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All bereaved parents are entitled to good care after stillbirth: a mixed-methods multicentre study (INSIGHT)

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Objective To understand challenges in care after stillbirth and provide tailored solutions.

Design Multi-centre case study.

Setting Three maternity hospitals.

Population Parents with a stillborn baby, maternity staff.

Methods Thematic analysis of parent interviews and staff focus groups and service provision investigation.

Outcomes 1 Themes; 2 Triangulation matrix; 3 Recommendations.

Results Twenty-one women, 14 partners, and 22 staff participated.

Service Provision: Care for parents after stillbirth varies excessively; there are misconceptions; post-mortem does not delay follow-up.

Presentation: Women 'do not feel right' before stillbirth; their management is haphazard and should be standardised.

Diagnosis: Stillbirth is an emergency for parents but not always for staff; communication can seem cold; well-designed bereavement space is critical.

Birth: Staff shift priorities to mother and future, but for parents their baby is still a baby; parents are not comfortable with staff recommending vaginal birth as the norm; there are several reasons why parents ask for a caesarean; better care involves clear communication, normal behaviour, and discussion of coping strategies.

Post-mortem: Parents are influenced by discussions with staff. Staff should 'sow seeds', clarify its respectful nature, delineate its purpose, and explain the timescale.

Follow-up: It is not standardised; parents wish to see their multi-professional team.

Conclusions There is unacceptable variation in care after stillbirth, and insensitive interactions between staff and bereaved parents. Understanding parents' needs, including why they ask for caesarean birth, will facilitate joint decision-making. Every bereaved parent is entitled to good, respectful care.

Keywords Bereavement, communication, mode of birth, post-mortem, stillbirth, training.

Tweetable Abstract Care too varied & interactions often insensitive after stillbirth; national pathway & training urgently needed

*The INSIGHT Study Group also included: Alex Heazell, Tim Draycott, Cathy Winter, Jemima Hillman, Rachel Cox, Jacqui Lewis, and Louise Davey as representative of a maternity lay/patient panel for research.

Plain Language Summary**Why and how was the study carried out?**

Previous studies have shown that improving care after stillbirth is important for families. We investigated the opinions of bereaved parents and maternity staff to find ways to improve care.

At three hospitals in 2013, all women who experienced a stillbirth were invited to an interview along with their partners. Thirty-five parents of 21 babies agreed to participate. Twenty-two obstetricians and midwives took part in focus group discussions.

What were the main findings?

- Care was often not as good as it should and could be. Communication with parents was not always as sensitive as they would have liked because staff did not have appropriate training.
- Some women reported they did not 'feel right' before going to hospital. Once they arrived, there was no standard approach to how care was given. Sometimes there were long delays before the death of the baby was confirmed and action was taken.
- After it had been confirmed that the baby had died, staff focussed on the mothers' needs, but the parents' priorities were still with their baby. There were several reasons why parents asked for a caesarean birth that staff had not considered.
- Staff influenced parents' decisions about post-mortem examinations. Parents found it helpful when staff explained the respectful nature and purpose of the examination.
- After discharge from hospital, there was no consistent plan for how follow-up care would be given. Parents would have liked more information about their next hospital appointment.

What are the limitations of the work?

The parents interviewed depended on their memories of the details of the care, which happened some time ago. In staff group discussions, junior doctors may not have spoken openly because there were senior doctors present. Further research is necessary to understand and improve care globally.

What is the implication for parents?

Every bereaved parent is entitled to the best possible care after stillbirth, but some do not get good care. Parents and staff made suggestions that can help to develop processes for how care is given after stillbirth. These suggestions can also inform staff training, so that every single parent is treated respectfully and participates in decision making.

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Introduction

In the UK, about 4000 babies per year are stillborn.¹ Globally, the figure is about two and a half million, yet stillbirth did not feature until recently on the global agenda.² Breaking the silence on stillbirth is one of 'parents' most heartfelt wishes³ and has at last become a global priority.² Systematic reviews of more than 200 studies show that the socio-economic impact of stillbirth on society is immense, ranging from stigma to disenfranchised grief; broken relationships to long term impact on the wider family; unresolved grief to clinical depression; chronic pain to substance use; increased use of health services to employment difficulties; and from staff despair to resignation.⁴ There is a lack of comprehensive programmes to support and guide staff. The few interventions that exist have had little or no impact, perhaps because they have not been mapped to the actual problems in bereavement care.⁴

Many problems stem from inadequate staff preparation. A survey of over 2000 UK staff found that one-third did not have satisfactory training to counsel parents after

stillbirth,⁵ and an international guideline identified an urgent need for research to improve care and experience.⁶ A survey of 473 parents showed that fewer than half of the parents felt involved in the decision-making process after stillbirth.⁷ A confidential enquiry of 133 term stillbirths showed wide variation in care, including inadequate communication between health professionals and parents.⁸ Interactions between parents and staff have been described as clumsy and insensitive,^{8,9} with partners ignored and little attention to women's needs,⁹ leading to a lasting negative impact on bereaved parents' memories.¹⁰

The need to improve care after stillbirth is urgent and has been reiterated in the NHS Maternity Review¹⁰ and two briefing notes for the UK parliament.^{11,12} What has not been known is how to effect improvements. The sparsity of empirical evidence and lack of awareness thereof has meant that teams draw on practice experience, which inevitably involves assumptions and misconceptions that might harm parents and their relationship with the health system. The aim of the INSIGHT study was to conduct an in-depth investigation of bereaved parents' perspectives and the

main challenges for staff that care for them, and identify how to improve care with specific examples of good and bad practice.

