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

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Consolidated criteria for reporting qualitative studies (COREQ): 32 item checklist

No	Item	Guide questions/description	Comment
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Ellie Schmidt.
2.	Credentials	What were the researcher's credentials?	BSc in Human Development and Family Studies, MSc in Social Research Methods and Statistics.
3.	Occupation	What was there occupation at the time of the study?	Research Assistant.
4.	Gender	Was the researcher male or female?	Female.
5.	Experience and training	What experience or training did the researcher have?	Trained social scientist with previous experience of conducting research with families.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to the study commencement?	No.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher?	The interviewer offered little information about her professional background and no personal details (I.e. not a mother herself), but did answer honestly if asked.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	Experienced researcher investigating families
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study?	Grounded theory.
Participant selection			
10	Sampling	How were participants selected?	Purposive, maximum variation sampling.
11.	Method of approach	How were participants approached?	Via a letters and up to three telephone calls.
12.	Sample size	How many participants were in the study?	25.
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	4 families declined participation when approached to arrange an interview.
Setting			
14.	Setting of data collection	Where was the data collected?	ES travelled to conduct 8 interviews in participant's own homes. 14 participants

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			preferred a telephone interview.
15.	Presence of non-participants	Was anyone else present besides the participants and the researcher?	No.
16.	Description of the sample	What are the important characteristics of the sample?	Their baby was [still]born between 2000 and 2010; NHS region; maternal age; parity, gestation at time of stillbirth.
Data Collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes.
18.	Repeat interviews	Were repeat interviews carried out?	No.
19.	Audio/visual recording	Did the research use audio or visual recording to collect data?	Audio recordings.
20.	Fieldnotes	Were field notes made during and/or after the interview or focus group?	During and after.
21.	Duration	What was the duration of the interviews or focus groups?	Between 42 minutes and 1 hour and 59 minutes.
22.	Data saturation	Was data saturation discussed?	Yes.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No.
Domain 3: Analysis and Findings			
24.	Number of data coders	How many data coders coded the data?	Three.
25.	Description of the coding tree	Do authors provide a description of the coding tree?	Yes.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data.
27.	Software	What software, if applicable, was used to manage the data?	MAXQDA
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Are participant's quotations presented to illustrate the themes/findings? Was each quotation identified?	Yes. Participant numbers are presented.
30.	Data and findings consistent	Is there consistency between the data presented and the findings?	Presented in table 2.
31.	Clarity of major themes	Are major themes clearly presented in the findings?	Three major themes are presented and an over-arching meta-theme.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

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Statements

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Competing interest statement

All authors have completed the Unified Competing Interest form and declare that all four had research support from the Stillbirth and Neonatal Death Society (SANDS) for the submitted work. Otherwise, none of the authors had a financial relationship with any organisations that might have an interest in the submitted work in the previous 3 years, and there are no other relationships or activities that could appear to have influenced the submitted work

Contribution statement

SD, AH and CK designed the study. EB contacted the participants and undertook the interviews. SD, AH and EB contributed to the analysis and the initial write-up of the findings. All authors contributed to the final manuscript.

Ethics statement

This study obtained ethics approval from both the University of Manchester (ID no 09392) and the University of Central Lancashire. . As the participants were not accessed through the NHS, IRAS approval was not required. All participants gave informed consent before taking part. Funding was obtained from the Stillbirth and Neonatal Death Society. The participants were accessed via the SANDS website, but the funders were not directly involved at any stage of the design of, recruitment to or running/analysis of the study, or of writing and submitting the paper. All researchers are independent from the funders, apart from the funding given for this specific study. All the authors had access to all the data for the study.

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

Abstract

Objective To obtain the views of bereaved parents about their interactions with health care 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 United Kingdom 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 individuals) participated. Births took place between 2002 and 2010. Specific practices were identified that were helpful to 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. Three key themes emerged: 'enduring and multiple loss': 'making irretrievable 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.

Conclusion 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.

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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 the study

- The study design facilitated purposive maximum variation sampling of a national cohort of bereaved mothers and fathers.
- Limitations include participants who were accessed via a self-help organisation (SANDS), and inclusion of few participants from minority groups.

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Introduction

In the United Kingdom (UK), around 4,000 babies are stillborn every year[1]. No expectant parent is prepared for the shock of a diagnosis of fetal death in utero, or of giving birth to a stillborn child, and the profound grief that follows. Research into the prevention and clinical management of stillbirth in high-income countries has increased in recent years[2]. Internationally, studies of maternity professionals report that caring for families experiencing a stillbirth is a stressful aspect of their work [3 4 5]. Previous qualitative research has investigated parents experience of induction, the role of caregivers and the experiences of women accessing bereavement support.[6 7 8] There are no in-depth studies from a UK-wide sample of bereaved parents. To understand more about the experience of stillbirth in the UK, SANDS (Stillbirth and Neonatal Death Society) has funded a programme of work in this area [5 9]. 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 COREQ participant selection flow diagram/Figure 1).[9] This was an e-questionnaire, advertised through the website of SANDS. 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. 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 [10]. 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.

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Data Collection

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

"*Tell me the story of what happened when your baby, [Name], was born*."*

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, AH, SD) read and re-read the interview transcripts individually, and then agreement was reached on the emerging themes and sub-themes 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 meta-theme, three key themes and ten sub-themes. (see table 2). MAXQDA software was used for data management.

Reflexive accounting[11 12]

SD, a midwife and academic, believed that services for parents experiencing stillbirth had improved greatly over the last two decades. She anticipated that the study would indicate some gaps in service provision. EBS, a social scientist, specialises in research with families. She had no previous experience working with maternity services, and approached the research with a high degree of openness. CK, a medical sociologist with over ten years experience in maternity research, hoped that greater recognition and understanding of

* All names in this paper have been changed to provide anonymity for the participants.

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parents perspectives would provide a catalyst for change. AH, 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 commenced after approval by the Research Ethics Committees of the University of Manchester (Ref: 09392), and of the University of Central Lancashire.

Results

Twenty-nine families were approached. Twenty-two families are represented in the study, including 25 respondents. Nineteen mothers were interviewed separately, and, in 3 instances, the mother and the father were interviewed together. For 8 interviews, EBS travelled to interview the family face-to-face. Fourteen families preferred a telephone interview. Table 1 provides additional information about participants' demographics and circumstances of the stillbirth.

Interviews lasted between 42 minutes and 1 hour and 59 minutes.

Findings

Table 2 gives the thematic structure of the findings. This is summarised by the meta-theme 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.

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Parents experiences (*enduring and multiple loss*)

In each of the interviews, parents recounted 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 [13 14], 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. Several 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.

<<Insert Box 1>>

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.

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.

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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 health care 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.

<<Insert Box 2>>

Across all interviews, parents emphasised their need to connect with and touch their child. 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 health care staff could be more directive. These findings contrast with the recommendation, based on to the findings of Hughes and colleagues [15], that "carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed."[16] For some of the respondents in our study, early rejection of the

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possibility 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 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, and 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 commence. 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 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 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

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aware of the physical deterioration they would observe, they were very upset when they noticed unexpected changes in their baby's appearance.

Many parents expressed a strong drive to find out why their baby died. Most emphasised the importance of discussions and accurate information about maternal and child blood tests, placental investigations, post mortem examination and any other tests that could be conducted. 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 didn't happen to others in the future. Others had a visceral sense of the need to protect their baby from being 'cut open'.

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 health care 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 d*enying.* 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 though caring, indifferent, or, at the extreme, hostile behaviours. When these messages

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were poorly communicated, or inconsistent, or revealed incompetence, parents' sense of loss was augmented. Parents were frustrated by confusion about appointments and miscommunication about when they should arrive at hospital for induction of labour, and distressed by 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). Respondents were shocked at the minimal regard for their needs and emotions shown by care givers and the distress this caused remained palpable many years after the event. As evident in box 3, in some cases, staff exhibited a kind of casual inhumanity that amounted to emotional abuse.

<<Insert Box 3 here>>

In stark contrast to the disregard evidenced in some parents accounts, 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 parents' experience. 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. Such care was reported to be given

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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. This study shows that once the hospital experience has passed parents spend a great deal of time processing what happened to them. In this study when care was not delivered well, parents were further wounded and 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. Emotional distance on the part of health professionals was perceived particularly negatively by parents. 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 [17], and a national emphasis in the UK on increasing caring behaviours among staff in health care provision in general. It is even more shocking to learn of such behaviours in the context of the loss of a baby.

In recent years the UK's National Institute for Clinical Excellence[27], the Royal College of Obstetricians and Gynaecologists[28], and the American College of Obstetrics and Gynaecology[29] have all issued new clinical guidance relating to the management of stillbirths. These guidelines include some references to what is known about care practices that may help bereaved parents cope at the time and in the years following a stillbirth, but research evidence of parents needs is limited. This was pointedly illustrated in the high profile 'seeing and holding your baby' campaign by the Stillbirth and Neonatal Death

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charity[30], which led to an amendment in the wording of the NICE guidelines. The current study offers new evidence of the importance of health professionals supporting families to see and hold their baby. This conflicts with earlier research findings. The study also revealed specific practices that 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 [18]. 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 amongst 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 of stillbirth [19 20 21 22]. All of these studies were quantitative in design, eliciting responses to pre-specified questions. Some data from these studies, and from Swedish qualitative research in this area [6 7] resonate with the findings reported in this paper. In particular, three of these studies noted positive effects of seeing and holding the baby, and of tokens of remembrance[19 20 22]. As far as we are aware, the current study is the only one providing in-depth data about the experiences of a national cohort of both fathers and mothers who have experienced a stillbirth.

Despite the significant lapses in humane treatment of some of the bereaved parents in this study, it was apparent from the accounts 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 health care staff to model, develop and express authentically caring behaviours. Extending this to all relevant health care settings might include innovative approaches to enhancing the capacity of health care staff to be emotionally intelligent in this context [23 24]. There is neurological evidence that personal emotional

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response influences cognitive empathy [25]. Affective experiences offer a way of engaging the emotional response of health care staff [26]. 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 high level 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 burn-out. Specific aspects of care noted as being helpful to parents (see box four) could be implemented as a matter of routine.

Beyond the experience of stillbirth, this study offers important insights into staff behaviours that support wellbeing, and those that are, at the extreme, emotionally damaging. The data suggest that tacking disrespectful and abusive behaviour in health care needs to go beyond tools, techniques and tick boxes, and towards a fundamental shift in empathic engagement based on affective learning.

