



1.5

HOURS

Continuing Education

Parents' Experiences About Support Following Stillbirth and Neonatal Death

Marcos Camacho Ávila, MSc, RM; Isabel María Fernández Medina, PhD, RN;
Francisca Rosa Jiménez-López, PhD, RN; José Granero-Molina, PhD, RN;
José Manuel Hernández-Padilla, PhD, RN; Encarnación Hernández Sánchez, PhD, MSc;
Cayetano Fernández-Sola, PhD, RN

ABSTRACT

Background: Stillbirth and neonatal death are one of the most stressful life events, with negative outcomes for parents. Society does not recognize this type of loss, and parental grieving is particularly complicated and intense.

Purpose: The aim of this study was to describe and understand the experiences of parents in relation to professional and social support following stillbirth and neonatal death.

Methods: This was a qualitative study based on Gadamer's hermeneutic phenomenology. Twenty-one semistructured interviews were carried out. Inductive analysis was used to find themes based on the data.

Results: Twenty-one parents (13 mothers and 8 fathers) from 6 families participated in the study. The analysis identified 2 main themes: (1) "professional care in dealing with parents' grief," with the subthemes "important aspects of professional care," "continuing of pathways of care"; and (2) "effects of social support in parental grief," including the subthemes "the silence that surrounds grieving parents," "family and other children: a key element," and "perinatal loss support groups: a reciprocal help."

Implications for Practice: Counseling and support according to parents' requirements by an interdisciplinary team of professionals educated in perinatal loss and ethical family-centered care is needed. A social support system for families is necessary to avoid negative emotional consequences.

Implications for Research: Further research is needed to analyze midwives' and nurses' experience as facilitators to improve parental grief and the difficulties experienced by the family, other children, and friends of parents with perinatal loss in providing support.

Key Words: grief, neonatal death, parents, perinatal loss, professional support, qualitative research, social support, stillbirth

Perinatal loss is a traumatic and painful experience for parents, with biological, psychological, social, and spiritual implications.^{1,2} Perinatal loss refers to miscarriage (unintended termination of the pregnancy before 20 weeks' gestation), stillbirth (the death of the fetus after 20 weeks' gestation before or during labor), and neonatal death (newborn's death in the first 28 days after birth).³ Despite technological advances, approximately 2% of all pregnancies end in

stillbirth.⁴ The worldwide incidence of perinatal loss rate, which includes stillbirths and neonatal deaths, has been estimated at 2.7 million deaths each year.⁵ Nevertheless, the perinatal loss rate in Spain is below the European average, 4.43 deaths for every 1000 births, affecting 2000 families per year.⁶ Although stillbirth and neonatal death occur in all types of women, some factors such as smoking during pregnancy,⁷ obesity,⁸ unhealthy substance consumption,⁹ high blood pressure or diabetes,¹⁰ multiple pregnancies, and previous perinatal loss¹¹ increase the risk.

Grief following perinatal loss is the normal and individual affective response of parents, which involves feeling of guilt, anger,¹² sadness, anxiety,^{12,13} irritability, depressed mood, and thoughts about the lost infant.¹⁴ Grief symptoms are similar across types of loss and gestational age.¹³ Although the course of grief is variable and depends on cultural elements,¹³ affective reactions usually decline in intensity within the first 12 months, and grief diminishes after about 2 years of perinatal loss.¹⁵ Most parents experience normal grief following perinatal loss, but 25% to 30% of women report intense grief reactions many years after the loss, that is, complicated grief.^{13,15} Intense and protracted grief is associated with high levels of anxiety,

Author Affiliations: Gynaecology and Obstetrics Unit, Hospital de Torrevieja, Alicante, Spain (Mr Camacho Ávila); Department of Nursing, Physiotherapy and Medicine, University of Almería, Spain (Drs Fernández Medina, Jiménez-López, Granero-Molina, Hernández-Padilla, and Fernández-Sola); Department of Nursing, University Católica de San Antonio, Murcia, Spain, and Gynaecology and Obstetrics Unit, Hospital de Torrevieja, Alicante, Spain (Dr Hernández Sánchez); and Faculty of Health Sciences, Universidad Autónoma de Chile, Temuco, Chile (Dr Fernández-Sola).

This work was supported by the Research Group Health Sciences CTS-451, and the Centro de Investigación en Salud (CEINSA), University of Almería.

The authors declare no conflicts of interest.

Correspondence: Isabel María Fernández Medina, PhD, RN, Department of Nursing, Physiotherapy and Medicine, University of Almería, Carretera Sacramento s/n 04120 La Cañada de San Urbano, Almería, Spain (isabel_medina@ual.es).

