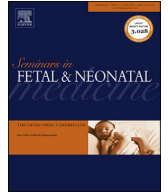




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Care following stillbirth in high-resource settings: Latest evidence, guidelines, and best practice points

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Third-trimester stillbirth affects approximately 2.6 million women worldwide each year. Although most stillbirths (98%) occur in low- and middle-income countries, most of the research on the impact of stillbirth and bereavement care has come from high-income countries. The impact of stillbirth ranges from stigma to disenfranchised grief, broken relationships, clinical depression, chronic pain, substance use, increased use of health services, employment difficulties, and debt. Appropriate bereavement care following a stillbirth is essential to minimise the negative socio-economic impact on parents and their families. This article presents the best practice points in stillbirth bereavement care, including taking an individualised and flexible approach. The latest published research, guidelines, and best practice points from high-income countries will be used and will highlight the gaps in the research which urgently need to be addressed. Research and investment in appropriate, respectful aftercare is needed to minimise the negative impact for parents.

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1. Introduction

Third trimester stillbirth affects approximately 2.6 million women worldwide each year [1]. Globally, stillbirth rates have declined more slowly than either maternal or child mortality [1]. In 2014, there were 3254 stillbirths in the UK affecting 4.7 in every 1000 pregnancies [2]. Globally, there are twice as many stillbirths as deaths due to HIV/AIDS and it is 14 times more frequent than sudden infant death syndrome, yet stillbirth remains under-researched and unrecognised in the global health agenda [3].

Stillbirth is associated with substantial psychosocial, economic, and intangible costs to women, their partners and families, healthcare providers, the government, and wider society [4]. The impact ranges from stigma to disenfranchised grief, broken relationships, clinical depression, chronic pain, substance use, increased use of health services, employment difficulties, and debt; and from staff despair to resignation [4,5]. Evidence has demonstrated that financial costs associated with stillbirth were 10–70% greater than that of a livebirth [6]. A recent systematic review found

that the most frequently reported experiences after stillbirth were negative psychological symptoms, including high rates of depressive symptoms, anxiety, post-traumatic stress, suicidal ideation, panic, and phobia [7]. In addition to efforts to prevent stillbirth, the systematic review highlighted the need for investment and research to develop high-quality aftercare to minimise the negative impact of stillbirth for parents worldwide.

Appropriate bereavement care following a stillbirth is essential to minimise the negative socio-economic impact on parents and their families. In the UK, a survey of more than 2000 healthcare professionals including midwives and obstetricians found that one-third did not have satisfactory training to counsel parents about investigations after stillbirth [8]. Furthermore, a survey of 473 parents showed that fewer than half of the parents felt involved in the decision-making process after stillbirth [9]. A confidential enquiry of 133 term antepartum stillbirths showed wide variation in postnatal and bereavement care, particularly highlighting inadequate communication between health professionals and parents [10]. Qualitative interviews with parents undertaken in the UK also found variation of care from the “best care possible to the worst imaginable” [11]. The overall findings of the qualitative interviews found that healthcare professionals involved in bereavement care have “one chance to get it right” [11]. Insensitive interactions were reported, with partners ignored and little attention paid by

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healthcare professionals to their individual needs [10–12]. Furthermore, these poorly managed interactions can lead to a negative and lasting impact on bereaved parents for years and sometimes decades [13,14].

Most stillbirths (98%) occur in low- and middle-income countries; however, much of the research on the impact of stillbirth and bereavement care has originated from high-income countries [1,4]. This chapter presents the best practice points in stillbirth bereavement care using the latest published research, guidelines, and best practice points from high-income countries, and we highlight the gaps in the research which urgently need to be addressed.

2. What is bereavement care?

Bereavement is the condition of loss resulting from a death, and grief is the natural psychological and emotional response to human loss [15]. The term “bereavement care” in the setting of stillbirth encompasses the formalised and informal care and support given to bereaved parents and their families to help them through the grieving process. This care begins in the immediate period following the diagnosis of stillbirth and continues throughout the postnatal period within the hospital and community settings. There are no quality standards for bereavement care for stillbirth; however, the UK National Institute for Health and Care Excellence’s ‘Guideline for end of life care’ suggests that people closely affected by a death are communicated with in a sensitive way and are offered immediate and continuing bereavement, emotional, and spiritual support appropriate to their needs and preferences [16].

