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GRINCAR
Grupo de investigación Cardiovascular

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Laboratorio de Investigación Cualitativa
en Ciencias da Saúde

Perinatal grief: Analysis of the difficulties and facilitating elements of family coping

(DPAFIS study)

Duelo perinatal: Análisis de las dificultades y de los elementos facilitadores presentes en el afrontamiento familiar

(Estudio DPAFIS)

Tesis doctoral defendida por Dña. Sara Fernández Basanta

Ferrol, 2020

Duelo perinatal: Análisis de las dificultades y de los elementos facilitadores presentes en el afrontamiento familiar (Estudio DPAFIS)

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Tesis doctoral con mención internacional UDC / 2020

Directoras: Carmen Coronado Carvajal y María Jesús Movilla Fernández

Programa Oficial de Doctorado en Ciencias de la Salud

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Report presented by Sara Fernández Basanta, student of the Official Doctoral Program of Health Sciences, in the Department of Health Sciences to apply for the title of Doctor with International Mention at University of A Coruña.

Ferrol, June 2020

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Dr. Carmen Coronado Carvajal, Associate Professor in the Department of Health Sciences at University of A Coruña, and Dr. María Jesús Movilla Fernández, Associate Professor at Department of Health Sciences at University of A Coruña

VALIDATED

That Ms. Sara Fernández Basanta, Graduated in Nursing and Master of Clinical Research from the University of A Coruña, has carried out the work *Perinatal grief: Analysis of the difficulties and facilitating elements of family coping (DPAFIS study)* in the GRINCAR Research Group - Laboratory of Qualitative Research in Health Sciences under our direction. The present dissertation meets the conditions to be presented as a Doctoral Thesis with an International Mention in the form of a compendium of research publications.

Dr. Carmen Coronado Carvajal Associate Professor at Department of Health Sciences University of A Coruña	Dr. María Jesús Movilla Fernández Associate Professor at Department of Health Sciences University of A Coruña

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Abstract

The pregnancy loss -involuntary pregnancy loss and termination of pregnancy for foetal anomaly- and neonatal death cause a varied, dynamic and highly individualized response in parents. Literature recognizes the special characteristics of these losses, due to the multiple losses that such a process entails for parents. However, the stigma surrounding these losses means that they are considered taboo losses and that they are silenced and made invisible in social and health settings.

The care provided by health professionals, and especially nurses and midwives, is crucial to the short- and long-term well-being of parents. However, healthcare professionals report being poorly prepared and how stressful and emotional demanding it is to provide care for parents who have suffered these losses. This care is often superficial and based on the performance of procedures.

Aims: This doctoral thesis is made up of two main axes. First, to know the experiences of parents in coping with pregnancy or perinatal losses and, later, to know the experiences of midwives and nurses in caring for parents who have suffered an involuntary loss of pregnancy.

Methodology: This doctoral thesis is composed of 4 qualitative research studies, of which an empirical study and a meta-ethnography were developed for each objective. Regarding the first aim, 16 Spanish women who suffered an involuntary loss of pregnancy have been interviewed through a grounded theory study and a meta-ethnography of 14 qualitative studies has been carried out to synthesize the research results regarding the coping experiences of parents after pregnancy and neonatal losses. For the second objective, a meta-ethnography was also carried out, which included ten primary qualitative studies to discover the experiences of midwives and nurses in caring for parents who have suffered an involuntary pregnancy loss. In addition, an interpretive phenomenological study was conducted in which 11 primary care midwives were interviewed.

Results: Regarding the experiences of parents, the coping strategies of parents were based on the experiences of connectedness/confrontation and disconnectedness/avoidance. These experiences were related through a dynamic process between the two. The use of these elements was conditioned by personal, social and cultural factors. On the other hand, the nurses and midwives who cared for parents who have suffered an involuntary pregnancy loss, faced difficulties that required leaving their comfort zone. This caused them not to get emotionally involved with parents and that, if they did, the care was based on their intuition.

Conclusions: The coping strategies of parents were based on the experiences of connectedness/confrontation and disconnectedness/avoidance through a dynamic process between the two. For nurses and midwives, caring for parents who have suffered these losses involved leaving their comfort zone and dealing with difficulties, which caused them not to get emotionally involved with parents or, if they did, it was using their intuition.

Resumen

La pérdida del embarazo -pérdidas involuntarias y terminaciones del embarazo debido a anomalías fetales- y la muerte neonatal generan una respuesta variada, dinámica y altamente individualizada en los padres. La investigación reconoce las características especiales de estas pérdidas, por las múltiples pérdidas que conlleva para los padres. Sin embargo, el estigma que rodea a estas pérdidas hace que se consideren pérdidas tabúes y que se silencien e invisibilicen en los entornos sociales y sanitarios.