Copyright © 2020 by The National Association of Neonatal Nurses

DOI: 10.1097/ANC.0000000000000703

depression,¹³ social phobia,¹⁵ and posttraumatic stress disorder.¹⁶ The prevalence of complicated grief in perinatal losses is more common than other losses.¹⁷ Numerous factors contribute to complicate grief in perinatal loss.¹² On the one hand, perinatal loss characteristically occurs unexpectedly and suddenly, and parents have no time to prepare for this situation.¹⁶ On the other hand, the lack of memories of their infant's existence¹⁷ and the self-blame for pregnancy loss¹² are other key elements that may lead to complicated grief. However, immediate and follow-up professional supportive care for parents after their loss⁴ and high levels of social support are protective factors for complicated grief.¹⁸ Previous research has demonstrated that healthcare professionals may increase the intensity and duration of parental grief if they do not provide adequate physical and emotional care.^{15,18,19} However, caring for bereaved parents is stressful and exhausting for midwives, and many of them experience difficulties in this area attributable to lack of training.¹⁹ Furthermore, perinatal loss usually receives insufficient social recognition, and when the death occurs before the birth, the ritual of mourning or a funeral is unusual.^{15,17} Society does not recognize their identity as parents, and the lack of the possibility to express perinatal grief interferes with the ability of parents to adjust to the loss.¹⁹ Additionally, fathers' grief is often ignored as the professional care and attention is focused on mothers, and feelings of grief are avoided.¹⁵ Parents may experience feelings of social isolation and disconnection from their social environment.^{15,19}

Worden's model defines grief as an adaptation in which "tasks" must be completed by the person who suffers a loss. These "tasks" are: to accept the reality of the loss; work through the pain of the loss; adjust to an environment in which the deceased child is missing; and find an enduring connection with the deceased child while embarking on a new life.²⁰ This way of approaching grief gives those suffering a loss an active role in their mourning.²¹ Although professional and social support in perinatal loss have been explored,¹³⁻¹⁹ perinatal grief has special characteristics, which make it different from other types of grief, and more evidence on parents' experience with professional and social support is required. Therefore, the aim of this study was to describe and understand the experiences of parents in relation to professional and social support following stillbirth and neonatal death.

What This Study Adds

- Identifies and characterizes barriers and facilitators to the grief process that parents may encounter.
- Establishes aspects of the significance of professional and social support during the grief process.
- Identifies the importance of developing strategies for supporting grieving parents.

METHODS

This study was approved by the Ethics and Research Committee of hospitals, and the Department of Nursing, Physiotherapy and Medicine of the University of Almería and followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Study Design

A qualitative study based on Gadamer's hermeneutic phenomenology was designed. For Gadamer, human experience cannot be understood without language. Understanding participants' stories requires being prepared to be told something through a dialogue, from which meanings emerge.²²

Participants

A convenience sample of parents who had suffered a stillbirth or neonatal death was recruited at 2 hospitals located in the southeast of Spain. Both hospitals have an average of 1400 births per year. Hospitals do not have an established protocol on perinatal loss. The help of a psychologist is not available at the hospitals. The history of perinatal losses in both hospitals over the last 5 years was consulted. In this period there were 52 stillbirths and 11 neonatal deaths. Families who fulfilled the inclusion criteria were contacted, and the aim of the study was explained to them. They were asked whether they were interested in participating in the study. The inclusion criteria were to be a mother or father 18 years and older at the time of perinatal loss, to have experienced a stillbirth or a neonatal death, and the loss had been suffered at least 2 years before the interview. Parents were excluded if they refused to participate in the study, spoke a language other than English or Spanish, or experienced a miscarriage, pregnancy termination due to genetic birth defect or multifetal pregnancy reduction. The main author of this study contacted the parents and conducted the interviews in-person.

Data Collection

In-depth interviews were used for data collection and took place between April 2017 and May 2018. A total of 31 mothers and 33 fathers agreed to participate, but 18 mothers and 25 fathers abandoned the study, 16 mothers and 13 fathers as they refused to discuss the matter, and the rest claimed they did not have time to do the interview. Interviews were performed in a private office in the university and had an average duration of 50 minutes. The interview started with an open-ended, general question: "What was your experience in relation to losing your baby?" Data collection concluded when data saturation had been reached. The interviews were audio-recorded and transcribed, and a hermeneutic unit was created and analyzed with Atlas-ti 8.0.

Data Analysis

The following steps were followed for the data analysis²³: (1) To decide whether the research question is pertinent to the methodological assumptions. Perinatal loss is a phenomenon of the life-world that can be understood from the perspective of hermeneutic phenomenology. (2) To identify the researchers' preunderstanding of the topic. The preunderstanding of the researchers came from their clinical experience as healthcare professionals who work or have worked in a delivery room as midwives. (3) To achieve understanding of the topic through dialogue with the participants. During the interviews, a spontaneous clarification regarding what the participants had discussed was achieved using follow-up questions ("Could you tell me what you mean when you say that the gynecologist had a cold manner?"). (4) To conduct a conversation between the researchers and the participants through the text. Each transcription was analyzed line by line to identify meaningful and important phrases and select them as quotes. Each quote was assigned a code that captured its meaning, grouped in units of meaning, subthemes, and themes. Data coding was performed individually by 3 researchers (I.M.F.M., J.G.M., and F.R.J.L.). They then compared their interpretations, so each unit of meaning, subtheme, and theme was agreed upon by consensus. (5) To ensure the rigor of the study, the participants were given the opportunity to confirm the transcriptions, units of meaning, subthemes, and themes by reading their answers. Additionally, all the participants' experiences were represented. The study's credibility was complemented by the triangulation of the researchers. All participants received a letter describing the aim of the study. Their participation was voluntary, and they signed an informed consent form. Anonymity and confidentiality of participants were assured.