Conclusion

Parents of still born babies are still at risk of experiencing inadequate, unsupportive, and even uncaring behaviours from staff. Professionals in hospital and in the community have only one chance to provide care that fosters the clinical, emotional, practical and psychosocial wellbeing of parents who have experienced still birth. 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, and the best chance of achieving optimum wellbeing in the longer term. For the sake of future parents in this situation, such care urgently needs to be implemented in all relevant health settings.

3,789 words

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

COREQ participant selection flow diagram/Figure 1

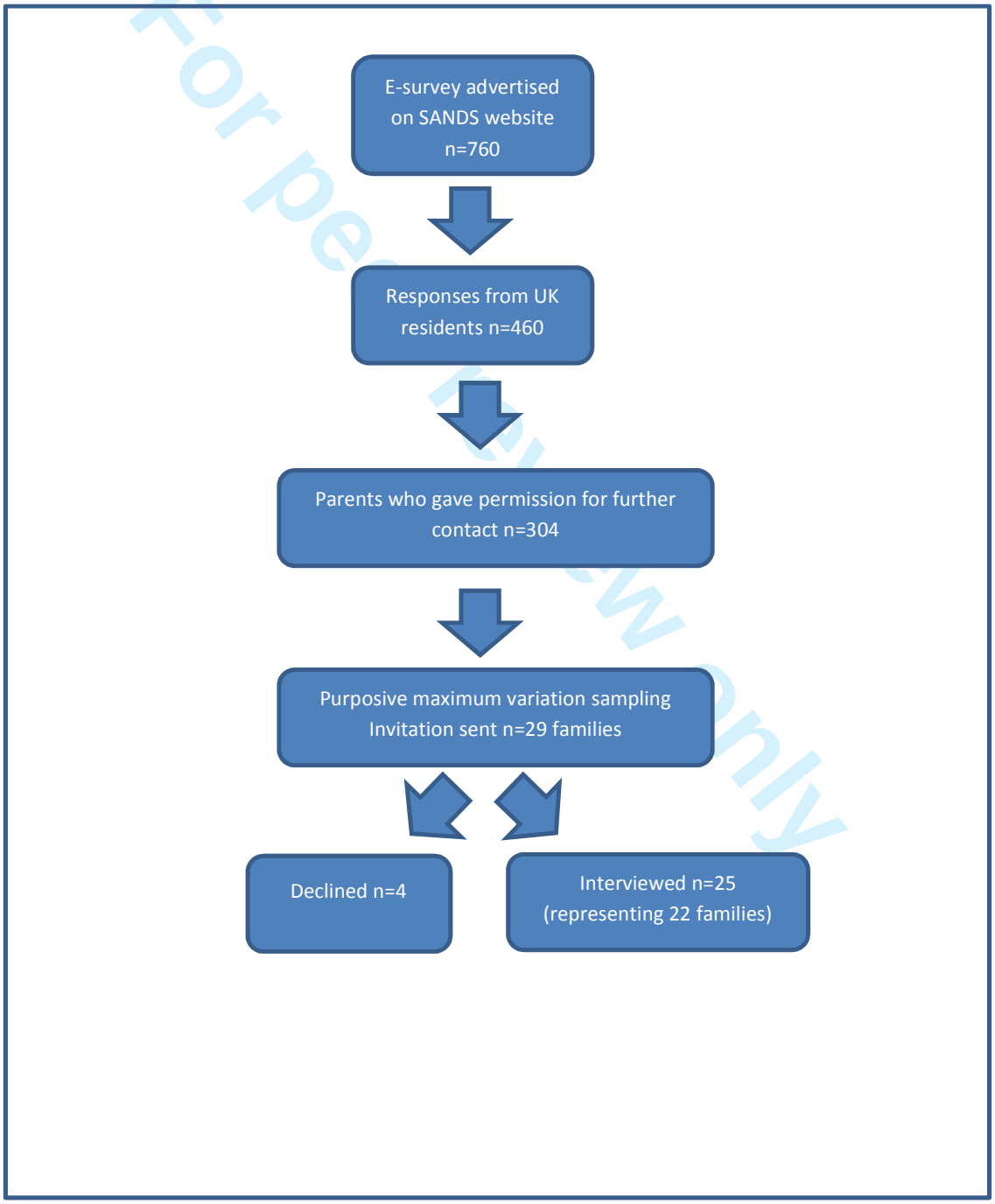

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Table 1: Location and year of stillbirth and mothers demographics (n = 22)

Region	n	Religion	n	Mother' 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 two: Thematic structure: Meta-theme: One chance to get it right

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

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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 but 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)

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 you're 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)

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

"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)

"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)

"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)

"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 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).

"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)

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

Practices that were helpful	Behaviours 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	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

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

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

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Statements

Funding statement

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Licencing statement

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Competing interest statement

All authors have completed the Unified Competing Interest form and declare that all four had research support from the Stillbirth and Neonatal Death Society (Sands) for the submitted work. Otherwise, none of the authors had a financial relationship with any organisations that might have an interest in the submitted work in the previous 3 years, and there are no other relationships or activities that could appear to have influenced the submitted work

Contribution statement

SD, AH and CK designed the study. EB contacted the participants an undertook the interviews. SD, AH and EB contributed to the analysis and the initial write-up of the findings. All authors contributed to the final manuscript.

Ethics statement

This study obtained ethics approval from both the University of Manchester (ID no 09392). As the participants were not accessed through the NHS, IRAS approval was not required. All participants gave informed consent before taking part. Funding was obtained from the Stillbirth and Neonatal Death Society. The participants were accessed via the Sands website, but the funders were not directly involved at any stage of the design of, recruitment to or running/analysis of the study, or of writing and submitting the paper. All researchers are independent from the funders, apart from the funding given for this specific study. All the authors had access to all the data for the study.

Data sharing

Participants did not give specific informed consent for data sharing but the presented data are anonymised and risk of identification is low

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Consolidated criteria for reporting qualitative studies (COREQ): 32 item checklist

No	Item	Guide questions/description	Comment
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Ellie Schmidt.
2.	Credentials	What were the researcher's credentials?	BSc in Human Development and Family Studies, MSc in Social Research Methods and Statistics.
3.	Occupation	What was there occupation at the time of the study?	Research Assistant.
4.	Gender	Was the researcher male or female?	Female.
5.	Experience and training	What experience or training did the researcher have?	Trained social scientist with previous experience of conducting research with families.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to the study commencement?	No.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher?	The interviewer offered little information about her professional background and no personal details (I.e. not a mother herself), but did answer honestly if asked.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	Experienced researcher investigating families
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study?	Grounded theory.
Participant selection			
10	Sampling	How were participants selected?	Purposive, maximum variation sampling.
11.	Method of approach	How were participants approached?	Via a letters and up to three telephone calls.
12.	Sample size	How many participants were in the study?	25.
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	4 families declined participation when approached to arrange an interview.
Setting			
14.	Setting of data collection	Where was the data collected?	ES travelled to conduct 8 interviews in participant's own homes. 14 participants preferred a telephone interview.
15.	Presence of non-participants	Was anyone else present besides the participants and the researcher?	No.

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16.	Description of the sample	What are the important characteristics of the sample?	Their baby was [still]born between 2000 and 2010; NHS region; maternal age; parity, gestation at time of stillbirth.
Data Collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes.
18.	Repeat interviews	Were repeat interviews carried out?	No.
19.	Audio/visual recording	Did the research use audio or visual recording to collect data?	Audio recordings.
20.	Fieldnotes	Were field notes made during and/or after the interview or focus group?	During and after.
21.	Duration	What was the duration of the interviews or focus groups?	Between 42 minutes and 1 hour and 59 minutes.
22.	Data saturation	Was data saturation discussed?	Yes.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No.
Domain 3: Analysis and Findings			
24.	Number of data coders	How many data coders coded the data?	Three.
25.	Description of the coding tree	Do authors provide a description of the coding tree?	Yes.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data.
27.	Software	What software, if applicable, was used to manage the data?	MAXQDA
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Are participant's quotations presented to illustrate the themes/findings? Was each quotation identified?	Yes. Participant numbers are presented.
30.	Data and findings consistent	Is there consistency between the data presented and the findings?	Presented in table 2.
31.	Clarity of major themes	Are major themes clearly presented in the findings?	Three major themes are presented and an over-arching meta-theme.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

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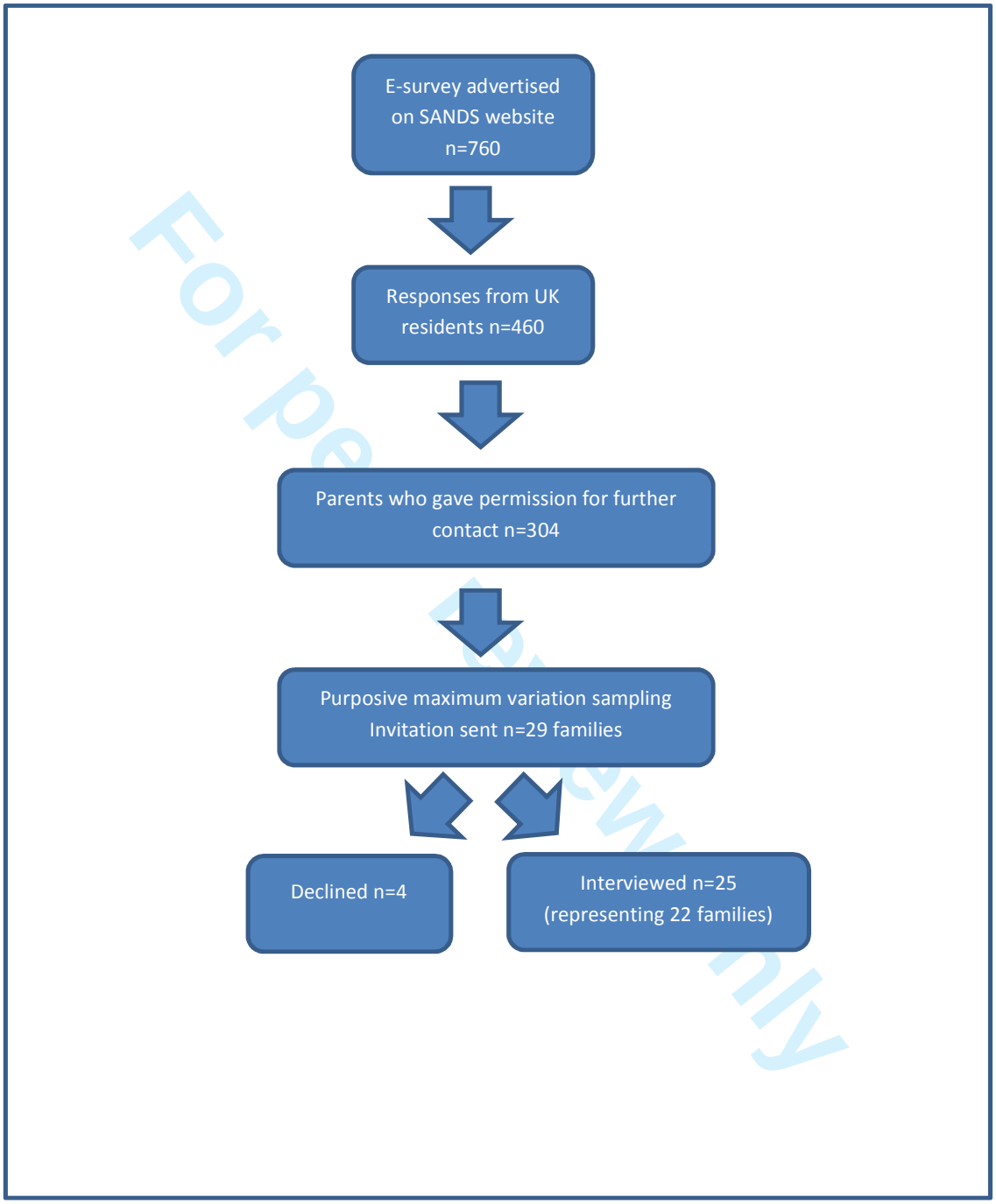
COREQ participant selection flow diagram/Figure 1