El cuidado de los profesionales sanitarios, y en especial de enfermeras y matronas, es crucial para el bienestar a corto y largo plazo de los padres. No obstante, los profesionales sanitarios informan lo poco preparado que se encuentran y de lo estresante y exigente que resulta el cuidado de estas pérdidas. Diversas dificultades a la hora de cuidar generan que a menudo este cuidado sea superficial y basado en la realización de técnicas.

Objetivos: Esta tesis doctoral se compone de dos ejes principales. Primero, conocer las experiencias de los padres en el afrontamiento de las pérdidas del embarazo o perinatales y, posteriormente, conocer las experiencias de las matronas y enfermeras en el cuidado de padres que han sufrido una pérdida involuntaria del embarazo.

Metodología: Esta tesis doctoral está compuesta de 4 estudios de investigación cualitativa, de los cuales un estudio empírico y una meta-etnografía fueron desarrollados para cada objetivo. Para responder al primero, se ha se han entrevistado a 16 mujeres españolas que sufrieron una pérdida involuntaria del embarazo mediante un estudio de teoría fundamentada y se ha llevado a cabo una meta-etnografía de 14 estudios cualitativos para sintetizar los resultados de investigación respecto a las experiencias de afrontamiento de los padres tras las pérdidas del embarazo y neonatales. Para el segundo objetivo, también se ha realizado una meta-etnografía que incluyó diez estudios cualitativos primarios para conocer las experiencias de matronas y enfermeras en el cuidado de las pérdidas involuntarias del embarazo. Además, se realizó un estudio fenomenológico interpretativo en el que se entrevistaron a 11 matronas de atención primaria.

Resultados: En cuanto a las experiencias de los padres, las estrategias de afrontamiento de los padres se basaron en las experiencias de conectividad/confrontación y no conectividad/evitación. Estas experiencias se relacionaron mediante un proceso dinámico entre ambas. El uso de estas estuvo condicionado por factores personales, sociales y culturales. Por otro lado, las enfermeras y matronas que cuidaron de padres que habían sufrido una pérdida involuntaria del embarazo, lidiaron con dificultades que exigieron abandonar la zona de confort. Esto ocasionó que no se involucraran emocionalmente con los padres y que, si lo hacían, el cuidado se basase en su intuición.

Conclusiones: Las estrategias de afrontamiento de los padres se basaron en las experiencias de conectividad/confrontación y no conectividad/evitación mediante un proceso dinámico entre ambas. Para las enfermeras y matronas, el cuidado de estas pérdidas implicó salir de la zona de confort y lidiar con dificultades, lo que ocasionó que no se involucraran emocionalmente con los padres o, si lo hacían, fuese bajo su intuición.

Resumo

A perda do embarazo -perdas involuntarias e a terminación do embarazo por anormalidades fetais- e a morte neonatal xeran unha resposta variada, dinámica e altamente individualizada nos pais. A investigación recoñece as características especiais destas perdas debido ás múltiples perdas que supón para eles. Sen embargo, o estigma en torno a estas perdas xera que se consideren perdas tabús e que se silencien e que non se visibilicen nos ámbitos sociais e sanitarios.

O coidado dos profesionais sanitarios, e especialmente das enfermeiras e matronas, é crucial para o benestar dos pais a curto e longo prazo. Non obstante, os profesionais sanitarios informan do pouco preparados que están e do estresante e esixente que é coidar destas perdas. Varias dificultades á hora de coidar xeran que este coidado a miúdo sexa superficial e baseado na realización de técnicas.

Obxectivos: Esta tese doutoral componse de dous eixes principais. En primeiro lugar, coñecer as experiencias dos pais no afrontamento das perdas do embarazo ou perinatais e, posteriormente, coñecer as experiencias das matronas e enfermeiras no coidado dos pais que sufriron unha perda involuntaria do embarazo.

Metodoloxía: Esta tese doutoral está composta por 4 estudos cualitativos de investigación, dos cales un estudo empírico e unha meta-etnografía foron elaborados para cada obxectivo. Para responder ao primeiro, entrevistáronse 16 mulleres españolas que sufriron unha perda involuntaria de embarazo a través dun estudo de teoría fundamenta e realizouse unha meta-etnografía de 14 estudos cualitativos para sintetizar os resultados da investigación sobre o afrontamento dos pais trala perda do embarazo ou dun bebé. Para o segundo obxectivo, tamén se levou a cabo unha meta-etnografía, que incluíu dez estudos cualitativos primarios para coñecer as experiencias das matronas e enfermeiras no coidado de perdas involuntarias do embarazo. Ademais, fíxose un estudo fenomenolóxico interpretativo no que se entrevistaron 11 matronas de atención primaria.