Methods

Three hospitals in the South West of England participated in the INSIGHT Study. All women and their partners/companions were invited to participate in a semi-structured interview if they had experienced a late intrauterine fetal death (gestational age of more than 23 weeks and 6 days) between January and November 2013. All obstetric consultants, obstetric trainees (level of training ST4 and above) and senior midwives (>5 years' experience, including caring for parents after stillbirth) working during the study in the three maternity units (Bristol Southmead Hospital, Gloucester Royal Hospital, and Taunton Musgrove Park Hospital), were invited to participate in focus groups. Service provision (audit, case notes, and governance) data were collected in each unit to provide context.

The study methodology, including the schedules for the semi-structured interviews and focus groups, were designed by a team comprising the clinical researchers (DS, CC, CW, AE, and TD), a bereaved parent co-investigator (CS), and two experienced qualitative researchers (SJ and KG), with input from a lay Public/Patient Involvement (PPI) panel and a multi-professional Project Advisory Board (PAB) with representation from Sands, the stillbirth and neonatal death charity. The topics for discussion were agreed in advance with the bereaved parent co-investigator, based on her experience supporting other bereaved families through Bristol Sands. The topics were grouped under four main areas — diagnosis and breaking bad news, mode of birth, post-mortem discussions, and follow-up period and consultation — based on the gaps previously identified by the authors during development of an international stillbirth guideline⁶ and the experience of the clinicians and the bereaved parent co-investigator. The qualitative researchers made suggestions about the ordering, wording and tone of the questions to facilitate engagement by the participants.

To recruit for the parent interviews, the PPI panel and the bereaved parent co-investigator recommended that the midwife who cared for the mother initially approached the bereaved parents on the day they were discharged from the hospital and were due to return to the community after the stillbirth. Women and their partners were given a brief information leaflet and were asked to indicate whether they agreed to receive further information using their preferred communication method (email or post). Those who agreed were sent a Research Pack six weeks after the initial discharge from hospital. The research team

contacted the parents by telephone approximately one week later. If they wished to participate, with or without their partners, the researcher recorded their consent. The final part of the call was to inform the parents that they would be contacted by the qualified (PhD) and experienced (female)¹³ psychologist (KG) to set a convenient date, time and location for the interview after their follow up appointment with a hospital consultant.

The interviews with parents were conducted at a place chosen by them, either at home or in a private room at the hospital away from the maternity unit. Each interview started with a familiarisation period. KG followed the interview schedule (Appendix 1a), using clarification questions and prompts as necessary. The interviews lasted one to two hours and were audio-recorded.

For the focus groups, all staff were initially emailed general study information. A second email was sent to all eligible staff inviting them to participate. Once at least two healthcare professionals from each professional group within each hospital had volunteered to participate, the dates and times for the focus groups were arranged. If further healthcare professionals volunteered to participate, they were encouraged to attend, up to a maximum of 10 participants per focus group.

The focus groups were conducted in private rooms within each hospital by an experienced chartered psychologist (SJ), and facilitated by a research midwife and another experienced qualitative researcher. The focus groups lasted one to two hours, and followed a specified schedule (Appendix 1b). They were also audio-recorded.

All audio recordings were transcribed verbatim and checked for accuracy with the aid of the field notes. For thematic analysis, a six-stage process was followed:¹⁴ familiarisation with the data; generation of initial codes; searching for themes; reviewing themes; defining themes; and naming themes. The two qualitative researchers (SJ+KG) conducted the analyses, with supervision and consultation from the wider team. Psychosocial issues and influences on participants' experience within each case were identified before considering common themes that transcended cases, with additional consideration to identify and describe diverse cases and the full range of experience.

Issues arising from the interviews and focus groups were examined and explored alongside a range of service provision data to determine their factual status. After the interviews and focus groups had been transcribed and checked, SJ and KG identified the required data. The list was extensive and covered a wide range of supplementary data from hospital floor plans with equipment identified and staffing rotas, to clinical notes and blank copies of relevant documents (e.g. post-mortem consent forms). The clinical research fellow and the research midwives contacted local leads within each hospital and audited the clinical notes of

all the stillbirth cases to establish timelines for each parent's journey.

We did not know *a priori* what the defining element would turn out to be. Possible examples for defining case studies had included: 1. Following diagnosis, women are offered one of three possible mode of birth choices, with those receiving their choice possibly having a very different experience from those who did not; 2. Geographic factors - women in more urban areas might have been better served than women in more rural locations; 3. Maternity unit factors - management, and therefore women's experiences of care, might vary significantly between units. However, no women in this study were offered a choice of mode of birth, with geography seemingly not a significant factor: the data from the three different maternity units did not differ in any significant ways. The factor that determined the structure (caseness) seemed to be the point at which the baby died. In this report, we focus on the data from the three maternity units relating to the experiences of fetal death diagnosed before labour.

