



Perinatal loss: key messages for infant removal at birth

An evidence review

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About this review

This rapid evidence review aims to identify key messages from research concerning families' experiences of perinatal loss and their perceptions of good practice that may be applicable to infant removal at birth.

This paper is part of a larger scale project funded by the Nuffield Foundation: *Born into Care: Developing best practice guidelines for when the state intervenes at birth*. This research project aims to improve professional practice when the state intervenes in the lives of newborn babies, by creating new national guidelines for practice for England and Wales.

This review also follows the publication of *Pre-birth assessment and infant removal at birth: experiences and challenges A literature review* (2019), published by the Nuffield Family Justice Observatory, which identified key messages from research concerning birth parent and professional perspectives on pre-birth assessment and the removal of infants at birth. The dearth of literature related to experiences and practices of infant removal at birth in the context of the increasing use of this intervention in the UK, prompted consideration of how gaps in the current evidence base may be addressed in the interim by findings from the literature related to perinatal loss, an experience that bears some similarities to infant removal at birth.

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Introduction

The 'Born into Care' series of work led by The Centre for Child and Family Justice Research at Lancaster University and published by the Nuffield Family Justice Observatory (NFJO), has made evident the rising numbers of newborns entering care proceedings in England and Wales (Broadhurst et al., 2018, Irouh et al., 2020). As part of their ongoing interest regarding infants in the family justice system, The Nuffield Foundation funded a research project led by The Centre for Child and Family Justice at Lancaster University in partnership with the Rees Centre at Oxford University, which aims to improve professional practice when a local authority intervenes in the lives of newborn babies, by creating new national guidelines for practice.

In 2019 a rapid evidence review published by the NFJO highlighted the dearth of literature related to families' experiences of infant removal at, or near, birth and their perceptions of good practice. This rapid evidence review follows that review and aims to address the knowledge gaps related to families' experiences of infant removal at, or near, birth and their perceptions of what constitutes good practice by distilling key messages from the comparatively larger body of research related to perinatal loss (i.e., late-term miscarriage, stillbirth and neonatal death).

There are some parallels between the experiences of perinatal loss and infant removal (for example, in terms of the maternity setting, families' intense feeling of loss and grief, the vulnerability of mothers in the perinatal period and the complexities for professionals in responding to sadness in a typically happy event). We acknowledge that the removal of a live infant at birth is not directly comparable to perinatal loss, which involves the death of a baby or the death of a foetus after 14 weeks' gestation. The parallels in the literature are drawn in particular from the families' perspectives on their feelings of loss and grief from infant and child removal into state care (Broadhurst & Mason, 2020; Kenny, Barrington, & Green, 2015; Mason et al., 2019; Nixon, Radtke, & Tutty, 2013). The appropriateness of drawing on this literature was also confirmed by the advisory group for the *Born into Care: Developing best practice guidelines for when the state intervenes at birth* project, which included those with lived experience of child removal and advocates for family members of infants removed into care.

An initial scoping of the topic revealed a large body of literature related to perinatal loss. Given the extent of the evidence, we focused our rapid evidence review on existing systematic reviews only, rather than primary research papers. Further details of our strategy for this rapid evidence review, including the search strategy, are given in Appendix 1. The following research questions underpinned our review and are used to structure this report:

1. What are the effects of perinatal loss on parents and other family members?
2. How do the effects of perinatal loss differ between family members?
3. How do professionals impact parents' experiences of perinatal loss?
4. What interventions or practices are said to improve parents' experiences of perinatal loss?

Across the 12 identified systematic reviews, perinatal loss was acknowledged as a distressing, life-changing experience; however, few studies focused on its specific psychological and psychosocial effects. There was some evidence that perinatal loss was associated with anxiety, depression, relationship breakdown and difficulties in mother-infant adaptation with subsequent children. Mothers and fathers appeared to have different psychological responses to perinatal loss with mothers reporting more intense grief responses and higher levels of anxiety and depression. Vulnerability factors were associated with worse psychological and psychosocial outcomes. There were no descriptions of the effects of perinatal loss on extended family members, such as siblings or grandparents, in the literature identified in this review.

Professionals were described as having a significant and memorable impact on parents' experiences of perinatal loss through their behaviours, actions, and verbal and non-verbal communication. Much of the good practice related to perinatal loss that was highlighted by parents might be what we would expect from standard care practices; for example, displaying empathy, promoting continuity of care and providing sensitive, relevant and clear information. Although there were limitations in the perinatal loss evidence base in terms of the quality and scope of research, it was

possible to distil some key messages. Some of these key messages may be relevant for practitioners, policy makers and researchers thinking about infant-parent separation at birth due to safeguarding concerns.

This document presents the background to the review, its methodology, the findings from the review on perinatal loss, and a summary section discussing key messages from the perinatal loss literature and their relevance to infant removal at, or near, birth.

Background

Child welfare policy in the UK emphasises the importance of early intervention to prevent maltreatment, nurture secure attachment and promote children's wellbeing (First 1001 Days All Party Parliamentary Group, 2015; Powell, 2019). If a local authority has significant concerns related to child welfare, they can, as a last resort, intervene by making an application to Court for an interim care order to allow them to separate the child from their family and place them in an alternative care provision. In England, children are most likely to be placed in care for the first time as infants (i.e., aged <12 months; Mc Grath-Lone, Dearden, Nasim, Harron, & Gilbert, 2015) and the number of infants in care has increased in recent years from 4,300 in 2006 to 6,010 in 2019 (Department for Education, 2010, 2020). There is also evidence that the number of care proceedings involving infants that occur within the first few weeks of birth is increasing in England and Wales (Alrouh et al., 2019; Broadhurst et al., 2018); for example, in Wales, the proportion of care proceedings involving infants which occurred within 2 weeks of birth increased from 40% in 2011 to 52% in 2018 (Alrouh et al., 2019).

