current guidelines are updated, there is due consideration of this new research evidence, alongside cautious consideration of what it means to use terms such as 'persuading'¹² and 'choice'²⁹ in practice. Healthcare professionals are currently open to criticism for not encouraging parents enough, but that is not to say it is right for all mothers to be presented with their baby. This could be perceived as a return to paternalism. However, the alternative rhetoric of choice, in which service users are assumed to have the knowledge, responsibility and accountability in making

decisions for themselves and their family with no awareness of the potential longer term consequences, may also be contrary to good care practices.^{30 31}

What is more, specific practices were important in ensuring 'a lifetime of memories in a few hours'. Box 4 lists practices and behaviours that parents found helpful in this study.

Given the qualitative nature of this study, it was not designed to be representative of the whole population of parents of children stillborn in the UK. Interviewees were recruited from respondents to an online survey, so the sample may be biased towards bereaved parents who are also internet users. However, in 2011, when this study was conducted, 83% of the population in the UK reported having used the internet.³² The survey also included few respondents of non-White British origin, and so the interview study also included few of these respondents. Given the over-representation of women in some of these groups among the population of those who experience stillbirth, this area of enquiry still needs to be addressed.

Two teams have addressed the question of the psychosocial effects of health service encounters in the context

Box 4 Practices and behaviours that were helpful for parents experiencing a stillbirth

Practices that were helpful

- Time to make decisions and choices about:
 - timing, place, manner of induction of labour
 - who will accompany the mother in labour and the postnatal period
 - labour pain relief
- Options on procedures such as the father cutting the cord, or washing and dressing the baby
- Holding the baby
- Good quality:
 - photographs
 - locks of hair
 - handprints
 - footprints
- Good storage of these mementos for those who did not want them while in hospital, so they could change their minds and still have the chance of obtaining them later
- Naming ceremonies
- Religious rituals
- Advice on practical issues:
 - lactation suppression
 - how to register the baby's birth
 - how to arrange for a funeral
 - consistent, empathic advice and information on the nature/value of post mortem

Behaviours that were helpful

- Once the death of the baby is recognized, regular and individualised updates and information during pregnancy/induction of labour/labour
- Skilled, competent and consistent care
- A hand to hold, compassionate touch, evidence
- Evidence that the loss of the baby has also affected staff
- Attention to detail in every communication to ensure that each encounter is as positive as possible.
- Sensitivity about the best time to offer the opportunity to hold the baby
- Being persistent in offering the chance to hold the baby, and to have mementos taken, so that women/partners do not miss this opportunity
- Ensuring the quality of mementos was as good as possible
- Careful, respectful handling of the baby at all times
- Using the baby's name in all conversations about him/her

of stillbirth.^{33–36} All of these studies were quantitative in design, eliciting responses to prespecified questions. Some data from these studies, and, as noted above, from US¹⁹ and Swedish^{16 17 20} qualitative research resonate with the findings reported in this paper. In particular, three of these studies noted positive effects of seeing and holding the baby, as well as of tokens of remembrance.^{33 34 36} As far as we are aware, the current study is the only one providing in-depth qualitative data about the experiences of a national cohort of both fathers and mothers who have experienced a stillbirth.

Despite the accounts of lapses in humane treatment reported by some of the bereaved parents in this study, it was apparent from the stories of excellent caring behaviours that respect and genuinely empathic attitudes can be enacted in institutional maternity settings to a very high standard. Where positive behaviours were reported, they seemed to be present at all levels of the organisation encountered by the parents. This suggests that institutional ethos might be vital in supporting healthcare staff to model, develop and express authentically caring behaviours. Extending this to all relevant healthcare settings might include innovative approaches to enhancing the capacity of healthcare staff to be emotionally intelligent in this context.^{37 38} There is neurological evidence that personal emotional response influences cognitive empathy.³⁹ Affective experiences offer a way of engaging the emotional response of healthcare staff.⁴⁰ Educational sessions building on this theory could involve the stories and experiences of families, ideally told personally, to reinforce how professionals can provide the right kind of care for families, consistently and empathically. It would also include recognition of, and engagement with, staff from all relevant professions who exhibit a high level of skills in this area (who may or may not be in senior/specialised roles) to find out what they do, how they do it and how to model and disseminate it. Effective support for staff who find themselves dealing with emotionally stressful events is essential, so that they do not face burnout. Specific aspects of care noted as being helpful to parents (box 4) could be implemented as a matter of routine.