2.1. General principles

The interactions between healthcare professionals can have a memorable impact on parents, and careful considered communication is essential throughout [17]. A recent systematic review found that clear, easily understandable and structured information given sensitively at appropriate times helps parents through their experience [17]. The review found that parents wished for acknowledgement of the stillbirth and prioritisation of their situation by healthcare staff. Continuity of care is important to parents and consideration should be made to ensure that they are under the care of a dedicated and consistent bereavement midwife and obstetrician [17]. An inclusive approach should be taken to ensure that partners are involved in decision-making where appropriate [17].

3. Diagnosis and breaking bad news

The diagnosis of a stillbirth by a healthcare professional is something that parents who experience this loss are likely to remember. The Investigation into Stillbirth to Inform and Guide Healthcare Training (INSIGHT) study in the UK demonstrated inconsistent management both before and after the diagnosis of stillbirth, with the degree of urgency and attention varying and often disappearing just after the bad news has been discussed with parents [18]. Therefore, it is important that this diagnosis is made in a timely manner by adequately trained healthcare professionals within a private environment [17]. National UK guidelines recommend that this diagnosis be made using real-time ultrasonography and confirmed by a second healthcare professional [19]. Mothers should be warned of the possibility of experiencing passive fetal movements of a stillborn baby, which are not rare [20]. If the mother reports passive fetal movements after the scans, a repeat scan may be offered if the mother requests or the clinical situation

necessitates [17,20]. A recent UK-based study interviewed healthcare professionals and found that the diagnosis of fetal death in utero is often difficult to confirm, particularly when senior staff are unavailable to make or confirm the diagnosis, for example during the night in the hospital [18]. Deferring diagnosis to the following day can lead to increased parental anxiety and therefore should be avoided [18]. The study recommended that every maternity unit should have a private room with at least one healthcare professional, experienced in confirming the diagnosis of stillbirth, available 24 Hours a day and seven days a week [18]. Health professionals undertaking the scanning should be trained to communicate empathetically and clearly using appropriate verbal and non-verbal cues [18]. Furthermore, the professional undertaking the scan should communicate clearly to the parents about the process prior to conducting the scan. The clinician should explain to parents that there may be silence during scanning process until the diagnosis can be made with certainty [21]. There is an urgent need for further ultrasonography skills and communication training for all healthcare professionals likely to be diagnosing stillbirths in maternity units [18]. In addition, it is crucial that every obstetric unit should have a protocol for primary care referral for suspected fetal death and an integrated care pathway when admitted to hospital [22].

4. Labour and birth

4.1. The interval between diagnosis and birth

Parents understandably find the birth experience challenging. Importance should be given to this experience taking place on a dedicated bereavement suite, in a separate location, from the standard maternity unit where mothers and babies might be heard [17,19]. It is vital that women and their partners feel supported throughout this experience and do not feel abandoned once the diagnosis of stillbirth has been made [17]. Recommendations about labour and birth should incorporate the mother’s preferences as well as her medical condition and previous intrapartum history [17,19]. Women should be strongly advised to take immediate steps towards delivery if there are appropriate indications such as: sepsis, pre-eclampsia, placental abruption, or membrane rupture; but a more flexible approach can be discussed if these factors are not present, including for the potential for expectant management [19]. Should a woman contemplate prolonged expectant management, they should be advised that the appearances of the baby may deteriorate and the value of the postmortem may be reduced [19]. Furthermore, they should be advised of the risk of disseminated intravascular coagulation (DIC) and should be tested twice weekly for DIC until birth. For some parents, prolonging the birth may increase anxiety and stress in the short and long term [21]. Erlandsson et al. investigated 515 mothers’ experiences of the time after the diagnosis of an intrauterine death until the delivery using an Internet-based survey [23]. For some mothers, the period of time prior to delivery meant receiving support from relatives, close friends and hospital staff, allowing them to adapt to the situation [23]. For other mothers it produced further stress in an already difficult situation [23].