Resultados: Respecto ás experiencias dos pais, as estratexias de afrontamento dos pais baseáronse nas experiencias de conectividade/confrontación e non conectividade/evitación. Estas experiencias relacionáronse a través dun proceso dinámico entre ambas. O uso destes elementos estivo condicionado por factores persoais, sociais e culturais. Por outra banda, as enfermeiras e parteiras ó coidado de pais que sufriron unha perda involuntaria do embarazo, trataron con dificultades que esixiron saír da zona de confort. Isto provocou que non se involucraran emocionalmente cos pais e que, se o fixeron, o coidado se baseara na súa intuición.

Conclusións: As estratexias de afrontamento dos pais baseáronse nas experiencias de conectividade/confrontación e non conectividade/evitación mediante un proceso dinámico entre ambos. Para as enfermeiras e matronas, coidar estas perdas implicaba saír da zona de confort e afrontar dificultades, provocando que non se involucrasen emocionalmente cos pais ou, se o facían, fose baixo a súa intuición.

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D&C	Dilation and curettage
EUROCAT	European network of population-based registries for the epidemiological surveillance of congenital anomalies
HCPs	Health Care Providers
ICD-10	International Classification of Diseases, 10th revision
NIPT	Non-invasive prenatal testing
TOPFAs	Terminations of pregnancy for foetal anomaly
SERGAS	Galician Health Service
WG	Week of gestation
WHO	World Health Organization

Chapter 1: Introduction

1.1 Pregnancy loss and neonatal death

For the following work, we have considered spontaneous abortions or miscarriages, foetal deaths or stillbirths, and perinatal deaths as part of these losses. Figure 1 shows an overview of the definitions of pregnancy and perinatal losses.

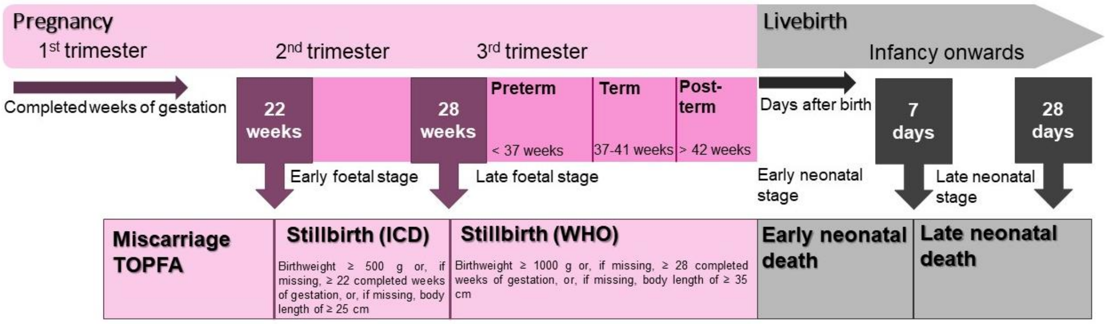

***Figure 1** Pregnancy and perinatal loss definitions (Lawn et al., 2011)*

1.1.1 Definitions

Spontaneous abortion refers to an unplanned pregnancy loss before 22 completed weeks by expulsion complete or incomplete of the products of conception from the uterus, by failure of the embryo to develop or by death of the foetus in utero (World Health Organization (WHO), 2017). The term **miscarriage** is preferred to spontaneous abortion because the word *abortion* is associated with elective termination (Farquharson & Stephenson, 2017; Griebel et al., 2005). In this type of loss, a distinction is made between **early pregnancy loss**, referring to the loss in which empty sac or sac with foetus but no foetal heart activity is confirmed less than 12 weeks, and **late pregnancy loss**, referred to the loss of the foetal heart > 12 weeks (Farquharson & Stephenson, 2017).

The International Classification of Diseases, 10th revision (ICD-10) (WHO, 2004) defines **foetal deaths** as *death prior to the complete expulsion or extraction from its mother of a product of conception regardless of the length of pregnancy*. Death is diagnosed by the fact that after separation, the foetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles". According to WHO (2006) early stillbirth is the birth of a baby with a birthweight of 500 g or more, 22 or more completed weeks of gestation, or a body length of 25 cm or more, who died before or during labour and birth. Third-trimester stillbirths are defined as stillbirths with birthweight of 1000 g or more, 28 weeks' gestation or more, or a body length of 35 cm or more.