The decision to remove an infant from their family at, or soon after, birth is fraught with moral, ethical and legal challenges; yet, despite the difficulties of this practice and its increasing use in the UK, there is limited research on the topic. A recent rapid review of evidence related to pre-birth assessments and infant removals at birth identified just 27 studies from the UK and other countries with similar child protection

systems (Mason et al., 2019).¹ The majority of these studies focused on pre-birth assessment, and Mason *et al.* (2019) noted that there was very little evidence related to the practice of infant removal at, or near, birth or on what might constitute good practice based on families' experiences.

It is clear that further empirical research is needed to address the gaps in the evidence base related to infant removal. However, in the interim, it may be possible to gain further insight into experiences of and good practice related to infant removal by examining the comparatively larger body of literature related to perinatal loss (i.e., late-term miscarriage, stillbirth and neonatal death). Perinatal loss, which involves the death of a baby, is undoubtedly a different experience from the removal of a live infant at birth; however, there are parallels in experience, in terms of families' intense feeling of loss and grief, mothers' vulnerability in the perinatal period, and the need for professionals to respond in a tailored and empathic manner.

This rapid evidence review was conducted to summarise published literature on families' experiences of perinatal loss with a view to distilling key messages that may enhance our understanding of families' experiences of infant removal at, or soon after, birth and their perceptions of good practice.

Methodology

This rapid evidence review built upon previous literature and policy work and followed approaches for a policy-relevant review, including being time-bound, responsive and using clear language (Oliver, Dickson, & Bangpan, 2015). This review took a systematic review approach while following rapid evidence review principles in order to be both rigorous and responsive. The protocol for this review was pre-registered on PROSPERO (see Appendix 1 for further information on methodology).

¹ Mason et al. (2019) define countries with similar child protection systems to the UK as Australia, Canada, New Zealand, and the USA.

The topic for this review was decided in consultation with the *Born into Care* project and the advisory board, which included policy makers, practitioners, and advocates for family members of infants removed into care.² Having selected a topic, this rapid evidence review began with a scoping period to determine its bounds. During this scoping period, a series of initial searches related to perinatal loss were completed. Options for the review based on the extent of the literature were presented to the project group from the Rees Centre, University of Oxford and Centre for Child and Family Justice, Lancaster University, in November 2019. It was decided that conducting a review of existing systematic reviews on perinatal loss would provide the greatest added benefit to the evidence base.

We carried out final database searches in June 2020 for systematic reviews that were written in English and included studies conducted in the UK or other high-income countries. We did not specify any time limit on when the systematic reviews (or the studies they included) were published. In July 2020 we carried out snowball searches of papers that cited (forward search) and were cited in the included systematic reviews (backward search) to identify any additional eligible studies.³

In total, 12 systematic reviews were included in the final sample. These reviews were published between 2006 and 2017 and included studies that were published from the 1970s up to 2015. There were restrictions on the type of studies that were eligible for inclusion in each systematic review: qualitative, quantitative and mixed-methods studies only (n=3), qualitative only (n=3), quantitative only (n=2), qualitative and quantitative only (n=2), intervention only (n=1), and randomised controlled trials (RCTs) only (n=1). The systematic review restricted to RCTs did not identify any eligible studies for inclusion. For the remaining 11 systematic reviews, the number of studies included ranged from 2 to 60. Most systematic reviews (n=6) included studies from high-income countries only, namely: Australia, Canada, Japan,

² A full list of advisory board members is available from the project website page on the Centre for Child & Family Justice Research: <https://www.cfj-lancaster.org.uk/projects/born-into-care-towards-inclusive-guidelines-when-the-state-intervenes-at-birth>.

³ Snowballing refers to the process of hand searching bibliographies of studies included in a review and screening studies that cite studies included in a review to search for other studies that may fit the eligibility criteria, but had not appeared in the original searches.

Netherlands, Norway, Republic of Ireland, Sweden, Taiwan, UK and US. Five reviews predominantly reported research from high-income countries, but also included a single study from a middle- or high to middle-income country, specifically: India (n=1), Nigeria (n=2) and South Africa (n=2). Seven systematic reviews focused on experiences of stillbirth only, 3 on stillbirth and neonatal death, 1 on late-term miscarriage and stillbirth and 1 on late-term miscarriage, stillbirth and neonatal death. The eligibility criteria of most systematic reviews were restricted to studies involving parents only (n=5), mothers only (n=2) or fathers only (n=1). The eligibility criteria of 3 reviews included the experiences of parents, siblings and grandparents and 1 included parents and professionals. Although some eligibility criteria included extended family members such as siblings and grandparents, there were no descriptions of the effects of perinatal loss on extended family members.

We quality appraised all included systematic reviews using the Critical Appraisal Skills Programme (CASP) Systematic Review Checklist. We then conducted a narrative, primarily aggregative synthesis by integrating findings from across the 12 included reviews. Further details of the review methodology are provided in Appendix 1 and key characteristics of the included systematic reviews are summarised in Appendix 2.