In a woman with an unscarred uterus, a combination of mifepristone and prostaglandin preparation such as misoprostol should be recommended as a first-line intervention for induction of labour [19]. An observational case-series study of 96 women found that vaginal birth was achieved in 87.5% of women within 24 h of administration of the first dose of misoprostol [24]. The study also found that mifepristone reduced the interval from induction to delivery by an average of 7 h [24].

4.2. Mode of birth

Mode of birth should be discussed in detail by an experienced obstetrician with the parents. Vaginal birth is the recommended mode of delivery, but caesarean birth may need to be considered for some parents. The INSIGHT Study interviewed parents in the UK to explore the maternity bereavement care they had experienced and reasons why bereaved families often ask for a caesarean birth rather than a vaginal birth [21]. Mothers felt that by giving them the option to choose the timing and mode of birth they could restore a sense of control, they could shorten the variably long process from diagnosis to discharge, and they could avoid labour pain by having a caesarean section [21]. Some parents believed that a quick caesarean section followed by resuscitation might save the baby, whereas others felt that the baby might still feel pain and that a caesarean birth is a less traumatic option for the baby [21]. Caesarean birth is not without risk to the mother, including surgical risks and the susceptibility of uterine rupture in the subsequent pregnancies. This is of particular importance in low- and middle-income countries whereby access to safe intrapartum care and monitoring in labour may be limited. Overall, it is crucial for healthcare professionals to understand the various reasons [21] why parents may request a caesarean birth rather than a vaginal birth, so that they can counsel women effectively about the risks and benefits and can help them make informed decisions regarding the birth of their baby. Joint decision-making is vital and support from healthcare professionals may help parents who feel emotionally unprepared for the birth [17].

4.3. Analgesia in labour

Pain relief options should be fully discussed with parents [17,19]. In addition, regional anaesthesia should be available and women should have the opportunity to meet with an obstetric anaesthetist [19].

4.4. Suppression of lactation

In the Listening to Parents Study and the MBRRACE confidential enquiry into antepartum stillbirths, more than one-third of women were not offered lactation suppression [10,25]. It is important to explain to women that following the birth of their baby they will begin to lactate, and many women become distressed if they are unprepared for this. Women should be advised that almost one-third of those who choose non-pharmacological measures are troubled by excessive discomfort [19]. Non-pharmacological measures may include support brassières, ice packs, and analgesics [19]. Dopamine agonists successfully suppress lactation in a high proportion of women (>90%) and are well tolerated; cabergoline has been found superior to bromocriptine [19]. However, dopamine agonists should not be administered to women with hypertension or pre-eclampsia as they have been associated with intracerebral haemorrhage [26].

4.5. Memory-making

A recently published systematic review investigating how to improve care after stillbirth suggested that memory-making should be an option for parents and should be offered more than once during their hospital admission [17]. Memory-making can take many different forms including activities such as seeing and holding the baby, photographs, taking hand and foot prints, and creating memory boxes. Currently there is mixed evidence about seeing and holding the baby after birth. In 2013, a Cochrane review concluded that the evidence of the potential detrimental effect of seeing and

holding the baby remains inconclusive [27]. A subsequent systematic review found that the evidence of impact of holding the stillborn baby on mental health and wellbeing was sparse and poor quality [28]. The studies included within the systematic review were too heterogeneous in their outcome measurements and the authors were unable to quantitatively synthesise the results to form a meaningful conclusion [28]. A recent secondary analysis of data from a postal survey of 468 women who had experienced a stillbirth found that women who had seen and held their baby had higher self-reported anxiety levels and relationship difficulties [29]. However, there should be caution in interpreting these data, as the survey had a low response rate (30.2%) and used self-reported outcome measures. Conversely, another systematic review suggested that parents seeing and holding their baby could be beneficial to their future well-being. It also identified strong evidence for parents to be given the option to see or hold their baby, with many women subsequently satisfied with their decision [30,31]. In summary, due to the mixed findings from research, parents should continue to be offered, but not forced, to hold their stillborn baby, unless more substantial evidence emerges. It is essential, when parents express a desire to see and hold their baby, that this is supported by experienced staff. There is a need for high-quality prospective research with standardised outcomes and outcome measurement tools with attention to confounders, to guide practitioners' and parents' decision-making and to ascertain the life-long impact of this decision process on parents.