As for **perinatal loss**, the period ranges from 22 weeks of gestation to one week of independent life (WHO, 2006), but in practice and in literature it is expanded (Fenstermacher & Hupcey, 2013; López García de Madinabeitia, 2011). For this reason, this thesis has also considered terminations of pregnancy for foetal anomaly (TOPFAs) and neonatal deaths.

Advances in pre-natal screening and diagnostic testing, alongside trends in later motherhood, has increased the probability of parents receiving a diagnosis of foetal anomaly. Most **TOPFAs** occur during the second trimester of pregnancy, before foetal viability. First- or mid-trimester terminations are legally and morally accepted in many countries (Garne et al., 2010; Korenromp et al., 2005). In Spain, Organic Law 2/2010, of March 3, on sexual and reproductive health and voluntary termination of pregnancy, establishes that pregnancy can be interrupted for medical reasons if the 22^{+6} weeks of gestation is not exceeded.

Finally, **neonatal death** has been defined by WHO as *deaths among live births during the first 28 completed days of life*. This definition can be further sub-divided into early neonatal deaths, deaths between 0 and 7 completed days of birth, and late neonatal deaths, deaths after 7 days to 28 completed days of birth (WHO, 2006).

1.1.2 Epidemiological data

Perinatal mortality has been reduced thanks to scientific advances and the quality of health care for pregnant women and new-borns (Dallay, 2013; Koopmans et al., 2013). Despite this, pregnancy loss is a relatively common occurrence, although the exact prevalence of these losses is difficult to estimate (Heazell et al., 2019).

Previous research establishes that between 20-30% of pregnancies end in miscarriage worldwide. However, the intrinsic feature of earliness or the intoxication of records with induced abortion rates could make it difficult to estimate miscarriages (Magnus et al., 2019).

Regarding the stillbirth, an estimated 2.6 million babies were stillborn in 2015 worldwide. However, these statistics do not represent the totality of losses, since it is estimated that less than 5% of stillbirths have death records (Heazell et al., 2019).

According to the Global Burden of Disease study (Lozano et al., 2012), congenital anomalies accounted for 510,400 deaths worldwide in 2010, which meant 1% of all deaths. European network of population-based registries for the epidemiological surveillance of congenital anomalies (EUROCAT) data showed that TOPFA is on average four times more frequent than infant deaths, and nearly three times more frequent than stillbirths and infant deaths combined (Boyle et al., 2018). This may be because recent advances in prenatal diagnosis allow diagnosing an increasing number of foetal abnormalities, and, consequently, the probability of terminating pregnancy is greater (Hume & Chasen, 2015; Kersting et al., 2009).

Finally, 2.5 million children died worldwide in the first month of life in 2018, approximately 7,000 neonatal deaths every day (Liu et al., 2015).

In the Spanish context, the National Institute of Statistics (NSI) (Instituto Nacional de Estadística, 2018a) reported that during 2018 the cases of late foetal mortality (≥ 500 gr or ≥ 22 SG) were 3.09‰ of the total number of births nationwide and 3.19‰ of the total born in Galicia. The perinatal mortality was 4.37‰ of the total born in Spain and 4.45‰ of the total born at the regional level (Instituto Nacional de Estadística, 2018b). Regarding infant mortality, in Spain it was 1.87‰ of the total live births, while in Galicia it was 1.69‰ of the total live births (Instituto Nacional de Estadística, 2018c).

As for the data of TOPFAs, the Ministry of Health, Consumption and Social Welfare in Spain (Ministerio de Sanidad, Consumo y Bienestar Social, 2019) published the data of voluntary interruptions of pregnancy of 2018, where 9.27% of these voluntary interruptions were due to foetal anomalies, which represented 3,454 cases at national level and 98 cases at regional level.

However, the literature emphasizes that these data may be under-declared, where estimates of the degree of the under-declaration would range between 25% and 50%. This may be due to the fact that the data used is collected from the Statistical Birth Bulletin, which depends on the voluntary declaration of parents, and not on the hospital's own registers. In this case, the physician must deliver this bulletin for parents to fill in and they are urged to deposit it in the Civil Registry. Although it is legally mandatory in cases ≥180 days of gestation, in some cases it is not done. On the other hand, this obligation only affects late losses, so there is a great lack of data for children under that gestational age (Juárez et al., 2012; Cirera Suárez et al., 2008).