To triangulate the findings from the data sets (parent interviews and staff focus groups) at the interpretation stage,¹⁵ the investigators examined them and developed a triangulation matrix. The two data sets were described as showing *convergence* when they generally agreed, *complementarity* when they described perspectives of the same issue, *dissonance* when they had contradictory findings, and *silence* when issues were discussed in one data set but not the other.¹⁵ The analysis and the ensuing recommendations were agreed in interactive investigator meetings and at the Project Advisory Board. Data saturation was achieved.

Full ethical (Ref: 12/SW/0330; NRES Committee South West - Central Bristol) and NHS research and innovation (Ref: 2762) approvals were obtained by a dedicated team including the bereaved parent co-investigator and the PPI panel representative.¹⁶ Written consent was obtained from all participants. The study adhered to COREQ principles.¹³

Patient involvement

A bereaved parent co-investigator and a patient panel were involved from the outset in all aspects of study conception, design, development of study documents for recruitment and consent, ethics approval,¹⁶ project management and steering, analysis and interpretation, and co-authorship of this manuscript.

Results

Data were collected from January 2013 to November 2013 from participants in three maternity units in the South West of England. Thirty-three stillbirths were diagnosed during this period; 21 of the mothers (64%) and 14 of

their partners agreed to participate in the study. One case involved death of one twin and survival of the other (surviving multiple), and four cases involved intrapartum stillbirths. These five cases will be reported separately. We focus in this report on the 16 remaining cases: singleton stillbirths with the fetal death diagnosed before the onset of labour. Additionally, three staff focus groups took place, one in each maternity unit. Between six and nine participants took part in each group, with a minimum of two obstetric consultants, two senior obstetric trainees, and two senior midwives per group, for a total of 22 participants (reported in aggregate without demographics to maintain confidentiality).

The themes arising from the parent interviews and the staff focus groups are summarised in Table S1 alongside example quotes. In addition to the four areas selected *a priori* (diagnosis, mode of birth, post-mortem, follow-up), another area featured strongly in parents' remarks even though not specifically prompted: the signs and symptoms preceding diagnosis and leading to presentation at the hospital. For staff, training and the emotional aspects of birth were also prominent and overarching.

When comparing the recounted experiences and opinions between parents and staff, there were areas of convergence or complementarity, but also areas of dissonance where the perceptions and opinions differed, and erroneous assumptions caused tension and interactions that could be viewed as insensitive. These areas are summarised in Table 1, alongside service provision (contextual) data and multidisciplinary recommendations arising from the interpretation of the integrated evidence, including specific suggestions by parents and staff.

In summary, despite each hospital having a guideline on how to manage intrauterine fetal death, there was a great deal of variation within and between hospitals in how the mothers' symptoms and signs were managed initially, and in how diagnosis was undertaken and reported to parents. Moreover, women were told that reduced fetal movement is an emergency, but when they reached the hospital they were not always treated by staff with any apparent sense of urgency. This was confusing, and parents did not like being left on their own for long periods of time without information. Some examples of the variation in diagnosis are given in Box 1. Figure 1 shows the large variation in timings between presentation and first scan, and between presentation and first intervention (induction of labour or caesarean birth), with case 14 having long delays before both diagnosis (being sent home for the stillbirth to be confirmed the next morning) and intervention.

Whereas families often asked for a caesarean birth, this was considered unacceptable by staff and gave rise to significant dissonance and tension, including two patient complaints in one maternity unit, largely because of lack of

