REVIEW ARTICLE

TITLE: Nursing interventions for perinatal bereavement care in neonatal intensive care units: A scoping review

ABSTRACT:

Background: Despite technological advances and specialist training of neonatal teams, perinatal deaths still occur. Such events are traumatic experiences for the parents and increase the risk of pathological grieving. Nursing is one of the main sources of support. However, the important work of nurses in these situations is made more difficult by the lack of recognised strategies that can be implemented to assist parents and family members in the bereavement process.

Aim: Identify nursing interventions to help parents of neonates admitted to neonatal intensive care units cope with perinatal loss.

Methods: A scoping review based on the methodological framework established by Arksey and O'Malley was used. A total of 327 relevant studies were identified through a bibliographic search in Pubmed, CINAHL Plus, APA PsycNET and Scopus between 2000 and 2019. The screening process included an initial analysis of the relevance of the abstract and, when required, an extensive review of the full paper.

Results: A total of 9 papers were finally selected which responded to the research question. All nine papers are from the USA and have different methodological characteristics. A number of effective interventions were identified, including legacy creation, support groups, family-centred accompaniment and follow-up, parental involvement in pre-mortem care, intergenerational bereavement programmes, and the use of technological and spiritual resources.

Conclusion: In general, the scant evidence that is available about nursing interventions around perinatal bereavement care underlines the requirement to thoroughly assess the effectiveness of those that have already been designed and implemented.

Implications for nursing practice and policy: This scoping review contributes to the potential implementation of effective interventions to deal with and help parents and family members cope with perinatal bereavement, with nursing staff as the main source of support and leading interventions which have family members in the care team. This review also makes a substantial contribution to the development of a practical and evidence-based clinical guide for nursing, with recommendations that can be adapted to effective quality care criteria. It is additionally intended to encourage visibility in health policies of care and attention to perinatal grief in neonatal intensive care units.

KEYWORDS: Family; Interventions; Intensive Care Units, Neonatal; Nursing; Parents; Perinatal grief.

TEXT

INTRODUCTION

The latest published data for 2016 show an average estimated global stillbirth rate (SBR) of 18.4 per 1000 births, which corresponds to a 25.5% decrease compared to the 2000 SBR of 24.7. It is estimated that there were 2.6 million stillbirths globally in 2015, with more than 7,178 deaths a day. However, this was 19.4% fewer than in 2000, representing an annual rate of reduction of 2% (WHO 2016). Progress in this respect is considered to be slowest in sub-Saharan Africa and certain regions of south Asia. The same systematic analysis reported that, of the 2.6 million neonatal mortalities in 2016 (representing approximately 7000 births per day), more than one million occurred on the first day of life and almost one million more in the following six days (WHO 2016). The high risk of morbimortality associated to this period is well-known (Blencowe *et al.* 2016). The etiology of neonatal mortality is multifactorial (Khan *et al.* 2014). The main direct causes are considered to be preterm birth, serious infections and asphyxia (Sankar *et al.* 2016). Because of the need for continuous specialist care in life-threatening situations, such care is usually given whenever possible by the neonatal team of a neonatal intensive care unit (NICU). However, an unwanted number of perinatal deaths in the first week of life (early neonatal mortality), still occur in such units (Blencowe *et al.* 2016) despite the specialist training the teams will have undergone and the technological advances that have been made in recent years.

BACKGROUND

The death of a neonate is an extremely traumatic experience for all concerned, but most especially of course for the parents. In the 20th century, the bond between parent and offspring was something that took place much later than happens now, and if a neonate died the parents

were simply separated from the baby to avoid any pain or suffering (Rubin 1976). Today, that bond is formed much earlier, in the initial stages of pregnancy (Zdolska-Wawrzkiewicz *et al*. 2019), and a perinatal death tends to have an enormous impact on parents and family (Flenady *et al*. 2014). When a baby is born in a critical condition and is admitted to a NICU, the parents find themselves having to deal with the undermining of the expectations generated during pregnancy and having to cope with an enormous range of feelings and preoccupations which can trigger high levels of stress, anxiety and depression (Flenady *et al*. 2014, Kersting & Nagl 2016). If the neonate dies, such emotions can manifest themselves in perinatal grieving, beginning with negation, incredulity, confusion, shock, anger, sadness, longing, desperation, guilt and shame, along with all the difficulties that not being prepared to deal with such a loss can entail (Ridaura *et al.* 2017).

In accordance with its definition as recorded in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM), grieving is a response to the loss of a loved one in which some individuals display symptoms such as sadness, insomnia, anorexia or weight loss which are characteristic of a major depression disorder (American Psychiatric Association 2013). Previous research studies have shown the major psychological impact that a perinatal loss represents on parents and family members at physical, social, spiritual and behavioural levels, often leading to pathological, complicated or dysfunctional grieving (Kersting & Nagl 2016). Subject to various manifestations, the symptoms of perinatal bereavement usually decrease in intensity at around 12 months (deMontigny *et al.* 2017). An assessment of the intensity and the repercussions of grief associated with a perinatal loss is key to a better understanding and handling of perinatal grieving (Hutti *et al*. 2017).

