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

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A B S T R A C T

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.

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 the 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].