Table 1. Triangulation¹⁵ and recommendations

Theme	Triangulation: Parents vs Staff	Multi-centre service provision audit	Recommendations for training, practice and policy
Signs and Symptoms	Silence – Signs and symptoms did not arise in the staff focus groups but were a critical component of care for parents even if not specifically asked about them.	<ul style="list-style-type: none"> The variation in management of the initial symptoms was so varied and haphazard – was likened to a ‘game of snakes and ladders’ 	<ul style="list-style-type: none"> Antenatal notes should make women aware of stillbirth and signpost them to further information There is a need to educate women and their partners about getting symptoms that are of concern and out of character to be checked urgently Every obstetric unit should have a protocol for primary care referral for suspected fetal death and an integrated care pathway for management once in hospital Healthcare professionals should be trained to deliver consistent care in response to worrying signs and symptoms
Diagnosis	<p>Convergence – Both a well-designed maternity unit and a specific care pathway are necessary</p> <p>Complementarity – The initial diagnosis of stillbirth is urgent but difficult for parents and staff alike. Expertise and training in diagnosis by scan were often missing. There was a great deal of variation within and between hospitals in how the diagnosis was undertaken and reported to parents. The main common characteristic was delay and deferral, particularly at night.</p> <p>Dissonance – For parents, management always remains ‘urgent’ whereas for professionals this urgency stops after the first scan, sometimes even before final confirmation. Parents valued personal space but not being left alone for long periods of time without information.</p>	<ul style="list-style-type: none"> There was large variation in the time taken to confirm diagnosis (Figure 1) Initial assessment to confirm diagnosis was possible in a private room only in one maternity unit; in a curtained area in the other two units 	<ul style="list-style-type: none"> Every unit should have private room 24/7 for confirming the diagnosis of stillbirth with scan and for giving parents time afterwards Every unit should always have available at least one professional experienced in confirming with certainty the diagnosis of stillbirth and trained in straightforward, empathic, but not over-emotional (‘touchy-feely’) communication Training in breaking the bad news should include all the professionals likely to be involved; for example, sonographers. The professional undertaking the scanning should warn parents about the silence during scanning and be aware of their non-verbal cues There is a range of grief reactions anticipated by psychological theories but not by maternity staff; healthcare professionals need structured training to manage these reactions Staff need to be aware of the importance of keeping parents informed of what is happening and sowing seeds slowly, along with well written information and normal expressions of empathy A private space is necessary for privacy, not for abandonment
Birth and Aftercare	<p>Convergence – Parents and staff agree that parents’ usual first reaction is to ask for a caesarean</p> <p>Dissonance – Staff automatically shift priorities to the mother, physical issues, and future pregnancies, whereas for bereaved parents their baby is still a baby. Staff wrongly assume that all families ask for a caesarean as the easy way out, whereas there are several different reasons (Panel B) why bereaved parents ask for one</p>	<ul style="list-style-type: none"> All units had a dedicated bereavement suite for vaginal birth. All units strived for 1:1 midwifery care, but it was not always possible. Two women had a caesarean for medical reasons (low placenta, previous history) There were two formal complaints from bereaved parents in the last 3 years in one unit, related to mode of birth; asking for a caesarean that was refused 	<ul style="list-style-type: none"> Staff should not automatically change focus away from the dead baby, as it creates tension To enable joint-decision making on mode (and timing) of birth, staff should first explore the reason(s) why families ask for a caesarean Discussions of mode of birth should include the thorough preparation of parents for every step of the process, and conclude with the development of a revised parent-centred birth plan One-to-one care is as important for bereaved parents as for other women in labour; arguably even more so given their emotional strain

Table 1. (Continued)

Theme	Triangulation: Parents vs Staff	Multi-centre service provision audit	Recommendations for training, practice and policy
Consent for Post-Mortem examination (PM)	<p>Convergence – Discussions with staff influenced parents significantly in their decision making</p> <p>Dissonance – Some staff found the PM consent forms onerous, but parents did not as long as their completion was supported by discussion with a professional they trusted. Some parents thought staff discouraged them from having a PM.</p>	<ul style="list-style-type: none"> • The role of chaplaincy varied among units • 57% consented to PM 	<ul style="list-style-type: none"> • The influence of all staff on decision-making makes critical their appropriate training to understand and communicate the purpose and respectful nature of PM and their ability to explain the role of staff involved in PM and the local processes and time-scales for PM • Not finding a reason for stillbirth is useful in its own right and should be framed in positive not negative terms
Follow-Up	<p>Convergence – Parents and staff agreed that the period between initial hospital discharge and follow-up consultation is characterised by delay, lack of information for parents, and varied support.</p> <p>Dissonance - Healthcare staff tend to assume that primary care (GPs, community midwives, health visitors) automatically continues care after parents are discharged, and follows-up and supports parents, including providing the appropriate diagnosis and management of psychological issues, counselling needs, and risk of depression. These assumptions are in contrast with what bereaved parents experienced in this study.</p>	<ul style="list-style-type: none"> • Two of the three units had a bereavement midwife, one without dedicated job description • The frequency, type, and number of people involved in follow-up contacts varied among cases and units • One unit offered hospital-based counselling • Average time to follow-up was 71 days with PM and 73 days without PM 	<ul style="list-style-type: none"> • Bereaved parents should be given information at initial discharge, including a single point of contact in the follow-up period • Care should be streamlined and standardised, including test result reports and letters • For follow-up consultations, every unit should provide a dedicated private space, a named known professional, and a pre-determined structure to the meeting and the output of the hospital follow-up consultation; the consultation should include assessments for pathological/complex grief • Better collaborative care at the interface between hospital and community is needed urgently
Staff Training in Caring for Parents with Stillbirth	<p>Silence – Training was not addressed by parents in this study.</p>	<ul style="list-style-type: none"> • One unit had teaching sessions provided by a local charity • Another had teaching suspended because there was no time to fit it in • The third unit started a 10-minute training session for staff after the INSIGHT study was completed 	<ul style="list-style-type: none"> • Dedicated training in care after stillbirth is needed and should focus on supporting the implementation of an evidence-based and parent-centre integrated care pathway • Training should include: evidence-based principles of care and management, common challenges, difficult situations and how to address them, psychological theories and their application in bereavement care, and good communication principles as well as techniques for self-composure and dealing with expected and unexpected grief reactions, the post-mortem consent process, and the necessary information to be given/discussed at discharge from hospital and in the community • Training should address common erroneous assumptions that often compromise care • Training of out-of-hours staff in ultrasound scanning skills to be able to diagnose intrauterine death competently and confidently is critical in providing 24/7 optimal care • Dedicated training modules are necessary for all staff likely to come into contact with bereaved parents including, for example, receptionists and porters