The neonatal team that attends the neonate and its family often faces the risk that the parents may develop complicated grieving processes in the event of the death of the neonate (Burden *et al*. 2016), and effective programmes are necessary to deal with such situations. The nursing staff

are one of the main sources of support for parents from the time of admittance of the neonate to the NICU, as well as in monitoring the biopsychosocial progress of the parents (Steen 2015, Hutti & Limbo 2019). Some of the actions that nursing staff need to take in such painful moments can be found in the literature, where special emphasis is placed on the importance of verbal and non-verbal communication (WHO 2017) to ensure that perinatal bereavement does not evolve into pathological grieving (Steen 2015). According to the Callista Roy adaptation model, focal and contextual stimuli can generate stress and responses mediated by diverse ways of coping. This model considers that the person is a holistic adaptive system in continuous interaction with the environment. As such, the interaction of parents with a hospital environment - or their not being able to care for their child - can be deeply stressful and bring about significant demands on the coping and adaptation processes which are required to avoid both physical and psychological health repercussions (Roy *et al.* 1999). For all of the above reasons, the quality of the nursing care will have a significant impact on the risk of development of complicated grieving and, in consequence, on the family recovery process (Craig *et al*. 2015).

AIMS

Perinatal bereavement care has become a forgotten issue within the health sector. There is little scientific evidence available to guide caregivers with respect to the implementation of effective interventions to better deal and cope with perinatal bereavement, as many of these described in the literature have not been properly assessed and their effectiveness has not been demonstrated. Nurses, in their role as a fundamental pillar in care-giving, are responsible for these interventions - in which the first step is to recognise and fully explore the best strategies that are available so that they can subsequently be integrated in care processes that avoid complicated grieving. Thus, the general aim of the study is to identify nursing interventions that can be used to tackle and deal with perinatal grieving in parents of neonate babies who have been admitted to NICUs. At the same time, the specific aims of this study are to describe nursing interventions

for the effective handling of perinatal bereavement according to their typology and nature, and to determine effective coping strategies.

METHODS

A scoping review design was chosen to achieve the aims proposed above. This technique involves mapping the relevant literature of an area of interest. The idea is to carry out a synthesis and analysis of the evidence in order to endow significant conceptual clarity about a specific theme, in this case perinatal bereavement care. “Scoping reviews are considered useful in nursing research” (Davis *et al*. 2009). The present scoping review follows the methodological framework described by Arksey and O'Malley (2005), with contributions from Davis *et al*. (2009). It is divided into five stages. This review also followed the guidelines outlined in the PRISMA extension for scoping reviews (Tricco *et al*. 2018) (Appendix 1).

Stage 1. Identifying the research question

The research question that was formulated was as follows: “What nursing interventions have been effectively implemented to tackle and help parents cope with the perinatal death of their baby in neonatal intensive care units?”

Stage 2. Identifying relevant studies

The bibliographic search was conducted from December 2018 to March 2019. The relevant studies were identified on the basis of a search of publications between 2000 and 2019. For the selection, keywords were identified, the search strategies were established and the article inclusion/exclusion criteria determined. Different database sources were used: PubMed; Nursing & Allied Health Literature (CINAHL) PLUS, APA PsycNET and Scopus with the combination

of the following keywords or thesauri: “Bereavement”, “Grief”, “Interventions”, “Intensive Care Units, Neonatal”, “Parents”, “Family”, “Nursing”. The Boolean operators “AND” and “OR” were used. When possible, the searches were managed using the Medical Subject Headings (MeSH) tool for information searches (Appendix 2).

Inclusion and exclusion criteria

In order to finetune the search through the scientific databases, a series of inclusion and exclusion criteria were defined. When the search was made, qualitative and experimental (clinical trials and quasi-experimental studies) were included. Given the context of the study, it was also decided to include quantitative studies with an observational design (cohort and case-control studies). With respect to the year of publication of the study, an extensive range was proposed (2000-2019), given the general gap in the body of knowledge in this respect, to ensure a more exhaustive search. Finally, as the mother tongue of the authors of the present study is Spanish and in order not to miss relevant papers, it was decided to include any paper written in Spanish whose title and abstract had also been written in English. No restriction was imposed on the type of intervention, except those whose purpose was to treat perinatal grief with pharmacological approaches. All the literature relating to stillbirth was also excluded, given that the topic of interest was neonatal death in the context of a NICU after admission for a critical condition or end-of-life process. With respect to the population the intervention is aimed at, this was limited to mothers and/or fathers and/or the immediate family who have experienced the death of an infant in the perinatal period in a NICU. Studies which involved spontaneous early miscarriages (before 20 weeks of gestation) or the ending of pregnancy for non-medical reasons were also excluded.

Stage 3. Study selection

The selection process was carried out following Davis *et al*. (2009). The aim was to highlight all the relevant documentation obtained in the search that focuses on any aspect of the topic under investigation. They also recommend the exclusion of comments and conclusions of works from which results that are not valid for the study cannot be extracted. For the selection process, the documents were firstly imported into Mendeley, version 1.19.3, and then screened for duplicates. The relevant articles were then examined, and each selection was subsequently made following the pre-established inclusion and exclusion criteria.

Stage 4. Charting the data

The documents that were finally selected were then charted. The information was reviewed in parallel by two members of the team (VG and EP), but the final decision was made at meetings with a third member of the research team (VG, EP, AL). The data table considered information related to author(s), year of publication, study aims, location and population, methodology, intervention, and evaluation of results.

Stage 5. Collating, summarising and reporting the results

To identify the results clearly and concisely, the results were synthesised with the principal topic of interventions currently used to treat perinatal grieving in NICUs classified into material, psychosocial, technological and/or spiritual resources.