Key Findings

Assessment of the literature

The 12 systematic reviews that we included synthesised findings based on their analysis of 252 empirical studies, which included qualitative, quantitative and mixed-methods designs. All of the systematic reviews included parents' experiences of perinatal loss, though some focused on mothers or fathers only. Experiences of siblings, grandparents and/or other immediate family were included in the scope of 3 reviews, but there was a paucity of evidence identified for these groups of family members. All systematic reviews included experiences of stillbirth and 5 also included late-term miscarriage and/or neonatal death in their definition of perinatal loss. Full details of the 12 systematic reviews are given in Appendix 2.

The systematic reviews that were included in this review varied in terms of their scope. Half of the reviews focused on describing the general experiences and outcomes of families who experienced perinatal loss and half focused on assessing the evidence of impact for specific types of interventions. Despite this heterogeneity in the aims of the identified systematic reviews, it was possible to extract and aggregate findings related to the research questions that our rapid review aimed to address. Findings have been grouped according to these four research questions. Individual systematic reviews had weaknesses in their reporting around the included studies and methodology, as specified in Appendix 2, but the overall body of literature was relevant and coherent for our review questions. In the description of findings for each question, we specify if there are issues relating to the adequacy, coherence or relevance of the synthesised evidence.

1. What are the effects of perinatal loss on parents and other family members?

Perinatal loss was acknowledged as a life-changing experience across all 12 systematic reviews; however, just 2 reviews focused on its specific psychological and psychosocial effects on mothers (Campbell-Jackson & Horsch, 2014) and fathers (Badenhorst, Riches, Turton, & Hughes, 2006). No systematic review of the effects of perinatal loss on siblings, grandparents or other extended family members was identified in this rapid evidence review.

Grief responses and symptoms of psychological distress were the effects of perinatal loss that were most often explored in the literature (Badenhorst et al., 2006; Campbell-Jackson & Horsch, 2014). Parents described a range of emotions and cognitive responses related to perinatal loss including shock, anger, regret, emptiness, loneliness and helplessness. Guilt and self-blame were also described as effects among mothers, as well as feelings of failure as a woman and a mother (Badenhorst et al., 2006; Campbell-Jackson & Horsch, 2014). There was evidence that parents who experience perinatal loss had elevated levels of anxiety and/or depression and low levels of wellbeing; however, the duration of these effects was unclear (Badenhorst et al., 2006; Campbell-Jackson & Horsch, 2014). Subsequent

pregnancies and post-partum periods were highlighted as times when women who had experienced perinatal loss could experience more anxiety, depression and psychological distress compared to other women (Campbell-Jackson & Horsch, 2014). There was limited research on the effects of perinatal loss on other psychological outcomes such as post-traumatic stress disorder (PTSD; Badenhorst et al., 2006; Campbell-Jackson & Horsch, 2014).

Similarly, there was limited research on the effects of perinatal loss on psychosocial outcomes. There was some evidence that mothers who experienced perinatal loss had higher rates of heavy drinking and tranquilizer use (Campbell-Jackson & Horsch, 2014). Conflict and dissatisfaction with relationships appeared to be more common among couples who had experienced perinatal loss, particularly in the short term (Badenhorst et al., 2006). More recent evidence suggested that the impact of stillbirth on relationship breakdown was evident up to 9 years later (Campbell-Jackson & Horsch, 2014). There was also some evidence that women could experience difficulties with mother-infant adaptation in subsequent pregnancies (Campbell-Jackson & Horsch, 2014). Wanting to withdraw from friendships and other supportive relationships was also mentioned as an effect of perinatal loss (Campbell-Jackson & Horsch, 2014).

Both systematic reviews highlighted that individual vulnerability factors, such as a lack of social support, a history of stressful life events and poor ego strength, are associated with worse psychological and psychosocial outcomes following perinatal loss (Badenhorst et al., 2006; Campbell-Jackson & Horsch, 2014). Other demographic characteristics such as being younger, having lower educational status, being unmarried and having no living children were also associated with poorer outcomes (Campbell-Jackson & Horsch, 2014).

2. How do the effects of perinatal loss differ between family members?

Grief responses were reported to be less intense among fathers who have experienced perinatal loss compared to mothers (Badenhorst et al., 2006). It was suggested that this difference may be attributed to fathers feeling the need to provide emotional support to mothers at the expense of processing their own feelings of grief

(Badenhorst et al., 2006). There may also be differences in grieving style between mothers and fathers, with fathers more likely to want to “move on” following perinatal loss (Badenhorst et al., 2006; Campbell-Jackson & Horsch, 2014). There was evidence that fathers had lower levels of anxiety and depression compared to mothers (Badenhorst et al., 2006) and higher levels of wellbeing (Campbell-Jackson & Horsch, 2014). There were no statistically significant differences in levels of PTSD between mothers and fathers (Badenhorst et al., 2006). No systematic review describing or comparing the effects of perinatal loss on siblings, grandparents or other extended family members was identified in this rapid evidence review.

3. How do professionals impact parents' experiences of perinatal loss?

Five systematic reviews focused on families' experiences of the health care system following perinatal loss including the important impact that professionals have (Crispus Jones, McKenzie-McHarg, & Horsch, 2015; Ellis et al., 2016; Gold, 2007; Peters, Lisy, Riitano, Jordan, & Aromataris, 2016; Peters, Lisy, Riitano, Jordan, & Aromataris, 2015). Across the literature, the behaviour, actions, and verbal and non-verbal communication of staff were described as having a significant and memorable impact on parents' overall experiences of perinatal loss. An insensitive comment, perceived avoidance by staff or even silence at a crucial moment had the capacity to become a negative interaction remembered by parents for months, and even years, later (Ellis et al., 2016; Gold, 2007). A lack of empathy and emotional support from staff was also described as having a negative impact on parents' overall experiences (Gold, 2007).