RESULTS

Twenty-one parents (13 mothers and 8 fathers) from 6 families participated in the study. The median age of participants was 35.6 years, 6 participants had a previous perinatal loss, and 14 participants had no other children. Regarding the type of losses, 81% (n = 17) were stillbirths and 19% (n = 4) were neonatal deaths. The gestational age of stillbirths ranged between 24 and 40 weeks, and the neonatal deaths took place between 3 and 6 days after birth. Participants' sociodemographics data are presented in Table 1.

Five subthemes emerged, and they were grouped into 2 main themes that help us to understand the experience of parents regarding professional and social support following stillbirth and neonatal death (Table 2).

Professional Care in Dealing With Parents' Grief

Stillbirth and neonatal death are family tragedies. Loss during pregnancy or shortly after delivery is a paradox for which no one is prepared. The professional practices carried out during the death of the child affect the way in which the parents later elaborate their grief. This topic shows the professional practices that are beneficial to parents and those that make it difficult to overcome the loss.

Important Aspects of Professional Care

Action, behavior, and attitudes of healthcare professionals had direct consequences on parents. Those parents who received sensitive and understanding physical and emotional care emphasized that this was essential to face this terrible situation. However, parents felt more stressed and powerless when health professionals focused more on the clinical part of the death rather than on the emotional part. Many parents perceived that inadequate care increases their feelings of anger at the loss.

The health professionals who treated me pampered me a lot, they told me everything at every step, they treated me extremely well all night ... At that moment you do not realize ... but later you appreciate it ... (Participant 15).

Another essential aspect of care was the information received. The lack of communication on the process to be carried out both in the case of stillbirth and neonatal death increased the pain and anguish of the parents. Parents understand that sometimes it is difficult for healthcare professionals to give a concrete and immediate answer about the cause of their infant's death, but they consider that this absence of information should be replaced by greater empathy in the communication of the news. The parents who received adequate information during the process perceived that they had greater control of the situation.

The way to tell you that your daughter does not have a heartbeat ... you ask her why several times and she does not answer you. Why don't you explain to a mother that her daughter is not alive? Nobody came to explain anything and reassure us, we were completely alone (Participant 10).

The rituals associated with grief were recognized as positive by the parents. Most of the midwives and nurses offered the parents possibilities such as seeing, and holding the infant, and giving the couple time to say goodbye to their infant. Almost all the mothers in our study agreed to hold their infant; however, the fathers were more reluctant to do this. Parents remember this moment as "the only opportunity" to be with their infant and provide all their affection, although some parents were confused and experienced contradictory feelings at the simultaneous

TABLE 1. Sociodemographic Data of the Participants (N = 21)

Participant	Gender	Age, y	Marital Status	Level of Education	Employment Status	Previous		Type of Loss	Gestational Age or Days of Life	Absence of Living Children
						Perinatal Loss	Perinatal Loss			
1	Female	26	Married	College degree	Full time	No	No	Perinatal	40 wk	Yes
2	Female	43	Married	College degree	Unemployed	No	No	Prenatal	30 wk	No
3	Female	38	Married	College degree	Full time	Yes	Yes	Perinatal	24 wk	Yes
4	Male	38	Married	Advanced degree	Full time	Yes	Yes	Perinatal	24 wk	Yes
5	Female	37	Married	College degree	Full time	No	No	Prenatal	34 wk	No
6	Female	43	Married	Advanced degree	Part time	No	No	Postnatal	6 d	Yes
7	Male	43	Married	Advanced degree	Part time	No	No	Postnatal	6 d	Yes
8	Female	33	Married	Some college	Full time	No	No	Postnatal	3 d	Yes
9	Male	33	Married	Some college	Part time	No	No	Postnatal	3 d	Yes
10	Female	31	Married	College degree	Unemployed	Yes	Yes	Prenatal	28 wk	No
11	Male	26	Married	Some college	Full time	No	No	Prenatal	40 wk	Yes
12	Female	30	Married	Some college	Unemployed	No	No	Prenatal	40 wk	Yes
13	Female	36	Single	College degree	Part time	No	No	Perinatal	24 wk	Yes
14	Female	33	Married	Advanced degree	Part time	Yes	Yes	Prenatal	36 wk	Yes
15	Female	37	Married	Some college	Full time	No	No	Prenatal	34 wk	Yes
16	Female	37	Married	College degree	Unemployed	Yes	Yes	Prenatal	38 wk	No
17	Male	38	Married	Some college	Full time	Yes	Yes	Prenatal	38 wk	No
18	Male	38	Married	Some college	Full time	No	No	Prenatal	37 wk	No
19	Female	35	Married	College degree	Full time	No	No	Prenatal	37 wk	No
20	Male	35	Single	College degree	Part time	No	No	Prenatal	38 wk	Yes
21	Male	37	Married	Advanced degree	Full time	No	No	Prenatal	25 wk	Yes