5. Postmortem discussion

A postmortem (autopsy) examination should be offered to parents to help explain the cause of the stillbirth, and it may guide the management of any future pregnancy [17,19]. Attempts to persuade parents to choose a postmortem should be avoided, to respect individual, cultural and religious beliefs that might make a postmortem unacceptable to parents [17,19]. An adequately trained health practitioner should obtain written consent for any invasive procedure on the baby including tissues taken for genetic analysis (although umbilical cord samples can be taken for genetic analysis with verbal consent) [19]. Further consent should be sought when tissues are retained for clinical investigation, research, and teaching [19]. A recent study interviewed parents and found that the health professionals taking consent are not always clear in their approach and that health professionals should consider discussing post-mortem early on, to allow time for the parents to think about their wishes [21]. Further evidence suggests that parents believe staff should receive improved training, to better facilitate tailored discussions, and that the provision of well-written information would help them make informed decisions about postmortem [17]. Healthcare professionals should be able to communicate the purpose of the postmortem in a respectful way and to explain local processes and timescales effectively [17]. It should also be explained that not all postmortem investigations will find the cause of the stillbirth and that not finding a reason in itself is useful and can be framed in positive terms, as important diagnoses (which may affect the recurrence risk in subsequent pregnancies) can sometimes be excluded [17].

Evidence suggests that parents may regret certain decisions they have made concerning postmortem and this may be due to inadequate information or poor communication [17]. A survey of 473 parents found that only two-thirds of parents were given written information about the postmortem and only half agreed to a full postmortem examination [25]. Parents' reasons for not agreeing to a postmortem were mainly due to their perception that they already knew the cause of death [25]. The process for obtaining consent is naturally difficult for parents and health

professionals, and so interventions may be required to support this decision-making process. A Cochrane review found no randomised controlled trials investigating interventions to support decision-making on autopsy or associated investigations [32]. The authors concluded that there are challenges in conducting randomised controlled trials in this area, and that meta-analyses of observational studies may be needed to resolve uncertainty [32]. Standardised outcomes and measurements will again need to be used to facilitate any such synthesis. Moreover, future research should focus on implementing and evaluating interventions to support decision-making around post-mortem discussions [32].

6. Perinatal mortality review process

Following a perinatal loss, there should be a robust, systematic and critical analysis of the medical and emotional care given to the bereaved parents. A formal perinatal mortality review or audit process can improve the future care of parents and also provides an opportunity to learn from mistakes or substandard care and prevent them from occurring again [33]. As a measure to help reduce the perinatal mortality rate in the Netherlands, a national standardised perinatal audit was introduced in 90 obstetric units [34]. Following the introduction of this formalised system, term perinatal mortality decreased from 2.3 to 2.0 per 1000 births [34].

In 2012, the UK Department of Health (DoH) established a Perinatal Mortality Task and Finish Group to improve the review process that takes place in each hospital following the death of a baby either before or shortly after birth. The DoH task group recommended a comprehensive and robust review of all losses from 22 weeks of gestation until 28 days after birth, which fits into three of the five domains of the NHS Outcomes Framework 2013–2014 [35]. Furthermore, the DoH task group and the recent Report of the Morecambe Bay Investigation by Dr Bill Kirkup have recommended that there should be scope for parental input into the process from the beginning [36]. This is in line with recommendations from the Francis inquiry (into Mid-Staffordshire Hospital), which recommends the need for a consistent culture of openness and candour in the NHS, so that errors can be addressed and lessons learnt [37]. Additionally, the MBRACE-UK Confidential Enquiry (published in November 2014) recommended that parents' perspectives of their care should be included in the standardised multidisciplinary review of their perinatal death and the results of the review shared with parents [10].

