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Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences

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Abstract

Background

2.7 million babies were stillborn in 2015 worldwide; behind these statistics lie the experiences of bereaved parents. The first Lancet series on stillbirth in 2011 described stillbirth as one of the “most shamefully

neglected” areas of public health, recommended improving interaction between families and frontline caregivers and made a plea for increased investment in relevant research.

Methods

A systematic review of qualitative, quantitative and mixed-method studies researching parents and healthcare professionals experiences of care after stillbirth in high-income westernised countries (Europe, North America, Australia and South Africa) was conducted. The review was designed to inform research, training and improve care for parents who experience stillbirth.

Results

Four thousand four hundred eighty eight abstracts were identified; 52 studies were eligible for inclusion. Synthesis and quantitative aggregation (meta-summary) was used to extract findings and calculate frequency effect sizes (FES%) for each theme (shown in *italics*), a measure of the prevalence of that finding in the included studies.

Researchers' areas of interest may influence reporting of findings in the literature and result in higher FES sizes, such as; *support memory making* (53 %) and *fathers have different needs* (18 %). Other parental findings were more unexpected; Parents want *increased public awareness* (20 %) and for *stillbirth care to be prioritised* (5 %).

Parental findings highlighted lessons for staff; *prepare parents for vaginal birth* (23 %), *discuss concerns* (13 %), *give options & time* (20 %), *privacy*

not abandonment (30 %), tailored post-mortem discussions (20 %) and post-natal information (30 %).

Parental and staff findings were often related; *behaviours and actions of staff have a memorable impact on parents (53 %)* whilst staff described *emotional, knowledge and system-based barriers to providing effective care (100 %)*. Parents reported distress being caused by midwives hiding behind 'doing' and ritualising guidelines whilst staff described distancing themselves from parents and focusing on tasks as coping strategies.

Parents and staff both identified the need for improved *training* (parents 25 % & staff 57 %); *continuity of care* (parents 15 % & staff 36 %); *supportive systems & structures* (parents 50 %); and *clear care pathways* (parents 5 %).

Conclusions

Parents' and healthcare workers' experiences of stillbirth can inform training, improve the provision of care and highlight areas for future research.

 [Peer Review reports](#)

Background

2.7 million babies were stillborn in 2015 worldwide [1]. In the UK, 3286 babies were stillborn in 2013 [2]; approximately 10 bereaved families every day.

The experiences of bereaved parents were recognised in a series of papers in the Lancet as key to bringing about change [3]. The 2011 series identified stillbirth as one of the “most shamefully neglected” areas of

public health and recommended improving interactions between families and frontline caregivers [4], and made a plea for increased investment in relevant research [5]. In 2016, the Lancet Ending Preventable Stillbirth Series addresses progress against the goals laid out in 2011 [6]. The series emphasised the enduring economic, psychological and social costs of stillbirth which need to be addressed, not only by stillbirth prevention, but also by improvements in care for bereaved families. In 2014, the World Health Organization released a statement on preventing and eliminating disrespect and abuse during facility-based childbirth [7]. This respectful and comprehensive care should include the newborn [8] and not end with death; dignified maternal and newborn care matters to grieving parents [9].

Critically, the provision of care for families when a child is stillborn is vitally important to prevent short and long-term negative outcomes [10]. Current care for bereaved parents after a baby dies is inconsistent [11, 12], and parents are more likely to develop prolonged psychological problems if professional support is not given [13]. Bereaved parents have been identified as a high-risk group for complicated grief [14], with up to 25 % suffering severe symptoms years after the death of their baby [15]. The support received by the mother following the death of her child was the single most important factor in predicting the nature of the grief process that she would experience [16].

Midwives find caring for bereaved families stressful and emotionally challenging [17], with many

experiencing difficulty with this area of practice [18], feeling unprepared due to a lack of support and training [19, 20]. While women and their families interpret the experience of stillbirth as the birth and death of a baby and a major family tragedy, hospital staff appear to view it as a clinical problem. This mismatch of focusing on 'clinical' rather than 'personal' care appeared to cause distress to parents [21].

Despite the impact stillbirth has on both parents and staff, it remains an area in which most obstetricians and midwives receive little or no training [22, 23], and 31 % of those who received training said it was inadequate [24]. A survey of over 2000 UK staff found that one third of respondents reported unsatisfactory training to counsel parents about investigations after stillbirth [25].

In 2009, the Cochrane Collaboration published a systematic review of the support available for parents and their families following perinatal death [26]. Of the three trials identified for potential inclusion in the review all were excluded because of the high loss-to-follow-up rate. Therefore, no judgment could be made on the advantages or disadvantages of certain behaviours or management currently used in bereavement care. As a result, the review authors recommended other study designs should be used to inform practice.

No previous research has systematically analysed the available evidence on parents' views on the experience of going through a stillbirth, or key healthcare workers experiences of caring for couples dealing with a stillbirth. This systematic review

aimed to assess the current available evidence, extract findings and highlight key themes that may help to guide midwifery and medical management, training of key healthcare workers and development of support services dealing with bereaved parents in the future.