TABLE 2. Themes, Subthemes, and Units of Meaning

Themes	Subthemes	Units of meaning
Professional care in dealing with parents' grief	Important aspects of professional care	Sensitive care Information Rituals Mementoes
	Continuing of pathways of care	Lack of specific hospital areas Lack of postnatal care Lack of information about resources Insufficient psychological assistance
Effects of social support in parental grief	The silence that surrounds grieving parents	Taboo Loneliness Isolation Inappropriate language
	Family and other children: a key element	Family support Partner support Other children
	Perinatal loss support groups: a reciprocal help	New pregnancy Additional support Acceptance Comfort

coexistence of life and death. The midwives and nurses also offered the possibility of keeping some kind of memory such as a photograph, a lock of hair, a cap, or a certificate with the footprint or the infant's hand. Receiving some of the objects that had been in contact with their infant later meant for the parents the recovery of the bond they had had with their infant, and it was a good way to remember them. This was the experience of a mother:

I kept five photos that I took and with the prints of her little feet ... I look at the photos, I put them away, and I am left in peace. At first, I could not bear seeing, but now it is a memory that helps me in this great pain ... (Participant 2).

On some occasions, mothers and fathers followed practices that are totally counterproductive for grieving parents or whose infant is in a critical condition in the neonatal intensive care unit, such as sharing the same maternity area with parents of healthy children. This practice increased the suffering and pain due to the loss of their infant, and as one participant says, they need specific areas where they are not continually reminded that they have lost their infants.

It causes you great grief and sadness to hear other infants cry in your room ... all the mothers with their infants, and I had just lost mine ... An unbearable experience that you want to run away from (Participant 16).

Continuing Pathways of Care

The parents showed the absence of care after death and hospital discharge feeling abandoned, marginalized, unprotected, and did not know what to expect during the postnatal period. The avoidance of grief

and the absence of care during this stage made parents think that they should quickly overcome the loss and continue with their lives.

When you leave the hospital, the health professionals ignore you and do not perceive that support or care you have at a first moment. We were very hurt, lost and needed a guide ... (Participant 14).

Most parents did not receive information about their rights, possible reactions, needs, and probable coping resources such as books, online resources, memorial websites, or support groups. As a father tells us, these resources would undoubtedly have served to help their grieving process and mitigate their pain. The search for support resources was more active in the fathers than in the mothers in our study.

In the hospital nobody told me about any book or something to see or read. We later looked for associations to be able to talk, but nobody told us about them. We would have liked the hospital to tell us that there were support groups instead of our looking for them, when you have so much pain it becomes even harder (Participant 9).

The parents mentioned the absence of psychological assistance during the hospitalization and death of their infants. Later, some parents were offered the possibility of receiving psychological help, but, nevertheless, many of them did not have this opportunity. The parents who received psychological assistance had difficulty accessing it and thought that the psychological care provided was limited and not very specific. Therefore, parents require greater hospital coordination and shorter waiting times since the delay in receiving psychological assistance aggravates the symptoms associated with grief.

Expressing our feelings with a psychologist who had more knowledge of the subject would have helped us a lot. It would not have taken away the pain, but it would have guided us and gave advice. I don't understand why we were not offered psychological help at times when you are so lost (Participant 2).

Effects of Social Support in Parental Grief

In the days and months following perinatal loss, parents had to face the loss of their infant in a society where mourning is denied due to the lack of awareness of this type of death. This theme reflects the difficulties faced by parents, as well as the support elements that contribute to the elaboration of grief. Subthemes involved “the silence that surrounds grieving parents,” “family and other children: a key element,” and “perinatal loss support group: a reciprocal help.”

The Silence That Surrounds Grieving Parents

The silence surrounding stillbirth and neonatal death had been identified as one of the most difficult parts of mourning. Parents felt that they could not express their emotions or remember their infant in public because the rest of society did not recognize their loss or understand their needs. It is difficult for society to see as real the existence of an infant that it has not known. People in the social environment think that bereavement after a stillbirth or neonatal death is less painful for parents. In addition, death in western culture is often a taboo subject, and its discussion is often particularly difficult as it often causes discomfort. All the elements of this situation lead parents to a deep feeling of loneliness and isolation.

Your family tells you that you cannot cry, that you have to get out of this situation ... They say “you are both young”; because we are young do we have to go through this? No one deserves it, neither young nor old, is the worst thing in life ... (Participant 11).

The inability of society to recognize the type of help that parents should receive, which kind of support is beneficial, and which is harmful, so that, in an attempt to minimize loss and pain, the use of inappropriate language increases feelings of grief. In addition, social relationships, especially that of mothers, were impaired. The feeling of biological failure and shame experienced by the mothers made them feel socially stigmatized and avoid contact with other people in their surroundings, especially couples with children.

Society does not understand it, it measures the pain by the size of the coffin, and you have to listen to people say things like: “It's okay, you'll have more children” ... it was my daughter and she's not going to come back, and I've lost her ... (Participant 2).

Family and Other Children: A Key Element

Relatives and close friends were key and essential elements to overcome the mourning process, but both mothers and fathers emphasized the support provided by their partner as a primary element to overcome the loss. However, some parents suppressed their own feelings because they thought they should “be strong” to adequately protect and support their partner.

My wife's support was crucial ... and my family, because they know what you feel and how to treat you, they helped me enormously so I wouldn't go under. But I think the greatest support of a man is his wife. If the wife doesn't support him, he will not be able to overcome it ... (Participant 10).