RESULTS

The results obtained via the bibliographic search and the description of the selected studies is described below.

Identification and selection of relevant papers

A total of 327 articles were identified in the database, 206 of which were excluded in the duplicate screening process and 80 after screening the titles. The relevance of each abstract of the 41 remaining articles was then analysed, which resulted in the elimination of 23 papers. A full-text analysis was then conducted of the remaining 18 articles. In this way, a total of 9 articles were finally identified and selected for in-depth assessment (Figure 1).

Characteristics of included studies

The characteristics of the studies that were finally selected are summarised in Table 1. All 9 studies were conducted in different parts of the USA. In line with the study design, six qualitative studies, one randomized controlled trial (RCT), one cohort study and one case-control study were considered. With respect to the study participants, all the studies considered families which had suffered the experience of a perinatal death, without including spontaneous early miscarriages or voluntary interruptions of the pregnancy. There were a total of 646 participants. The articles selected for the review varied in their methodological characteristics, with an overall moderate-to-high methodological quality. In general, the evidence that is explored is scant, but diverse interventions are found worthy of consideration, reproduction and assessment by other authors. All the studies highlight the need to implement effective intervention programmes to deal with perinatal bereavement due to the high risk of the development of pathological grieving.

Most relevant findings: interventions to deal with perinatal bereavement

Through the scoping review that was performed, it was possible to identify the existence of different interventions to help parents and family members cope with perinatal bereavement in

NICUs (Table 1). The interventions described in the studies were classified by type as using material, psychosocial, technological or spiritual resources.

Material resources

To date, diverse material resources have been found to be useful in helping parents and family cope with perinatal bereavement in NICUs. For example, in the development of one intervention programme, Gibson *et al.* (2011) guided the family through the bereavement process by anticipating their physical, spiritual and emotional needs, using health education measures and encouraging the participation of all the family in a process known as 'legacy creation', and generally helping the family to feel themselves in control of the bereavement process. In another study, Akard *et al.* (2018) demonstrated that legacy creation improved the coping process, with positive effects on parental and sibling distress during the perinatal bereavement process. This was also evidenced by Levick *et al.* (2017), extending the elaboration of a legacy of the neonate to all family members. It was observed that bereaving families found meaning and purpose in the act of legacy creation at the time of a neonate death, helping them to keep their memories intact.

The authors also highlight the importance of involving the family in the care process and ensuring the progenitors have the opportunity to bathe, dress and hold their infant, supported by the effect of musicotherapy with recordings of the heartbeat of the neonate, as a way of strengthening the bond with their baby as they said their farewells (Levick *et al*. 2017). Other additional legacy elements which have been shown to have a consoling effect for the parents in the bereavement process include moulds or impressions of the face, hands and feet of the baby (Gibson *et al.* 2011, Levick *et al.* 2017). Among other resources included in the family support folder used by Gibson *et al.* (2011) are a list of state-wide support groups and community resources, poetry, a handmade bookmark and relevant literature. In this respect, the research

developed by Akard *et al*. (2018) makes clear the benefits of digital storytelling, and its positive influence on the decision-making process is also evidenced by Levick *et al.* (2017). According to Roose & Blanford (2011), other written support materials are also beneficial.

Psychosocial resources

One resource that has been investigated by several authors is that of parent support groups, headed by nurses with a background in the fields of psychology and social work (Reilly-Smorawski *et al.* 2002) or co-facilitated by them (DiMarco *et al.* 2001). Such groups foster follow-up individualized contacts (Levick *et al.* 2017) and meetings between bereaved parents (Reilly-Smorawski *et al.* 2002), and offer genuine feelings of ongoing support, helping them learn how to tolerate the grief and pain as a couple and to remove the fear of speaking about their deceased child. These groups also offer help in decision-making processes on questions such as future pregnancies through support group discussions, and have been identified as a useful intervention (Reilly-Smorawski et al. 2002).

In another study, Roose & Blanford (2011) showed that the care and guidance of health support staff was useful for all the family. Other support group programmes, also with favourable results, were set up by an interdisciplinary team (Levick *et al.* 2017), while Akard *et al.* (2018) identified nurses as ideal support figures in the perinatal bereavement process.

It was also found that the implementation of an intergenerational programme to deal with perinatal bereavement was useful to help families cope with the process. In this respect, Dimarco *et al.* (2001) were able to show that parents perceive their corresponding partner, extended family and friends as indispensable figures during the grieving process. This was also evidenced in other studies (Roose & Blanford 2011).

Technological resources

The use of photographs and videos of the neonate was the most commonly used technological resource, constituting a guaranteed legacy and facilitating an ongoing bond with the child after its death (Gibson *et al.* 2011, Levick *et al.* 2017, Akard *et al.* 2018). The study developed by Blood et al. (Blood & Cacciatore 2014) approved the use of memento mori photography in cases of perinatal mortality. Though not always requested by the parents despite its value, it can be effective in generating positive feelings in the parents. In another study, the addition of a neonatal-bereavement-support DVD to standard bereavement care practices was not so successful, with more serious symptoms of depression and higher grief at 3 months reported in those who had visualized the video as opposed to those who had not. Very few parents recommended its use (Rosenbaum *et al.* 2015).