Methods

Objective

The objective was to review and meta-summarise studies of parents' and healthcare workers' experience of maternity bereavement care for stillbirth, in Western High-Income-Country hospital settings, with the aim of developing practical learning points that can be applied to clinical training for healthcare workers.

Design

The study was designed by a multi-professional research team, with experience in stillbirth research, to inform research, training, and ultimately improve care for parents who experience late (≥ 24 weeks gestation) intrauterine fetal death (stillbirth). Synthesis and quantitative aggregation (meta-summary) of qualitative data [27] was used as it allows aggregation and interpretation of studies that may be excluded from Cochrane reviews.

Search strategy

Search terms were formulated using the SPIDER Framework [28]. Due to poor systematic indexing of

qualitative research on many databases, all synonyms and North American variations for stillbirth were searched, alongside thesaurus terms on databases, to improve the sensitivity of the search strategy (Additional file [1](#)).

The databases searched included; AMED, EMBASE, MEDLINE, Psych INFO, BNI and CINAHL.

Databases were searched up to March 2014 by a medical librarian (SB). The initial search took place in November 2013 with monthly automated search updates via NICE evidence. Conference abstracts from the International Stillbirth Alliance and First Candle conferences have also been hand-searched for eligibility.

Eligibility criteria

The inclusion and exclusion criteria were set to optimise the number of relevant studies chosen for inclusion. Qualitative, quantitative and mixed-method studies that assessed parents' or healthcare workers experience of care after stillbirth were included. The meta-summary focused on Western High-Income Countries; European, North American, Australian and South African studies were included. Studies from other settings were excluded as healthcare provision and cultural and religious practices are likely to be sufficiently different to render aggregation with Western studies inadvisable. In relation to this, studies not available in English were excluded. As international definitions of stillbirth vary and many papers researched a combination of fetal loss types it was difficult to set a

gestational age for study exclusion without losing a large amount of relevant data therefore, only studies exclusively addressing miscarriage, fetal loss before 24 weeks, lethal fetal diagnosis or neonatal death were excluded. Studies addressing views of indirect family members were excluded. The words *coil*, *device* and *mirena* were set as exclusion criteria to reduce inappropriate cross-referencing with the shortened term for intrauterine device (IUD). No date limitations were set. All relevant studies with original data, from ethnography to large surveys, were eligible for inclusion. Conference abstracts that contained extractable findings were included. Review articles, dissertations and books were excluded.

Study selection

Combining search results provided an initial screen. Six investigators (AE, CC, CS, SB, SJ and DS) excluded studies by screening abstracts. Reasons for exclusion included: duplicates; topic not relevant to stillbirth care; topic not relevant to parent or staff experience; location of study non-western or low-middle income country; not available in English; review articles; dissertations. Disagreements on whether to include or exclude studies were discussed by the research team to reach a consensus. This generated a list of potential full text articles which were obtained (SB) and assessed independently by two investigators (AE and CC). Full text articles were excluded using the same criteria, with the addition of; no relevant findings found in data.

Data extraction

Data extraction was performed by two investigators (AE and CC). A data extraction form was developed to help standardize and log the data extraction process (Additional file [2](#)). In the validation phase, two investigators (AE and CC) completed the data extraction form for the same three papers and inter-rater reliability was concluded by consensus of the research team (AE, CC, CS, SB, SJ and DS). In the definitive phase two investigators (AE and CC) independently extracted findings from relevant papers.

Data analysis

Data analysis was based on the meta-summary approach, a quantitative aggregation of qualitative findings, developed by Sandelowski [[27](#)]. The method comprises: (a) extraction of relevant statements of *findings* from each report; (b) reduction of these statements into abstracted findings; and, (c) calculation of effect sizes. The primary research team (AE, CC, CS and DS) reviewed and discussed all of the extracted findings. With consensus the research team summarized the findings into thematic sentences. The thematic sentences were developed with clinicians in mind and written as learning points for healthcare professionals to help them improve care for bereaved parents.

In the method an inter-study matrix organizes reports by the abstracted findings, and an intra-study matrix organizes the findings by the reports, thereby allowing the same information to be seen in different