Mothers, more so than fathers, explained that the presence of other children kept them occupied and provided distraction that helped them to overcome the loss. Women who did not have children experienced greater feelings of stress and loneliness. Some parents talked about their plans for another pregnancy and explained that this was a new motivation to overcome the painful process of mourning and alleviate suffering and grief although most felt worried about the possibility of a new perinatal loss.

It's a good thing I had another child, if not, I don't know what would have happened to me, because of him I managed to get out of my grief, I know I have to take care of him and I can't let anything happen to him ... he takes my mind off, I don't have time to think ... I relied a lot on him to try to overcome the loss (Participant 6).

Perinatal Loss Support Groups: A Reciprocal Help

Perinatal loss support groups provide parents with a unique opportunity to talk about the topic in an empathic environment where their loss is accepted without any kind of prejudice. Talking with other parents who have gone through the same or a similar situation makes parents feel more understood. The sense of belonging to a group of peers helped them rebuild their identity and try to regain normality in their lives.

Talking with couples who have gone through the same thing as us helps us to realize that there are people who have been through the same as you ... (Participant 11).

Support groups provide a sense of community and were valued by parents as a resource for additional support, empowerment, and comfort. In addition, some parents felt the need to support other parents with perinatal loss through their own experience, and this help provided to other parents helped them overcome their own loss. A better understanding of the feelings experienced by both men and women allowed both partners to provide more effective support.

We talked about our experience, our anger, our grief and our feelings. The feeling that they are people who have been through the same thing as you and understand you was very positive and comforting ... nobody better than them to understand you ... (Participant 20).

DISCUSSION

The aim of this study was to describe and understand the experiences of parents in relation to professional and social support following stillbirth and neonatal death. Worden²⁰ sees grief as an active and particular process in which parents must accept the reality of the loss, experience their pain, and adapt to an environment in which the loved one is absent. Parents who have suffered stillbirth and neonatal death need professional and social support during the hospital period and after hospital discharge. However, the inability to recognize the mourning associated with perinatal loss, the lack of information, the absence of follow-up appointments, and certain hospital practices aggravate the emotions of the parents and interfere with the evolution of grief.

In relation to our results, immediately after receiving the news of the death of their infant, the parents demonstrate that sensitive and empathetic care according to their needs has a positive effect on how they cope with the death of their infant.¹² However, indifference and insensitive care can aggravate the difficult experience and make the grieving process even more complicated.²⁴ The inadequate care experienced by some parents may be related to the lack of knowledge of health professionals about the physical, emotional, and perinatal loss²⁵ and on how their own actions and behavior affect parents.^{25,26} The lack of knowledge and training in perinatal loss causes health professionals to feel uncomfortable and insecure when taking care of grieving parents.²⁵ As seen in other studies, parents often receive little information, or this is usually inappropriate.²⁷ The form whereby the news is communicated can have a positive or negative influence on the support and care perceived by the parents.²⁸ The silence, or the few explanations as well as the absence of empathic expressions, causes the parents to feel alone, terrified, and insecure in the face of the diagnosis of stillbirth or neonatal death.^{28,29} According to our results, the difficulties expressed by health professionals in relation to the communication of the news could be related to this fact.²⁶ In addition, the lack of education in how to provide emotional support to families causes fatigue and emotional and mental exhaustion in health professionals.³⁰ This fact could explain their behavior toward parents who suffer a perinatal loss.

Midwives and nurses often encourage parents to hold their infants after death and save mementoes to give to parents. The findings of the current study suggest that practices such as seeing, holding the

infant, and keeping memories such as photographs, footprints, or other objects help parents in the process of mourning.^{31,32} Performing these practices allows parents to create a bond with their infant and proves the existence of their infant and their parenthood.³¹ Health professionals should inform and offer these practices to parents, giving them time to make decisions and respect their preferences at all times.³² For Meyer et al,²⁴ parents who did not have the chance to say goodbye to their infant and who did not keep objects related to him or her had a more complicated grief.

Some of the parents of our study reported that they were placed during their hospital stay in the same maternity ward as other parents with healthy infants. The evidence shows that this practice increases the feelings of mourning of fathers and mothers and the guilt of women because they could not give birth to a healthy infant.³³ It is therefore advisable to create an intimate and reserved space where families can be cared for and express their pain without any type of interruption.³⁴ In contrast, the placement of parents in a hospital room outside the maternity area could increase the parents' feelings of stress when being attended by health personnel unfamiliar with their current situation.³⁵

The parents mentioned that there is an absence of care and information after hospital discharge, and that this interferes with their grieving process. Clear and respectful information about postnatal physical changes,³⁵ follow-up and support from psychologists,³⁵ support references, and additional information they can access about perinatal loss to access if needed may have a positive effect on the experience after perinatal loss.^{36,37} Psychological care, as in other studies, is usually not very specific.³⁸ However, providing psychological care and support to parents whose infants are hospitalized in the neonatal intensive care unit and after hospital discharge improves their relationships with their infants and helps them to cope with the stress and grief in case of loss.³⁹ Arrival home after a stillbirth or neonatal death is marked by loneliness and abandonment by health professionals.³⁶ An information packet with coping resources such as readings, online resources, memorial websites, and how to find help could help parents cope with their grief after hospital discharge.⁴⁰