Beyond the experience of stillbirth, this study offers important insights into staff behaviours that support well-being, and those that are, at the extreme, emotionally damaging. The study suggests that tackling lack of caring behaviour in healthcare needs to go beyond tools, techniques and tick boxes, and towards a fundamental shift in empathic engagement based on affective learning.

CONCLUSION

No parent whose baby is stillborn should experience inadequate, unsupportive or even uncaring behaviours from staff. Professionals in hospitals and in the community have only one chance to provide care that fosters the clinical, emotional, practical and psychosocial well-

being of parents who have experienced stillbirth. By ensuring that parents receive care that is clinically skilled, emotionally intelligent, consistent and authentically caring, there is the best chance that, even in the midst of a difficult situation, they will have the healthiest experience possible, as well as the best chance of achieving optimum well-being in the longer term. Staff in all relevant health settings need to be supported and encouraged to recognise and respond to their one chance to get it right, for the sake of all future parents who experience such a loss.

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REFERENCES

- Confidential enquiry into maternal child health. *Perinatal mortality 2008: England, Wales and Northern Ireland*. London: Centre for Enquiries into Maternal and Child Health, 2010.
- Cousens S, Blencowe H, Stanton C, *et al*. National, regional, and worldwide estimates of stillbirth rates in 2009 with trends since 1995: a systematic analysis. *Lancet* 2011;77:1319–30.
- Cacciatore J. Psychosocial care. In: Spong CY, ed. *Stillbirth: prediction, prevention and management*. Chichester: Blackwell, 2011:203–28.
- Rådestad I, Steineck G, Nordin C, *et al*. Psychological complications after stillbirth—influence of memories and immediate management: population based study. *BMJ* 1996 15;312:1505–8.
- LaRoche C, Lalinec-Michaud M, Engelsmann F, *et al*. Grief reactions to perinatal death—a follow-up study. *Can J Psychiatry* 1984;29:14–19.
- Turton P, Badenhorst W, Pawlby S, *et al*. Psychological vulnerability in children next-born after stillbirth: a case-control follow-up study. *J Child Psychol Psychiatry* 2009;50:1451–8.
- Cacciatore J. The silent birth: a commentary. *Soc Work* 2009;54:91–4.
- Chan MF, Lou FL, Zang YL, *et al*. Attitudes of midwives towards perinatal bereavement in Hong Kong. *Midwifery* 2007;23:309–21.
- Gold KJ, Kuznia AL, Hayward RA. How physicians cope with stillbirth or neonatal death: a national survey of obstetricians. *Obstet Gynecol* 2008;112:29–34.
- Downe S, Kingdon C, Kennedy R, *et al*. E. Post-mortem examination after stillbirth: views of UK-based practitioners. *Eur J Obstet Gynecol Reprod Biol* 2012;162:33–7.
- Frøen JF, Cacciatore J, McClure EM, *et al*. Lancet's stillbirths series steering committee. Stillbirths: why they matter. *Lancet* 2011;377:1353–66.
- Royal College of Obstetricians and Gynaecologists. *Green-top guideline 55—late intrauterine fetal death and stillbirth*. London: Royal College of Obstetricians and Gynaecologists, 2010.
- American College of Obstetricians and Gynecologists. Management of stillbirth. ACOG practice bulletin no 102. *Obstet Gynecol* 2009;113:478–61.
- Flenady V, King J, Charles A, *et al*. PSANZ clinical practice guideline for perinatal mortality. Version 2.2 April 2009. www.stillbirthalliance.org.au/guideline1.htm (accessed 31 Jan 2013).