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

Abstract

Objective To obtain the views of bereaved parents about their interactions with health care 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 United Kingdom 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 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 irretrievable 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.

Conclusion 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.

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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 the 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 earlier national e-survey) and inclusion of few participants from non-white, British backgrounds.

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Introduction

In the United Kingdom (UK), around 4,000 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 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 (PTSD)[4, 5, 6]. Due 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 9 10]. Recently, the Lancet stillbirth series emphasised the unique status of stillbirth, and that grief may be exacerbated by social stigma, marginalisation and by the standard of care provided for parents[11]. 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, 13, 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 experience of induction of labour, the role of caregivers and the experiences of women accessing bereavement support after stillbirth[16, 17, 18]. Very recently, two studies have examined the experiences of parents in the USA[19] 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

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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 COREQ participant selection flow diagram/Figure 1)[21]. This was an e-questionnaire, advertised through the website of Sands. 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. 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:

"*Tell me the story of what happened when your baby, [Name], was born*."[1]

and

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

Data Analysis

[1] All names in this paper have been changed to provide anonymity for the participants.

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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, AH, SD) read and re-read the interview transcripts individually, and then agreement was reached on the emerging themes and sub-themes 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 meta-theme, three key themes and ten sub-themes. (see table 2). MAXQDA software was used for data management.

Reflexive accounting[23 24]

SD, a midwife and academic, believed that services for parents experiencing stillbirth had improved greatly over the last two decades. She anticipated that the study would indicate some gaps in service provision. EBS, a social scientist, specialises in research with families. She had no previous experience working with maternity services, and approached the research with a high degree of openness. CK, a medical sociologist with over ten years experience in maternity research, hoped that greater recognition and understanding of parents perspectives would provide a catalyst for change. AH, 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 commenced after approval by the Research Ethics Committee of the University of Manchester (Ref: 09392).

Results

Twenty-nine families were approached. Twenty-two families are represented in the study, including 25 respondents. Nineteen mothers were interviewed separately, and, in 3 instances, the mother and the father were interviewed together. For 8 interviews, EBS travelled to interview the family face-to-face. Fourteen families preferred a telephone interview. Table 1 provides additional information about participants' demographics and circumstances of the stillbirth.

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Interviews lasted between 42 minutes and 1 hour and 59 minutes.

Findings

Table 2 gives the thematic structure of the findings. This is summarised by the meta-theme 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. Several 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.

<<Insert Box 1>>

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 post-mortem. 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 didn't happen to others in the future.

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 health care 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

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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.

<<Insert Box 2>>

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 health care staff could be more assertive. These findings contrast with the recommendation, based on the findings of Hughes and colleagues[27], that "carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed"[28]. 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 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, and 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.

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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 commence. 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 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.

Many parents expressed a strong desire to find out why their baby died. Most emphasised the importance of discussions and accurate information about maternal and child blood tests, placental investigations, post mortem 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 health care 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.

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(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 though caring, indifferent, or, at the extreme, hostile behaviours. When these messages were poorly communicated, or inconsistent, or led parents to question clinical judgment 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 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 care givers. The distress this caused remained evident in their accounts many years after the event (see box three).

<<Insert Box 3 here>>

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

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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 parents' experience. 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 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 [29], and a national emphasis in the UK on increasing caring behaviours among staff in health care provision in general.

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As noted in the introduction, the Royal College of Obstetricians and Gynaecologists[12], and the American College of Obstetrics and Gynaecology[13] have issued new guidance relating to the management of stillbirths. The RCOG guidelines state that "*carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed* (ref p.19)." Our data suggest that, for some parents at least, persuasion might, in fact, be appropriate. Some respondents explicitly praised members of staff who were directive about seeing and holding their baby, and a few were highly critical when 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 NICE Guidance in this area[30] , 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 stillborn 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"[30] 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 [31 32].

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[33]. The survey also included few respondents of non-White British origin, and so the interview study also included few of

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these respondents. Given the over-representation of women in some of these groups amongst 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 of stillbirth[34 35 36 37]. All of these studies were quantitative in design, eliciting responses to pre-specified questions. Some data from these studies, and, as noted above, from US[19] and Swedish[16 17 20] qualitative research resonates with the findings reported in this paper. In particular, three of these studies noted positive effects of seeing and holding the baby, and of tokens of remembrance[34 35 37]. 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 health care staff to model, develop and express authentically caring behaviours. Extending this to all relevant health care settings might include innovative approaches to enhancing the capacity of health care staff to be emotionally intelligent in this context[38 39]. There is neurological evidence that personal emotional response influences cognitive empathy[40]. Affective experiences offer a way of engaging the emotional response of health care staff [41]. 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 high level 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 burn-out. Specific aspects of care noted as being helpful to parents (see box four) could be implemented as a matter of routine.

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Beyond the experience of stillbirth, this study offers important insights into staff behaviours that support wellbeing, and those that are, at the extreme, emotionally damaging. The study suggests that tacking lack of caring behaviour in health care 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 hospital and in the community have only one chance to provide care that fosters the clinical, emotional, practical and psychosocial wellbeing of parents who have experienced still birth. 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, and the best chance of achieving optimum wellbeing 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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Table 1: Location and year of stillbirth and mothers demographics (n = 22)

Region	n	Religion	n	Mother' 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 two: Thematic structure

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

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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)

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 you're 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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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)

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

Practices that were helpful	Behaviours 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	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

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APPENDIX 1 (Web file only)

Interview topic guide: Bereaved parents' experiences of stillbirth in UK hospitals

Prior to each interview ES prepared a reference sheet listing what was already known about each family's experience of stillbirth so she could ensure the interviews were conducted as sensitively as possible. She also had the name and contact number of the local SANDS representative on this sheet to give to mothers and fathers if needed.

Following explanation of study, the interview process and written informed consent being obtained the interviewer sought to establish a rapport using unstructured dialogue based around the following opening sequence of questions (probes in italics).

1. Introduction

"Thank you for agreeing to this interview. I have read your answers to the on-line questionnaire, but this interview is an opportunity for you to say more, to help us understand in more detail, about what happened when your baby was born."

Can we start at the beginning; can you tell me the story of what happened when your baby [name] was born?

- *What sort of pregnancy had it been? (straightforward/complicated)*
- *When did you find out about your baby's death?*
- *How did you learn your baby had died? Who was present?*
- *How far along in your pregnancy were you?*

What happened after you had your baby?

- *Did you see/hold/spend time with[name o f/ your baby]*
- *How did you feel immediately after birth?*
- *Have your feelings changed over time?*
- *Were the doctors or midwives able to tell you why your baby died?*

2. Interactions with healthcare professionals

What was it like for you, interacting with different health care staff around the time [name of baby] was born?

- Where there any particular staff that you remember as influencing your care – for better or worse?
- In what ways?
- Were there certain members of staff that you relied on when you were in hospital?
- Did you see a bereavement midwife or counsellor?
- After you left hospital, did you have any further contact with any of the staff?
- With whom and when (i.e. subsequent pregnancy)?

3. Counselling and decision-making

How did hospital staff help you through such a difficult time?

- *In what ways did staff support you after [name of baby] died?*
- *What were the things they did that were helpful?*
- *Can you explain why those things were particularly helpful?*
- *Was there anything they did that you found particularly upsetting?*
- *How do you think they could they have done things differently?*

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Some parents have told us that they found it very difficult to make decisions about things like funeral arrangements, or medical investigations to find out what caused the stillbirth. **How did you go about making tough decisions like those?**

- *At what point did you know that there were decisions to make?*
- *Which decisions were the hardest to make?*
- *Was there anything that made those decisions easier or harder to make?*

4. Post-mortem

One of the things we are particularly interested in is how parents decide about the tests to find out why their baby died. **Can you tell me about the first-time a post-mortem was mentioned?**

- *What was your reaction?*
- *Was anyone or anything particularly influential in your decision as to whether to have a post-mortem or not?*
- *Did anyone have a strong opinion?*

What information did you get about the options for tests that could be carried out?

- *When was that information given to you?*
- *In what format?*
- *In what ways did you find that information helpful?*
- *Did you have any questions that went unanswered?*
- *How much time did you have before you had to make a final decision about which tests you wanted to have?*

What were the most important factors that you took into consideration as you made your decision about a post-mortem for [name of baby]?

- *What did you feel were the pros and cons?*

Additional questions depending on interviewees responses to above, asked at interviewers discretion.

Can you give me a bit more detail about the key considerations for you?

- *About the baby*
- *Cultural or religious*
- *Negative media attention (Bad press)*
- *Required transfer to another hospital*

If had a post-mortem:

- *How did you feel about the consent process and form you were asked to sign?*
- *How has having the post-mortem made a difference to your feelings?*
- *If subsequent pregnancies – How have the results of the post-mortem affected them?*

How do you feel about having had the post-mortem now?

5. Summarising

To conclude, what advice would you give to doctors and midwives who care for people who have stillbirths in the future?