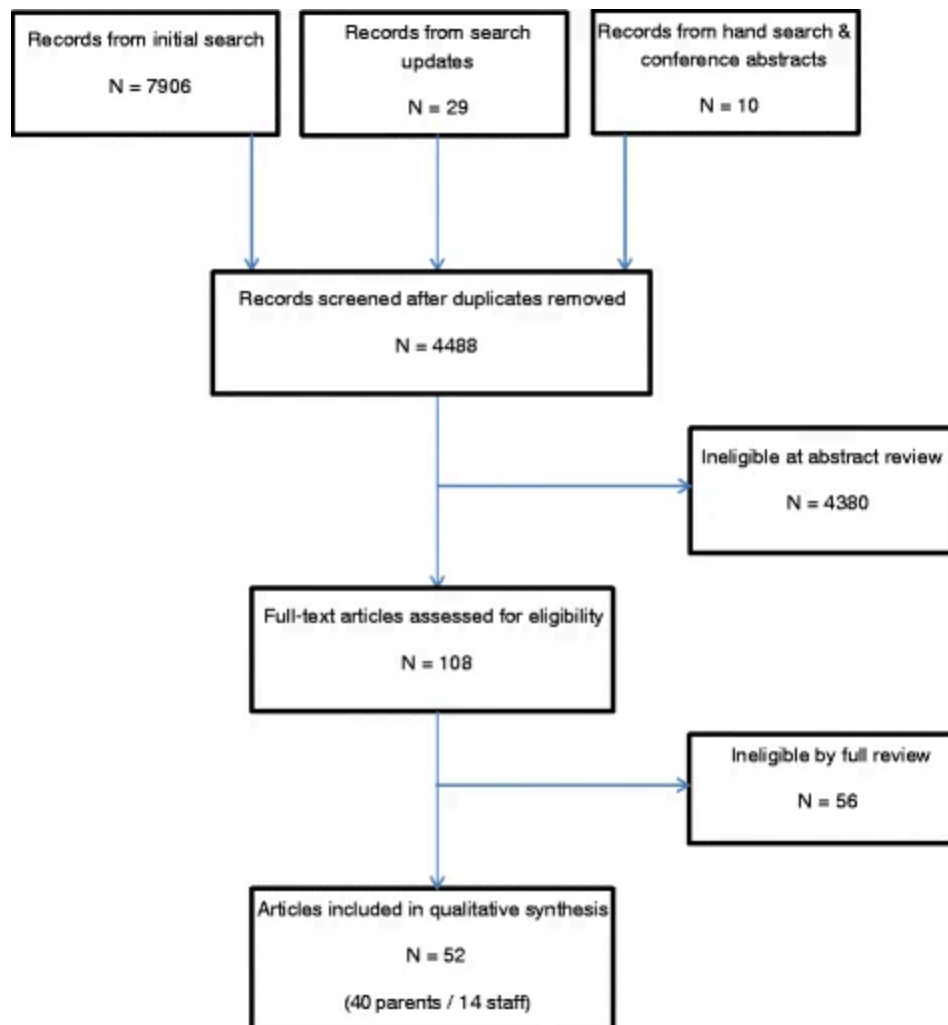
ways. The inter-study matrix is used to calculate the frequency effect size (FES) of each abstracted finding, which is defined as the number of reports containing the finding divided by the total number of reports [27]. The intra-study matrix is used to calculate the intensity effect size (IES), which is defined as the number of findings produced in each study divided by the total number of findings across all studies [27]. The calculation of effect sizes is a way to unite the empirical precision of quantitative research with the descriptive precision of qualitative research. The calculation of effect sizes constitutes a quantitative transformation of qualitative data to extract more meaning, verify the presence of patterns or themes across studies, and add a quantitative 'weight' to each finding and to each study. This method facilitates the interpretation and usability of the results for healthcare professionals. FES and IES were calculated for parent and staff studies separately.

Results and discussion

Study selection

The initial search strategy identified 7906 abstracts. An additional 29 abstracts were identified by database updates and 10 conference abstracts were identified by hand search. After duplication and eligibility screening 108 were selected for full text extraction. Of the 108 full-text papers reviewed 52 were eligible for inclusion (Fig. 1).

Fig. 1



PRISMA flow diagram. Legend: 52 studies eligible for inclusion; 40 parent studies and 14 staff studies (2 studies addressed both parents + staff)

Findings

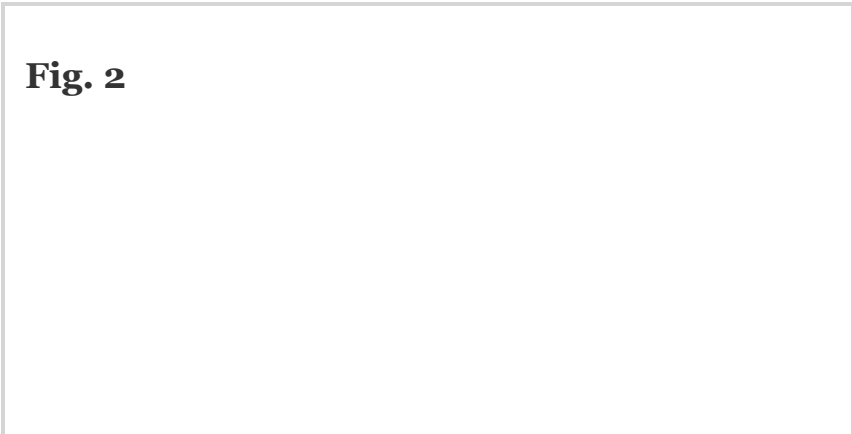
Of the 52 studies included, 40 articles related to parents' experiences and 14 to healthcare workers experiences of stillbirth care. The majority of papers reported questionnaire, interview and focus group studies, analyzed using a variety of qualitative methods and statistics. A few personal accounts were eligible for inclusion; study size therefore, varied from 1 to 2631 participants. Articles were published over an 18-year period from 1996 to 2013. Studies were conducted in nine countries. Parent studies

were conducted across eight countries (Table 1) and Staff studies were conducted across five countries (Table 2). Overall 623 individual findings were extracted from the studies. Twenty-three parent themes with thematic sentences were identified and used for calculation of FES (Table 3; Fig. 2) and IES (Additional file 3). Eight staff themes with thematic sentences were identified and used for calculation of FES (Table 4; Fig. 3) and IES (Additional file 4). Tables 3 and 4 present a representative selection of the extracted findings which were used by the research team to develop the thematic sentences; these tables help to describe the thematic sentences in more depth. A summary of each included study can be found in Additional files 3 and 4.

