



CASE STUDY

Caring for families experiencing stillbirth: Evidence-based guidance for maternity care providers



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ABSTRACT

Background: Evidence-based guidance is needed to inform care provided to mothers and families who experience stillbirth. This paper focuses upon how meaningful and culturally appropriate care can be provided to mothers and families from when they are informed that their baby will be stillborn to many years after the experience. Avoidable suffering may be occurring in the clinical setting.

Aims: To promote and inform meaningful and culturally appropriate evidence-informed practice amongst maternity care providers caring for mothers and families who experience stillbirth.

Methods: A comprehensive systematic review was conducted which primarily synthesised relevant qualitative research studies. An expert advisory group comprised of stillbirth researchers, clinicians, and parents who have experienced stillbirth provided guidance for the review and the development of implications for practice.

Findings: Grieving parents want staff to demonstrate sensitivity and empathy, validate their emotions, provide clear, information, and be aware that the timing of information may be distressing. Parents want support and guidance when making decisions about seeing and holding their baby. Sensitivity, respect, collaboration, and information are essential throughout the experience of stillbirth. Culturally appropriate care is important and may require staff to accommodate different cultural practices.

Conclusion: The findings of the review and expert consensus inform the provision of meaningful and culturally appropriate care for mothers and families that have experienced stillbirth. Evidence informed implications for practice are provided to guide the actions, communication, and behaviours of maternity care providers.

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1. Introduction

The stillbirth rate in Australia is around 3.5 per 1000 births.¹ Even with this relatively high prevalence, there is a lack of clear evidence-based guidance available to support and inform maternity care providers who provide care for families that experience stillbirth. The actions and behaviours of maternity care providers from the point that a baby has been diagnosed as no longer alive, and throughout the experience of stillbirth may be critical for the ability of families to cope with stillbirth.² Perhaps as a result of being ill-equipped to appropriately work with families around the time of stillbirth, the best standard of care and support may not be provided.³ Parents who experience stillbirth are at risk of potentially harmful psychosocial effects including grief, depression, anxiety,

and self-blame.^{2,4–6} Between diagnosis and birth, mothers can suffer significantly.⁷ Waiting to give birth may even be more distressing than the birth itself.^{8,9} For this reason, they need supportive and sensitive care from maternity care providers from before confirmation that their baby has died or will be stillborn.⁷ Recent research has also focussed upon the impact that stillbirth has on fathers and their experiences of care provided by maternity care providers.¹⁰ Parents are rarely prepared for the experience of stillbirth and may benefit from information provided by maternity care providers in the antenatal period.^{2,11} The negative effects of experiencing stillbirth may be lessened by receiving care from care providers who are trained and prepared to help parents cope with the tragic experience.^{5–8,11–17} Research has found that parents' negative experiences and outcomes may be compounded, or in some cases inadvertently caused, by interactions with maternity care providers throughout the experience of stillbirth.² In some cases, maternity care providers may not be adequately prepared or trained to provide the appropriate supportive and sensitive care required.³ Maternity

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care providers may be emotionally affected by stillbirth themselves and this can influence their interaction with parents and the quality of care that is provided.^{5,12}

A recent Cochrane systematic review sought to assess the effectiveness of support strategies for mothers, fathers, and families after perinatal death, including stillbirth.¹⁸ This review sought randomised trials that assessed any form of support aimed at encouraging acceptance of loss, bereavement counselling, or specialised psychotherapy or counselling for parents and families who had experienced perinatal death. The review was not able to include any studies because of the high loss of participants at follow-up. The authors concluded that practical guidance for the support for families affected by perinatal death could not be provided from an examination of trials and experimental evidence alone.¹⁸ There is a pressing need for a systematic review of the current evidence on this topic to be conducted that encompasses more than randomised trials, and seeks the best available evidence from other types of research including quantitative research. A comprehensive systematic review, which provided the evidence base for the development of the implications for practice presented in this paper, was undertaken to investigate the effectiveness, meaningfulness, and cultural appropriateness of non-pharmacological, psychosocial supportive care interventions and care strategies for families to improve their psychological well-being throughout the experience of stillbirth.¹⁹ In order to capture the range of experiences of care that parents may have during a stillbirth, this review considered language studies conducted in developed countries that are applicable to inform guidance for Australian maternity care providers who provide care to parents and families from a range of cultural backgrounds. This paper presents the implications for practice relevant to the care of mothers and families that have been developed from the synthesised findings of the comprehensive review and input of an expert advisory group of stillbirth researchers, clinical staff, and parents who have experienced stillbirth.