THANK YOU

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

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Licencing statement

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Competing interest statement

All authors have completed the Unified Competing Interest form and declare that all four had research support from the Stillbirth and Neonatal Death Society (Sands) for the submitted work. Otherwise, none of the authors had a financial relationship with any organisations that might have an interest in the submitted work in the previous 3 years, and there are no other relationships or activities that could appear to have influenced the submitted work

Contribution statement

SD, AH and CK designed the study. EB contacted the participants an undertook the interviews. SD, AH and EB contributed to the analysis and the initial write-up of the findings. All authors contributed to the final manuscript.

Ethics statement

This study obtained ethics approval from both the University of Manchester (ID no 09392). As the participants were not accessed through the NHS, IRAS approval was not required. All participants gave informed consent before taking part. Funding was obtained from the Stillbirth and Neonatal Death Society. The participants were accessed via the Sands website, but the funders were not directly involved at any stage of the design of, recruitment to or running/analysis of the study, or of writing and submitting the paper. All researchers are independent from the funders, apart from the funding given for this specific study. All the authors had access to all the data for the study.

Data sharing

Participants did not give specific informed consent for data sharing but the presented data are anonymised and risk of identification is low

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Consolidated criteria for reporting qualitative studies (COREQ): 32 item checklist

No	Item	Guide questions/description	Comment
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Ellie Schmidt.
2.	Credentials	What were the researcher's credentials?	BSc in Human Development and Family Studies, MSc in Social Research Methods and Statistics.
3.	Occupation	What was there occupation at the time of the study?	Research Assistant.
4.	Gender	Was the researcher male or female?	Female.
5.	Experience and training	What experience or training did the researcher have?	Trained social scientist with previous experience of conducting research with families.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to the study commencement?	No.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher?	The interviewer offered little information about her professional background and no personal details (I.e. not a mother herself), but did answer honestly if asked.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	Experienced researcher investigating families
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study?	Grounded theory.
Participant selection			
10	Sampling	How were participants selected?	Purposive, maximum variation sampling.
11.	Method of approach	How were participants approached?	Via a letters and up to three telephone calls.
12.	Sample size	How many participants were in the study?	25.
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	4 families declined participation when approached to arrange an interview.
Setting			
14.	Setting of data collection	Where was the data collected?	ES travelled to conduct 8 interviews in participant's own homes. 14 participants preferred a telephone interview.
15.	Presence of non-participants	Was anyone else present besides the participants and the researcher?	No.

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16.	Description of the sample	What are the important characteristics of the sample?	Their baby was [still]born between 2000 and 2010; NHS region; maternal age; parity, gestation at time of stillbirth.
Data Collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes.
18.	Repeat interviews	Were repeat interviews carried out?	No.
19.	Audio/visual recording	Did the research use audio or visual recording to collect data?	Audio recordings.
20.	Fieldnotes	Were field notes made during and/or after the interview or focus group?	During and after.
21.	Duration	What was the duration of the interviews or focus groups?	Between 42 minutes and 1 hour and 59 minutes.
22.	Data saturation	Was data saturation discussed?	Yes.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No.
Domain 3: Analysis and Findings			
24.	Number of data coders	How many data coders coded the data?	Three.
25.	Description of the coding tree	Do authors provide a description of the coding tree?	Yes.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data.
27.	Software	What software, if applicable, was used to manage the data?	MAXQDA
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Are participant's quotations presented to illustrate the themes/findings? Was each quotation identified?	Yes. Participant numbers are presented.
30.	Data and findings consistent	Is there consistency between the data presented and the findings?	Presented in table 2.
31.	Clarity of major themes	Are major themes clearly presented in the findings?	Three major themes are presented and an over-arching meta-theme.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

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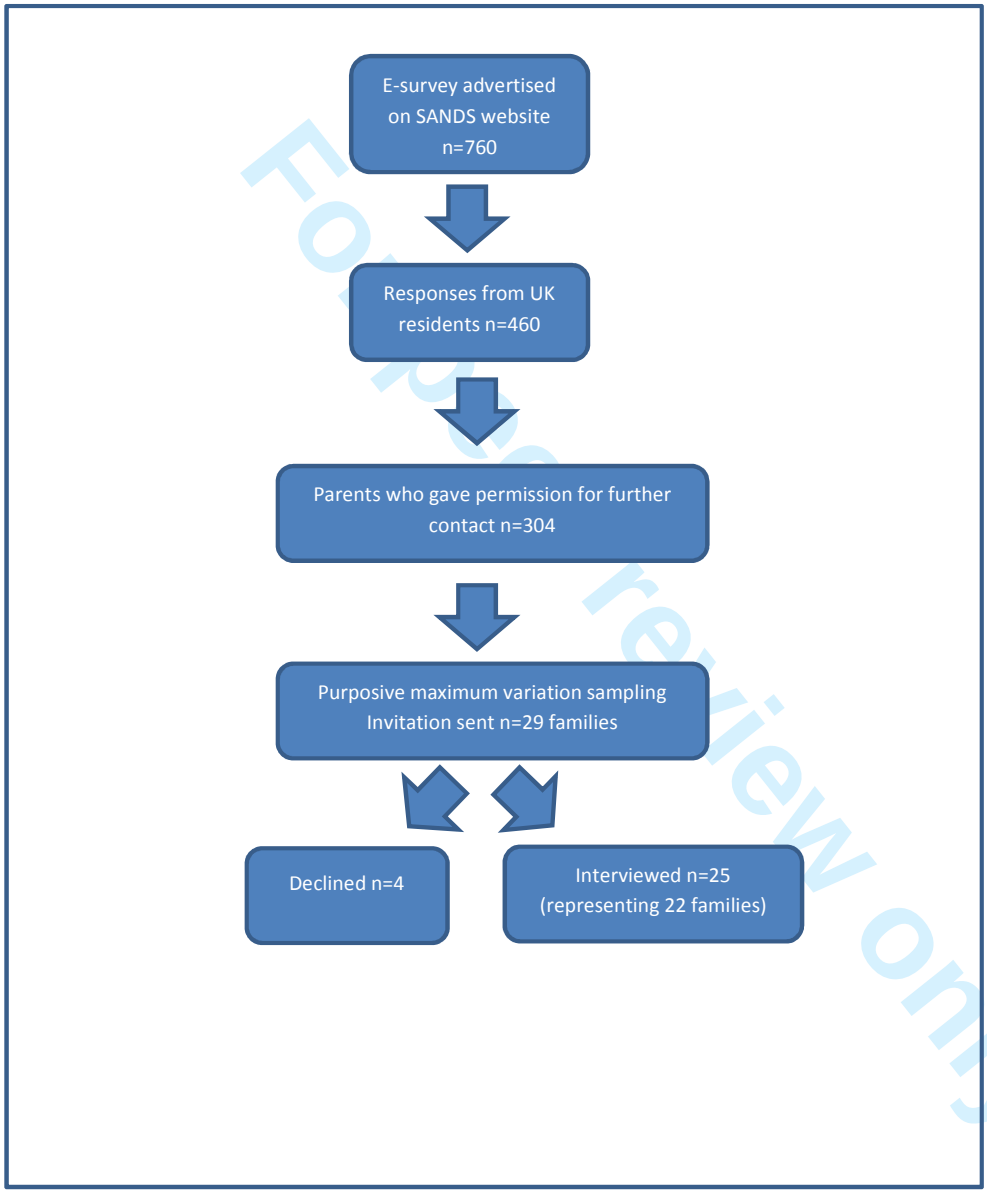
COREQ participant selection flow diagram/Figure 1



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

Abstract

Objective To obtain the views of bereaved parents about their interactions with health care 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 United Kingdom 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 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 irretrievable 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.

Conclusion 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.

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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 the 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 earlier national e-survey) and inclusion of few participants from non-white, British backgrounds.

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Introduction

In the United Kingdom (UK), around 4,000 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 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 (PTSD)[4, 5, 6]. Due 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 9 10]. Recently, the Lancet stillbirth series emphasised the unique status of stillbirth, and that grief may be exacerbated by social stigma, marginalisation and by the standard of care provided for parents[11]. 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, 13, 14].

In high-income countries research into the prevention and clinical management of stillbirth, such as determining ~~investigations which are most useful~~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 which~~studies that describe ~~parents~~parents' experiences so that the quality of care can be improved. Previous qualitative research has investigated experience of induction of labour, the role of caregivers and the experiences of women accessing bereavement support after stillbirth[16, 17, 18]. Very recently, two studies have examined the experiences of parents in the USA[19] 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.

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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 COREQ participant selection flow diagram/Figure 1)[21]. This was an e-questionnaire, advertised through the website of Sands. 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. 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:

"*Tell me the story of what happened when your baby, [Name], was born*."[1]

and

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

Data Analysis

[1] All names in this paper have been changed to provide anonymity for the participants.

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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, AH, SD) read and re-read the interview transcripts individually, and then agreement was reached on the emerging themes and sub-themes 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 meta-theme, three key themes and ten sub-themes. (see table 2). MAXQDA software was used for data management.

Reflexive accounting[23 24]

SD, a midwife and academic, believed that services for parents experiencing stillbirth had improved greatly over the last two decades. She anticipated that the study would indicate some gaps in service provision. EBS, a social scientist, specialises in research with families. She had no previous experience working with maternity services, and approached the research with a high degree of openness. CK, a medical sociologist with over ten years experience in maternity research, hoped that greater recognition and understanding of parents perspectives would provide a catalyst for change. AH, 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 commenced after approval by the Research Ethics Committee of the University of Manchester (Ref: 09392).

Results

Twenty-nine families were approached. Twenty-two families are represented in the study, including 25 respondents. Nineteen mothers were interviewed separately, and, in 3 instances, the mother and the father were interviewed together. For 8 interviews, EBS travelled to interview the family face-to-face. Fourteen families preferred a telephone interview. Table 1 provides additional information about participants' demographics and circumstances of the stillbirth.

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Interviews lasted between 42 minutes and 1 hour and 59 minutes.

Findings

Table 2 gives the thematic structure of the findings. This is summarised by the meta-theme 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. Several 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.

<<Insert Box 1>>

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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 post-mortem. 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 didn't happen to others in the future.

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 health care 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

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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.

<<Insert Box 2>>

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 health care staff could be more assertive. These findings contrast with the recommendation, based on ~~to~~ the findings of Hughes and colleagues[27], that "carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed"[28]. For some of the respondents in our study, their early rejection of the ~~possibility~~ 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 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, and 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.

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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 commence. 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 ~~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 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.