Stillbirth and neonatal death present a situation where the grieving process is exacerbated by social circumstances.⁴¹ The social and family context perceives stillbirth and neonatal death in a totally different way than that experienced by parents.⁴¹ Grief is often avoided, and the pain of the parents is silenced, giving rise to an unauthorized grief; that is, parents' surroundings minimize the importance of the loss.⁴¹ The absence of rituals or religious rites after perinatal loss contributes to the lack of social recognition.⁴²

Evidence on coping with stillbirth and neonatal death grief shows that mothers often take refuge in other children to cope with the loss.⁴³ The siblings also suffer loss but are often cut off from the grieving process.⁴⁴ Mothers and fathers, although they express fear about the outcome of a new pregnancy, think that this would reduce their grief and emotional emptiness, a result similar to other studies,^{44,45} but a new pregnancy without the mother being prepared could bring problems for the next infant.⁴⁴ However, having another infant after neonatal death reduces the symptoms of prolonged grief and posttraumatic stress among parents.⁴⁶ Parents are subjected to a social isolation in which it is not possible to express their emotions, but they need to talk about it, be heard, and have their pain respected.⁴⁷ Perinatal loss support groups allow them to break their isolation, talk about their infant, and share their experience.^{43,48} The expression of emotions helps to reduce fear and anxiety and to advance along the path of mourning.^{43,47,48}

LIMITATIONS

The study has certain limitations, which should be considered. Some of the fathers interviewed were partners of the mothers included in the study, and, although the interviews were conducted separately, the results could have been influenced. Finally, the situations where stillbirth and neonatal death occur are different from each other, which may also have influenced the responses of our participants.

IMPLICATIONS FOR PRACTICE

Knowing the needs and requirements of parents who suffer from stillbirth or neonatal death allows us to improve the care that is provided both during the hospital stay and afterward. Most of the

problems suffered by parents are related to the care experienced during the hospital stay, and the absence of follow-up appointments and support resources after hospital discharge. Therefore, it is necessary that health professionals who care for bereaved families receive specific training and develop actions and specific programs adapted to the needs of families with stillbirth or neonatal death. For example, a follow-up program for families could develop discussions of their feelings of grief and facilitate the detection of parents with specific needs and complicated grief. Community programs with a social worker could help to visualize the problems associated with stillbirth and neonatal death, create support networks, and mitigate the pain and suffering of parents. A telephone service through which parents could resolve their doubts and needs could be set up. In relation to the improvement of care, it may be necessary to pay attention to the emotional needs of health professionals who attend to bereaved parents. Therefore, the inclusion of a psychologist in the team who is in charge of assisting the parents from the moment when the loss occurs and who works with the emotional health of the other health professionals who care for these parents could be beneficial. Finally, a palliative care team should also be involved in the process of end-of-life care.

IMPLICATIONS FOR RESEARCH

More evidence is needed on the attitudes and behavior of healthcare professionals on perinatal loss to determine the factors that influence parental grief. The barriers encountered by health professionals in caring for grieving parents should also be studied. The emotional support received by health professionals who attend perinatal loss should be explored,

Summary of Recommendations for Practice and Research

What we know:	<ul style="list-style-type: none"> • The traumatic nature of perinatal and neonatal losses. • Perinatal and neonatal losses are not socially recognized. • Healthcare professionals experience difficulties related to caring for bereaved parents. • The care experience has a direct impact on the physical and emotional health of the parents.
What needs to be studied:	<ul style="list-style-type: none"> • Staff's attitudes and behaviors regarding parental grief. • Emotional needs of healthcare professionals. • Family, other children, and friends' experiences as a support element in parental grief. • The effectiveness of current interventions on parental grief over time.
What we can do today:	<ul style="list-style-type: none"> • Provide professional counseling and support. • Provide emotional support for parents and healthcare professionals. • Offer mementoes and memorable experiences with their child. • Give information about resources after discharge. • Identify social barriers that make supporting parental grief difficult. • Educate healthcare professionals about parents' needs after perinatal and neonatal loss.

as well as their influence on the care provided to families. The point of view of family members, other children, and friends as a support element in parental grief should also be examined. The opinion of healthcare professionals and parents on how to improve the level of social education to support parental grief should also be explored.

CONCLUSIONS

This study has highlighted the fact that parents who suffer stillbirth and neonatal death have specific needs and requirements that are not always fulfilled. The experiences associated with support and professional care can intervene in the elaboration of grief. Seeing, picking up the child, and keeping memories are beneficial practices for parents. However, sharing the same physical space with other women with healthy infants, the absence of information, monitoring, and psychological care make it difficult to overcome the loss. Family support, friends, and the presence of other children minimize the pain and suffering of parents, but lack of social support increases the feelings associated with grief.

Acknowledgments

We are grateful to all participants for their contribution to the study and sharing their experiences with us.

