
Title: Women and Birth
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ArticleTitle: Clinical practice guidelines for perinatal bereavement care -- An overview
Description: Vol/Iss: Volume 33, Issue Date: March 2020 Pages: 2, March 2020, Pages 107-110
Vol: Volume 33, Issue Date: March 2020 Pages: 2, March 2020, Pages 107-110

Women and Birth 33 (2020) 107–110

Contents lists available at ScienceDirect

Women and Birth

journal homepage: www.elsevier.com/locate/wombi

Clinical practice guidelines for perinatal bereavement care — An overview

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ARTICLE INFO

Article history:
Received 14 December 2018
Received in revised form 25 January 2019
Accepted 27 January 2019

Keywords:
Stillbirth
Perinatal death
Bereavement
Guideline
Respectful maternity care

ABSTRACT

Background: High quality perinatal bereavement care is critical for women and families following stillbirth or newborn death. It is a challenging area of practice and a difficult area for guideline development due to a sparse and disparate evidence base.
Aim: We present an overview of the newly updated Perinatal Society of Australia and New Zealand/ Stillbirth Centre of Research Excellence guideline for perinatal bereavement care. The guideline aims to provide clear guidance for maternity health care providers and their services to support the provision of care that meets the needs of bereaved parents.
Discussion: The *Guideline for Respectful and Supportive Perinatal Bereavement Care* is underpinned by a review of current research combined with extensive stakeholder consultation that included parents and their organisations and clinicians from a variety of disciplines. The Guideline contains 49 recommendations that reflect five fundamental goals of care: good communication; shared decision-making; recognition of parenthood; effective support; and organisational response.
Conclusion: Best available research, parents' lived experiences and maternity care providers' insights have contributed to a set of implementable recommendations that address the needs of bereaved parents.

Statement of significance

Problem or issue

High quality bereavement care is critical for the immediate and long-term wellbeing of women and families following stillbirth or newborn death.

What is already known

Perinatal bereavement care is a challenging area of practice. Guidance for health care professionals is essential to address diverse parent needs but the evidence base is sparse and disparate.

What this paper adds

The *Guideline for Respectful and Supportive Perinatal Bereavement Care* presents 49 recommendations for health care professionals and maternity care facilities that bring together research, parents' lived experiences and maternity care providers' insights.

1. Background

Despite marked declines in perinatal mortality in high resource settings, the death of a baby is a reality for many parents. In Australia in the two years between 2013–2014, 6000 babies died before or soon after birth: 4400 babies were stillborn (of at least 20 weeks gestation or with birth weight of at least 400 g) and 1600 babies were born alive but died within the first 28 days of life.[1] Stillbirth rates in Australia have plateaued for two decades and while reductions may be possible, recent studies highlight the challenges of achieving any major reduction rapidly.[2,3] High quality perinatal bereavement care must always be available.

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https://doi.org/10.1016/j.wombi.2019.01.008
1871-5192/

Stillbirth exacts an enormous psychological and social toll on mothers, fathers, families, health systems and society.[4] Parents' grief can be overwhelming and the repercussions for families can be long-lasting and life-changing.[4–7] For women who suffer stillbirth, an estimated 60–70% will experience grief-related depressive symptoms at clinically significant levels one year after their baby's death. These symptoms endure for at least four years after loss in about half of those women.[4] The quality of bereavement care is an important determinant of immediate and longer-term wellbeing, but health care professionals often report feeling poorly equipped to provide parents with the support needed, and at the same time, feel personally and professionally affected by a baby's death.[8,9]

2. Guideline for respectful and supportive perinatal bereavement care

The revised *Guideline for Respectful and Supportive Perinatal Bereavement Care*, developed by the Perinatal Society of Australia and New Zealand (PSANZ) and the Australian Stillbirth Centre of Research Excellence (Stillbirth CRE), aims to improve the quality of bereavement care for parents who experience stillbirth or neonatal death. The Guideline provides recommendations based on best available evidence to assist maternity services and health care professionals working in this challenging area of practice. Hospital-based care and practices are the primary focus but attention is also given to the interface between hospital and the community and the longer-term support needs of women and families. The Guideline is part of the broader PSANZ/Stillbirth CRE *Clinical Practice Guideline for Care around Stillbirth and Neonatal Death*,[10] but is also designed as a standalone resource.