Professionals were also identified as playing a crucial role in parents' decision-making related to seeing and/or holding their baby following stillbirth (Kingdon, Givens, O'Donnell, & Turner, 2015). Although recent systematic reviews have found that evidence of the impact of seeing and/or holding their stillborn baby on parents' mental health and wellbeing outcomes is sparse and conflicting, there is clear evidence that many who chose not to do so subsequently regretted their decision (Hennegan, Henderson, & Redshaw, 2015; Kingdon, Givens, et al., 2015).

4. What interventions or practices improve parents' experiences of perinatal loss?

There was little evidence about interventions that may improve parents' experiences of perinatal loss from studies using experimental methods. A review of randomised controlled trials (RCTs) of psychosocial interventions following stillbirth identified no eligible studies (Koopmans, Wilson, Cacciatore, & Flenady, 2013). A more recent review of experimental interventions to improve mental and/or physical health among women who had experienced stillbirth identified just one study in a high-income setting (Huberty, Matthews, Leiferman, Hermer, & Cacciatore, 2017). This intervention involved a program of meetings with a grief support team and was associated with lower anger-hostility symptoms among a small sample of women from the USA. There were no other significant differences in grief symptoms or mental health outcomes associated with this intervention (Huberty et al., 2017).

Evidence from non-experimental studies described support groups as a helpful intervention for many parents who had experienced stillbirth (Ellis et al., 2016). For example, mothers who reported attending as little as a single support group meeting reported fewer mental health issues (Crispus Jones et al., 2015). There was also some evidence that cognitive behavioural therapy (CBT) could reduce grief and PTSD symptoms (Crispus Jones et al., 2015).

The most commonly studied practice to improve parents' experiences of perinatal loss was contact with the baby following stillbirth. Three reviews focused specifically on the effects of parents' having contact with their stillborn baby (Hennegan et al., 2015; Kingdon, Givens, et al., 2015; Kingdon, O'Donnell, Givens, & Turner, 2015) and contact was discussed in several other reviews (Campbell-Jackson & Horsch, 2014; Crispus Jones et al., 2015; Gold, 2007). Overall, there was conflicting evidence on the effect of parents having contact with their stillborn child (Crispus Jones et al., 2015). For example, holding their stillborn baby was associated with lower levels of depression for mothers during subsequent pregnancies, but higher levels of anxiety. For women who were not pregnant at the time of follow-up, there was no significant difference in anxiety and depression between those who had and had not had contact with their stillborn baby. There was evidence that subtle differences in the manner in which contact takes place may determine the long-term

consequences of such contact (Crispus Jones et al., 2015). For example, the likelihood of depression was influenced by whether a mother was able to see and hold her stillborn child for as long as she wanted (Campbell-Jackson & Horsch, 2014; Crispus Jones et al., 2015). Opportunities to create mementoes of a stillborn baby (e.g., taking photos, making hand and foot prints, keeping a lock of hair, etc.) was a practice that was also examined in several reviews (Crispus Jones et al., 2015; Gold, 2007; Hennegan et al., 2015; Peters et al., 2016; Peters et al., 2015). There was some evidence that creating, keeping and sharing mementoes had a positive impact on parents' self-reported experiences (Crispus Jones et al., 2015), but this was not consistent across the evidence base (Hennegan et al., 2015). However, it was clear that overall parents were grateful to have such mementoes, even those who initially turned down the opportunity to take part in memory-making activities (Campbell-Jackson & Horsch, 2014). The consensus from the literature was that spending time with and making memories of their baby should be an option that is supported and offered more than once to parents who experience a stillbirth, despite the lack of clear evidence on its effects.

Much of what was described by parents as improving their experiences of perinatal loss related to aspects of standard care from health professionals, rather than specific interventions. Sensitive, genuine and individualised care was seen as key to improving parents' experiences of perinatal loss. Parents valued staff who showed empathy and expressed their own emotions during a tragic time (Peters et al., 2016). Staff were also viewed as having the potential to be an important source of emotional support to parents through their interactions and simple gestures of care and empathy; for example, by taking the time to talk to parents and staying with them (Gold, 2007; Kingdon, O'Donnell, et al., 2015; Peters et al., 2015). Continuity of care and carers was important to parents for emotional support and also to avoid situations where staff were unaware of their circumstances (Ellis et al., 2016; Peters et al., 2015). Providing care in a sensitive location was seen as having a positive impact on parents' experiences by avoiding potential distress through contact with other new or expectant parents and the cries of newborn babies (Ellis et al., 2016; Kingdon, O'Donnell, et al., 2015; Peters et al., 2015). Although parents appreciated privacy, they did not want to be abandoned by staff (Ellis et al., 2016; Kingdon, O'Donnell, et al., 2015). Parents reported more positive experiences when they felt

that they were acknowledged, respected and treated as parents despite their loss (Campbell-Jackson & Horsch, 2014; Gold, 2007; Kingdon, O'Donnell, et al., 2015). Treating and handling their stillborn baby in a respectful, gentle and positive way was also paramount to parents' experiences (Ellis et al., 2016; Kingdon, O'Donnell, et al., 2015; Peters et al., 2016).