1.1.3 Risk factors and aetiology

Early pregnancy losses are one of the most common complications in the first trimester of pregnancy. The incidence of these is 31%, although only 10% in clinically recognized pregnancies (Jones & Kost, 2007). As for the second-trimester losses, the incidence amounts to 1% (Silver, 2007). Approximately 32% of stillbirths occur between the 22nd and 28th week of gestation (WG) (Smith et al., 2018).

We have classified risk factors and etiology according to maternal conditions, fetal conditions, obstetric conditions and others (García-Enguídanos et al., 2002; Lawn et al., 2005; Magnus et al., 2019; Silver, 2007; Winbo et al., 2001).

Table 1 summarizes the main risk factors and the ethology for pregnancy and neonatal losses.

Table 1 *Risk factors and aetiology of pregnancy and neonatal losses*

RISK FACTORS	AETIOLOGY
Maternal conditions	
• Maternal age • Maternal weight • Exposures (caffeine, tobacco, drugs and alcohol, workplace toxicants) • Demographics (Socio-economic status and race and ethnicity) • Uterine anatomic defects • Menstrual disorders • Medical disorders (Endocrine disorders, diabetes, hypertensive disorders, anaemia, jaundice, malaria, syphilis, HIV, renal disease, hepatises, epilepsy, systemic lupus erythematosus…)	• Maternal diseases • Uterine anatomic defects • Systemic Maternal Infections • Alloimmune factors
Foetal conditions	
• Infections (virus, bacterial and others) • Unexplained small for date infants	• Congenital anomalies • Specific foetal conditions (iso-immunization, unexplained hydrops fetalis, tumours, specific foetal infections) • Infections (virus, bacterial and others) • Unexplained small for date infants • Placental abruption
Obstetrics conditions	
• Previous miscarriages • Previous induced abortion • Previous deliveries • Intrapartum factors (malpresentation, obstructed labour/dystocia, prolonged second stage, maternal fever during labour (38ºC), rupture of membranes 24 hours, meconium staining of liquor)	• Multiple births • Obstetric complications. For example, uterine rupture, disproportion, malpresentation, cord prolapse, cord compression, placenta previa, foetal blood loss, or precipitate labour) • Unexplained asphyxia • Foetal–Maternal Haemorrhage
Specific infant conditions	
• Infants > 32 weeks with septicaemia, meningitis or pneumonia. • Term infants with respiratory distress syndrome • Neonatal tetanus • Diarrhoea • Unexplained immaturity	• Infants > 32 weeks with septicaemia, meningitis or pneumonia. • Term infants with respiratory distress syndrome or sudden infant death syndrome. • Neonatal tetanus • Accidents causing neonatal death • Unexplained asphyxia • Diarrhoea • Unexplained immaturity
Other conditions	
• Antiphospholipid antibodies • Cytokines	• Unexplained stillbirth < 37 gestational weeks. • Unexplained stillbirth ≥ 37 gestational weeks. • Unclassified cases

According to the literature, maternal age and a prior early pregnancy loss are the main risks for pregnancy and neonatal losses. At the age of >35 years, the association with foetal chromosomal abnormalities is strong (García-Enguídanos et al., 2002; Lawn et al., 2005; Magnus et al., 2019; Silver, 2007; Winbo et al., 2001). For example, the following table (Table 2) shows the percentage of abortion risk according to maternal age (Shorter et al., 2019).

Table 2 *Risk of miscarriage by maternal age**

Maternal age	**Miscarriage risk**
16-20	15%
21-25	11%
26-30	12%
31-35	17%
36-40	30%
41-45	60%

**From (Shorter et al., 2019)*

As for the aetiology, the majority of sporadic losses <10 weeks of gestation result from random numeric chromosome errors, specifically, trisomy, monosomy, and polyploidy. Approximately 60% of early pregnancy losses are associated with sporadic chromosomal anomalies, primarily trisomy (Practice Committee of the American Society for Reproductive Medicine, 2012).

1.1.4 Clinical manifestations

The main clinical manifestations associated with pregnancy losses are vaginal bleeding and abdominal pain. It is estimated that between 20% and 40% of pregnant women will experience bleeding during the first trimester of pregnancy. However, in many cases this bleeding will not lead to a loss of pregnancy in the very early weeks of pregnancy and it may be related to endometrial implantation (Breeze, 2016).

Occasionally vaginal bleeding may be accompanied by pain, such as cramping of medium to severe intensity, especially during passage of gestational tissue. This pain can be constant or intermittent and is often associated with vaginal bleeding. In addition, women may also notice a loss or reduction of pregnancy symptoms, such as decreased breast tenderness and/or nausea and vomiting (Carolan & Wright, 2016; Punches et al., 2018).