References

- Fernández-Alcántara M, Cruz-Quintana F, Pérez-Marfil N, Robles-Ortega H. Factores psicológicos implicados en el duelo perinatal. *Index Enfermería*. 2012;21(2):48-52.
- Rosenbaum JL, Smith JR, Zollfrank R. Neonatal end-of-life spiritual support care. *J Perinat Neonatal Nurs*. 2011;25(1):61-69.
- Barfield WD. Committee on fetus and newborn. Standard terminology for fetal, infant 1 and perinatal deaths. *Pediatrics*. 2016;137(5).
- Hutti MH, Polivka B, White S, et al. Experiences of nurses who care for women after fetal loss. *J Obstet Gynec Neonatal Nurs*. 2016;46(1):17-27.
- Lawn JE, Blencowe H, Waiswa P, et al. Stillbirths: rates, risk factors, and acceleration towards 2030. *Lancet*. 2016;387(10018):587-603.
- Instituto Nacional de Estadística. Demografía y población, estadísticas de nacimientos, muertes fetales y neonatales. <http://www.ine.es>. Published March 2019. Accessed June 2019.
- Bay B, Boie S, Kesmodel US. Risk of stillbirth in low-risk singleton term pregnancies following fertility treatment: a national cohort study. *BJOG*. 2019;126(2):253-260.
- Heazell AE, Li M, Budd J, et al. Association between maternal sleep practices and late stillbirth—findings from a stillbirth case-control study. *BJOG*. 2017;125(2):254-262.
- Hirose A, Alwy F, Atuhairwe S, et al. Disentangling the contributions of maternal and fetal factors to estimate stillbirth risks for intrapartum adverse events in Tanzania and Uganda. *Int J Gynaecol Obstet*. 2019;144(1):37-48.
- Hegelund ER, Poulsen GJ, Mortensen LH. Educational Attainment and Pregnancy outcomes: A Danish Register-Based Study of the Influence of Childhood Social Disadvantage on Later Socioeconomic Disparities in Induced Abortion, Spontaneous Abortion, Stillbirth and Preterm Delivery. *Matern Child Health J*. 2019;23(6):839-846.
- Gardosi J, Madurasinghe V, Williams M, Malik A, Francis A. Maternal and fetal risk factors for stillbirth: population based study. *BMJ*. 2013;346(f108):1-14.
- Cassaday TM. Impact of pregnancy loss on psychological functioning and grief outcomes. *Obstet Gynecol Clin North Am*. 2018;45(3):525-533.
- Heazell AE, Siassakos D, Blencowe H, et al. Stillbirths: economic and psychosocial consequences. *Lancet*. 2016;387(10018):604-616.
- Tseng YF, Cheng HR, Chen YP, Yang SF, Cheng PT. Grief reactions of couples to perinatal loss: a one-year prospective follow-up. *J Clin Nurs*. 2017;26(23/24):5133-5142.
- Burden C, Bradley S, Storey C, et al. From grief, guilt pain and stigma to hope and pride—a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BMC Pregnancy Childbirth*. 2016;16:9.
- Krosch DJ, Shakespeare-Finch J. Grief, traumatic stress, and post-traumatic growth in women who have experienced pregnancy loss. *Psychol Trauma*. 2017;9(4):425-433.
- Kokou-Kpolou K, Megalaki O, Nieuviarts N. Persistent depressive and grief symptoms for up to 10 years following perinatal loss: involvement of negative cognitions. *J Affect Disord*. 2018;241:360-366.
- Hutti MH, Myers J, Hall LA, et al. Predicting grief intensity after recent perinatal loss. *J Psychosom Res*. 2017;101:128-134.
- Markin RD, Zilcha-Mano S. Cultural processes in psychotherapy for perinatal loss: breaking the cultural taboo against perinatal grief. *Psychotherapy*. 2018;55(1):20-26.
- Worden JW. *El Tratamiento Del Duelo*. 1st ed. Barcelona, Spain: Paidós; 2015.
- Payás A. *Las Tareas Del Duelo*. 2nd ed. Barcelona, Spain: Paidós; 2015.
- Gadamer HG. *Truth and Method*. 1st ed. London, England: Bloomsbury Academic; 2013.
- Fleming V, Gaidys U, Robb Y. Hermeneutics research in nursing: developing a Gadamerian-based research method. *Nurs Inq*. 2003;10(2):113-120.
- Meyer AC, Opoku C, Gold KJ. "They Say I Should not Think About It": a qualitative study exploring the experience of infant loss for bereaved mothers in Kumasi, Ghana. *Omega (Westport)*. 2016;77(3):267-279.
- Willis P. Nurses' perspective on caring for women experiencing perinatal loss. *MCN AM J Matern Child Nurs*. 2019;44(1):46-51.
- Downe S, Schmidt E, Kingdon C, Heazell AE. Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. *BMJ Open*. 2013;3(2).
- Rådestad I, Malm MC, Lindgren H, Pettersson K, Larsson LL. Being alone in silence—mothers' experiences upon confirmation of their baby's death in utero. *Midwifery*. 2014;30(3):e91-e95.
- Pullen S, Golden MA, Cacciatore J. "I'll never forget those cold words as long as I live": parent perceptions of death notification for stillbirth. *J Soc Work End Life Palliat Care*. 2012;8(4):339-355.
- Fenstermacher KH, Hupey JE. Support for young black urban women after perinatal loss. *MCN AM J Matern Child Nurs*. 2019;44(1):13-19.
- Hall SL, Cross J, Selix NW, et al. Recommendations for enhancing psychosocial support of NICU parents through staff education and support. *J Perinatol*. 2015;35(suppl 1):S29-S36.
- Kingdon C, O'Donnell E, Givens J, Turner M. The role of healthcare professionals in encouraging parents to see and hold their stillborn baby: a meta-synthesis of qualitative studies. *PLoS One*. 2015;10(7):e0130059.
- Lisy K, Peters MD, Riitano D, Jordan Z, Aromataris E. Provision of meaningful care at diagnosis, birth, and after stillbirth: a qualitative synthesis of parents' experiences. *Birth*. 2016;43(1):6-19.
- Gopichandran V, Subramaniam S, Kalsingh MJ. Psycho-social impact of stillbirths on women and their families in Tamil Nadu, India—a qualitative study. *BMC Pregnancy Childbirth*. 2018;18(1):109.
- Punches BE, Johnson KD, Acquavita SP, Felblinger DM, Gillespie GL. Patient perspectives of pregnancy loss in the emergency department. *Int Emerg Nurs*. 2019;43:61-66.
- Peters MD, Lisy K, Riitano D, Jordan Z, Aromataris E. Caring for families experiencing stillbirth: evidence-based guidance for maternity care providers. *Women Birth*. 2015;28(4):272-278.
- Peters MD, Lisy K, Riitano D, Jordan Z, Aromataris E. Providing meaningful care for families experiencing stillbirth: a meta-synthesis of qualitative evidence. *J Perinatol*. 2016;36(1):3-9.
- Siassakos D, Jackson S, Gleeson K, et al. All bereaved parents are entitled to good care after stillbirth: a mixed-methods multicentre study (INSIGHT). *BJOG*. 2018;125(2):160-170.
- Ellis A, Chebsey C, Storey C, et al. Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. *BMC Pregnancy Childbirth*. 2016;16:16.
- Hynan MT, Hall SL. Psychosocial program standards for NICU parents. *J Perinatol*. 2015;35(suppl 1):S1-S4.
- Catlin A, Carter BS. Creation of a neonatal end-of-life palliative-care protocol. *J Clin Ethic*. 2001;12(3):316-318.
- Kelley MC, Trinidad SB. Silent loss and the clinical encounter: parents' and physicians' experiences of stillbirth—a qualitative analysis. *BMC Pregnancy Childbirth*. 2012;12:137.
- Markin RD, Zilcha-Mano S. Cultural processes in psychotherapy for perinatal loss: breaking the cultural taboo against perinatal grief. *Psychotherapy (Chic)*. 2018;55(1):20-26.