Providing sensitive, relevant and clear information was valued by parents (Ellis et al., 2016; Gold, 2007; Kingdon, O'Donnell, et al., 2015; Peters et al., 2016); for example, information about the grieving process (Gold, 2007) or information about lactation tailored to women who have experienced perinatal loss, rather than about breastfeeding for new mothers. Individualised follow-up care, including referrals to support services, help with practical arrangements related to stillbirth and additional follow-up appointments to reflect and ask questions about their experiences, were also considered important aspects of parents' experiences (Peters et al., 2015). Additional support and monitoring during subsequent pregnancies was also highlighted as important by parents (Peters et al., 2015).

Summary

This rapid evidence review was conducted to summarise published literature on the topic of perinatal loss (specifically, late-term miscarriage, stillbirth and neonatal death) with a view to distilling key messages that may enhance our understanding of families' experiences of infant removal at, or soon after, birth and inform good practice.

Appraisal of the literature

In total, we identified 12 systematic reviews that met the inclusion criteria of our rapid evidence review. Based on our assessment using the CASP Systematic Review Checklist, these reviews were generally of good quality with clear review questions, appropriate inclusion criteria and relevant outcomes selected (Appendix 2). However, there were common issues with the primary studies included in the systematic reviews, such as small sample sizes, potential biases in participation and sampling, loss to follow-up in longitudinal studies and a lack of interventional research designs. Indeed, a consistent message across the included systematic

reviews was that more good quality primary research related to perinatal loss was needed (Badenhorst et al., 2006).

Key messages from the perinatal loss literature and their relevance to infant removal at birth

Screening and support for psychological and psychosocial effects

Our review highlighted similarities between perinatal loss and infant removal in terms of the range of emotions and cognitive responses these experiences elicited for parents; for example, shock, anger, regret, emptiness, loneliness, helplessness, guilt and (for women) feelings of failure. Our review also found that parents who experienced perinatal loss had poor psychological and psychosocial outcomes, such as anxiety, depression and some types of alcohol and substance misuse. It is, therefore, likely that parents who experience infant removal at, or near, birth are similarly at risk of poor psychological and psychosocial outcomes. These outcomes were worse among parents with vulnerability factors, such as a lack of social support, lower educational status and a history of stressful life events, which are likely to be prevalent among parents who have experienced infant removal. Screening for mental health issues such as anxiety, depression and PTSD may provide evidence of the scale of these issues among parents who experience infant removal and help to identify those in need of support. There was very little research that evaluated interventions aimed at improving parents' psychological and psychosocial outcomes following perinatal loss. There was limited evidence that meetings with a grief support team (Huberty et al., 2017), attending a support group and CBT were helpful interventions (Crispus Jones et al., 2015). Parents who have experienced infant removal may benefit from similar interventions, but careful thought regarding the particular nature of the grief response may be needed. Further robust research is needed.

The role of contact and memory-making activities

In the studies identified in our review, the most commonly studied practices to improve parents' experiences of perinatal loss were having contact with the baby and memory-making activities following stillbirth. Despite the lack of clear evidence of their effects, the consensus from the literature was that these activities should be an option that is supported and offered more than once to parents who experience a

stillbirth as most parents who engage in these activities report positive experiences, and many who do not subsequently regret their decisions. Current Royal College of Obstetrician and Gynaecologists (RCOG) guidelines reflect this finding (Royal College of Obstetricians and Gynaecologists, 2010). There are no equivalent guidelines for infant removal at birth and providing opportunities for memory making activities do not appear to be a routine part of postnatal care for these parents (Mason et al., 2019). Providing opportunities to create memories of their baby by, for example, taking photographs, footprints or keeping cot cards may be beneficial to parents experiencing infant removal. The development of guidelines related to infant removal for healthcare staff may also be beneficial.

In terms of contact with a stillborn baby, one of the key factors associated with its impact was the amount of time parents had with their baby: parents who spent as long as they wanted with their stillborn baby reported more positive experiences. In the context of infant removal, holding and spending time with the baby for as long as the parents wish may not be appropriate in all cases (e.g., where there are serious and immediate child protection concerns); however, there may be cases in which this practice could be improved and where more choice could be given.

Empathetic, sensitive and individualised care from professionals

Interactions with professionals had a profound impact on parents' experiences of perinatal loss. An insensitive comment at a crucial moment could be remembered as a negative interaction many years later (Ellis et al., 2016; Gold, 2007). For parents experiencing infant removal that involves feeling of guilt, shame and stigma, it is particularly important that interactions with staff are based on a foundation of respect and non-judgement. Parents who experienced perinatal loss valued professionals who showed empathy and acknowledged their identity as parents, despite the difficult and tragic circumstances of their baby's birth. Parents also appreciated sensitive and individualised care, such as having a private room on the maternity ward to avoid exposure to other new and expectant parents and babies and being given information that was appropriate for their circumstances (e.g., related to breastfeeding). Simple adaptations to standard care practices such as these examples may also benefit parents who experience infant removal who have

reported issues related to a lack of empathy from staff and privacy in other studies (Mason et al., 2019).

Being informed and prepared

Following a diagnosis of intrauterine death, parents appreciated being given clear information about what would happen during labour and after the birth of their stillborn baby. They particularly appreciated practical advice that allowed them to prepare, such as bringing a camera to take photos of the baby and knowing what would happen to their baby after the birth. Other studies have shown that parents whose baby is removed at birth are not always clear about the process of removal, or may not even be aware that it will happen (Mason et al., 2019). Ensuring parents whose infant will be removed at birth are fully informed and allowing them time to prepare could improve their experiences and minimise distress.