Alternately, some women are asymptomatic, and pregnancy losses would be without signs or symptoms and discovered incidentally or on routine ultrasound (Carolan & Wright, 2016).

1.1.5 Diagnosis

The timing of diagnosis of pregnancy losses may be at the request of women, if they present the signs and symptoms described above, or opportunistically.

Currently the Spanish Health System, and specifically Galicia (Galician Health Service - SERGAS) (Grupo de trabajo de la Guía de práctica clínica de atención en el embarazo y puerperio, 2014; Xunta de Galicia, 2008), has the following calendar of monitoring visits (Figure 2):

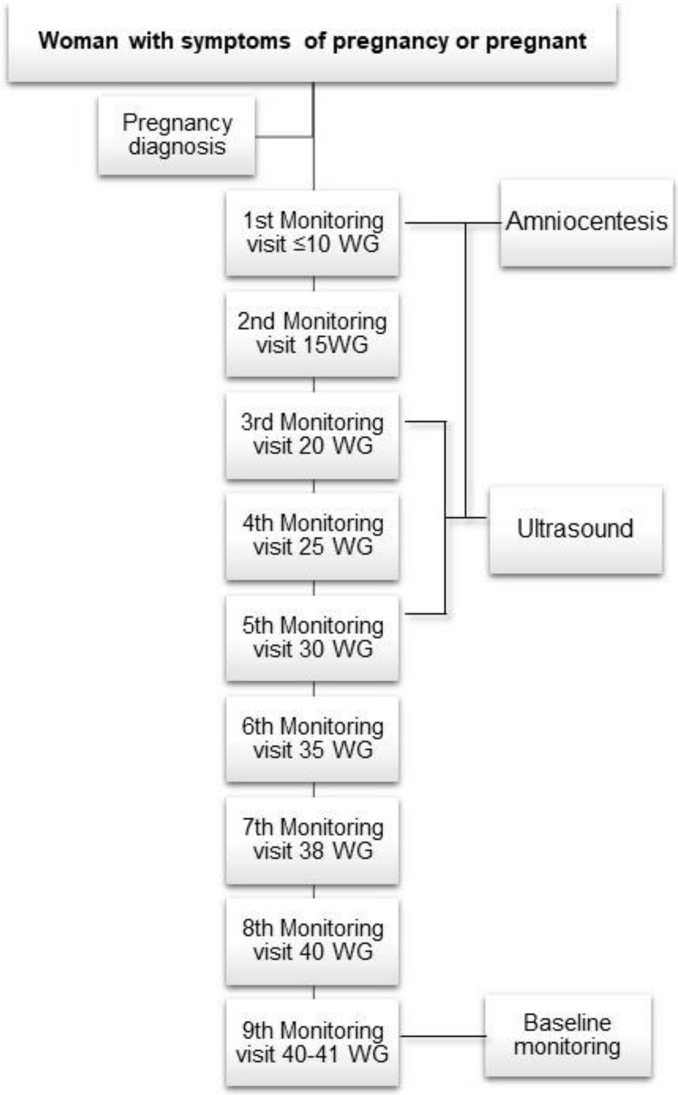

Figure 2 *Risk-free pregnancy monitoring visits.*

*****Abbreviation****: WG week of gestation*

The key moments for a diagnosis of pregnancy loss or foetal abnormality occur around 11 to 13 weeks of gestation, through ultrasound of the first trimester and chromosomal screening, and from 17 to 20 weeks of gestation, through amniocentesis and the ultrasound of the second trimester (Table 3). Furthermore, since 2011 a new technology called non-invasive prenatal testing (NIPT) has been incorporated, which consists of the analysis of foetal DNA fragments present in maternal plasma. The analysis of these cells allows to detect trisomy in the foetus. The test is performed from 10th WG (García Pérez et al., 2016).

Table 3 *Diagnosis test and weeks of gestation*

Weeks of gestation	Diagnostic tests
11-13 WG	• Chromosomopathy screening: combined test • First-trimester ultrasound
15-17 WG	• Chromosomopathy screening: quadruple test if the first trimester screening cannot be done • Amniocentesis according to risk factors
20 WG	• Second-trimester ultrasound

**Abbreviation*: WG week of gestation*

On the other hand, when a woman goes to the emergency department with vaginal bleeding and/or abdominal pain, an assessment is performed to determine the possible loss of pregnancy. This evaluation includes a pregnancy test, a physical examination, ultrasound, and various diagnostic laboratory specimens in the woman's medical history (Punches et al., 2018). In advanced losses, the absence of foetal heartbeat through ultrasound is the test that confirms the diagnosis.