Table 1 Location of parent studies

Table 2 Location of Staff studies

Table 3 Parent thematic sentences



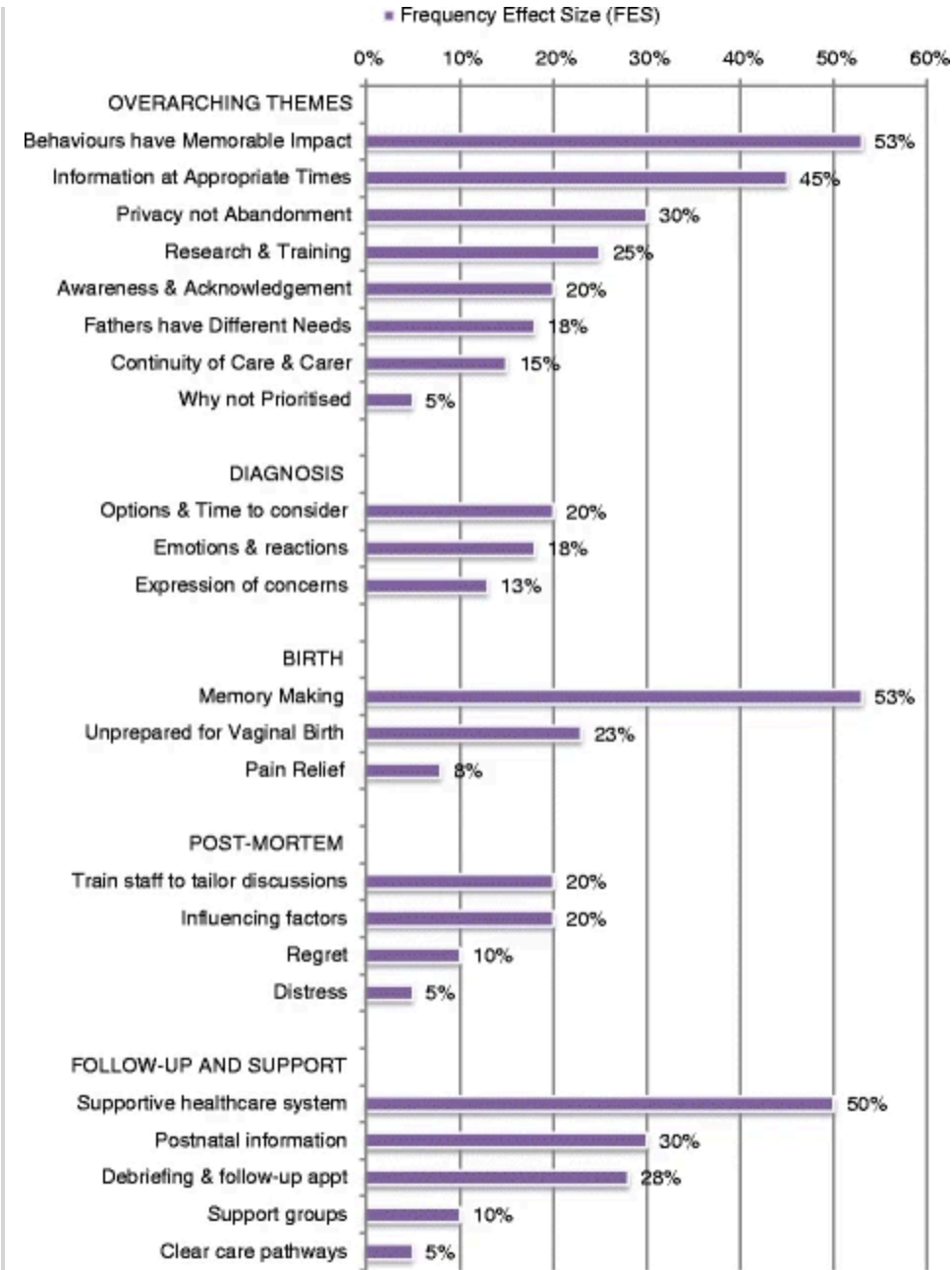


Chart of parent thematic sentence frequency effect sizes

Table 4 Staff thematic sentences

Fig. 3

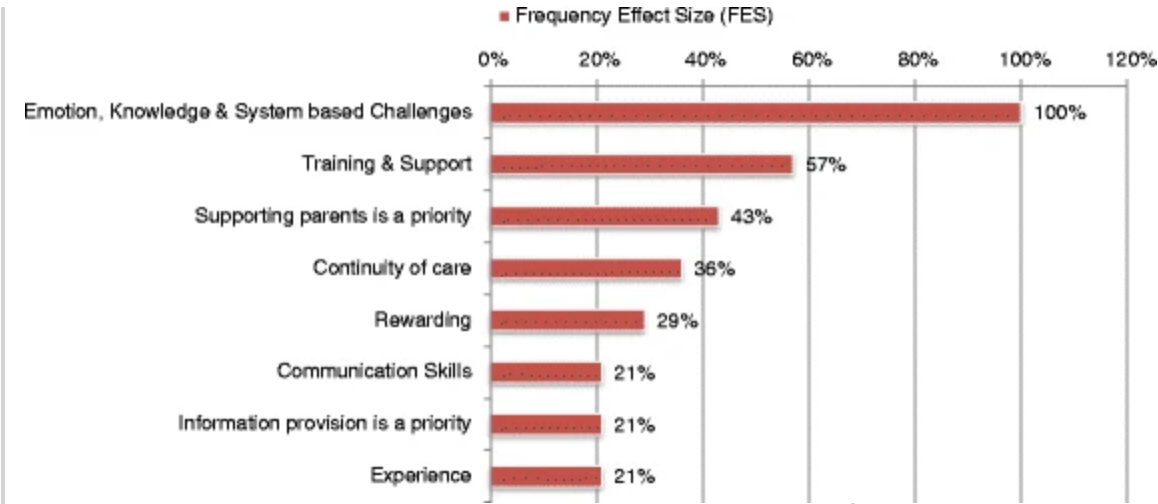


Chart of staff thematic sentence frequency effect sizes

Parent themes were catagorised by the area of care that they related to; *Diagnosis, Birth, Post-mortem*, or labeled as *Overarching* if reported in more than one of these areas. Staff themes were analysed and presented separately.

Overarching thematic sentences

1. Behaviours and actions of staff can have a memorable impact on parents, FES 53 % [21, 29–48] – All verbal and non-verbal communication with and around parents can have a memorable impact. Hospital policy, procedures and systems can cause distress to parents. See Table 5 for a completed list of positive and negative behaviours and actions of staff, as reported by parents in the included papers.

Table 5 Behaviours & Actions of staff that can have a memorable impact

2. Clear, easily understandable and structured information given sensitively at appropriate times, helps parents through their experience, FES 45 % [[21](#), [31](#), [32](#), [34](#), [36](#), [37](#), [39–42](#), [44–51](#)] – Parents describe insufficient information provision from diagnosis through to the birth of their baby. Acknowledgment of the event and parent's concerns is imperative for holistic care. Individualised information, delivered sensitively and in the right pace for parents can help them through their experience.
3. Parents want privacy not abandonment, FES 30 % [[21](#), [31](#), [33–35](#), [37](#), [39](#), [41](#), [42](#), [46](#), [47](#), [51](#)] – Parents wanted the space to support each other in private but positively reported healthcare professionals who spent time with them. Seeing and hearing other mothers and babies added to parents suffering.
4. Research and multiprofessional training is important for all staff to improve standards of bereavement care, FES 25 % [[31](#), [35](#), [37](#), [38](#), [40](#), [52–56](#)] – Parents feel that there is a significant gap in healthcare professionals' knowledge and comfort level dealing with perinatal loss and bereavement after stillbirth. All healthcare professionals who have contact with parents, within the hospital and community, should receive special training to improve care.