Support for subsequent pregnancies and parenting

Additional support during subsequent pregnancies was highlighted as important in parents' experiences of stillbirth (Peters et al., 2015). Often parents sought additional appointments to reassure them that their baby was well and valued continuity of care as it meant they did not have to repeat their history to numerous professionals. The issues of continuity of care or consistency of worker have also been shown to be important to parents within the child protection and family justice system (Broadhurst et al., 2017, Mason et al., 2019). Previous experience of insensitive practice has also been shown to impact future engagement with professionals. It is, therefore, important that professionals work to build and maintain supportive relationships with parents who experience infant removal at birth. There was also some evidence that women who experienced perinatal loss had difficulties with mother-infant adaptation in subsequent pregnancies (Campbell-Jackson & Horsch, 2014). Mothers who have previously had an infant removed at birth may also encounter such difficulties and require additional support to come to terms with the loss and complicated nature of their grief (Broadhurst et al., 2017, 2019, 2020).

Conclusion

This rapid evidence review further highlights the parallels in experiences for parents who experience perinatal loss and infant removal at, or near, birth. Findings from perinatal loss literature with implications for infant removal include the importance of screening and support for psychological and psychosocial effects, opportunities for memory making about the baby, being informed and prepared about what is happening, support for subsequent pregnancies and parenting as well as empathetic, sensitive and individualised care from professionals. However, despite having a larger and more longstanding body of literature, there is little research on the psychological and psychosocial outcomes of parents who experience perinatal loss or on the types of intervention that may help to improve these outcomes that could be used to address these gaps in our knowledge related to infant removal, at or near, birth. As such, there is an imperative for further empirical research in this area. The important role of healthcare professionals on parents' experiences reinforces the need for training related to infant removal for perinatal health and social work professionals, and for the development of practice guidelines.

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Appendices

Appendix 1: Methodology

The first step in this rapid review was to map review options and confirm the review topic that would be feasible and relevant for policy and practice. The advisory board and project team confirmed the overall topic and the relevance of perinatal loss. Then, several scoping searches were done which revealed the vast extent of the literature on perinatal loss and the existence of current systematic reviews. Several options in scope and review questions were presented to the project team, and it was decided that a review of existing systematic reviews would be most relevant. We returned to the project team when particular questions arose when creating the protocol.

The second step was to create a protocol outlining the research questions, inclusion and exclusion criteria for the literature search, search strategy and search strings. We used guidance documents from PROSPERO and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)⁴ statement, which sets out an evidence-based minimum set of items for reporting in systematic reviews, to develop the protocol. The finalised protocol was registered on PROSPERO in July 2020 (registration number: CRD42020194315). Key details of the review protocol are described in this Appendix.

Research questions

This review aimed to summarise the evidence from existing systematic reviews related to the following research questions:

1. What are the effects of perinatal loss on parents and other family members?

⁴ For further details, see the adapted tool for reporting systematic reviews of qualitative and quantitative evidence:
http://toolkit4mixedstudiesreviews.pbworks.com/w/file/107458323/Reporting_template_MSR.pdf

2. How do experiences of perinatal loss differ between mothers, fathers and other family members?
3. What impacts do professional practices have on families' experiences of perinatal loss?
4. What professional practices are said to improve parents' experiences of perinatal loss?

Inclusion and Exclusion Criteria

The following inclusion and exclusion criteria were applied during the literature search:

Inclusion criteria:

- Systematic reviews
- Written in English
- Including studies conducted in high-income countries
- Reporting the experiences of parents and other family members
- Perinatal loss defined as stillbirth (≥ 20 weeks' gestation), late-term miscarriage (during the 2nd trimester) or neonatal death (≤ 28 days of life)

Exclusion criteria:

- Termination of pregnancy or early miscarriage (before 20 weeks' gestation)
- Child death after the neonatal period
- Primary research, literature reviews or scoping reviews

There is a large body of evidence related to experiences of perinatal loss. Given the time constraints of this rapid evidence review, we decided to focus only on relevant, existing systematic reviews. We excluded literature reviews as this type of review does not apply systematic methods when identifying relevant studies for inclusion. We excluded scoping reviews as this type of review focuses on identifying gaps in an evidence base rather than summarising existing evidence.

The language skills of the review team meant that only systematic reviews in English could be considered for inclusion. We chose to focus on systematic reviews that included studies from high-income countries to maximise the potential generalisability and applicability of any findings to the UK. We chose to exclude

studies of miscarriage before 20 weeks' gestation, termination of pregnancy or the death of a child after the neonatal period as we felt that these experiences were less comparable to infant removal at birth.

Information sources

In July 2020, a comprehensive search of the following electronic, academic databases was conducted: PsychINFO, Embase and Medline (via Ovid); PubMed; Scopus; CINAHL; ProQuest Social Science Premium Collection; Social Care Online; the Cochrane Library; Joanna Briggs Institute website; NICE guidelines; and Google Scholar. Given the time and resource constraints, a search of grey literature was not included as part of this rapid review.

Search strategy

Box 1 outlines the search string used in this rapid review. Depending on the database being searched, different combinations of symbols and brackets were used to denote combinations of words and wildcard characters. Where possible, search strings were searched in the title, abstracts or key word fields only.