1.1.6 Clinical management

There are different options for the clinical management of miscarriages, which will depend on the type of miscarriage (Breeze, 2016; Shorter et al., 2019). These options include:

- **Expectant treatment**: This management involves allowing the natural process of expulsion of uterine products of conception to occur without intervention. In these situations, women should be informed regarding the expected length of the process, symptoms of pain and bleeding that they are likely to experience, and how to seek emergency medical assistance. This treatment is of choice for threats of abortion and uncomplicated complete spontaneous miscarriages. In the case of incomplete miscarriages, 60% of women experience complete expulsion of products in the ensuing two weeks and 90% by six to eight weeks. Missed miscarriages generally take longer to expel (Breeze, 2016; Shorter et al., 2019; Volgsten et al., 2018).

- **Medical treatment**: Medical management involves the use of misoprostol -a prostaglandin E1 analogue- for medical evacuation of the uterus. Vaginal or oral routes of administration are both associated with potent and sustained contractile effects on the myometrium (Breeze, 2016; Shorter et al., 2019).
- **Surgical treatment**: It consists of the surgical evacuation of the uterus through a Dilation (in some cases) and Curettage (D&C) (Nanda et al., 2012).

The clinical management options in stillbirths are three (Silver, 2007; Smith & Fretts, 2007):

- **Expectant management**: This involves waiting for the woman to give birth spontaneously, but under analytical controls.
- **Labour induction**: This is the administration of vaginal prostaglandins, when the cervix is not mature, or intravenous oxytocin, if Bishop's index is favourable.

- **Mixed management**: With this type, some time is given to women until they feel psychologically and emotionally prepared. The childbirth will be later induced.

The most common practice after intrauterine death is the induction of labour in the first 24 hours after the loss. Delay of induction has theoretical risks of disseminated intravascular coagulation and infection, however, these risks decrease in the absence of further obvious complications (Smith & Fretts, 2007).

After diagnosis of TOPFAs, parents find themselves in the dilemma of a therapeutic termination of pregnancy or to continue with the pregnancy, knowing that the outcome will still mean the loss of their baby. Currently there are two options for a therapeutic termination of pregnancy in the second-trimester of pregnancy; firstly, surgical removal of the foetus. This procedure involves the dilatation of the cervix and extraction of the foetus vaginally and is performed in an operative setting under anaesthetic. The second option is medical induction of labour resulting in the birth of the baby (Jones et al., 2017; Pitt et al., 2016).

In case of neonatal loss, once a situation is diagnosed in which there is no chance of meaningful survival, end-of-life care is delivered to a new born and family. The focus of this type of care is on pain and symptom management, and whole care of the new born and family (Cortezzo et al., 2013; Moura et al., 2011).

Understanding the cause of a pregnancy or baby loss is important to parents. Pathological examinations of miscarriage tissue or post mortem examination, which include autopsies, surgical investigations, imaging and other tests, are important because they provide information that allows parents to build the loss and helps them plan for future pregnancies and assist them in the management of these pregnancies (Cronin et al., 2018; Heazell et al., 2012; Horey et al., 2013). International guidance is clear that high-quality post-mortem examination should be offered to all parents after stillbirth (Flenady et al., 2011).

In our context, the University Hospital Complex of Ferrol has action protocols for miscarriages, voluntary interruptions of pregnancy and stillbirths. The following table (Table 4) summarizes the clinical management and the department involved depending on the WG in which the loss occurred.

Table 4 *Clinical management according to the weeks of gestation in involuntary pregnancy losses*

Week of gestation	Clinical department	Clinical management
≤8 WG	Gynaecology emergencies	Medical treatment (800µg misoprostol vaginal route in a single dose) • Home • Admission to the gynaecology service *Surgical treatment if it is needed
8-22 WG	• Gynaecology emergencies • Gynaecology department or Labour and delivery department	Medical treatment (Misoprostol vaginally and repeat dose at 4-6 hours) • Admission to the gynaecology service or Labour and delivery department *Surgical treatment if it is needed
>22 WG	• Gynaecology emergencies • Labour and delivery department	Labour induction • Labour and delivery department

TOPFAs, detected through amniocentesis in 17 WG or on the ultrasound of the second-trimester of pregnancy, are referred to the private Health System, due to the conscientious objection of gynaecologists of the Public Health System. In the TOPFAs of <20 WG, pregnancy termination is performed in private health system hospitals in Galicia (in the cities of A Coruña or Vigo). In pregnancies of more than 20 WG, the termination is performed in a private clinic in Madrid (more than 600 km away). From 23 WG, the termination of pregnancy must be authorized by the Clinical Committee of the Autonomous Community of Galicia. This committee is located at the Álvaro Cunqueiro Hospital in Vigo.