Box 1. Variation in Diagnosis

- Mother being given the diagnosis before the second confirmatory scan had been performed
- Mother had a physical examination before staff started to try to find the baby’s heartbeat
- One mother was left sitting in the waiting room and was then seen in an ordinary room in the unit
- A long delay while staff changed shift – the mother reported being left sitting for 20 to 30 minutes with nothing being done
- Being moved between several rooms during the process of diagnosis with no explanations as to why this was happening
- Being made to wait for two hours alone for a final confirmatory scan despite being in labour with contractions coming every 2 minutes (it turned out later that the staff on duty had not called the consultant in)
- One woman reported being left on her own with her Mum “for ages” after she had been diagnosed
- One couple was sent home to return the next morning for confirmation of the diagnosis

Box 2. Reasons why bereaved families often ask for a caesarean birth

Parents

- To restore women’s sense of control by giving them the option to choose the timing and mode of birth
- Parents have not prepared sufficiently for a vaginal birth process, particularly with the added complexity of a stillbirth
- To shorten the (variably long) process from diagnosis to eventual birth and discharge
- Parents’ wish to avoid labour pains

Baby

- Some parents believe that a quick caesarean section followed by resuscitation might save the baby
- Because their baby is still a baby to the bereaved parents, they do not appreciate the automatic shift of priorities to the mother and her future pregnancies, and the consequent recommendation of vaginal birth
- For some parents, a baby that has died might still feel pain, and caesarean birth is perceived as less traumatic for the baby

staff awareness of the several different reasons why parents (and their families) might ask for a caesarean birth (Box 2). Parents were not prepared for a vaginal birth, which felt imposed on them by staff. There was provision of a private space for birth in all three units, but provision of 1:1 care was not always possible (Table 1).

With regards to discussions around post-mortem examination of the baby (PM), parents reported many decisions to make once their baby was born. Parents stated that at the time of the PM discussion they had not realised how

important the choices they made during this time might eventually be. Some parents had not consented to a post mortem, but stated that they would have agreed to a PM if the healthcare professionals had convinced them that it was respectful and useful. Parents found useful the ‘drip feeding’ of information by the healthcare professionals and the trusting relationships they formed, especially with the midwives.

Timeline of events: First presentation to first intervention

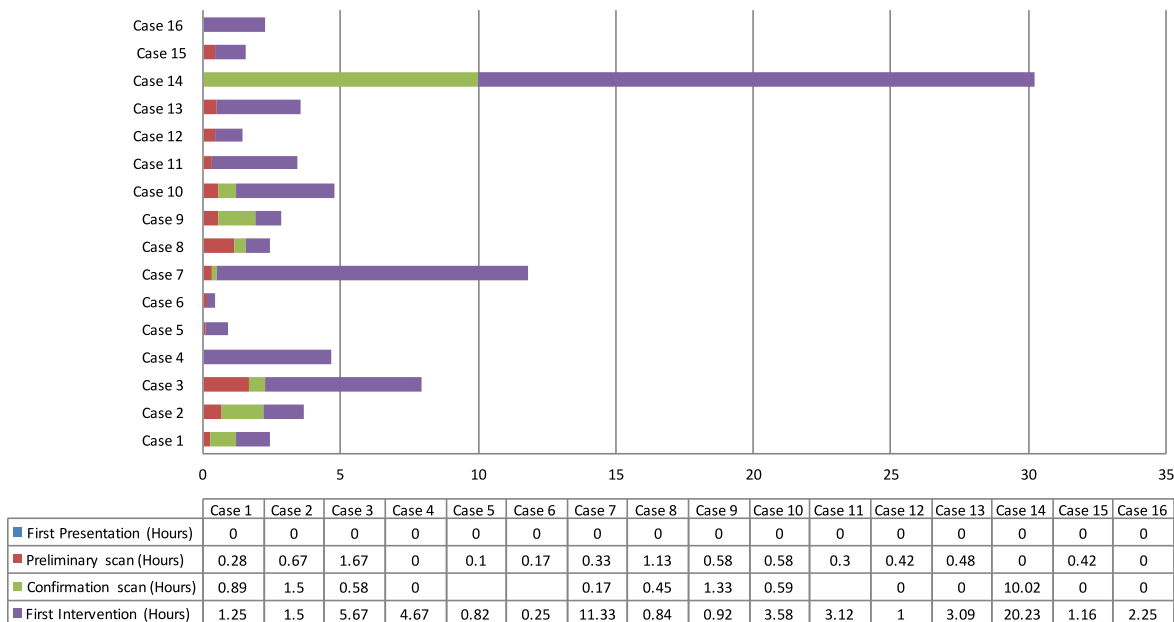


Figure 1. Variation in Urgency (0 indicates immediate, empty indicates not done)