Box 1: Example search string

(Perinatal adj4 loss) OR (pregnancy adj4 loss) OR (late?term adj1 miscarriage) OR (in?utero adj4 death) OR (intra?uterine adj4 death) OR (perinatal adj4 death) OR stillbirth OR (intrapartum adj4 death) OR (baby adj4 death) OR (baby adj1 dies) OR (infant adj4 death) OR (infant adj1 dies) OR (neonat* adj4 death) OR (neonate adj1 dies) OR (newborn adj4 death) OR (newborn adj1 dies)

AND

Attitude* OR experience* OR perspective* OR opinion* OR view* OR effect* OR impact*

AND

Parent* OR mother* OR women OR father* OR men OR caregiver* OR family OR families OR grandparent* OR sibling*

AND

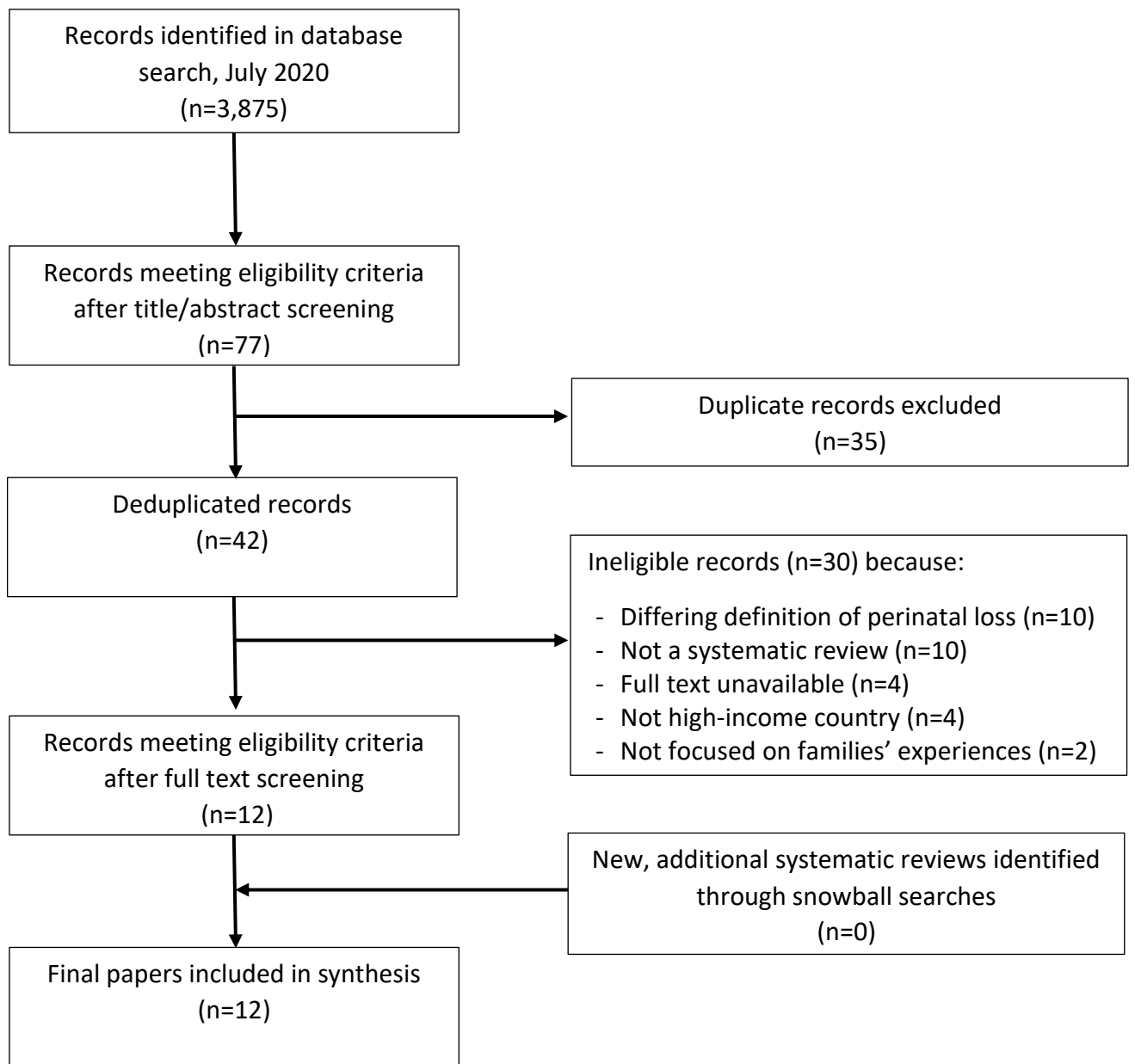
Systematic review* OR meta?analysis OR meta?synthesis

Study screening and selection

As recommended by PRISMA, Figure 1 provides a flow diagram of the study screening and selection process. The initial searches in July 2020 identified 3,875 records. Source titles and abstracts were initially reviewed against the inclusion/exclusion criteria, 77 records were retained and uploaded to Mendeley, a referencing software package. After checking for duplicates, 35 records were excluded. The full texts of the remaining 42 records were reviewed against the inclusion/exclusion criteria and 30 were excluded. The majority of studies were excluded because the definition of perinatal loss did not align with the definition specified in this rapid review (n=10). Other reasons for exclusion following full-text screening were: conference abstract reporting a systematic review (n=6); literature review or protocol for a systematic review (n=4); focused on low- and/or middle-income countries (n=4); does not focus on experiences of parents and other family members (n=2). No full texts were available online for 4 potentially eligible records. The authors of these systematic reviews were contacted directly but full texts were not provided. Overall, 12 systematic reviews were included in this rapid review.