Many parents expressed a strong desire~~rive~~ to find out why their baby died. Most emphasised the importance of discussions and accurate information about maternal and child blood tests, placental investigations, post mortem 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 health care 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

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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 though caring, indifferent, or, at the extreme, hostile behaviours. When these messages were poorly communicated, or inconsistent, or led parents to question clinical judgment or skill, their sense of loss was augmented. Parents reported ~~were~~ frustration~~ted~~ in relation to confused information~~by confusion~~ about appointments, ~~-~~and miscommunication about when they should arrive at hospital for induction of labour. They recounted ~~, and~~ distress related to ~~ed by~~ 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 r~~R~~espondents expressed ~~were~~ shock~~ed~~ at the minimal regard for their needs and emotions shown by care givers. T~~ and t~~he distress this caused remained evident in their accounts~~palpable~~ many years after the event (see box three).

<<Insert Box 3 here>>

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

Comment [SD1]: Deleted: ' to the disregard evidenced in some parents accounts

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(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 parents' experience. 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. ~~This study shows that~~ O~~o~~nce the hospital experience had passed, respondents in this study ~~s~~ ~~passed parents~~ spent~~d~~ a great deal of time processing what happened to them. When care was not delivered well, parents were further ~~wounded and~~ 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

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care and support in some maternity care settings [29], and a national emphasis in the UK on increasing caring behaviours among staff in health care provision in general.

Comment [SD2]: Deleted: It is even more shocking to learn of such behaviours in the context of the loss of a baby

As noted in the introduction, the Royal College of Obstetricians and Gynaecologists[12], and the American College of Obstetrics and Gynaecology[13] have issued new guidance relating to the management of stillbirths. The RCOG guidelines state that "*carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed* (ref p.19)." Our data suggest that, for some parents at least, persuasion might, in fact, be appropriate. Some respondents explicitly praised members of staff who were directive about seeing and holding their baby, and a few were highly critical when 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 NICE Guidance in this area[30] , 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 stillborn 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"[30] 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 [31 32].

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

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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[33]. 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 amongst 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 of stillbirth[34 35 36 37]. All of these studies were quantitative in design, eliciting responses to pre-specified questions. Some data from these studies, and, as noted above, from US[19] and Swedish[16 17 20] qualitative research resonates with the findings reported in this paper. In particular, three of these studies noted positive effects of seeing and holding the baby, and of tokens of remembrance[34 35 37]. 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 ~~significant~~ accounts of lapses in humane treatment reported by~~of~~ some of the bereaved parents in this study, it was apparent from the ~~accounts~~ 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 health care staff to model, develop and express authentically caring behaviours. Extending this to all relevant health care settings might include innovative approaches to enhancing the capacity of health care staff to be emotionally intelligent in this context[38 39]. There is neurological evidence that personal emotional response influences cognitive empathy[40]. Affective experiences offer a way of engaging the emotional response of health care staff [41]. 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 high level 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

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model and disseminate it. Effective support for staff who find themselves dealing with emotionally stressful events is essential, so that they do not face burn-out. Specific aspects of care noted as being helpful to parents (see box four) could be implemented as a matter of routine.

Beyond the experience of stillbirth, this study offers important insights into staff behaviours that support wellbeing, and those that are, at the extreme, emotionally damaging. The study suggests that tacking lack of caring behaviour in health care 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. ~~Parents of stillborn babies are still at risk of experiencing inadequate, unsupportive, and even uncaring behaviours from staff.~~ Professionals in hospital and in the community have only one chance to provide care that fosters the clinical, emotional, practical and psychosocial wellbeing of parents who have experienced still birth. 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, and the best chance of achieving optimum wellbeing in the longer term. S~~For the sake of future parents in this situation,~~ taff 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. ~~such care urgently needs to be implemented in all relevant health settings.~~

4,162~~43~~ words

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

Region	n	Religion	n	Mother' 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 two: Thematic structure

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

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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)

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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 you're 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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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)

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

Practices that were helpful	Behaviours 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	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

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APPENDIX 1 (Web file only)

Interview topic guide: Bereaved parents' experiences of stillbirth in UK hospitals

Prior to each interview ES prepared a reference sheet listing what was already known about each family's experience of stillbirth so she could ensure the interviews were conducted as sensitively as possible. She also had the name and contact number of the local SANDS representative on this sheet to give to mothers and fathers if needed.

Following explanation of study, the interview process and written informed consent being obtained the interviewer sought to establish a rapport using unstructured dialogue based around the following opening sequence of questions (probes in italics).

1. Introduction

"Thank you for agreeing to this interview. I have read your answers to the on-line questionnaire, but this interview is an opportunity for you to say more, to help us understand in more detail, about what happened when your baby was born."

Can we start at the beginning; can you tell me the story of what happened when your baby [name] was born?

- *What sort of pregnancy had it been? (straightforward/complicated)*
- *When did you find out about your baby's death?*
- *How did you learn your baby had died? Who was present?*
- *How far along in your pregnancy were you?*

What happened after you had your baby?

- *Did you see/hold/spend time with[name o f/ your baby]*
- *How did you feel immediately after birth?*
- *Have your feelings changed over time?*
- *Were the doctors or midwives able to tell you why your baby died?*

2. Interactions with healthcare professionals

What was it like for you, interacting with different health care staff around the time [name of baby] was born?

- Where there any particular staff that you remember as influencing your care – for better or worse?
- In what ways?
- Were there certain members of staff that you relied on when you were in hospital?
- Did you see a bereavement midwife or counsellor?
- After you left hospital, did you have any further contact with any of the staff?
- With whom and when (i.e. subsequent pregnancy)?

3. Counselling and decision-making

How did hospital staff help you through such a difficult time?

- *In what ways did staff support you after [name of baby] died?*
- *What were the things they did that were helpful?*
- *Can you explain why those things were particularly helpful?*
- *Was there anything they did that you found particularly upsetting?*
- *How do you think they could they have done things differently?*

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Some parents have told us that they found it very difficult to make decisions about things like funeral arrangements, or medical investigations to find out what caused the stillbirth. **How did you go about making tough decisions like those?**

- *At what point did you know that there were decisions to make?*
- *Which decisions were the hardest to make?*
- *Was there anything that made those decisions easier or harder to make?*

4. Post-mortem

One of the things we are particularly interested in is how parents decide about the tests to find out why their baby died. **Can you tell me about the first-time a post-mortem was mentioned?**

- *What was your reaction?*
- *Was anyone or anything particularly influential in your decision as to whether to have a post-mortem or not?*
- *Did anyone have a strong opinion?*

What information did you get about the options for tests that could be carried out?

- *When was that information given to you?*
- *In what format?*
- *In what ways did you find that information helpful?*
- *Did you have any questions that went unanswered?*
- *How much time did you have before you had to make a final decision about which tests you wanted to have?*

What were the most important factors that you took into consideration as you made your decision about a post-mortem for [name of baby]?

- *What did you feel were the pros and cons?*

Additional questions depending on interviewees responses to above, asked at interviewers discretion.

Can you give me a bit more detail about the key considerations for you?

- *About the baby*
- *Cultural or religious*
- *Negative media attention (Bad press)*
- *Required transfer to another hospital*

If had a post-mortem:

- *How did you feel about the consent process and form you were asked to sign?*
- *How has having the post-mortem made a difference to your feelings?*
- *If subsequent pregnancies – How have the results of the post-mortem affected them?*

How do you feel about having had the post-mortem now?

5. Summarising

To conclude, what advice would you give to doctors and midwives who care for people who have stillbirths in the future?

THANK YOU

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

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

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Statements

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Competing interest statement

All authors have completed the Unified Competing Interest form and declare that all four had research support from the Stillbirth and Neonatal Death Society (Sands) for the submitted work. Otherwise, none of the authors had a financial relationship with any organisations that might have an interest in the submitted work in the previous 3 years, and there are no other relationships or activities that could appear to have influenced the submitted work

Contribution statement

SD, AH and CK designed the study. EB contacted the participants an undertook the interviews. SD, AH and EB contributed to the analysis and the initial write-up of the findings. All authors contributed to the final manuscript.

Ethics statement

This study obtained ethics approval from both the University of Manchester (ID no 09392). As the participants were not accessed through the NHS, IRAS approval was not required. All participants gave informed consent before taking part. Funding was obtained from the Stillbirth and Neonatal Death Society. The participants were accessed via the Sands website, but the funders were not directly involved at any stage of the design of, recruitment to or running/analysis of the study, or of writing and submitting the paper. All researchers are independent from the funders, apart from the funding given for this specific study. All the authors had access to all the data for the study.

Data sharing

Participants did not give specific informed consent for data sharing but the presented data are anonymised and risk of identification is low

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Consolidated criteria for reporting qualitative studies (COREQ): 32 item checklist

No	Item	Guide questions/description	Comment
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Ellie Schmidt.
2.	Credentials	What were the researcher's credentials?	BSc in Human Development and Family Studies, MSc in Social Research Methods and Statistics.
3.	Occupation	What was there occupation at the time of the study?	Research Assistant.
4.	Gender	Was the researcher male or female?	Female.
5.	Experience and training	What experience or training did the researcher have?	Trained social scientist with previous experience of conducting research with families.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to the study commencement?	No.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher?	The interviewer offered little information about her professional background and no personal details (I.e. not a mother herself), but did answer honestly if asked.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	Experienced researcher investigating families
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study?	Grounded theory.
Participant selection			
10	Sampling	How were participants selected?	Purposive, maximum variation sampling.
11.	Method of approach	How were participants approached?	Via a letters and up to three telephone calls.
12.	Sample size	How many participants were in the study?	25.
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	4 families declined participation when approached to arrange an interview.
Setting			
14.	Setting of data collection	Where was the data collected?	ES travelled to conduct 8 interviews in participant's own homes. 14 participants preferred a telephone interview.
15.	Presence of non-participants	Was anyone else present besides the participants and the researcher?	No.