Spiritual resources

Religion constitutes an important defence mechanism for bereaved parents, helping them to alleviate their pain and suffering, and numerous associated emotional benefits have been reported. ~~The use of~~ Spiritual activities has been related to a reduction in symptoms of pain, depression and perinatal post-traumatic stress disorder (PTSD) (Hawthorne *et al*. 2016), and to an improvement in the personal growth of grieving mothers which increases with the extent and intensity of the religious activities. It has been shown that it is vitally important to individualize the intervention plan according to the race/origin, ethnic group and religion of the parents/family involved (Hawthorne *et al.* 2016). Other authors, including Levick *et al.* (2017), also noted the importance - in all aspects of perinatal bereavement care - of taking into account differences in religious/spiritual beliefs.

DISCUSSION

Perinatal mortality care continues to be a virtually forgotten topic in health policies, despite the high number of perinatal deaths (Blencowe *et al*. 2016) and its importance in family-centred care planning. This has caused some disquiet among the neonatal nursing profession. For many years, perinatal bereavement care was beset by controversy until the start of the present century when the topic began to be reconsidered. This allowed new research studies to be conducted, which would conclude in recommendations for its practice (Warland & Davis 2011) and open a new pathway to establishing care protocols. The purpose of this scoping review is to provide greater clarity about the topic, selecting and analysing the evidence that is available about effective nursing interventions in the event of perinatal bereavement of parents of neonates admitted to NICUs who, in view of the risk of developing a dysfunctional grieving, are offered quality care by skilled and knowledgeable neonatal teams. The findings of the present scoping review shed light on diverse perinatal bereavement care programmes in NICUs. These can be classified by type according to the resources that are used (material, psychosocial, technological and spiritual) in order to identify and raise awareness of the interventions that have been implemented to date.

The evidence that has been analysed identifies legacy creation, which can be understood as a permanent record of memories, as one of the principal interventions that have been developed to date (Gibson *et al.* 2011, Blood & Cacciatore 2014, Akard *et al.* 2018). "The creation of a legacy is one of the most effective perinatal bereavement care strategies" (Levick *et al.* 2017), as it allows the parents/family to maintain a connection with the deceased neonate (Klass *et al.* 1996) and "helps them find meaning and solace through the act of generating memories at the time of such a loss" (Levick *et al.* 2017). Another strategy found in the interventions that were analysed is related to psychoeducation, through the use of literature and other community resources for grief support. In this respect, Gibson et al. (2011) reported the efficacy of creating

a family support folder, and it was concluded that there is a need to consider programmes which consist of a combination of diverse interventions as opposed to isolated interventions of a single type. As pointed out by Akard et al. (2018) in their study, legacy interventions, including storytelling, can "provide opportunities to explore moral dynamics as individual and collective processes through which moral behaviour and attitudes emerge, evolve, spread and disappear in the context of the NICU", fomenting and enhancing the ability to communicate. Positive results were seen in the decision-making processes of the parents, with the aim being to make them feel in control of the situation. Legacy creation is also approved as an intervention measure by other authors (Gibson *et al.* 2011, Blood & Cacciatore 2014, Levick *et al.* 2017). In addition, other studies have pointed out that this type of intervention does not entail any counter-therapeutic effect (Gold 2007). As well as a family support folder, other interventions of a similar nature involve the creation of a physical representation of the deceased neonate by means of impressions in clay or other materials of the hands and feet of the baby, with 3D impressions also gaining in popularity. Such techniques are also considered another effective coping mechanism (Harvey *et al.* 2008, Levick *et al.* 2017).

In a NICU context, it is well known that the active participation of progenitors in the care of the neonate has a protective effect on parental adaptation to the hospitalization process (Catlin & Carter 2002, Gibson *et al.* 2011, Levick *et al.* 2017). Even though the units may be open 24 hours a day, the time that the parents can be at their child's side is always less than they would ideally like, and it is in this regard that parental participation acquires greater meaning and importance (Dyer 2005). That is, in the event of an anticipated perinatal death, it is extremely important that the parents have been involved in the basic care practices, including holding, dressing and bathing their baby, with a view to strengthening the parent-offspring bond and the exercising of their care-giving role when the time comes for them to bid farewell because the infant has died (Levick *et al.* 2017). In this aspect, and when the prognosis of survival is poor, some authors have stressed the importance of the active accompaniment of the parents, after

their needs have been assessed, as it can help them substantially in dealing with a complicated situation that can trigger postnatal grief syndromes even one year after the loss (Gibson *et al.* 2011, Levick *et al.* 2017, Akard *et al.* 2018). In this respect, there is also rising interest in the enforcement of parental support groups, as they enable the parents to freely express themselves in an atmosphere of trust about the various questions that worry them, helping them to endure the grief and pain they are suffering, dissipating their fear of speaking about their deceased baby, and strengthening their decision-making capacity (DiMarco *et al.* 2001). In a study by Reilly-Smorawski *et al.* (2002), parents who participated in these support groups described them as 'lifesavers'. The construction of relationships was the cornerstone of the programme, enabling an emotional balance to be maintained through the expression of feelings. As suggested by Roose & Blanford (2011), it also worth considering during the perinatal bereavement process the potential benefit of the presence and participation of the extended family - grandparents and siblings - as an essential source of support. This evaluation was made after implementation of their intergenerational perinatal bereavement programme, which could be used as a complement to a parental support programme. The intergenerational programme strengthened the bond between siblings, which provided comfort to the parents. In the programme, the grandparents were able to explain how it is possible to understand life's experiences and give meaning to the loss of the child, helped by the acknowledgement and acceptance of generational differences. In this respect, the presence of family members as a unit was a key strategy in coping with perinatal bereavement in conjunction with other previously described interventions.