Table 2. Comparison and contribution to the literature

	Systematic reviews ^{19,20}	Listening to parents national survey ⁷	MBRRACE-UK national enquiry ¹	What INSIGHT adds: Summary
Signs and Symptoms	<ul style="list-style-type: none"> Staff should support parents to express their concerns 	<ul style="list-style-type: none"> Two thirds felt something was wrong before their baby died At the point when parents felt something was wrong, only 57% felt that their concerns were taken seriously 		<ul style="list-style-type: none"> There is a need to educate both parents and staff; but also to have systems in place to support training (tools, pathways)
Diagnosis and Breaking News	<ul style="list-style-type: none"> Parents have a range of emotions and reactions Parents appreciate having options and adequate time to consider them 	<ul style="list-style-type: none"> Less than half were involved in decision making One third did not feel listened to 	<ul style="list-style-type: none"> Examples of poor practice included one woman sent home to return the next day for a repeat scan to confirm the fetal death, and one who waited 2 hours 	<ul style="list-style-type: none"> There is need to train ALL relevant staff in ultrasound scanning, but also in communication and empathic skills
Birth and Aftercare	<ul style="list-style-type: none"> Support and Information from staff may help parents who feel emotionally unprepared for a vaginal birth Pain relief options should be fully discussed 	<ul style="list-style-type: none"> Only 8% were offered a caesarean birth One in five were left alone and worried Less than half had a room away from live crying babies 	<ul style="list-style-type: none"> Care was sometimes compromised by delays in analgesia, absence of the midwife for several hours, women labouring on the antenatal ward, and delays in care without reason 	<ul style="list-style-type: none"> Staff should be educated in discussing mode of birth with bereaved parents, without forgetting that a baby is always a baby (even if it has died)
Consent for Post-Mortem (PM)	<ul style="list-style-type: none"> Staff should be trained to provide tailored PM discussions Many factors influence PM consent Parents may regret PM decisions Long delays and inconclusive PM results cause distress 	<ul style="list-style-type: none"> One in eight were not asked about a PM Less than half found out the results of the PM within 8 weeks 	<ul style="list-style-type: none"> One third of cases had no documented PM offer Only two thirds of parents were seen within 12 weeks 	<ul style="list-style-type: none"> Discussions with all staff influence the parents' decision more than staff think
Follow-Up	<ul style="list-style-type: none"> Emotional support is necessary Need information on what to expect postnatally The debriefing and follow-up appointment help resolve uncertainty Clear care pathways are required at the interface between primary and secondary care 	<ul style="list-style-type: none"> A third were not given information about lactation suppression There was gap in care and handover between services Care was variable, with staff uncomfortable about calling or visiting 	<ul style="list-style-type: none"> Only half had documented lactation suppression discussion There was lack of documented handover to other healthcare professionals and organisations 	<ul style="list-style-type: none"> Delays, substandard care, and lack of continuity can be prevented with streamlined pathways and should not be blamed on investigations (e.g. PM)

The median time to follow-up consultation (with a consultant obstetrician) was very similar, regardless of whether parents consented to a post-mortem examination of the baby: 71 days with a PM and 73 days without a PM. Between their discharge from hospital and their return for the follow-up consultation, parents would have appreciated being given information as to who was their nominated caregiver, the timescale involved, and the purpose of the follow-up consultation. There were also misunderstandings, delays, lack of clarity, and some inappropriate

settings (for example antenatal clinics) for the follow-up consultation.

Discussion

Main findings

The INSIGHT study reveals that, despite the best intentions of staff who care for bereaved parents, care after stillbirth is often not as good as it should and could be. There is no standardised approach to the management of the initial

Table 3. Proposed intervention to improve bereavement care (based on the findings and recommendations arising from the INSIGHT study and supported by the literature)

Integrated care pathway (ICP)	Staff training	Notes
Signposting in maternity notes for information on stillbirth and reduced fetal movements	Training in ICP implementation Common challenges and ways to address them	No safety tool works without training ²¹
Referral process for reduced or absent fetal movements	Triage of reduced fetal movements in compliance with national standards	Supported by information leaflets that empower parents
Urgent diagnostic and confirmation scan	Breaking bad news skills Responding to grief reactions Emotional composure techniques	Scan training outside the remit of bereavement care intervention but crucial
Identify and inform responsible senior clinician	Communication and empathic skills	
Accompany parents to private space	National stillbirth guidelines	Module on diverse reasons for caesarean birth requests
Discussion of mode and timing of birth	Patient-led consent process	
Interval to allow parents to consider options	Issues that affect parents (e.g. support for seeing and holding the baby)	Birth plan specific to stillbirth (not 'labour as usual') and including analgesia
Labour and birth: New birth plan	Module on involving partners	
Discussion of post-mortem (PM) and other investigations	Use of PM guidance, proformas, and consent forms Issues relevant to diverse cultures and religions	Both before (sow the seeds) and after birth
Initial discharge from hospital	Information to include in discharge	Use evidence-based tools (e.g. checklists) ²⁰ to support training and pathway implementation
Assigned point of contact		
Follow-up consultation with maternity professional(s) (Invite wider family and involve multidisciplinary team)	Items to include in discussion	Use evidence-based tools (e.g. checklists) ²⁰ to support training and pathway implementation
Referral pathway for mental health support and/or counselling	Identification of mental health symptoms and/or need for counselling	