5. Parents wish for increased awareness and acknowledgement of stillbirth, FES 20 % [[21](#), [31](#), [37](#), [38](#), [47](#), [50](#), [57](#), [58](#)] – Stillbirth is a taboo subject for society. Parents feel isolated by the lack of support and understanding that they

receive. Parents want increased awareness and recognition of stillbirth.

6. Fathers may have different needs to mothers; they want to be involved in decision making and often focus on practical tasks, FES 18 % [[30](#), [33](#), [34](#), [36](#), [37](#), [40](#), [47](#)] – Fathers have a special need for information and participation. Fathers can find it difficult to express themselves. They want to protect and support their partner but feel frustrated and helpless if they cannot do this.
7. Continuity of care and carer is important to parents, FES 15 % [[34](#), [37](#), [40](#), [41](#), [46](#), [48](#)] – Parents appreciated and feel reassured by meeting with familiar staff throughout their care.
8. Parents with a baby who died in-utero may feel that their care is not appropriately prioritised by staff, FES 5 % [[39](#), [48](#)] – Parents felt they were not considered important once their baby had died. Waiting to see professionals, having multiple carers, changing rooms and receiving insufficient information made parents feel their care was not a priority to staff.

Diagnosis thematic sentences

9. To be involved in decision making parents appreciate being given options and the time to consider them, FES 20 % [[38](#), [41–43](#), [47](#), [50](#), [51](#), [59](#)] – Giving parents information and allowing them the time to consider the options empowers parents and enables them to be involved with decision making. Lack of information is

perceived as an obstacle to parents' participation and control.

10. Parents have a range of emotions and reactions because stillbirth is a life changing event, FES 18 % [[33](#), [36](#), [37](#), [46–48](#)] – Parents reactions to the diagnosis of stillbirth are unique. Parents describe a diverse range of emotions from sorrow to anger and denial. Parents commonly found it difficult to comprehend what had happened. Healthcare professionals need to be aware of this normal range of responses, allow parents to express their feelings and support them through this time.
11. Staff should support parents to express their concerns, FES 13 % [[35](#), [41](#), [47](#), [48](#), [50](#)] – Many parents suspected something was wrong with their baby prior to presentation and described how their symptoms were not always taken seriously by healthcare professionals. Parents reported difficulty communicating their worry as they did not want to be viewed as troublesome.