Snowball searches were carried out for the 12 included systematic reviews and an additional 1,618 records were screened against the inclusion/exclusion criteria. In total, 12 records that met the inclusion/exclusion criteria were identified; however, 11 of these records were duplicates of the already included systematic reviews and 1 was a report version of an already included systematic review and so no new, additional sources were identified through the snowball search.

Figure 1: Flowchart



Critical Appraisal

We quality appraised all included systematic reviews using the Critical Appraisal Skills Programme Systematic Review Checklist.

Analysis and Assessment of Evidence

We carried out a descriptive, narrative review by using the *a priori* research questions as a framework for identifying and coding relevant themes from the aggregate findings of the included systematic reviews. We then assessed the overall confidence in the evidence acknowledging the richness and heterogeneity of the data and the limitations of the eligible studies, including variation in study quality. This process was guided by the GRADE-CERQual dimensions of methodological limitations, relevance, coherence and adequacy.

Appendix 2: Description of included systematic reviews

Primary author (Year)	Type of perinatal loss	Family members eligible for inclusion	Review objective	Type of eligible studies	Number of included studies	Countries included studies were conducted in	Limitations from critical appraisal
Badenhorst (2006)	Stillbirth and neonatal death	Fathers only	To review the available evidence on the psychological effects of perinatal death on fathers.	Qualitative and quantitative	17	Not reported	Excluded 10 studies with <5 participants. Does not report the countries of the included studies.
Campbell-Jackson (2014)	Stillbirth from 20+ weeks	Mothers only	To summarise evidence on psychosocial responses to stillbirth.	Qualitative and quantitative	26	Australia, US, UK, Canada, Taiwan, Netherlands, Sweden, Nigeria, Japan.	No details of any critical appraisal of included studies.
Crispus Jones (2015)	Late-term miscarriage & stillbirth	Parents only	To review evidence of interventions to alleviate parental distress following stillbirth.	Quantitative only	10	US, UK, Sweden, Canada.	No details of any critical appraisal of included studies.

Primary author (Year)	Type of perinatal loss	Family members eligible for inclusion	Review objective	Type of eligible studies	Number of included studies	Countries included studies were conducted in	Limitations from critical appraisal
Ellis (2016)	Stillbirth from 24+ weeks	Parents & professionals	To understand and improve care after stillbirth.	Quantitative, qualitative & mixed-methods	52	Australia, Canada, Norway, South Africa, Sweden, Republic of Ireland, US, UK	No details of any critical appraisal of included studies. Does not provide a table of characteristics of the included studies.
Gold (2007)	Late-term miscarriage, stillbirth & neonatal death	Parents only	To summarise parents' experiences of interactions with staff following stillbirth.	Quantitative, qualitative & mixed-methods	60	US	No details of any critical appraisal of included studies. Does not provide a table of characteristics of the included studies.
Hennegan (2015)	Stillbirth and neonatal death	Parents only	To summarise evidence on holding baby.	Quantitative only	18	US, Canada, Australia, Taiwan, UK, Norway, Nigeria, Sweden.	No limitations from our assessment using CASP systematic review checklist. Very rigorous review.

Primary author (Year)	Type of perinatal loss	Family members eligible for inclusion	Review objective	Type of eligible studies	Number of included studies	Countries included studies were conducted in	Limitations from critical appraisal
Huberty (2017)	Stillbirth from 20+ weeks	Mothers only	To summarise evidence on intervention studies following stillbirth.	Intervention studies only	2	India, US.	No details of any critical appraisal of included studies.
Kingdon, Givens et al. (2015)	Stillbirth from 20+ weeks	Parents only	To summarise evidence on the impact of professionals on parents' experience of holding baby.	Qualitative only	12	UK, Canada, Sweden, US, Japan, Australia.	No limitations from our assessment using CASP systematic review checklist. Review demonstrates rich rigour.
Kingdon, O'Donnell, et al. (2015)	Stillbirth from 20+ weeks	Parents only	To identify and synthesize available research reporting parental outcomes related to seeing and holding baby.	Quantitative, qualitative & mixed-methods	23	US, Sweden, UK, Canada, Japan, Australia.	Does not provide a table of characteristics of the included studies.

Primary author (Year)	Type of perinatal loss	Family members eligible for inclusion	Review objective	Type of eligible studies	Number of included studies	Countries included studies were conducted in	Limitations from critical appraisal
Koopmans (2015)	Stillbirth and neonatal death	Mothers, fathers, siblings and/or grandparents.	To assess the effect of any form of intervention on parents and families who experience perinatal death.	RCTs only	0	Not applicable.	No limitations from our assessment using CASP systematic review checklist. Very rigorous review.
Peters (2015)	Stillbirth from 20+ weeks	Mothers, fathers, siblings and/or grandparents.	To inform practice based on evidence of psychosocial supportive care interventions.	Qualitative only	22	Australia, US, Sweden, Canada, Taiwan, UK, South Africa, Japan, Norway.	Does not provide a table of characteristics of the included studies.
Peters (2016)	Stillbirth from 20+ weeks	Mothers, fathers, siblings and/or grandparents.	To explore the meaningfulness of care related to stillbirth.	Qualitative only	10	Australia, US, UK, Canada, Sweden, South Africa.	Does not provide a table of characteristics of the included studies.