The content of the *Guideline for Respectful and Supportive Perinatal Bereavement Care* aligns with, and draws on, key international initiatives, including: Respectful Maternity Care Charter — The Universal Rights of Childbearing Women[11]; the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death[12]; and the Research of Evidence based Stillbirth care Principles to Establish global Consensus on respectful Treatment (RESPECT) working group. Improving bereavement care following any death in pregnancy or childbirth is a priority worldwide.[13]

Perinatal bereavement care is a difficult area for guideline development due to the relatively sparse and limited evidence available and its highly sensitive and emotionally charged content. A Cochrane review of the effectiveness of interventions intended to provide psychological support or counselling to mothers, fathers or families after perinatal loss, found no eligible randomised controlled trials.[14] The review underlined the challenge of conducting research with experimental study designs in this area and the need to rely on non-randomised and observational studies to guide practice.

Meanwhile a growing body of research, including systematic reviews [7,8,15–17] helps to inform best practice care around stillbirth and neonatal deaths, despite the variable quality of the available evidence included in these reviews. This meant that developing best practice recommendations required an approach that combined a review of published evidence with expert consensus, based on extensive consultation to incorporate insights and experience from a large multidisciplinary group that included parent organisations, clinicians, policy makers and researchers from the field. A guideline update group comprising more than 50 members provided expert input and advice based on their experience of perinatal bereavement care. Sands Australia and Women's Healthcare Australasia remain key partners as peak consumer and maternity care provider organisations.

3. Overview of the guideline

The *Guideline for Respectful and Supportive Perinatal Bereavement Care* contains 49 recommendations; 41 are directed at

Box 1. Foundations for respectful and supportive perinatal bereavement care based on current published literature.

Respectful and supportive perinatal bereavement care:

- Addresses the psychosocial, physical and practical needs of parents and families with consideration of parent preferences, circumstances and cultural context. Care begins with the first signs of concern about a baby, continues through pregnancy to birth, postnatal care and longer-term support including subsequent pregnancies.
- Acknowledges the baby and the impact of the baby's death on parents.
- Recognises that perinatal bereavement may be associated with intense grief and may include high levels of anxiety, depression, guilt, anger and self-blame.
- Understands that perinatal deaths can profoundly affect health care professionals and that support for health care professionals is essential for the optimal care of parents.
- Involves empathic and compassionate communication, appropriate non-verbal communication and respect for privacy. Both spoken and written communication needs to be understandable and to avoid euphemisms (e.g., "lost the baby") and other terms that may be ambiguous or unfamiliar to parents (e.g., "fetal demise").
- Recognises that parents come from a wide range of cultural and spiritual backgrounds, so it is important to check with parents to gain understanding of their needs, and not make assumptions.
- Includes shared decision making by:
  - Recognising the many difficult and complex decisions faced by parents
  - Respecting different approaches to making decisions
  - Understanding that parents' concerns, preferences, goals and wishes may change
  - Adequate time, information and support from health care professionals.
- Ensures care practices and approaches that respect all babies and acknowledge parenthood are integral to perinatal bereavement care.
- Recognises parenthood by offering and supporting options for parents to create memories from spending time with their baby and collecting mementoes of their baby to the extent that they wish.
- Recognises that organisational support and financial commitment is required to create the necessary conditions and structures to enable the implementation, monitoring and evaluation of best practice perinatal bereavement care.

individual health care professionals and 8 are directed at maternity care facilities. This distinction explicitly recognises the critical importance of organisational level support in enabling and supporting health care professionals to deliver best practice care. The full guideline is available https://www.stillbirthcre.org.au/resources/clinical-practice-guidelines/.

The specific actions of individuals are critical but need to be contextualised within a broader philosophy of care. The recommendations for respectful and supportive perinatal bereavement care are based on 10 foundations for care that reflect core themes prominent in the published literature,[7,8,15–19] and widely perceived as essential for perinatal bereavement care that is respectful and supportive (Box 1).

An organising framework setting out four overarching goals of care was developed to assist in grouping and categorising the actions and interventions in perinatal bereavement, which covers a broad scope of practice (Fig. 1). The framework contextualises the Guideline recommendations and reinforces the notion that specific practices and actions do not occur in isolation but contribute to the overall goals and experience of care. Similarly, the care provided by health care professionals is inextricably related to organisational responses, the fifth element of the framework.

4. Goals of best practice perinatal bereavement care

While the goals of care that drive the Guideline are distinct, they are inter-related and relevant to all interactions with bereaved parents across the full spectrum of care. The goals are consistent with the requirement for comprehensive bereavement care after the death of a child to be longitudinal, multifaceted and interdisciplinary.[20] Each goal has associated practices and actions that are covered in the guideline recommendations.