43. Mills TA, Ricklesford C, Cooke A, Heazell AE, Whitworth M, Lavender T. Parents' experiences and expectations of care in pregnancy after stillbirth or neonatal death: a metasynthesis. *BJOG*. 2014;121(8):943-950.

44. Alison E, Chebsey C, Storey C, et al. Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. *BMC Pregnancy Childbirth*. 2016;16:16.

45. Koopmans L, Wilson T, Cacciatore J, Flenady V. Support for mothers, fathers and families after perinatal death. *Cochrane Database Syst Rev*. 2013;(6):CD000452.

46. Keim MC, Fortney CA, Shultz EL, Winning A, Gerhardt CA, Baughcum A. Parent distress and the decision to have another child after an infant's death in the NICU. *J Obstet Gynecol Neonatal Nurs*. 2017;46(3):446-455.

47. Krautter C. Supporting families experiencing perinatal bereavement. *Soins PEDIATR Pueric*. 2019;40(306):28-31.

48. Baughcum AE, Fortney CA, Winning A, et al. Perspectives from bereaved parents on improving end of life care in the NICU. *Clin Pract Pediatr Psychol*. 2017;5(4):392-403.

For another continuing education article related to perinatal death, go to NursingCenter.com.

<p>Instructions:</p> <ul style="list-style-type: none"> • Read the article. The test for this CE activity can only be taken online at www.nursingcenter.com. Tests can no longer be mailed or faxed. You will need to create (its free!) and login to your personal CE Planner account before taking online tests. Your planner will keep track of all your Lippincott Professional Development online CE activities for you. • There is only one correct answer for each question. A passing score for this test is 12 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost. • For questions, contact Lippincott Professional Development: 1-800-787-8985. 	<p>Registration Deadline: March 4, 2022</p> <p>Disclosure Statement: The authors and planners have disclosed that they have no financial relationships related to this article.</p> <p>Provider Accreditation: Lippincott Professional Development will award 1.5 contact hours for this continuing nursing education activity. Lippincott Professional Development is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.</p> <p>This activity is also provider approved by the California Board of Registered Nursing, Provider Number CEP11749 for 1.5 contact hours. Lippincott</p>	<p>Professional Development is also an approved provider of continuing nursing education by the District of Columbia, Georgia, Florida, West Virginia, New Mexico, and South Carolina CE Broker #50-1223. Your certificate is valid in all states.</p> <p>This article has been approved by the National Association for Neonatal Nurses Certification Board for Category B credit toward recertification as an NNP.</p> <p>Payment: The registration fee for this test is \$11.95 for NANN members and \$17.95 for nonmembers.</p> <p>DOI: 10.1097/ANC.0000000000000716</p>
---	--	---