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Commentary

Meeting the needs of parents after a stillbirth or neonatal death

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Impact of stillbirth and neonatal death on mothers, fathers and families

The death of a child around the time of birth is highly contradictory to the 'natural order' of life, and has profound effects on parents and families. Shock, anger, emptiness, helplessness and loneliness are common responses for mothers and fathers. Even in high-income settings, where support services are more likely to be available, approximately one in five parents whose baby dies at or soon after birth will display intense and enduring grief following the loss.[1–3] Maternal distress from the loss of a baby can exert intergenerational consequences, affecting the family constellation for surviving children as well as carrying over into a subsequent pregnancy.[2] Families suffer disruption to family relationships and substantial economic burden.[2] In the USA perinatal and child death is conservatively estimated to cost about $1.5 billion per year with the global costs likely to far exceed this figure.[4]

Around the world four million babies die each year, and an additional three million babies die as late pregnancy stillbirths (after 28 weeks). These numbers almost double when using the definitions of stillbirth and neonatal deaths of high-income countries (i.e. from 20 weeks of gestation).[5] The vast majority of these deaths occur in low- and middle-income countries with around half occurring in labour.[6] The reality behind these data is grim: every hour of every day more than one thousand families experience the loss of a child around the time of birth. As many of the deaths are not counted in mortality data, even these numbers are an underestimate of actual rates. Underreporting is linked to negative attitudes about the value of these lost lives and reflects the lack of support mothers and fathers receive during this time of significant tragedy.[7]

Attitudes and perceptions—holding back progress

In regions of the world where most deaths occur, maternal grief may be compounded by social stigma, blame and marginalisation.[7] Practices of isolating women and their newborns and a perception that the newborn is not a person[8] contribute to suboptimal care for parents when a baby dies. Under the most extreme conditions, where a family cannot meet basic needs for food and shelter, the time and resources to grieve are unlikely to be available. Moreover, the close linkages between poverty, education of women and disempowerment mean that women who have lost a baby are especially vulnerable. Stigma associated with a baby's death is prevalent across the economic spectrum and contributes to social isolation and feelings of shame to further undermine the support available to grieving mothers.[7]

A survey of 2490 healthcare professionals across 135 countries showed that in low- and middle-income settings, disposal of the baby's body frequently occurs without any recognition or ritual, such as naming, funeral rites, or the baby being held or dressed by the mother.[7] Similarly, the survey showed beliefs in the mother's 'sins' and evil spirits as causes of stillbirth are rife, and that stillbirth is

commonly believed to be the natural selection of babies never meant to live.[7] Of the 1070 mothers responding to the survey from across 32 countries (largely high-income), one in two reported that grieving is not accepted in public, and that undivided support for her loss was not provided. In many settings, reproduction is central to women's perceived purpose in society. In this survey, one in five women responded that women experiencing the loss of a baby to stillbirth are marginalised as a failure, both as a mother and as a spouse, and considered impure or taboo. Further, four of five women live in communities that expect women to forget their loss and to have another baby.[7] To avoid stigmatisation and shame, women may hide their babies' deaths completely. However, women need and want recognition for their babies. A recent study in Ethiopia reported that despite contrasting community views, women believe stillbirth and neonatal death should be made visible and that highlighting the magnitude of the problem will ensure appropriate allocation of resources to reduce these deaths.[8] In the global survey mentioned above,[7] parents in high-income countries consistently reported that their baby was perceived as a taboo object and unequal in human value to an older child who died.[7] These findings contrast with health professionals' positive views of care provided. Yet, high-income countries are not homogeneous in their views as this survey showed; while 18 of 30 (64%) of Norwegian parents report that a stillborn baby is often or always perceived equally as a deceased child and 22 (78%) report that mothers receive undivided support, only 42 (12%) and 64 (18%) respectively, of the 390 responses from Italian parents perceive this recognition and support.[7]

The needs of parents when their baby dies

High levels of distress are part of the normal grieving process following a baby's death and although some parents develop mental health problems, most do not.[2] What helps to protect and sustain parents and families in the aftermath of such an unambiguously tragic loss? High-quality evidence on specific support interventions following stillbirth or neonatal death is lacking[9] and different interventions will be required for different settings and cultural groups, but essential ingredients of quality care include a deep respect for the individuality and diversity of parents' grief and respect for the deceased child.

Social support

Support from doctors, nurses and particularly family is associated with lower levels of anxiety and depression in mothers following a stillbirth.[10] Support from partners, family and wider social networks may reduce maternal distress in the long-term. The role of support groups after perinatal loss is unclear although benefits, particularly for women, are reported.[10]

Being a parent and creating memories

In high-income country settings, parenting and caring for the dead baby have been reported to produce positive memories and to aid the grieving process by creating a bond and sense of identity of the child.[9] For women in low- and middle-income countries, such opportunities are frequently not provided nor an accepted part of care.[7] While both harm and benefits have been associated with seeing and holding a stillborn baby, best practice guidelines recommend that all parents should be offered a choice and be supported in their decision making.[11,12] Studies suggest that bereaved parents value and benefit from contact with their stillborn baby particularly when this occurs in a supportive environment.[3] Clinical guidelines support memory-making activities such as bathing and dressing the baby, talking to the baby and using the baby's name, engaging in religious or naming ceremonies, introducing the baby to extended family, and capturing interactions in photographs and movies.[12] General consensus is that bereaved parents should be offered items of memorabilia such as photos, hand/footprints and special clothing or blankets when a baby dies.[12] Having such items has been found to reduce negative outcomes for parents.[2]