Bereaved parents' experience of stillbirth in UK hospitals

15. Flenady V, Middleton P, Smith GC, *et al.* Stillbirths: the way forward in high-income countries. *Lancet* 2011;377:1703–17.
16. Saflund K, Sjogren B, Wredling R. The role of caregivers after a stillbirth: views and experiences of parents. *Birth* 2004;31:132–7.
17. Trulsson O, Radestad I. The silent child—Mothers' experiences before, during, and after stillbirth. *Birth* 2004;31:189–95.
18. Cacciatore J, Bushfield S. Stillbirth: the mother's experience and implications for improving care. *J Soc Work End Life Palliat Care* 2007;3:59–79.
19. Kelley MC, Trinidad SB. Silent loss and the clinical encounter: parents' and physicians' experiences of stillbirth—a qualitative analysis. *BMC Pregnancy Childbirth* 2012;12:137.
20. Erlandsson K, Warland J, Cacciatore J, *et al.* (on line early) Seeing and holding a stillborn baby: Mothers' feelings in relation to how their babies were presented to them after birth—Findings from an online questionnaire. *Midwifery* 2012. doi:10.1016/j.midw.2012.01.007
21. Heazell A, McLaughlin MJ, Schmidt E, *et al.* A difficult conversation? The views and experiences of parents and professionals on the consent process for perinatal postmortem after stillbirth. *BJOG* 2012;119:987–97.
22. Patton M. *Qualitative research and evaluation methods*. 3rd edn. Thousand Oaks, CA: Sage Publications, 2002.
23. Walsh D, Downe S. Appraising the quality of qualitative research. *Midwifery* 2006;22:108–19.
24. Newton BJ, Rothlingova Z, Gutteridge R, *et al.* No room for reflexivity? Critical reflections following a systematic review of qualitative research. *J Health Psychol* 2012;17:866–85.
25. Kohner N, Henley A. *When a baby dies: the experience of late miscarriage, stillbirth and neonatal death*. London: Routledge, 2001.
26. Murphy S. Reclaiming a moral identity: stillbirth, stigma and 'moral mothers'. *Midwifery*. 2012;28:416–20.
27. Hughes P, Turton P, Hopper E, *et al.* Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet* 2002;360:114–18.
28. Bowser D, Hill A. *Exploring evidence for disrespect and abuse in facility-based childbirth: report of a landscape analysis*. 2010. <http://www.tractionproject.org/sites/default/files/upload/RFA/Respectful%20Care%20at%20Birth%209-20-101%20Final.pdf> (accessed 25 Jul 2012).
29. National Institute for Clinical Excellence. Guideline CG45 antenatal and postnatal mental health 2007, Amended 2010 (recommendation 1.3.1.4).
30. Mol A. *The logic of care: health and the problem of patient choice*. London: Routledge, 2008.
31. Kingdon C, Neilson J, Singleton V, *et al.* Choice and birth method: mixed-method study of caesarean delivery for maternal request. *BJOG* 2009;116:886–95.
32. Office for National Statistics Internet Access Quarterly Update 2011 Q3
33. Cacciatore J, Rådestad I, Frederik Frøen J. Effects of contact with stillborn babies on maternal anxiety and depression. *Birth* 2008;35:313–20.
34. Rådestad I, Steineck G, Nordin C, *et al.* Psychological complications after stillbirth—influence of memories and immediate management: population based study. *BMJ* 1996;15:312:1505–8.
35. Rådestad I, Nordin C, Steineck G, *et al.* A comparison of women's memories of care during pregnancy, labour and delivery after stillbirth or live birth. *Midwifery* 1998;14:111–17.
36. Rådestad I, Surkan PJ, Steineck G, *et al.* Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery* 2009;25:422–9.
37. Pilkington A, Hart J, Bundy C. Training obstetricians and gynaecologists to be emotionally intelligent. *J Obstet Gynaecol* 2012;32:10–13.
38. Norfolk T, Birdi K, Walsh D. The role of empathy in establishing rapport in the consultation: a new model. *Med Educ* 2007;41:690–7.
39. Schnell K, Bluschke S, Konradt B, *et al.* Functional relations of empathy and mentalizing: an fMRI study on the neural basis of cognitive empathy. *Neuroimage* 2011;54:1743–54.
40. Fox FE, Rodham KJ, Harris MF, *et al.* Experiencing 'the other side': a study of empathy and empowerment in general practitioners who have been patients. *Qual Health Res* 2009;19:1580–8.



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