Evidence from a large focus group undertaken with bereaved parents (Parents' Active Role & Engagement in The review of their Stillbirth/perinatal death Study: PARENTS 1 Study), which investigated their knowledge of the Perinatal Mortality Review process, showed that parents were largely unaware that a review of their child's death took place, and they found it distressing that they had not been involved or kept informed [38]. Parents were unanimously in favour of the opportunity to contribute information, and would welcome a flexible system that could provide them with feedback, outcomes, and lessons learnt following the review [38]. Further work to evaluate a perinatal mortality review process with parental involvement is currently under way (PARENTS 2 Study).

7. Follow-up

Follow-up should be offered to parents, as debriefing may help resolve uncertainty [17,19]. Prior to hospital discharge, parents should be supplied with information about what to expect in the postnatal period on their return to the community setting, and this should include a single point of contact in the follow-up period [17].

There is no evidence to inform the optimum location, timing, and frequency of such appointments [17]. Six to ten weeks is common practice for the interval between discharge from hospital and the appointment, largely mediated by the timeframe to perform post-natal investigations (e.g. autopsy/placental histology). The consultation should be led by someone experienced in bereavement [17,19]. This should ideally be with a senior obstetrician whom the parents have met before. A personalised approach should be taken, using the baby's name within the consultation unless the parents prefer not to [17]. It is important that all results, including postmortem investigations, are made available for this appointment since long delays and inconclusive results may cause distress to parents [17]. It is recognised that many parents find it distressing to return to the unit where their baby was born and therefore consideration should be made to the environment where the consultation takes place. It is important that the follow-up is comprehensive in nature, yet tailored to the parents' needs. Evidence suggests that parents appreciate a system where emotional support is made available following birth and discharge from hospital [17]. The cause of stillbirth should be discussed and there should be acknowledgements if there were mistakes. The primary focus of the consultation should be around the stillborn baby and the parents [19]. However, the possibility of future pregnancy and the level of antenatal care the parents are likely to receive should also be discussed within the consultation [19]. Further investigations may need to be organised and advice or treatment may be required to improve maternal health for subsequent pregnancies. The consultation may include assessments for complex grief with appropriate referral mechanisms, should bereavement counselling or further psychological assessment be required [21].

Clear pathways are required at the interface of primary and secondary care [17]. Therefore, good communication to the primary health care team (including general practitioners, community midwives and health visitors) is required regarding the outcome of this consultation to ensure continuity of care. The INSIGHT Study found that parents and healthcare professionals agreed that the period between hospital discharge and follow-up consultation is characterised by delay and lack of information for parents, as well as varied levels of support [21]. There was the assumption that follow-up with the primary health care team would automatically be arranged, which contrasted with what bereaved parents experienced [21]. Streamlined, standardised, and collaborative care is urgently needed between hospital and community settings.

8. Interventions that might aid psychological recovery

Interventions are required to reduce the negative impact of stillbirth on parents and families. However, an individualised, flexible approach should be adopted, taking into account individual and cultural responses to death. The Royal College of Obstetricians and Gynaecologists (RCOG) Intrauterine and Fetal Death Guideline recommends that a contact with counselling and support groups should be offered to all women and their partners and that other members of the family such children and grandparents should also be considered [19]. However, there is a paucity of evidence to support this intervention [4].

A mixed-methods narrative systematic review assessed the current available evidence on interventions to reduce the negative impact of stillbirth for bereaved parents and families who experience stillbirth [4]. Forty-three studies provided evidence on what works to reduce the negative effects of stillbirths, concerning which no randomised controlled trials were found [4]. The types of support described by the literature included emotional support,

informational support, esteem and network support, and tangible support [4]. Tangible support was subdivided into seeing and holding the baby, making memories through photographs, rituals to help saying goodbye including funeral arrangements, postmortem discussions, and formal counselling input [4]. Within this systematic review only four studies assessing the outcomes of parents who had received counselling support were found worldwide [4]. The numbers within each study were too small to draw definitive conclusions [4]. Furthermore, the review found that a minority of interventional studies included fathers and the wider family [4]. It is important to note that not all parents may need psychological input, as grief can be a “normal” part of the bereavement process. Therefore, future comparative research should focus on how to support those parents and the wider family following stillbirth who might benefit from psychological input.