Birth thematic sentences

12. Spending time and making memories with their baby should be an option that is supported and offered more than once, FES 53 % [[21](#), [29](#), [31](#), [32](#), [35–37](#), [39](#), [40](#), [42–44](#), [46–50](#), [58–61](#)] – Parents who decide not to see and hold their baby often later regret this decision. Parents should be made aware of this and offered the opportunity more than once. Parents' choices

should be supported by staff and the time spent with their baby should be led by the parents.

13. Support and information from staff may help parents who feel emotionally unprepared for a vaginal birth, FES 23 % [[21](#), [32](#), [33](#), [37](#), [46–48](#), [51](#), [58](#)] – Many parents did not expect to have to go through labour and vaginal birth, their immediate supposition was that their baby would be delivered by caesarean section. It is important to explain the options and the reasons why one of the options may be better in their individual circumstances. For vaginal birth parents need information, advice and support at every step. In retrospect, women reported being empowered by a vaginal birth.

14. Pain relief options should be fully discussed with parents, FES 8 % [[31](#), [47](#), [50](#)] – Advantages and disadvantages of pain relief options should be fully discussed. Some mothers who were sedated held regrets about the lost opportunity to be with their baby.

Post-mortem thematic sentences

15. Parents want improved training so that staff can provide tailored discussions and written information to help them make informed decisions about post-mortem and funeral arrangements, FES 20 % [[25](#), [35–37](#), [40](#), [52](#), [53](#), [56](#)] – Staff should be trained to discuss information regarding post-mortem and funeral arrangement options with parents in a clear and empathic manner. Parents appreciate information tailored to their individual

circumstances and supplementary written information to help them make an informed decision.

16. There are many factors which influence parents decision whether to have a post-mortem, FES 20 % [[25](#), [35](#), [38](#), [46](#), [52](#), [53](#), [56](#), [62](#)] – There are many reasons why parents choose to have a post-mortem or not. See Table [6](#) for a completed list of the reasons reported by parents in the included papers. The barriers perceived by staff are often different than those reported by parents.

Table 6 Factors that influence parents decision whether to have a post-mortem

17. Parents may regret certain decisions made regarding post-mortem and funeral arrangements, FES 10 % [[31](#), [35](#), [50](#), [53](#)] – Parents who decline post-mortem regret their decision more commonly than parents who accept post-mortem. Parents may also regret not arranging their own funeral.
18. Long delays and inconclusive results can cause distress to parents, FES 5 % [[36](#), [37](#)] – A lack of communication about timescales and the meaning of post-mortem results may further parents distress.

Follow-up and support thematic sentences

19. Parents would appreciate a healthcare system ready to provide emotional support following birth and discharge from hospital, FES 50 % [[21](#), [29](#), [31–38](#), [42](#), [43](#), [45–47](#), [50](#), [59](#), [63–65](#)] – Parents experience stillbirth not as a medical problem, but as the birth and death of a baby. Parents perceived a lack of contact in the post-natal period as an indicator that they should get on with recovery quickly and quietly. Hospitals should consider developing specialist bereavement support services and employing specifically trained staff.
20. Parents should be supplied with information about what to expect post-natally, FES 30 % [[31](#), [34–38](#), [40](#), [47](#), [50](#), [51](#), [61](#), [64](#)] – Differing needs and reactions often cause misunderstanding between parents. Parents feel unprepared for the postnatal period and are unaware of their entitlements and the services available. See Table [7](#) for a completed list of the post-natal information that parents in the included papers recommended should be discussed.

Table 7 Information about what to expect postnatally should include

21. A debriefing and follow-up appointment can help resolve uncertainty, FES 28 % [[29](#), [31](#), [32](#), [35](#), [37](#), [39](#), [42](#), [46](#), [47](#), [50](#), [51](#)] – A well-executed follow-up and debriefing appointment is beneficial to the parents grieving process. Good preparation and structure can aid this. See Table [8](#) for a completed list of parents

recommendations for the debriefing and follow-up appointment from the included papers.

Table 8 Debriefing and Follow-up appointment

- 22. Support groups are helpful for many parents, FES 10 % [29, 37, 38, 66] – Talking with other bereaved parents, feeling that they are not alone, can help parents to deal with the death of their baby.
- 23. Clear care pathways are required at the interface between primary and secondary care, FES 5 % [31, 65] – Clear administrative processes should be in place for dealing with bereaved parents.

Staff thematic sentences

- 1. There are challenges that may prevent staff from providing effective bereavement care; Emotion, Knowledge and System based, FES 100 % [19, 20, 25, 37, 67–76] – Caring for bereaved parents is challenging for staff. Healthcare professionals often lack confidence in their personal ability to provide good quality care for parents. Hospitals protocols and processes create barriers to providing holistic and individualised care. See Table 9 for a comprehensive list of the challenges staff reported in the included studies.