presentation, resulting in inconsistency and at times severe delays before diagnosis is confirmed. Once the diagnosis is made, any urgency in management disappears for staff but not parents. Assumptions, misconceptions, and lack of staff training result in insensitive interactions and lack of joint decision-making, particularly with regards to mode of birth or the decision to have a post-mortem examination of the baby. After discharge from the hospital, there is no standardised pathway or protocol for seamless handover and transition across caregivers. Parents and staff have described how care could be improved, including through better education.

Strengths and limitations

This is the first in-depth study to investigate and triangulate with a specific framework the experiences and recommendations of bereaved parents and the staff who care for them, along with service provision data to put the findings into context. For example, the delays and inconsistencies in management captured by the INSIGHT study were not just reported but confirmed, and the reasons clarified for the first time in the literature.

The staff focus group discussions could have been inhibited by the presence of senior clinicians, but this was not observed. For example, junior doctors freely commented on their lack of scan training. However, some findings might reflect opinion rather than clinical reality; ethnographic observation would be needed for confirmation.

With regards to parent interviews, they relied on recall. We had therefore arranged for the interviews to take place reasonably soon after the stillbirth, at a time suitable for capturing the parents' experience. Some issues — for example 'not feeling right' before diagnosis — could be explored in more detail in a longitudinal study of late pregnancy.

Whereas the study took place in three maternity hospitals in the same region (southwest England), which might reduce generalisability, their catchment areas had varied demographics. Moreover, comparison to the worldwide literature (Table 2) revealed many similarities; some findings and recommendations may be applicable to other high- and middle-income settings. Moreover, the INSIGHT study went beyond the literature to reveal some previously Unreported misconceptions with regards to mode of birth, for example, and to provide specific recommendations to implement

improvements, inform education programmes, and help design integrated care pathways and tools to support parents and staff alike. We acknowledge that the findings are not directly applicable to low-income countries or to parents from all cultures and religions, and further research is necessary to understand and improve care in other settings.

Interpretation

It is important to make prospective parents aware of the possibility of stillbirth before it happens. Stillbirth is ten times more common than sudden infant death syndrome,¹⁷ yet parents might only be aware of the latter. A brief mention of stillbirth in maternity notes alongside signposting to further information might strike the balance between scaring all women about pregnancy outcome and preventing them from being totally unprepared in the event. In the UK, awareness and management of reduced fetal movement has been prioritised¹⁸ in an effort to prevent stillbirths from happening. The INSIGHT findings show that educating parents about the symptoms and signs of stillbirth and, if they occur, having systems in place to manage them consistently, are essential to reduce the potential for harm^{4,19} that might otherwise occur.

INSIGHT has revealed that parents can be exposed to further avoidable harm because staff, particularly out-of-hours, might not have been trained adequately in either practical (ultrasound confirmation of fetal death) or communication skills that are necessary for effective and sensitive handling of the diagnosis. It might not be poor staff that fail parents, but poor training that fails staff.

Training for staff should move beyond standard technical and non-technical skills, and should start with a clear understanding of bereaved parents' reactions and the underlying reasons. The tension between staff and parents with regards to the latter's requests for caesarean birth, with reasons for this disconnect explored for the first time, is a clear example that care cannot and will not improve without first exploring the problems in depth. In INSIGHT, not a single set of bereaved parents was offered a choice between different modes of birth, similar to what had been shown in previous studies (Table 2) yet never fully understood. Moreover, the study revealed that the disconnect between staff and parents (Table 1) had led to complaints. It is obvious that staff should be trained to reach joint decisions, not by paternalistically resisting requests, but by appropriately preparing both parents for birth and afterwards, and supporting their desires to retain or regain some sense of control.²⁰ Staff should also be trained to focus on the current pregnancy, respecting the baby that has died, and not immediately shifting priorities to the future. It is also obvious that training staff in exchanging appropriate information with parents and maintaining a respectful attitude will help parents reach decisions that they will be less likely to

regret long-term such as in regards to mode of birth or post-mortem examination of the baby.

Table 3 synthesises the findings from INSIGHT to describe what an evidence-based intervention to improve bereavement care might look like. Additional components not addressed by INSIGHT might be necessary for a comprehensive intervention, for example involving parents in the hospital perinatal mortality review process.

Conclusion

Staff training alone will not suffice for improving care. Similar to surgical safety,²¹ it is the combination of evidence-based tools, integrated care pathways, and training in how to use these tools that is likely to improve care for bereaved parents after a stillbirth. It is imperative to standardise processes, while educating staff to address the parents' and their own needs, so they neither 'make it up as they go' nor are they or the parents 'scarred for life'. It is time to understand, time to educate, time to stop preventable harm after stillbirth. Every bereaved parent is entitled to good care.