The in-depth analysis that was conducted of the scientific evidence also revealed the positive effect of other technology-based interventions. In this respect, optimum and ongoing care in combination with the generation of feelings of attachment to the recently deceased neonate are of vital importance to help in coping with the moments of pain which are so tangible in perinatal bereavement (Currie *et al.* 2016). Photography is one possible option for this purpose, although

there is some reticence about offering the service in these situations and it is not generally used at the present time as a coping mechanism (Gold 2007, Harvey *et al.* 2008). However, various studies have concluded that NICUs should offer photographic services to the parents as means of retaining the memory of the deceased neonate (Umamanita & El Parto es Nuestro 2009, Cacciatore & Flint 2012). Various psychosocial interventions have been developed for cases of neonatal bereavement, with benefits seen in in terms of their effectiveness in parents and other relatives by providing comfort and thereby easing the coping process (Roose & Blanford 2011, Blood & Cacciatore 2014, Akard *et al*. 2018). On occasions, faced with the physical and/or emotional shock and the state of crisis that such a loss can entail, some parents may immediately reject the offer of a photographic record. However, after some reflection and once they have regained some control over their emotions, they may well change their mind and express a desire to have such a record, and so it recommendable to keep such photographs for a period of time after the event (Cacciatore & Flint 2012, Blood & Cacciatore 2014). The use of CDs to store images of the baby's stay in the NICU is another of the interventions found in the literature. These provide a continuous record of the baby, helping in the establishment of a positive bond of affection and protecting against the development of pathological grief (Gibson *et al.* 2011, Rosenbaum *et al.* 2015, Akard *et al.* 2018). Among other resources that have been used, parents gave positive assessments of the importance and effect of musicotherapy (Akard *et al.* 2018). However, to date no studies have been published confirming these results, with this remaining a potential future subject of research. Finally, although with fewer references, mention should also be made of the intervention involving periodic telephone calls during the first year of the bereavement process (DiMarco *et al*. 2001, Reilly-Smorawski *et al*. 2002, Covington 2009, Gibson *et al*. 2011, Roose & Blanford 2011, Levick *et al*. 2017, Akard *et al*. 2018). This was also considered a good way of assisting parents in the grieving process and one which they appreciate as it demonstrates the continued concern about their wellbeing. It is also a useful tool for the caregivers in that it facilitates the follow-up and monitoring of the emotional state of the parents during the grieving process.

Another important resource in the construction of a good support and care relationship between caregivers and parents is related to the beliefs and the cultural, religious and spiritual practices of the family concerned. It is extremely important to be aware of the potential of religion as a coping mechanism in the event of a prenatal death (Levick *et al.* 2017), a question which has been highlighted by various authors (Moon & Gordon 2009, Fenstermacher & Hupcey 2013). When faced with a perinatal loss, the ways and rules as to how the bereavement is manifested vary to a large extent according to the beliefs and practices of those who are affected, making it important to implement protocols or guidelines which will also vary according to these beliefs and sociocultural differences, with an additional possible effect on the acceptance of the implementation of other previously analysed interventions (Chichester 2005, Cacciatore & Flint 2012, Blood & Cacciatore 2014). To date, very few studies have assessed spiritual and/or religious-centred interventions aimed at parents in the bereavement process after a perinatal death. Parents in such a process have reported how their faith in God enabled them to manage their grief, helping them to make sense of their loss (Lichtenthal *et al.* 2010). Previous studies have shown the emotional benefits that the belief in a supreme being can provide in helping parents and family members cope with the pain (Meert *et al.* 2005). In this respect, Hawthorne *et al*. (2016) proposed diverse religious/spiritual-based strategies as coping mechanisms, which include the aim of helping the parents find meaning in their loss. However, the results of such mechanisms were inconclusive in terms of the disappearance or decrease of the symptoms of pain. The beliefs and practices of the family may only be beneficial after some time has elapsed, and "it not uncommon for the parents to initially express feelings of anger and blame towards their God and/or towards themselves", seeing the death as some sort of punishment. In their study, Meert *et al.* (2005) confirm this hypothesis. Though it requires further research, the use of spiritual activities which foster self-reflection and self-confidence is worth considering as an aid to help with the bereavement coping process (Hawthorne *et al.* 2016).

A special mention should also be made of how various authors who have analysed this variable

have identified “nurses as the ideal caregivers to help ease the bereavement process” (DiMarco *et al.* 2001, Reilly-Smorawski *et al.* 2002, Gibson *et al.* 2011, Roose & Blanford 2011, Blood & Cacciatore 2014, Rosenbaum *et al.* 2015, Hawthorne *et al.* 2016, Levick *et al.* 2017, Akard *et al.* 2018). All these authors consider that the neonatal nursing team is one of the main sources of support for the parents from the instant that the neonate is admitted to the NICU, as well as in their subsequent biopsychosocial monitoring. In this respect, if there is a lack of preparation and training on the part of the healthcare team, it will be difficult to avoid the complications that this will entail. Nonetheless, it is at this point that the nursing staff must perform their most important role as a recognised and valued caregiver and provider of emotional support (Sutan *et al.* 2010). The importance of this role cannot be stressed enough, and should be used to justify, motivate and promote perinatal bereavement coping strategies within the nursing process framework. Such strategies range from the early assessment and identification of risk factors related to perinatal loss and how it is manifested, to the identification of diagnoses following the NANDA-I taxonomy (Nanda International 2018) concerning coping responses to grieving (00136) and complicated grieving (00135), and the planning, execution and evaluation of care plans that ensure an integrated optimum care and are effective and useful in dealing with perinatal grieving.