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16.	Description of the sample	What are the important characteristics of the sample?	Their baby was [still]born between 2000 and 2010; NHS region; maternal age; parity, gestation at time of stillbirth.
Data Collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes.
18.	Repeat interviews	Were repeat interviews carried out?	No.
19.	Audio/visual recording	Did the research use audio or visual recording to collect data?	Audio recordings.
20.	Fieldnotes	Were field notes made during and/or after the interview or focus group?	During and after.
21.	Duration	What was the duration of the interviews or focus groups?	Between 42 minutes and 1 hour and 59 minutes.
22.	Data saturation	Was data saturation discussed?	Yes.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No.
Domain 3: Analysis and Findings			
24.	Number of data coders	How many data coders coded the data?	Three.
25.	Description of the coding tree	Do authors provide a description of the coding tree?	Yes.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data.
27.	Software	What software, if applicable, was used to manage the data?	MAXQDA
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Are participant's quotations presented to illustrate the themes/findings? Was each quotation identified?	Yes. Participant numbers are presented.
30.	Data and findings consistent	Is there consistency between the data presented and the findings?	Presented in table 2.
31.	Clarity of major themes	Are major themes clearly presented in the findings?	Three major themes are presented and an over-arching meta-theme.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

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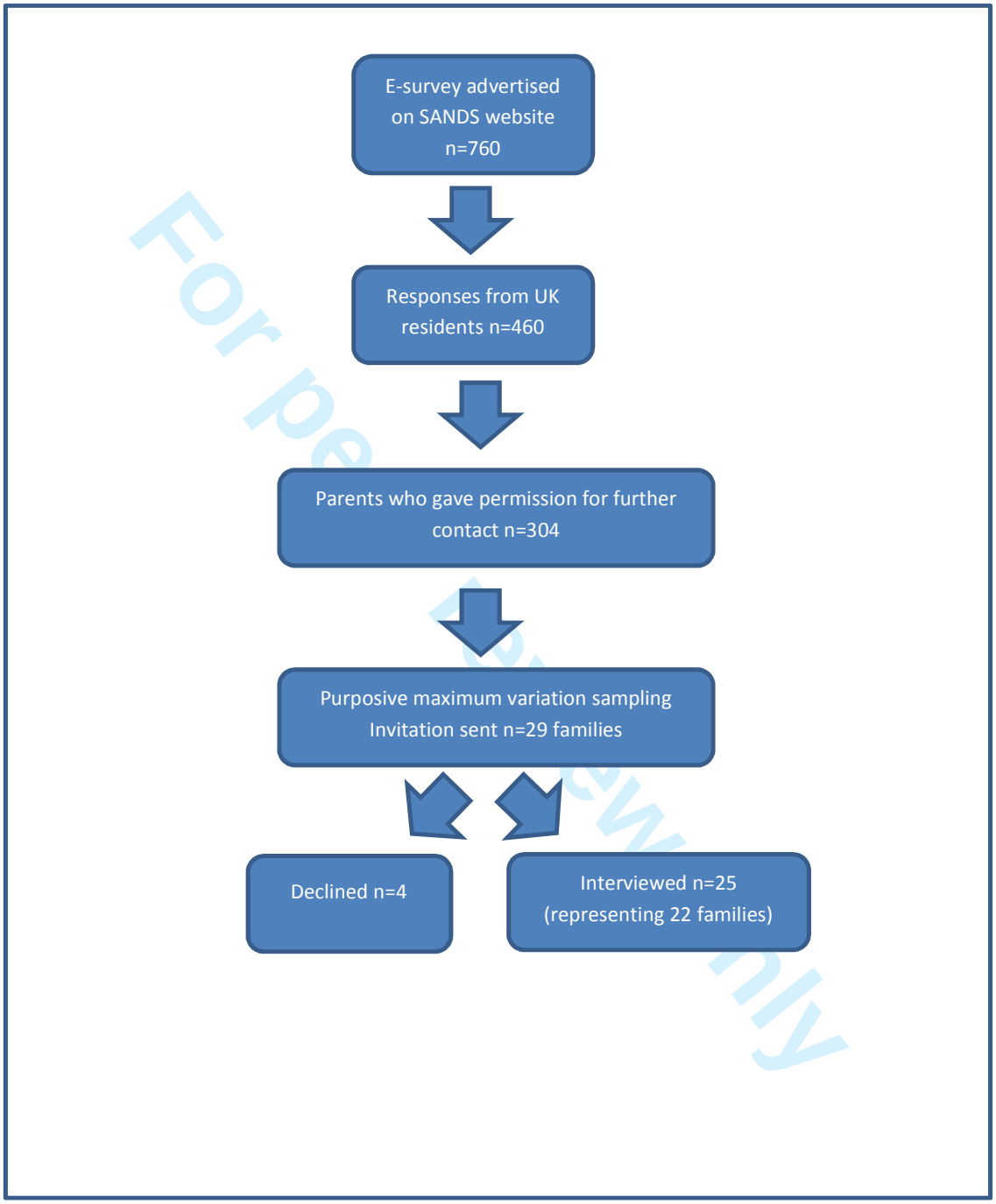
COREQ participant selection flow diagram/Figure 1



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

Abstract

Objective To obtain the views of bereaved parents about their interactions with health care 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 United Kingdom 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 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 irretrievable 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.

Conclusion 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.

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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 the 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 earlier national e-survey) and inclusion of few participants from non-white, British backgrounds.

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Introduction

In the United Kingdom (UK), around 4,000 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 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 (PTSD)[4, 5, 6]. Due 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 9 10]. Recently, the Lancet stillbirth series emphasised the unique status of stillbirth, and that grief may be exacerbated by social stigma, marginalisation and by the standard of care provided for parents[11]. 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, 13, 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 experience of induction of labour, the role of caregivers and the experiences of women accessing bereavement support after stillbirth[16, 17, 18]. Very recently, two studies have examined the experiences of parents in the USA[19] 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

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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 COREQ participant selection flow diagram/Figure 1)[21]. This was an e-questionnaire, advertised through the website of Sands. 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. 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:

"*Tell me the story of what happened when your baby, [Name], was born*."[1]

and

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

Data Analysis

[1] All names in this paper have been changed to provide anonymity for the participants.

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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, AH, SD) read and re-read the interview transcripts individually, and then agreement was reached on the emerging themes and sub-themes 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 meta-theme, three key themes and ten sub-themes. (see table 2). MAXQDA software was used for data management.

Reflexive accounting[23 24]

SD, a midwife and academic, believed that services for parents experiencing stillbirth had improved greatly over the last two decades. She anticipated that the study would indicate some gaps in service provision. EBS, a social scientist, specialises in research with families. She had no previous experience working with maternity services, and approached the research with a high degree of openness. CK, a medical sociologist with over ten years experience in maternity research, hoped that greater recognition and understanding of parents perspectives would provide a catalyst for change. AH, 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 commenced after approval by the Research Ethics Committee of the University of Manchester (Ref: 09392).

Results

Twenty-nine families were approached. Twenty-two families are represented in the study, including 25 respondents. Nineteen mothers were interviewed separately, and, in 3 instances, the mother and the father were interviewed together. For 8 interviews, EBS travelled to interview the family face-to-face. Fourteen families preferred a telephone interview. Table 1 provides additional information about participants' demographics and circumstances of the stillbirth.

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Interviews lasted between 42 minutes and 1 hour and 59 minutes.

Findings

Table 2 gives the thematic structure of the findings. This is summarised by the meta-theme 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.

<<Insert Box 1>>

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 post-mortem. 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 didn't happen to others in the future.

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 health care 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

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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.

<<Insert Box 2>>

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 health care staff could be more assertive. These findings contrast with the recommendation, based on the findings of Hughes and colleagues[27], that "carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed"[28]. 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 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, and 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.

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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 commence. 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 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, post mortem 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 health care 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

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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 though caring, indifferent, or, at the extreme, hostile behaviours. When these messages were poorly communicated, or inconsistent, or led parents to question clinical judgment 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 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 care givers. The distress this caused remained evident in their accounts many years after the event (see box three).

<<Insert Box 3 here>>

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

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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 parents' experience. 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 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 [29], and a national emphasis in the UK on increasing caring behaviours among staff in health care provision in general.

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As noted in the introduction, the Royal College of Obstetricians and Gynaecologists[12], and the American College of Obstetrics and Gynaecology[13] have issued new guidance relating to the management of stillbirths. The RCOG guidelines state that "*carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed* (ref p.19)." Our data suggest that, for some parents at least, persuasion might, in fact, be appropriate. Some respondents explicitly praised members of staff who were directive about seeing and holding their baby, and a few were highly critical when 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 NICE Guidance in this area[30] , 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 stillborn 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"[30] 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 [31 32].

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[33]. The survey also included

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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 amongst 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 of stillbirth[34 35 36 37]. All of these studies were quantitative in design, eliciting responses to pre-specified questions. Some data from these studies, and, as noted above, from US[19] and Swedish[16 17 20] qualitative research resonates with the findings reported in this paper. In particular, three of these studies noted positive effects of seeing and holding the baby, and of tokens of remembrance[34 35 37]. 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 health care staff to model, develop and express authentically caring behaviours. Extending this to all relevant health care settings might include innovative approaches to enhancing the capacity of health care staff to be emotionally intelligent in this context[38 39]. There is neurological evidence that personal emotional response influences cognitive empathy[40]. Affective experiences offer a way of engaging the emotional response of health care staff [41]. 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 high level 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 burn-out. Specific aspects of care noted

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as being helpful to parents (see box four) could be implemented as a matter of routine.

Beyond the experience of stillbirth, this study offers important insights into staff behaviours that support wellbeing, and those that are, at the extreme, emotionally damaging. The study suggests that tacking lack of caring behaviour in health care 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 hospital and in the community have only one chance to provide care that fosters the clinical, emotional, practical and psychosocial wellbeing of parents who have experienced still birth. 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, and the best chance of achieving optimum wellbeing 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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Table 1: Location and year of stillbirth and mothers demographics (n = 22)

Region	n	Religion	n	Mother' 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 two: Thematic structure

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

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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)

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 you're 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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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)

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

Practices that were helpful	Behaviours 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	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

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APPENDIX 1 (Web file only)

Interview topic guide: Bereaved parents' experiences of stillbirth in UK hospitals

Prior to each interview ES prepared a reference sheet listing what was already known about each family's experience of stillbirth so she could ensure the interviews were conducted as sensitively as possible. She also had the name and contact number of the local SANDS representative on this sheet to give to mothers and fathers if needed.

Following explanation of study, the interview process and written informed consent being obtained the interviewer sought to establish a rapport using unstructured dialogue based around the following opening sequence of questions (probes in italics).

1. Introduction

"Thank you for agreeing to this interview. I have read your answers to the on-line questionnaire, but this interview is an opportunity for you to say more, to help us understand in more detail, about what happened when your baby was born."

Can we start at the beginning; can you tell me the story of what happened when your baby [name] was born?

- *What sort of pregnancy had it been? (straightforward/complicated)*
- *When did you find out about your baby's death?*
- *How did you learn your baby had died? Who was present?*
- *How far along in your pregnancy were you?*

What happened after you had your baby?

- *Did you see/hold/spend time with[name o f/ your baby]*
- *How did you feel immediately after birth?*
- *Have your feelings changed over time?*
- *Were the doctors or midwives able to tell you why your baby died?*

2. Interactions with healthcare professionals

What was it like for you, interacting with different health care staff around the time [name of baby] was born?