Good communication is a core component of respectful and supportive perinatal bereavement care and is the issue most often raised in studies of parents' experiences of care.[8,21,22] Good communication involves finding the right words, the right approach, and giving attention to both what is said and how it is said. Health care professionals cannot take away parents' emotional pain and distress, but by communicating in a sensitive and compassionate manner they can provide comfort and avoid adding further distress. In all communication with parents, it is important to remember that stress and grief can greatly reduce people's ability to absorb, process and retain information.[16,21,23] Parents may need information to be given more than once. Supporting verbal information with written or electronic resources, including reliable internet sites, is widely shown to be of benefit for parents.[16,17,24] Written information needs to be clear and sensitively written. Medical terms should be explained in understandable language.[23] Good communication involves ensuring cultural safety and recognition of the beliefs and practices important to parents and families around the time of a baby's death.

Fig. 1. Framework for the practice of respectful and supportive perinatal bereavement care.

Shared decision making in health care is "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences".[25] Decisional conflict (or uncertainty about the decision made), limited information, and less involvement in decision making are predictors of regret about medical decisions.[26] Applied to perinatal bereavement care when parents face many difficult and time-critical decisions, the value parents place on supported and informed decision making is well-documented.[8,27] Decisions can include the mode and timing of the baby's birth as well as end-of-life care. Decisions after a baby has died include those relating to seeing and holding the baby, autopsy and other investigations, and funeral arrangements. Supporting parents in their decision making requires more than one conversation. Decision support includes giving parents options, time to consider those options, and opportunities to discuss and revisit decisions.[8] Providing options is critical as parents are often not in a position to recognise what is possible and what ultimately might be important to them.

Recognition of parenthood begins by acknowledging the baby, the relationship that parents may already have established with the baby, and the enormity of the loss that has occurred. Care practices that honour their baby and acknowledge parenthood are central to the respectful and supportive care of parents.[15–17] Treating a baby with the care and respect accorded to a living baby may help to validate and normalise parents' experiences. Some actions are relatively easy for health care professionals to implement and are impactful, such as calling a baby by name, talking to and dressing the baby. Health care professionals play an important role in empowering parents to engage in normal parenting activities. A culturally sensitive approach and appropriate discussions with all parents are essential to ensuring parents' preferences and concerns are understood and met.

Effective support addresses the short- and long-term needs of parents and other family members. Support should be based on recognition that parents have experienced the birth and death of a baby with consideration of psychological, physical health and practical support needs.[8] Parents require immediate support to manage the initial stage of their grief and pathways to the support in their community once they have left hospital.[8,28]

A "flexible menu of support offerings" that recognises a continuum of support needs and the importance of collaboration between hospital, community and families should be made available to all parents.[28,29] Little evidence exists to indicate who is most likely to benefit from different types of psychological support[30] and not all parents will require formal interventions.[28] Some parents may find the support they need in their existing networks while others may benefit from specific supportive interventions or a combination of supports that will meet their needs at different times.[28] Parent support groups and the support of those who have had similar experiences may be helpful for many parents.[8,30]

Organisational response is necessary to create the conditions and formal structures that foster support and enable health care professionals to provide high quality perinatal bereavement care.[8,16] Acknowledging that respectful and supportive perinatal bereavement care is a responsibility shared between the organisation and individual health care providers is critical to developing environments that enable and support sustainable best practice care. For this reason, eight of the recommendations are directed at

the organisational level and are intended to guide maternity care services to develop a service-wide approach. Education, training and support for staff and evidence-based policies and protocols on key aspects of perinatal bereavement care are explicitly recognised.

5. Conclusion

The *Guideline for Respectful and Supportive Perinatal Bereavement Care* combines available research with lived experience and clinical insight to present a set of implementable recommendations that address the needs of bereaved parents. The Guideline is intended to be a living document that is updated every two years. A number of important areas warrant particular attention and will be given priority as part of the research program of the Stillbirth CRE. Among these are Indigenous women's experiences and needs; care in subsequent pregnancy; and best practices for engagement of parents in perinatal mortality review.

Conflicts of interest

None to declare.

Acknowledgements

We gratefully acknowledge all members of the Perinatal Bereavement Care Guideline Update Group for their guidance, input and feedback. We thank Trish Wilson for ongoing contributions and Sarah Henry, Deanna Futia, Christine Andrews and Reshika Chand for administrative assistance. The work reported in this publication is part of the Centre of Research Excellence in Stillbirth (Stillbirth CRE). Core funding to support the Stillbirth CRE is provided by the National Health and Medical Research Council (NHMRC).

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