After analysing the evidence related to interventions for the care and attention of perinatal bereavement that were found to be effective in a prior analysis, it can be concluded that a successful intervention requires the NICU nursing team to consider the implementation of a wide range of strategies of varying nature from the moment of the perinatal loss, or at an earlier stage when that loss has been anticipated. A synthesis of the strategies that have been found to be effective is provided in Table 2 (DiMarco *et al.* 2001, Reilly-Smorawski *et al.* 2002, Gibson *et al.* 2011, Roose & Blanford 2011, Blood & Cacciatore 2014, Rosenbaum *et al.* 2015, Hawthorne *et al.* 2016, Levick *et al.* 2017, Akard *et al.* 2018). The implementation and evaluation of these strategies in a context of strong parental vulnerability should be attended on

a case-to-case basis, with a view to guiding future actions in this respect and taking a progressive step in the humanization of NICU caregiving.

Strengths and limitations of the review

Scoping review techniques essentially involve mapping the scientific literature related to the area of interest, with the ultimate aim of synthesising and analysing the evidence in order to confer greater conceptual clarity with respect to the topic of interest. In this respect, one of the strengths of this work is that it scrupulously follows the methodological framework described by Arksey and O'Malley and with significant contributions from Davis et al. Another strength is that the analysis of the evidence obtained from the systematic search that was performed enabled the identification of nursing interventions that can be used to tackle and deal with perinatal grieving in parents of neonates who have been admitted to NICUs, and to fill critical gaps in the body of knowledge. A first limitation of this review is that all of the studies were from the US. Although this may have the benefit of greater homogeneity between the selected studies, the fact that the health care system in the US differs from other countries is a limitation when trying to publish in an international journal. However, the major limitation is the scant evidence that has been published on the topic, which resulted in the obligation to consider observational studies in the analysis. Nonetheless, this aspect is to some extent compensated by the methodological quality of the studies, all of which were positively evaluated in this respect (Appendix 3). According to a study published by Steen et al. (Steen 2015), there is a major concern among NICU nurses about the lack of detailed information on how to deal with and help bereaved families cope with a perinatal loss. The absence of helpful guidelines makes it more difficult to take appropriate actions. At the present time, we are unaware of any plans for training programmes for NICU nurses which would ensure optimum caregiving in the perinatal bereavement process, and perhaps herein lies the crux of the problem of such scant evidence in

the literature. Given such an absence of training programmes, the design, implementation and evaluation of possible strategies, along with the dissemination of the results, is made more difficult, confirming once again that perinatal bereavement care is one of the forgotten health policies and that the stigmas and taboos attached to perinatal loss have persisted over time.

Future recommendations

Based on the present work, we propose the active participation of neonatal teams in the design of programmes that offer care and attention in cases of perinatal bereavement and, in this way, help avoid the risk of triggering pathological or complicated grieving. The professional nursing staff, as a key part of this process and responsible for this care practice, should be involved in the training of the rest of the team and in raising awareness of the benefits of the correct implementation of the coping mechanisms employed. Finally, and most importantly of all, there is a vital need to invest time and effort in the long-term evaluation of the effects of the implementation of new protocols or procedures. This will ensure their relevance and suitability and, in short, improve the quality of the care that nurses provide to fathers and mothers who experience a perinatal bereavement and the consequent fracturing of their hopes and dreams. As nurses, our goal is to strive for the emotional wellbeing of the family and to prevent the emergence of complicated or unresolved grieving after such a devastating loss.

Implications for nursing and health policy

The results obtained in this scoping review open the way for the implementation of effective interventions to deal with and help parents and family members cope with perinatal bereavement. In such situations, as has been seen, the nursing staff are the main source of support, although consideration may also be given to extending the actions that can be taken to a multidisciplinary team. While protocols are being established in this respect in our NICUs, there

remains a need to redefine, update and standardise them in accordance with the scientific evidence. This present scoping review contributes substantially to the development of a practical and evidence-based clinical guide, with recommendations that can be adapted to effective quality care criteria. It is additionally intended to encourage visibility in health policies of care and attention to perinatal grief in NICUs, from necessary support and involvement of international organizations such as the World Health Organization and the International Council of Nurses.

CONCLUSIONS

The results of this scoping review show that the implementation of nursing interventions based on the use of material, psychosocial, technological and spiritual resources is vitally important and offers a substantial contribution to appropriately dealing with and helping parents cope with perinatal bereavement in NICUs. Such resources are useful tools for the neonatal nursing staff, who are key elements in the perinatal bereavement care process.

The review and in-depth analysis that was performed found a wide-ranging series of effective perinatal bereavement care interventions that need to be considered as a whole rather than individually with a view to meeting the biopsychosocial needs of the bereaved family. The interventions that were found to have a positive effect include: parental participation in the basic care needs of the neonate from the moment of its admittance to the NICU; the creation of a legacy or memory box which can include objects of significance to the parents, literature and/or details of state/community resources; the physical representation or impression in clay or some other material of the neonate; the use of photography; the establishment of parent-based support groups and/or intergenerational groups comprised of members of the family. Other interventions that have been analysed, such as using a support DVD, were shown to be ineffective, however, and their use should not be considered. It was also found that cultural, religious and spiritual

practices are elements that are inherent to the grieving process and can constitute an effective coping mechanism in the event of a perinatal loss.