Table 9 Challenges that prevent staff from providing effective bereavement

care

2. Staff want improved training and a supportive working environment, FES 57 % [[19](#), [20](#), [25](#), [37](#), [70](#), [74–76](#)] – Targeted education and training would help to prepare staff and increase confidence in providing stillbirth care. Staff want a more supportive environment to help them deal with practical aspects and emotional impact of stillbirth.
3. Emotional support and acknowledging the birth and death of a baby is an important part of bereavement care, FES 43 % [[20](#), [37](#), [67](#), [70](#), [73](#), [74](#)] – Staff feel that it is important to support parents emotional reactions and grief responses, however many worry that encouraging parents to talk may make them feel worse.
4. Continuity of care is important to staff, FES 36 % [[20](#), [68](#), [70](#), [73](#), [74](#)] – Having time to spend with parents helps to enhance relationships and build rapport, which are essential for staff to feel that they are providing quality care however, staffing constraints can impede this.
5. Caring for bereaved parents can be rewarding for staff, FES 29 % [[20](#), [67](#), [70](#), [74](#)] – Utilising their skills to help parents deal with their grief is satisfying for staff.
6. Verbal and non-verbal communication skills are important, FES 21 % [[20](#), [37](#), [73](#)] – Following a stillbirth, staff struggle with not knowing what to say, or how and when to say it. Listening was identified as an important skill to staff.

7. Providing parents with information, enabling them to be actively involved in decision making, is a staff priority, FES 21 % [[20](#), [70](#), [75](#)] – Staff feel that sharing information and knowledge is a way of relieving anxiety, assisting parents to gain control and become active participants in decision making regarding their care.

8. Experience and knowledge may ease the provision of bereavement care but can increase the emotional burden felt by staff, FES 21 % [[19](#), [69](#), [71](#)] – Experienced staff feel that they have more to offer parents and can find caring for bereaved parents rewarding. Experience helps staff to provide support and information for parents however, experienced doctors may feel guilt and depression following a diagnosis of stillbirth.

Discussion

Main findings

This systematic review aimed to describe parents' and health professionals' views to help guide clinical management. We were able to identify inter-related experiences of parents and staff which can inform care delivery. Parents reporting dissatisfaction with the way the diagnosis was conveyed to them, not feeling involved with decision making, and not being given adequate time to come to terms with their loss and make decisions [[11](#), [77](#), [78](#)]. Critically, it was clear that staff actions and attitudes have a huge influence on parents' decision making and ability to cope with the events [[25](#), [77](#)]. There is evidence that empathy and caring staff positively influence parents' memories of their child [[79](#)] whilst a mismatch in

parents' and healthcare workers' perception and management of stillbirth can cause long-lasting distress to parents [21]. Inadequate staff training was identified by staff and parents as impacting upon care provision for bereaved parents [22–25].

Strengths and limitations

The main strength of this review is its inclusivity. The meta-summary method allows inclusion of studies of varied methodology that would not be considered for inclusion in Cochrane reviews. In addition, to capture data as widely as possible, we only excluded studies assessing the impact of miscarriage, termination of pregnancy and neonatal death alone. By limiting the location of the studies involved we also aimed to come up with a useful set of results and clinical recommendations applicable to high-income western settings, like our own. Although these restrict our findings, we believe that many of the experiences will be useful to also help improve care for parents bereaved through miscarriage, termination of pregnancy for fetal abnormality or the death of a baby after birth.

The main limitation is that this review was limited to high-income western studies. We recognise that access to healthcare and cultural differences in other countries may lead to different results and recommendations and therefore our findings need to be interpreted with caution in other locations. However, many of the findings fit within the WHO agenda for respectful care and so may still be applicable and adaptable for low-middle income settings [7]. We recognise that even within high-

income western countries the results represent a generalisation of the key themes found in the literature and that personal experiences will vary therefore, it is important to always tailor care to individual parent's circumstances.

High frequency effect sizes (FES) reflect high levels of reporting of these themes in the literature however, it is important to recognise that a high FES may reflect the focus of previous research over what is necessarily important to parents. We noticed that many of high FES themes, such as '*memory making*' and '*father's needs*', included findings from papers published by the same research team, who commonly have a particular research interest and publish multiple articles on similar topics. In contrast, many of the themes with low FES, such as '*public awareness*' and '*prioritisation of stillbirth care*', appeared to be coincidental findings, reported several times across multiple articles even though they were not usually directly related to the main aims of the studies. FES should therefore be interpreted with some caution, taken as a representation of the literature body rather than as a direct measure of importance to parents. In addition, themes with low FES may indicate areas of stillbirth care that require further research.