2. Methods

The systematic review was conducted according to an a priori systematic review protocol.²⁰ The review's phenomenon of interest was the experiences of families with interventions and care strategies implemented by maternity care providers throughout the experience of stillbirth; from the time of diagnosis to any time in the weeks, months, and years that followed. Family was defined as mothers, fathers, siblings and/or grandparents. Stillbirth was defined as the death of a baby in utero at any time from 20-weeks until immediately before birth. This is in line with the standard definition used in Australia.²¹ Papers that included families that had experienced perinatal death (after birth), neonatal death, miscarriage, termination of pregnancy for non-medical reasons or pregnancy loss before 20 weeks were excluded. Studies that investigated the death of a baby that matched the definition of stillbirth used in the review were included if participant data and findings could be disaggregated from those of ineligible participants.

A comprehensive search for published and grey literature was conducted during February to April 2014 across a number of databases including PubMed, CINAHL, EMBASE, PsycINFO, and selected trial registries and stillbirth related websites. Initial keywords included: the initial keywords used were: stillbirth; stillborn; foetal death; intrauterine death; perinatal death; psychosocial; psychotherap*; bereave*; grief; emotion*; depressi*; guilt. Only English language publications were considered for inclusion; publication date was not limited. The reference lists of included studies were examined to identify additional studies. No grey literature was identified that met the inclusion criteria for the

review. Twenty four qualitative studies were assessed for methodological quality by two independent reviewers prior to inclusion in the review using Joanna Briggs Institute (JBI) critical appraisal tools.^{22,23} Findings were extracted from papers included in the review using standardised JBI data extraction instruments.^{22,23} Meta-aggregative synthesis of the findings was performed using JBI-QARI (Joanna Briggs Institute, Adelaide, Australia).²² Common themes among findings were identified and used to group findings into categories. Developed categories were further brought together based upon similarity in meaning, to produce synthesised findings intended to be reliable representations of the primary authors' findings and intent that may be used as a basis for evidence-based guidance.^{24,25} A more detailed discussion of the methodological approach and methods used are detailed in a separate publication.²⁶

Members of the expert advisory group provided input throughout the project via three, face to face meetings, teleconferences and email correspondence with the research team. Advisory group members were asked to draw upon their professional knowledge and expertise, as well as their personal experiences as maternity care providers, clinicians, and parents of stillborn babies to provide advice. The role of the expert advisory group was to fulfil three main objectives; firstly, to provide guidance and feedback on the conduct of the systematic review to ensure that it located relevant evidence, secondly, to provide insight on the synthesis and interpretation of the findings of the review, and finally, to assist in the development of the implications for practice from the findings of the review to ensure that they would be suitable and practical in real-world practice and be appropriate for maternity care providers, mothers and families. Draft copies of the protocol and review were circulated to members of the group prior to meetings and members were invited to provide comment, critique, and guidance. Details of the protocol and the proposed conduct of the review were considered at the first face to face meeting while the full review report was considered in detail at the second face to face meeting of the advisory group and research team. To develop the implications for practice reported on in this paper, the results and conclusions of the systematic review were discussed in depth and members provided detailed feedback on what the implications for practice were and how they should be presented. Draft implications for practice were provided to the expert advisory group for input and comment and were further refined through detailed discussion at the final, face to face meeting. The advisory group provided additional depth and detail pertinent to the provision of care for mothers and families that was used to enrich and supplement the review findings.

3. Findings

Twenty two qualitative studies were included in the comprehensive systematic review. Overall, the studies were of moderate to high methodological quality with only one study receiving three out of ten possible negative responses to the critical appraisal criteria.^{22,23} Two studies of low methodological quality were excluded. Full details regarding the methodological quality of the included studies is presented in the systematic review report.¹⁹ The included studies were conducted in Australia (3),^{13,27,28} the United States (5),^{5,7,15,29,30} Sweden (5),^{2,8,9,31,32} Canada (1),³³ Taiwan (3),^{34–36} the United Kingdom (2),^{11,12} South Africa (1),⁶ Japan (1),¹⁷ and Norway (1).¹⁶ Most studies included mothers aged between 18 and 41 years; one study included mothers up to the age of 62.⁶ Some studies included both fathers and mothers as a couple,^{2,5,7,11,31,36} A small number of studies involved fathers (aged between 28 and 54) only.^{27,28,30,32,33} The time since stillbirth reported in the included studies most commonly ranged from two

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