Notwithstanding the above, there is a clear need to evaluate the effect of interventions that have been developed but not yet subjected to proper assessment in a research process. Such evaluations should be headed by nurses, the key figure in the attention, care and support that is offered to mothers and fathers who experience perinatal loss in the framework of a neonatal intensive care unit.

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Table 1. Characteristics of the selected studies

AUTHOR AND YEAR OF PUBLICATION	AIMS	LOCATION	STUDY POPULATION	METHODOLOGY	INTERVENTION	EVALUATION OF RESULTS
AKARD *et al.* (2018)	To explore parental perception of a legacy creation intervention after the death of a neonate.	Monroe Carell Jr. Children's Hospital, Vanderbilt (USA)	Parents with experience of perinatal death in NICUs. (n = 3 mothers; n = 3 fathers; N = 6)	Qualitative study studio based on focus group interviews, with evaluation between 10 and 12 months after the death of the neonate.	Legacy creation. Creation of memories through the compilation of mementos and physical representations of the recently deceased neonate.	Digital storytelling is beneficial, keeping alive the memory of the deceased neonate. Telling stories is an effective intervention. The inclusion of photographs and videos is requested by parents. The parents identify nurses as the ideal caregivers in such situations. The programme improves communication and decision-making.
BLOOD *et al.* (2014)	To verify the efficacy of photography as a bereavement coping resource for parents who have suffered a perinatal loss.	Arizona State University, Phoenix (USA)	Parents with experience of perinatal death in NICUs. (n = 93 parents with postmortem (memento mori) photographs taken for the purpose of overcoming grief or as mementos; n = 11 parents without; N = 104)	Qualitative study.	Psychosocial intervention using the practice of photography in the perinatal bereavement process.	Almost all the participants considered the intervention to be effective and approved the use of postmortem photography. Parents who did not have the photographs subsequently expressed a degree of desire to have a photograph of their deceased neonate. Some parents, encouraged by the health workers, took the photograph after initially rejecting it. 78.8% of parents were asked if they wanted postmortem remembrance photography.

DIMARCO *et al.* (2001)	To determine differences in reactions to bereavement between parents who attended a support group and parents who did not, and to determine whether the support group was of help to deal with the perinatal loss.	Ohio (USA).	Parents with experience of perinatal death. (n = 67 support group parents; n = 54 control group parents; N = 121)	Epidemiological, observational, analytic and retrospective design. For the assessment, a questionnaire with 13 questions was issued which incorporated the Hogan Grief Reaction Checklist (HGRC), with scores given for despair, panic behaviour, personal growth, blame and anger, detachment and disorganization.	Support groups of 8-12 people, aimed at parents who had experienced a perinatal loss, co-chaired by a nurse for a 2 hour period. The topics that were discussed varied according to the needs of each participant.	There were no significant differences between groups by age, sex or religion. Most attended between 8 and 12 sessions. The women obtained higher scores in the subscales of despair, panic and detachment. More than 35% considered the intervention to be useful. In both groups, the parents perceived their partner, extended family and friends as "more useful".
GIBSON *et al.* (2011)	To describe the development of an integrated bereavement programme for families and NICU personnel.	Riley Hospital for Children, Indiana University Health (US).	Parents with experience of perinatal death in NICUs. (N = 2)	Qualitative study. Selection, analysis and study of cases with a view to developing a NICU bereavement intervention programme. Follow-up at 12 months.	NICU bereavement programme: - Elaboration of a family support folder with lists of state-wide support groups and a book titled Empty Cradle, Broken Heart. - Educating the family about how to keep their baby comfortable when dying. - Offering a private place to say their farewells. - Photographs, hand and feet moulds. - Parents are offered a CD with photographs and any object they wish to take form the baby's headboard. A suicide protocol is also employed to detect any possible suicidal ideas of the parents.	No evaluation is presented of the programme.
HAWTHORNE *et al.* (2016)	To test the relationships between	Florida International University,	Parents with experience of perinatal death in	Observational analytic study. Cohort study.	Spiritual and religious coping strategies.	"Grief-stricken parents experience many emotional benefits associated with the use of