Interpretation of results

There were some common themes that ran through the parent results, informing key lessons that can be learnt in the provision of care after stillbirth, from the time of diagnosis to hospital discharge and follow-up. Providing parents with understandable information,

discussing options with them and tailoring care to their individual needs were common themes throughout the included studies. To achieve this knowledge-based and practical training are required to improve key healthcare workers ability and comfort providing personalised stillbirth care. Behaviours and actions of healthcare workers at all stages of care could leave a memorable effect on parents, including; ultrasonographers, general practitioners and health visitors as well as key maternity staff like midwives and obstetricians [38, 54]. This highlights the need for truly multi-disciplinary training to improve bereavement care for parents, crossing the primary and secondary care boundaries. Healthcare workers involved even prior to diagnosis could leave a memorable impact on parents [51, 69], so increased staff awareness of stillbirth is required to improve healthcare workers' empathy towards parents' pregnancy concerns. We note that there were a limited number of articles on healthcare workers' experiences eligible for inclusion and therefore, limited conclusions can be made. However, it was noticeable that there were a number of similarities and associations between parent and staff themes. Parents and staff both place similar importance on '*providing support*' and '*continuity of care*' to parents. Even when parent and staff findings did not directly mirror each other, associations could often be made. For example, staff described '*emotional, knowledge and system-based barriers to providing effective care*' which required often them to develop coping strategies such as distancing themselves from parents and focusing on

tasks [74], whilst parents reported distress being caused by actions like midwives hiding behind 'doing' and ritualising guidelines [36], with these *'behaviours and actions of staff leaving a memorable impact on parents'*. Parents and staff also recommend similar improvements for training and service provision including; *'improved training'*, *'continuity of care'*, *'supportive systems and structures'*, and *'clear care pathways'*.

There were some differences between parents' and healthcare workers' experiences. Noticeably parents' reasoning for choosing whether or not to have a post-mortem was different to those expected by healthcare workers [25]. Importantly we need to recognise that parents reported that midwives commonly influenced their decision whether to have a post-mortem [25] and that parents who chose not to have a post-mortem were more likely to experience feelings of *'regret'* [31, 35, 50, 53] therefore, it is important that all key healthcare workers are trained to provide information and *'tailored discussions'* around post-mortem decisions.

There were a number of findings that directly linked to service provision. Parents appreciated the availability of private rooms away from the noises and sights of the main maternity wards [39].

Hospitals should therefore consider developing a bereavement suite for parents experiencing a stillbirth. Parents also appreciated continuity of care, meeting the same staff members throughout their journey, which may have implications for staffing in hospitals. Specialist bereavement staff and clear care pathways also improved parents' and healthcare

workers' experiences [31, 68]. Hospitals should therefore consider employing specialist bereavement staff to help support parents, act as a lead contact for parents awaiting follow-up and ensure care pathways are completed in a timely fashion. Alongside this training and support for other key multidisciplinary healthcare workers could help to improve parents' experiences of care after stillbirth. Healthcare workers expressed the need for support during and after providing care for parents with stillbirth [20]. Even when formal services were available, they commonly were not used, with staff preferring to seek more informal support from their co-workers [19]. This mismatch needs to be recognised and time for informal support should be accommodated during work time.

Whilst there is a need for increased investment into research exploring the reasons for stillbirth and reducing stillbirth rates [5] the provision of care for families when such an event does occur remains vitally important to reduce the psychological impact on parents [10]. There is paucity of evidence that addresses the benefits and drawbacks of care provision and psychological interventions after fetal loss. A Cochrane review concluded there was insufficient evidence from randomised controlled trials to indicate whether or not there is benefit from interventions for families after perinatal loss [26]. In reality, randomised controlled trials which meet the inclusion criteria for the Cochrane review will be difficult to conduct, therefore developments in care will need to rely upon other forms of evidence. This systematic review has led to clinical and training

recommendations that may improve care for bereaved parents but further research is needed to investigate these areas in more detail. Research is also needed in Low and Middle income countries where additional challenges for parents and healthcare workers are likely.

Conclusion

Stillbirth has been recognised as one of the most neglected areas of public health. This systematic review highlights the importance of good quality bereavement care after stillbirth and the impact poor care can have on parents. Specific developments in training and service provision could help to improve care for bereaved parents, which may in turn improve psychological outcomes for parents. Further research is needed to assess the benefit and impact of these developments on parents.

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Additional information

Competing interests

There are no competing financial interests as the project was self-funded. DS, CS, AH and VF are executive members of the International Stillbirth Alliance and have no financial interest from this association. DS is also a member of the PROMPT Maternity Foundation and has no financial interest from this association.

Authors' contributions

The study was designed by AE, CS, SJ and DS. The literature search was performed by AE and SB. Abstracts were assessed for inclusion by AE, CC, CS, SB, SJ and DS. Data extraction was performed by AE and CC. Data analysis and interpretation was performed by AE, CC, CS and DS. FES and IES were calculated by AE. The manuscript was written by AE and CC. The manuscript was critically reviewed by DS, VF and AH. All authors read and approved the final manuscript.

Authors' information

DS, CS, AH and VF are executive members of the International Stillbirth Alliance. DS is a member of the PROMPT Maternity Foundation.

Additional files

Additional file 1:

Search strategy. (PDF 318 kb)

Additional file 2:

Data collection form. (PDF 322 kb)

Additional file 3:

Parent Intensity Effect Size table, excel, description of individual articles used in the parent data set. (XLSX 22 kb)

Additional file 4:

Staff Intensity Effect Size table, excel, description of individual articles used in the staff data set. (XLSX 13 kb)

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