Counselling and other therapeutic interventions

Interventions including bereavement counselling, specialised psychotherapy and informal community-based support are suggested to improve outcomes for parents following perinatal loss but evidence is sparse.[8] High-risk groups such as parents who have previously lost children, women undergoing termination of pregnancy for fetal anomalies and parents with grief complicated by other adverse life events or circumstances may benefit from mental health interventions.[13] Prescribing sedatives for women is common in some settings,[14] despite the limited evidence for benefit. Pharmacological management of grief should only be considered in the presence of an established psychological disorder for which medication is indicated after careful assessment by a well-trained mental health expert.[10] Web-based mental health services, including informative websites, online self-help groups, virtual counselling services and automated therapy programmes, have emerged recently and may be useful support options for some parents. Although online support groups and memorial websites have become very popular, their value has not been systematically evaluated.

Maternity healthcare professionals play an important role

The actions of healthcare professionals matter for parents' immediate and longer-term wellbeing. Optimal care requires awareness of current evidence regarding perinatal loss, the impact of losing a baby, and the diversity of parents' experiences. A patient-centred approach that responds to the sociocultural context and unique needs of each bereaved parent[2] is the foundation of sensitive communication, information provision and supported decision making, all of which are vital elements of perinatal bereavement care. A recent study in Ireland highlighted the gap in training and support and the significant impact of stillbirth on obstetricians, professionally and personally.[15] Perinatal bereavement care requires organisational responses including staff development to address training gaps and debriefing and clinical supervision to prevent burnout of staff in highly emotionally demanding roles.

Information for decision making

Parents whose baby has died face many difficult decisions in the context of overwhelming grief and frequently have a diminished capacity to absorb and retain information. Maternity staff who are calm and supportive and who provide objective information while balancing guidance with parental autonomy, can assist parents to make informed decisions while minimising regret. Staff should ensure that their own values and opinions do not influence grieving parents. Encouraging parents' autonomy in decision making can be beneficial in grief in the long term. Critical information should be repeated, and verbal information should be reinforced with parent-centred printed materials.

An autopsy examination remains the standard investigation for stillbirth but in countries where this is available, the decision can be difficult.[16] Emotional, practical and psychosocial barriers to autopsy consent exist for staff and parents. To avoid further burden on parents and due to their own discomfort, healthcare professionals may not broach the topic well, if at all. However, parents who decline postmortem examination more often regret this decision compared with those who accept.[16] Education for healthcare professionals is needed to ensure competency for the provision of accurate and sensitive counselling about autopsy.

Birthing options

In low- and middle-income countries, a high proportion of stillbirths occur intrapartum and may be associated with serious complications such as prolonged obstructed labour, uterine rupture or hypertensive disease. The need to resolve the precipitating obstetric complication may determine the mode of delivery. In well-resourced settings, where fetal demise is diagnosed, women require information about how the birth can be achieved and the implications for safety, for recovery and for future pregnancy. A natural parental response is sometimes to request immediate operative delivery and a recommendation to proceed with labour and vaginal delivery may be construed as insensitive. However, with due attention to individualised advice and effective arrangements for pain relief during labour, concerns and distress about 'labouring with a dead baby' can be resolved.

Key recommendations for maternity-care providers

1 *Respect:* Quality bereavement care demands deep respect for the individuality and diversity of parents' grief. Recognition and valuing of the deceased baby is critical.
2 *Information:* Maternity staff should provide objective information in a calm, supportive manner, while balancing guidance with parental autonomy. Critical information should be repeated and reinforced with parent-centred printed materials.
3 *Creating memories:* Activities such as holding, bathing and dressing the baby, talking to the baby and using the baby's name, engaging in religious or naming ceremonies, introducing the baby to extended family, and capturing interactions in photographs and movies should be supported. Parents should be offered items of memorabilia such as photos, hand/footprints and special clothing or blankets when a baby dies.
4 *Professional development and support:* All maternity-care providers need to receive training to ensure that they are equipped to provide appropriate care following a perinatal death. Staff confronted with such losses need ready access to debriefing and support.

Summary

The death of a child around the time of birth is one of the most profoundly distressing events any parent will experience. These deaths are not uncommon, but are often hidden, along with the grief of mothers, fathers and families. Social stigma and negative attitudes are inextricably linked to underreporting of babies' deaths in low- and middle-income countries. A failure to recognise the value of these lost lives leads to disenfranchised grief and diminished preventive efforts to reduce stillbirth and neonatal deaths. Acknowledging these deaths to bring them 'out of the shadows'[17] and compassionate, respectful care for parents suffering perinatal loss, irrespective of country or

resources, are critical to addressing the totality of the burden of this public health problem.

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VF planned and wrote the manuscript with feedback from all authors: FB, LK, TW, WS and JC. All authors approved the final version of the manuscript.

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