	spiritual/religious coping strategies and the suffering, mental health (depressions and post-traumatic stress disorder) and personal growth of parents of recently deceased neonates, with and without control by ethnic group and religion.	Miami (USA)	NICUs. (n = 114 mothers; n = 51 fathers; N = 165)	Study variables: - Hogan Grief Reaction Checklist (HGRC) - Beck depression inventory (BDI-II) - Revised impact of event scale (IES-R) Spiritual coping strategies (SCS) scale		religion" as a defence mechanism to deal with their suffering and maintain their mental health. The use of spiritual activities is strongly correlated with all the results for the mothers and fathers who participated. Their use is associated with a decrease in the symptoms of pain, depression and post-traumatic stress disorder in mothers in the grieving process.
LEVICK *et al.* (2017)	To describe an integrated approach to provide bereavement care services to families of deceased neonates in NICUs, as well as to provide training and support to NICU personnel.	Helen DeVos Children's Hospital, Michigan St. (USA)	Parents in the grieving process in NICUs. (N = 36)	Qualitative study based on individual experiences and suggestions to improve the care service. Evaluation through postal surveys 13 months after the death of the neonate. Data collection from June 2011 to December 2016.	NICU bereavement programme: - Verification list preparing mementos for the family members. - Musicotherapy, with recording of the neonate's heartbeat. - Holding and bathing the baby. - Photography and DVD. - Help with ink prints and/or plaster moulds of the neonate. - Titles of useful books offered. - Offer of memory boxes to the siblings of the neonate. - Sending of cards and follow-up calls for 12 months.	"Grieving families find meaning and purpose in the act of creating mementos at the time of their baby's death". They suggest the use of impressions of the face and hands of the baby as additional memento elements to provide solace to the parents in the grieving process.
REILLY-SMORAWSKI *et al.* (2002)	To describe the developmental stages of a grief support programme for parents of neonates who die in NICUs, with a	Massachusetts General Hospital, Boston (USA)	Parents with experience of perinatal death in NICUs. Sample size is not specified. Population of	Qualitative study. Qualitative evaluation at 11 weeks through a brief and informal survey with 12 questions. 14 year programme follow-up.	Parental support group for 12 weeks after the death of the neonate. - Headed by healthcare workers. - Discussion topics: death of the baby, grieving experiences, future problems and problems between the couple. - After the programme concluded, the participants were offered the	The pros and cons of the intervention were established. After a 14 year long analysis, it was found that: Meetings with other parents offer a genuine feeling of ongoing support.

	14-year analysis.		predominantly middle-class married couples residing in the metropolitan area.		possibility of group meetings at 3 month intervals for one year for follow-up purposes and to observe their feelings at particularly important moments (anniversary of the death of the neonate, Mother's Day, Christmas, etc.). - After 3 months they were contacted by phone for control purposes.	After the programme had concluded, the parents reported they were not afraid to talk about the deceased baby. The programme facilitates decision-making.
ROOSE *et al.* (2011)	To identify and assess the use of intergenerational support services and educational provision for parents and grandparents in a perinatal bereavement programme.	Hinsdale Hospital, Illinois (USA).	Parents and grandparents in a perinatal bereavement process. (n = 79 mothers; n = 20 fathers; n = 8 grandparents; N = 107)	Qualitative study. Programme assessment via survey and telephonic follow-up. The survey included questions related to the support services and the efficacy of these support groups for the siblings and grandparents of the deceased neonate.	Development of a perinatal bereavement programme with an intergenerational nature (Still Missed). Mission: To support parents and the family through a monthly support group, an annual remembrance service, various rituals and mementos. The participants were attended by qualified bereavement counselling workers, with visits to inpatients, follow-up calls and bereavement conferences, and were provided with a wide variety of written support material.	The inclusion of grandparents at the time of the loss was considered useful by 62% of the parents, while 80% considered very useful the creation of a legacy between the deceased neonate and sibling. 80% of the parents with children 3 years old or less and 77% with children 4 years old or more did not take their children to bid farewell to the baby. 73% of the children who were three years old or less and 59% of those who were 4 years old or more did not attend the funeral.
ROSENBAUM *et al.* (2015)	To test the effect of a support DVD on perinatal grieving of parents who have experienced the death of their baby in a NICU, and to compare the effect with that of standard bereavement care (SBC).	University Medical School, Washington (USA)	Parents with experience of perinatal death in NICUs. (n=56 families in SBC; and 51 families in SBC/DVD; N = 107)	Randomized control trial(RCT) Random selection of English-speaking parents whose babies died between January 2018 and October 2010. Divided into a control group (SBC) and experimental group (SBC/DVD).	- The SBC consisted of care attention from a multidisciplinary team. - A CD was offered with photographs, a package with hair cuttings of the baby, plaster casts of the hands and feet, and clothing. - The SBC team held follow-up meetings between 8 and 12 weeks after the death of the neonate. - In addition to the above, the SBC/DVD was offered a DVD.	In general, it was found that the parents who watched the DVD reported significantly lower educational attainment, more severe depressive symptoms and greater pain at the loss at 3 months than those who did not.

				For the assessment, interviews were conducted by telephone at 3 and 12 months after the death of the neonate. Measured variables: Perinatal pain; Depression (CES-D); Spiritual beliefs (Royal Free Interview); Social provisions scale (SPS); Assessment of DVD use.		

Table 2. Effective interventions to help deal with the perinatal grieving process*

1. Participation of parents in the basic care of the neonate from the moment of its admittance to the NICU.
2. Creation of a memory box with all manner of personal objects of significance.
3. Physical representation of the hands and feet of the neonate and 3D facial images.
4. Psychoeducational documents and literature for parents and siblings.
5. Peer support groups chaired by a professional counsellor.
6. Intergenerational family support group with all the members of the family.
7. Photographs of the deceased neonate[1] (in paper or digital format).
8. Musicotherapy (neonate heartbeat recordings).
9. Periodic control and follow-up telephone calls during the first year of bereavement.
10. Spiritual self-reflection and self-confidence interventions.

* General consideration: The manifestations of grief at a perinatal loss vary depending on cultural standards and religious beliefs.

[1] It should be noted that while the offer of photographs may initially be rejected, the parents may subsequently change their mind and request them.

Figure 1. Search and selection hierarchy adapted to scoping reviews, formulated by Davis et al. (2009).