- Where there any particular staff that you remember as influencing your care – for better or worse?
- In what ways?
- Were there certain members of staff that you relied on when you were in hospital?
- Did you see a bereavement midwife or counsellor?
- After you left hospital, did you have any further contact with any of the staff?
- With whom and when (i.e. subsequent pregnancy)?

3. Counselling and decision-making

How did hospital staff help you through such a difficult time?

- *In what ways did staff support you after [name of baby] died?*
- *What were the things they did that were helpful?*
- *Can you explain why those things were particularly helpful?*
- *Was there anything they did that you found particularly upsetting?*
- *How do you think they could they have done things differently?*

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Some parents have told us that they found it very difficult to make decisions about things like funeral arrangements, or medical investigations to find out what caused the stillbirth. **How did you go about making tough decisions like those?**

- *At what point did you know that there were decisions to make?*
- *Which decisions were the hardest to make?*
- *Was there anything that made those decisions easier or harder to make?*

4. Post-mortem

One of the things we are particularly interested in is how parents decide about the tests to find out why their baby died. **Can you tell me about the first-time a post-mortem was mentioned?**

- *What was your reaction?*
- *Was anyone or anything particularly influential in your decision as to whether to have a post-mortem or not?*
- *Did anyone have a strong opinion?*

What information did you get about the options for tests that could be carried out?

- *When was that information given to you?*
- *In what format?*
- *In what ways did you find that information helpful?*
- *Did you have any questions that went unanswered?*
- *How much time did you have before you had to make a final decision about which tests you wanted to have?*

What were the most important factors that you took into consideration as you made your decision about a post-mortem for [name of baby]?

- *What did you feel were the pros and cons?*

Additional questions depending on interviewees responses to above, asked at interviewers discretion.

Can you give me a bit more detail about the key considerations for you?

- *About the baby*
- *Cultural or religious*
- *Negative media attention (Bad press)*
- *Required transfer to another hospital*

If had a post-mortem:

- *How did you feel about the consent process and form you were asked to sign?*
- *How has having the post-mortem made a difference to your feelings?*
- *If subsequent pregnancies – How have the results of the post-mortem affected them?*

How do you feel about having had the post-mortem now?

5. Summarising

To conclude, what advice would you give to doctors and midwives who care for people who have stillbirths in the future?

THANK YOU

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

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Statements

Funding statement

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Licencing statement

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Competing interest statement

All authors have completed the Unified Competing Interest form and declare that all four had research support from the Stillbirth and Neonatal Death Society (Sands) for the submitted work. Otherwise, none of the authors had a financial relationship with any organisations that might have an interest in the submitted work in the previous 3 years, and there are no other relationships or activities that could appear to have influenced the submitted work

Contribution statement

SD, AH and CK designed the study. EB contacted the participants an undertook the interviews. SD, AH and EB contributed to the analysis and the initial write-up of the findings. All authors contributed to the final manuscript.

Ethics statement

This study obtained ethics approval from both the University of Manchester (ID no 09392). As the participants were not accessed through the NHS, IRAS approval was not required. All participants gave informed consent before taking part. Funding was obtained from the Stillbirth and Neonatal Death Society. The participants were accessed via the Sands website, but the funders were not directly involved at any stage of the design of, recruitment to or running/analysis of the study, or of writing and submitting the paper. All researchers are independent from the funders, apart from the funding given for this specific study. All the authors had access to all the data for the study.

Data sharing

Participants did not give specific informed consent for data sharing but the presented data are anonymised and risk of identification is low

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Consolidated criteria for reporting qualitative studies (COREQ): 32 item checklist

No	Item	Guide questions/description	Comment
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Ellie Schmidt.
2.	Credentials	What were the researcher's credentials?	BSc in Human Development and Family Studies, MSc in Social Research Methods and Statistics.
3.	Occupation	What was there occupation at the time of the study?	Research Assistant.
4.	Gender	Was the researcher male or female?	Female.
5.	Experience and training	What experience or training did the researcher have?	Trained social scientist with previous experience of conducting research with families.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to the study commencement?	No.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher?	The interviewer offered little information about her professional background and no personal details (I.e. not a mother herself), but did answer honestly if asked.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	Experienced researcher investigating families
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study?	Grounded theory.
Participant selection			
10	Sampling	How were participants selected?	Purposive, maximum variation sampling.
11.	Method of approach	How were participants approached?	Via a letters and up to three telephone calls.
12.	Sample size	How many participants were in the study?	25.
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	4 families declined participation when approached to arrange an interview.
Setting			
14.	Setting of data collection	Where was the data collected?	ES travelled to conduct 8 interviews in participant's own homes. 14 participants preferred a telephone interview.
15.	Presence of non-participants	Was anyone else present besides the participants and the researcher?	No.

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16.	Description of the sample	What are the important characteristics of the sample?	Their baby was [still]born between 2000 and 2010; NHS region; maternal age; parity, gestation at time of stillbirth.
Data Collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes.
18.	Repeat interviews	Were repeat interviews carried out?	No.
19.	Audio/visual recording	Did the research use audio or visual recording to collect data?	Audio recordings.
20.	Fieldnotes	Were field notes made during and/or after the interview or focus group?	During and after.
21.	Duration	What was the duration of the interviews or focus groups?	Between 42 minutes and 1 hour and 59 minutes.
22.	Data saturation	Was data saturation discussed?	Yes.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No.
Domain 3: Analysis and Findings			
24.	Number of data coders	How many data coders coded the data?	Three.
25.	Description of the coding tree	Do authors provide a description of the coding tree?	Yes.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data.
27.	Software	What software, if applicable, was used to manage the data?	MAXQDA
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Are participant's quotations presented to illustrate the themes/findings? Was each quotation identified?	Yes. Participant numbers are presented.
30.	Data and findings consistent	Is there consistency between the data presented and the findings?	Presented in table 2.
31.	Clarity of major themes	Are major themes clearly presented in the findings?	Three major themes are presented and an over-arching meta-theme.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

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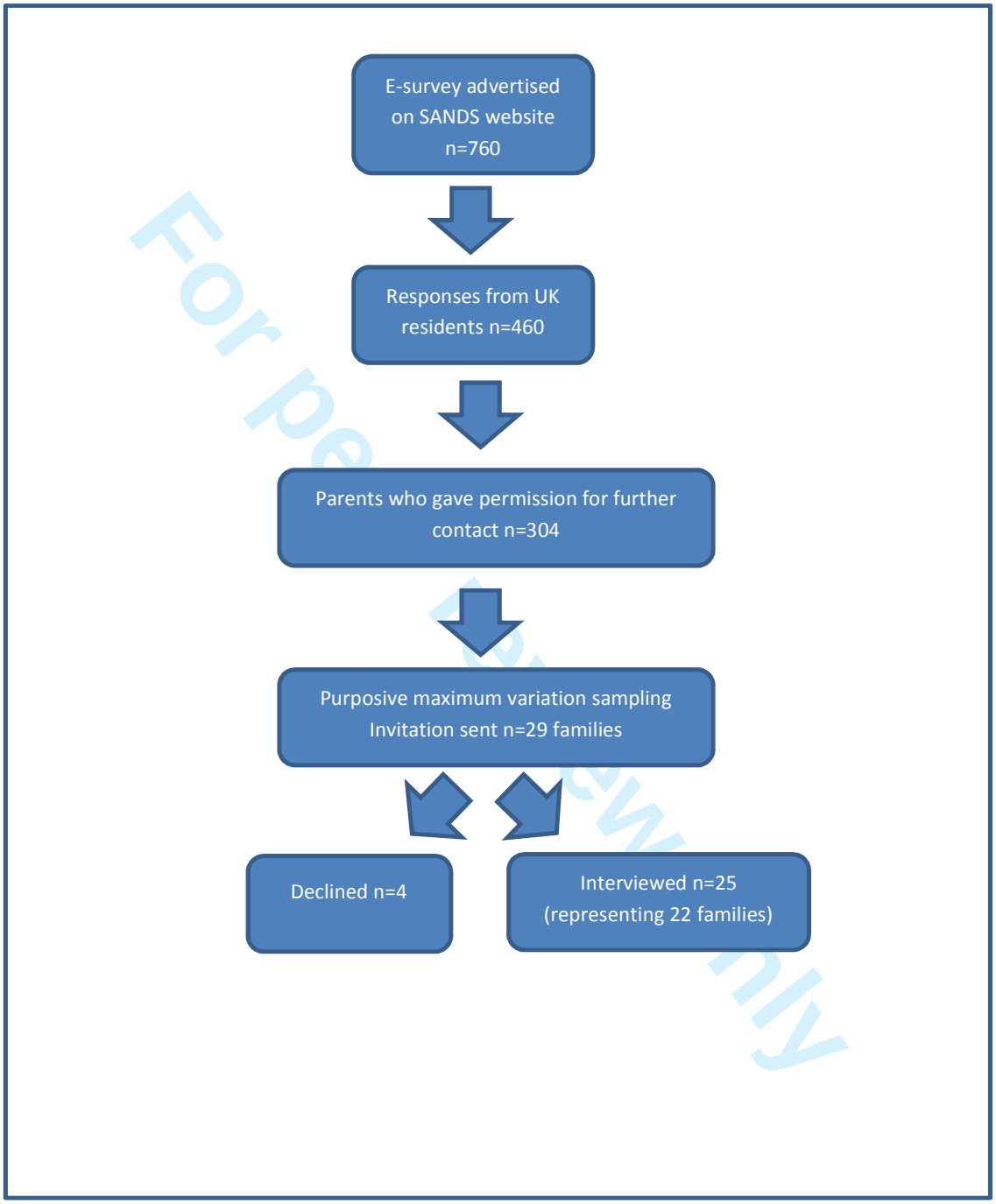
COREQ participant selection flow diagram/Figure 1



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

Abstract

Objective To obtain the views of bereaved parents about their interactions with health care 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 United Kingdom 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 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 irretrievable 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.

Conclusion 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.

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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 the 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 earlier national e-survey) and inclusion of few participants from non-white, British backgrounds.

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Introduction

In the United Kingdom (UK), around 4,000 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 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 (PTSD)[4, 5, 6]. Due 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 9 10]. Recently, the Lancet stillbirth series emphasised the unique status of stillbirth, and that grief may be exacerbated by social stigma, marginalisation and by the standard of care provided for parents[11]. 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, 13, 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 experience of induction of labour, the role of caregivers and the experiences of women accessing bereavement support after stillbirth[16, 17, 18]. Very recently, two studies have examined the experiences of parents in the USA[19] 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

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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 COREQ participant selection flow diagram/Figure 1)[21]. This was an e-questionnaire, advertised through the website of Sands. 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. 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:

"*Tell me the story of what happened when your baby, [Name], was born*."[1]

and

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

Data Analysis

[1] All names in this paper have been changed to provide anonymity for the participants.