Disclosure of interest

Full disclosure of interests available to view online as supporting information.

Authorship

All authors have made substantial contributions to the conception or design of the work, to the acquisition, analysis, and interpretation of data for the work, and to drafting the work or revising it critically for important intellectual content. All authors gave final approval of the version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part are appropriately investigated and resolved. Guarantor: Dimitrios Siassakos. The guarantor affirms that the manuscript is an honest, accurate, and transparent account of the study being reported, that no important aspects of the study have been omitted, and that any discrepancies from the study as have been explained.

Ethics and approvals

The study received full ethics (REC Ref No: 12/SW/0330; NRES Committee South West - Central Bristol) and NHS research and innovation (R&I Ref No: 2762) approvals. There was written informed consent from all participants, parents and staff. All authors had full access to all the data (including reports and tables) in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Themes & Quotes. ■

References

- Manktelow BN, Smith LK, Seaton SE, Hyman-Taylor P, Kurinczuk JJ, Field DJ, et al. MBRRACE-UK perinatal mortality surveillance report: UK perinatal deaths for births from January to December 2014. University of Leicester, UK. 2016 [https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK-PMS-Report-2014.pdf] Accessed 5 June 2017.
- Qureshi ZU, Millum J, Blencowe H, Kelley M, Fottrell E, Lawn JE, et al. Stillbirth should be given greater priority on the global health agenda. *BMJ* 2015;351:h4620.
- Horton R, Samarasekera U. Stillbirths: ending an epidemic of grief. *The Lancet* 2016;387:515–16.
- Heazell AE, Siassakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J, et al. Stillbirths: economic and psychosocial consequences. *The Lancet* 2016;387:604–16.
- Heazell AE, McLaughlin MJ, Schmidt EB, Cox P, Flenady V, Khong TY, et al. A difficult conversation? The views and experiences of parents and professionals on the consent process for perinatal postmortem after stillbirth. *BJOG* 2012;119:987–97.
- Siassakos D, Fox R, Draycott T, Winter C, for the Royal College of Obstetricians and Gynaecologists. Lateintrauterine fetal death and stillbirth. Green-top guideline No. 55. 2010 [https://www.rcog.org.uk/globalassets/documents/guidelines/gtg_55.pdf] Accessed 5 June 2017.
- Redshaw M, Rowe R, Henderson J, for the National Perinatal Epidemiology Unit, University of Oxford. Listening to parents after stillbirth or the death of their baby after birth. 2014 [https://www.npeu.ox.ac.uk/downloads/files/listeningtoparents/Listening%20to%20Parents%20Report%20-%20March%202014%20-%20FINAL%20-%20PROTECTED.pdf] Accessed 5 June 2017.
- Draper ES, Kurinczuk JJ, Kenyon S, editors. MBRRACE-UK perinatal confidential enquiry: term, singleton, normally formed, antepartum stillbirth. University of Leicester, UK. 2015. [https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK%20Perinatal%20Report%202015.pdf] Accessed 5 June 2017.
- Boynton P. Stories of stillbirth. *The Lancet* 2016;387:525.
- National Maternity Review. Better births. Improving outcomes of maternity services in England: a five year forward view for maternity care, 2016 [https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf] Accessed 5 June 2017.
- Montacute R, Bunn S. Bereavement care after the loss of a baby in the UK. Houses of Parliament Parliamentary Office for Science and Technology Postbrief 21. 2016 [file:///C:/Users/Acer/Downloads/POST-PB-0021.pdf] Accessed 5 June 2017.
- Montacute R, Bunn S. Infant mortality and stillbirth in the UK. Houses of Parliament Parliamentary Office for Science and Technology POSTNOTE 527, 2016 [file:///C:/Users/Acer/Downloads/POST-PN-0527.pdf] Accessed 5 June 2017.
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psych* 2006;3:77–101.
- O’Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ* 2010;341:c4587.
- Siassakos D, Storey C, Davey L, Insight Study Team. Stillbirth: public/patient involvement in sensitive research and research ethics. *BJOG* 2015;122:1111.
- Fretts RC. The stillbirth ‘scandal’. *BMC Pregnancy Childbirth* 2015;15 (Suppl 1):A11.
- O’Connor D. Saving babies’ lives: a care bundle for reducing stillbirth. NHS England, 2016 [https://www.england.nhs.uk/wp-content/uploads/2016/03/saving-babies-lives-car-bundl.pdf] Accessed 6 June 2017.
- Burden C, Bradley S, Storey C, Ellis A, Heazell AEP, Downe S, et al. From grief, guilt pain and stigma to hope and pride – a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BMC Pregnancy Childbirth* 2016;16:9.
- Ellis A, Chebsey C, Storey C, Bradley S, Jackson S, Flenady V, et al. Systematic review to understand and improve care after stillbirth: a review of parents’ and healthcare professionals’ experiences. *BMC Pregnancy Childbirth* 2016;16:16.
- Latibeaudiere M, Phillips J, Siassakos D, Winter C, Draycott T, Fox R. Implementation strategies – moving guidance into practice. *Obstetrician Gynaecol* 2013;15:51–7.