9. Care in subsequent pregnancies

Most parents conceive within one year of experiencing a stillbirth. It is known that risk of stillbirth and other pregnancy complications is increased for parents who have had a previous stillbirth [39]. There is little evidence to guide management of subsequent pregnancies following stillbirth [40]. A recently published survey of 2716 parents from 40 high- and middle-income countries found that a wide variation of antenatal care was provided across different geographic regions [41]. Additional antenatal appointment and ultrasound scans were provided; however, access to psychological care was less frequently supplied. Furthermore, the survey found that parents whose stillbirth occurred at more than 30 weeks of gestation were more likely to receive additional care such as the option for early delivery [41]. The RCOG guidelines recommend that decisions for an early delivery following unexplained stillbirth should consider the gestational age of the previous stillbirth, previous intrapartum history, and the safety of induction of labour for mother and baby [19]. A metasynthesis of qualitative literature also highlighted the value of emotional and psychological support from healthcare providers in improving care in pregnancy after stillbirth [42]. Further research should explore the roles of specialist services, formal training for staff, and the development of clinical guidelines providing care in pregnancies after stillbirth [41]. It might also be useful to consider dedicated follow-up clinics for parents who experience stillbirth or perinatal death, with involvement of the multidisciplinary team including a bereavement midwife, and/or neonatologist for deaths occurring after birth.

10. Healthcare professional training

There is an urgent need for evidence-based training in care after stillbirth using a parent-centred integrated pathway to improve the experience of bereaved parents [21]. Training should include evidence-based principles of care and management in the context of bereavement care, including common challenges and how to address them, psychological theories, and good communication principles. Communication skills training should focus on techniques for dealing with grief reactions, communicating the diagnosis of stillbirth, respectfully discussing the postmortem consent process, and the processes after discharge from hospital [21]. A multi-disciplinary approach should be taken to encompass doctors, midwives, paediatricians, ultrasonographers, allied health professionals, and general practitioners, with improved links between primary and secondary care [21]. Finally, there is a training need for all out-of-hours staff to be trained in ultrasound scanning to be able to diagnose intrauterine death competently and confidently [21].

Best practice points

- Healthcare professionals should be trained in confirming the diagnosis of stillbirth, available 24 h a day and seven days a week.
- Sensitive and empathetic communication should be adopted by healthcare professionals in contact with parents who experience stillbirth.
- An individualised patient-centred approach should be adopted.
- Continuity of care should be adopted by maternity units with dedicated obstetricians and midwives experienced in bereavement care.
- A flexible approach should be taken regarding discussion around mode of delivery and healthcare professionals should explore why parents might choose a caesarean birth.
- Pain relief should be available and discussed with all parents.
- Lactation suppression should be offered to all women (in the absence of contraindications).
- Memory-making, including seeing and holding the baby, should be offered to parents.
- Postmortem should be offered to all parents by a healthcare professional trained in postmortem consent.
- Parents' perspectives of their care should be included in the standardised multidisciplinary review of their stillbirth.
- A consultant follow-up appointment should be offered, encompassing clinical and emotional aspects of care.
- Counselling and support groups should be offered to those who need psychological input.
- Care in subsequent pregnancies should be individualised and informed by the cause of prior stillbirth.

Research directions

- Evidence-based training in care after stillbirth using a parent-centred integrated pathway to improve the experience of parents experiencing stillbirth.
- Improvement of the primary and secondary care interface.
- Exploring the role of counselling and peer support in bereavement care.
- Improvement in evidence for interventions after stillbirth.
- Development of standardised outcomes and outcome measurement tools applicable to stillbirth to measure the effectiveness of interventions.
- Exploring the role of the parental involvement in the perinatal mortality review process.
- Exploring the role of specialist services delivering care in subsequent pregnancies after stillbirth.
- Further research and better understanding of the needs of bereaved parents in low- and middle-income countries as well as ethnic minority groups in high-income countries.

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