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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, AH, SD) read and re-read the interview transcripts individually, and then agreement was reached on the emerging themes and sub-themes 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 meta-theme, three key themes and ten sub-themes. (see table 2). MAXQDA software was used for data management.

Reflexive accounting[23 24]

SD, a midwife and academic, believed that services for parents experiencing stillbirth had improved greatly over the last two decades. She anticipated that the study would indicate some gaps in service provision. EBS, a social scientist, specialises in research with families. She had no previous experience working with maternity services, and approached the research with a high degree of openness. CK, a medical sociologist with over ten years experience in maternity research, hoped that greater recognition and understanding of parents perspectives would provide a catalyst for change. AH, 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 commenced after approval by the Research Ethics Committee of the University of Manchester (Ref: 09392).

Results

Twenty-nine families were approached. Twenty-two families are represented in the study, including 25 respondents. Nineteen mothers were interviewed separately, and, in 3 instances, the mother and the father were interviewed together. For 8 interviews, EBS travelled to interview the family face-to-face. Fourteen families preferred a telephone interview. Table 1 provides additional information about participants' demographics and circumstances of the stillbirth.

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Interviews lasted between 42 minutes and 1 hour and 59 minutes.

Findings

Table 2 gives the thematic structure of the findings. This is summarised by the meta-theme 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.

<<Insert Box 1>>

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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 post-mortem. 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 didn't happen to others in the future.

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 health care 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

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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.

<<Insert Box 2>>

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 health care staff could be more assertive. These findings contrast with the recommendation, based on the findings of Hughes and colleagues[27], that "carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed"[28]. 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 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, and 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.

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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 commence. 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 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, post mortem 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 health care 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

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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 though caring, indifferent, or, at the extreme, hostile behaviours. When these messages were poorly communicated, or inconsistent, or led parents to question clinical judgment 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 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 care givers. The distress this caused remained evident in their accounts many years after the event (see box three).

<<Insert Box 3 here>>

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

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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 parents' experience. 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 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 [29], and a national emphasis in the UK on increasing caring behaviours among staff in health care provision in general.

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As noted in the introduction, the Royal College of Obstetricians and Gynaecologists[12], and the American College of Obstetrics and Gynaecology[13] have issued new guidance relating to the management of stillbirths. The RCOG guidelines state that "*carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed* (ref p.19)." Our data suggest that, for some parents at least, persuasion might, in fact, be appropriate. Some respondents explicitly praised members of staff who were directive about seeing and holding their baby, and a few were highly critical when 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 NICE Guidance in this area[30] , 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 stillborn 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"[30] 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 [31 32].

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[33]. The survey also included

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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 amongst 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 of stillbirth[34 35 36 37]. All of these studies were quantitative in design, eliciting responses to pre-specified questions. Some data from these studies, and, as noted above, from US[19] and Swedish[16 17 20] qualitative research resonates with the findings reported in this paper. In particular, three of these studies noted positive effects of seeing and holding the baby, and of tokens of remembrance[34 35 37]. 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 health care staff to model, develop and express authentically caring behaviours. Extending this to all relevant health care settings might include innovative approaches to enhancing the capacity of health care staff to be emotionally intelligent in this context[38 39]. There is neurological evidence that personal emotional response influences cognitive empathy[40]. Affective experiences offer a way of engaging the emotional response of health care staff [41]. 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 high level 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 burn-out. Specific aspects of care noted

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as being helpful to parents (see box four) could be implemented as a matter of routine.

Beyond the experience of stillbirth, this study offers important insights into staff behaviours that support wellbeing, and those that are, at the extreme, emotionally damaging. The study suggests that tacking lack of caring behaviour in health care 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 hospital and in the community have only one chance to provide care that fosters the clinical, emotional, practical and psychosocial wellbeing of parents who have experienced still birth. 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, and the best chance of achieving optimum wellbeing 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.

4,162 words

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

Region	n	Religion	n	Mother' 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 two: Thematic structure

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

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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)

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 you're 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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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)

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

Practices that were helpful	Behaviours 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	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

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APPENDIX 1 (Web file only)

Interview topic guide: Bereaved parents' experiences of stillbirth in UK hospitals

Prior to each interview ES prepared a reference sheet listing what was already known about each family's experience of stillbirth so she could ensure the interviews were conducted as sensitively as possible. She also had the name and contact number of the local SANDS representative on this sheet to give to mothers and fathers if needed.

Following explanation of study, the interview process and written informed consent being obtained the interviewer sought to establish a rapport using unstructured dialogue based around the following opening sequence of questions (probes in italics).

1. Introduction

"Thank you for agreeing to this interview. I have read your answers to the on-line questionnaire, but this interview is an opportunity for you to say more, to help us understand in more detail, about what happened when your baby was born."

Can we start at the beginning; can you tell me the story of what happened when your baby [name] was born?

- *What sort of pregnancy had it been? (straightforward/complicated)*
- *When did you find out about your baby's death?*
- *How did you learn your baby had died? Who was present?*
- *How far along in your pregnancy were you?*

What happened after you had your baby?

- *Did you see/hold/spend time with[name o f/ your baby]*
- *How did you feel immediately after birth?*
- *Have your feelings changed over time?*
- *Were the doctors or midwives able to tell you why your baby died?*

2. Interactions with healthcare professionals

What was it like for you, interacting with different health care staff around the time [name of baby] was born?

- Where there any particular staff that you remember as influencing your care – for better or worse?
- In what ways?
- Were there certain members of staff that you relied on when you were in hospital?
- Did you see a bereavement midwife or counsellor?
- After you left hospital, did you have any further contact with any of the staff?
- With whom and when (i.e. subsequent pregnancy)?

3. Counselling and decision-making

How did hospital staff help you through such a difficult time?

- *In what ways did staff support you after [name of baby] died?*
- *What were the things they did that were helpful?*
- *Can you explain why those things were particularly helpful?*
- *Was there anything they did that you found particularly upsetting?*
- *How do you think they could they have done things differently?*

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Some parents have told us that they found it very difficult to make decisions about things like funeral arrangements, or medical investigations to find out what caused the stillbirth. **How did you go about making tough decisions like those?**

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What were the most important factors that you took into consideration as you made your decision about a post-mortem for [name of baby]?

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Additional questions depending on interviewees responses to above, asked at interviewers discretion.

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How do you feel about having had the post-mortem now?

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To conclude, what advice would you give to doctors and midwives who care for people who have stillbirths in the future?

THANK YOU

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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)

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 you're 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)

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)

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

Practices that were helpful	Behaviours 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	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

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APPENDIX 1 (Web file only)

Interview topic guide: Bereaved parents' experiences of stillbirth in UK hospitals

Prior to each interview ES prepared a reference sheet listing what was already known about each family's experience of stillbirth so she could ensure the interviews were conducted as sensitively as possible. She also had the name and contact number of the local SANDS representative on this sheet to give to mothers and fathers if needed.

Following explanation of study, the interview process and written informed consent being obtained the interviewer sought to establish a rapport using unstructured dialogue based around the following opening sequence of questions (probes in italics).

1. Introduction

"Thank you for agreeing to this interview. I have read your answers to the on-line questionnaire, but this interview is an opportunity for you to say more, to help us understand in more detail, about what happened when your baby was born."

Can we start at the beginning; can you tell me the story of what happened when your baby [name] was born?

- *What sort of pregnancy had it been? (straightforward/complicated)*
- *When did you find out about your baby's death?*
- *How did you learn your baby had died? Who was present?*
- *How far along in your pregnancy were you?*

What happened after you had your baby?

- *Did you see/hold/spend time with[name o f/ your baby]*
- *How did you feel immediately after birth?*
- *Have your feelings changed over time?*
- *Were the doctors or midwives able to tell you why your baby died?*

2. Interactions with healthcare professionals

What was it like for you, interacting with different health care staff around the time [name of baby] was born?

- Where there any particular staff that you remember as influencing your care – for better or worse?
- In what ways?
- Were there certain members of staff that you relied on when you were in hospital?
- Did you see a bereavement midwife or counsellor?
- After you left hospital, did you have any further contact with any of the staff?
- With whom and when (i.e. subsequent pregnancy)?

3. Counselling and decision-making

How did hospital staff help you through such a difficult time?

- *In what ways did staff support you after [name of baby] died?*
- *What were the things they did that were helpful?*
- *Can you explain why those things were particularly helpful?*
- *Was there anything they did that you found particularly upsetting?*
- *How do you think they could they have done things differently?*

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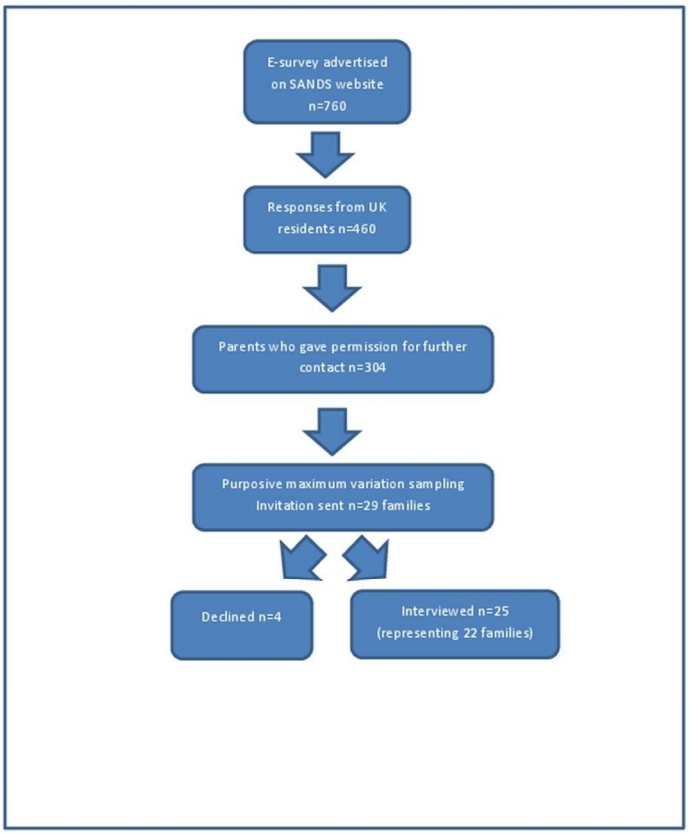
COREQ participant selection flow diagram/Figure 1



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