In 2016, the media echoed the complaint made by the Galician Platform for the Abortion Rights at the Maternal and Child Hospital of A Coruña (see the news). The reason for the complaint was due to the alleged breach of international protocols regarding the care of women who terminate pregnancy due to foetal abnormalities, since healthcare was not guaranteed during the process. The president of the Galician government, after the defence of the health professionals of the Gynaecology and Obstetrics services of SERGAS, has admitted the possibility that dysfunctions can occur in terms of care.

These action protocols only include the clinical management of pregnancy losses, and hardly mention emotional aspects of care. For instance, the protocol of action in cases of stillbirths only mentions the possibility of delaying the induction to childbirth between 12 and 24 hours if the bereaved parents involved need it as well as granting the consent to parents to see and hold the baby as long as they wish. Health care providers (HCPs) who attend to these parents should remain with them and not be changed whenever possible. Moreover, actions of low sensitivity in these situations also appear as the mandatory offer of preconception counselling in the follow-up consultation.

1.1.7 Emotional management

The emotional support to bereaved parents is important and can have long-term implications for their well-being (Crawley et al., 2013; Downe et al., 2013; Schott & Henley, 2009). This support should not be exclusive around the time of their baby's death, but should be a long-term support (Harper et al., 2011).

Cochrane Collaboration published a systematic review about support for parents and their families following perinatal death (Koopmans et al., 2013). Due to the high loss-to-follow-up rate, the three identified trials could not be included. As a result, the authors of the review recommended that other designs should be used to inform the practice (Ellis et al., 2016; Koopmans et al., 2013).

Emotional support must be provided by all HCPs who are in contact with bereaved parents. However, nurses and midwives are recognized by parents as the reference professionals in the care of losses, in addition to being the best placed in the provision of whole care (Cacciatore, 2013; Gold, 2007).

Emotional support should be based on four main axes (Ellis et al., 2016; Evans, 2012; Flenady et al., 2014; Kingdon et al., 2015; Koopmans et al., 2013; Mills et al., 2014; O'Connell et al., 2016; Peters et al., 2015).

1. Respect

Quality bereavement care demands deep respect for the individuality and diversity of parents' grief and needs. It is important that parents' feelings are recognized and normalized by HCPs, in addition to the recognition and valuing of the deceased baby.

2. Information

The given information to parents must be objective, sensitive, accessible and supportive, where the respect for parental autonomy is balanced between the guide provided by their HCPs. Whenever necessary, all critical information should be repeated and reinforced verbally and with the delivery of written information.

On the other hand, it can be helpful for HCPs to be available to listen to parents' feelings and concerns and answer their questions.

3. Creating memories

Activities such as holding, bathing and dressing the baby, talking to the baby and using the baby's name, engaging in religious or naming ceremonies, introducing the baby to the extended family, and capturing interactions in photographs and videos should be supported. Parents should be offered mementos such as photos, and hand/footprints and special clothing or blankets when a baby dies. Especially in early losses, in which evidence of maternity/paternity is scarce, any items related to the baby should be offered to the parents.

4. **Professional development and support**

All HCPs need to receive training to ensure an appropriate care following a pregnancy or neonatal loss. Furthermore, HCPs confronted with such losses need to receive support that allows them to deal with and take care of future cases.

1.1.8 Civil registration

In Spain in 2009, the modification of the Law of June 8, 1957, was proposed on the Civil Registry to reflect filiation and give a name to the foetus born dead or to the live birth that has not exceeded 24 hours of life. Until then, all babies who died in the first 24 hours of life were recorded as *the deceased male or female foetus*. Since 2011, Law 20/2011, of July 21, of the Civil Registry entered into force, which establishes in article 30 that the conditions for registration are birth with life and complete detachment of the mother's womb. With this modification the requirements of ‘24-hour survival’ and ‘human form’ have been removed.

On the other hand, babies with more than 180 days of intrauterine life who do not meet these two requirements of the Civil Code, can access the so-called *abortion file*, regulated in articles 45 of the Civil Registry Law, and 171 to 174 of its regulation.

Finally, from July 22, 2014, after the fourth additional provision of Law 20/2011 entered into force, it is allowed to register in a file of the Civil Registry the deaths that occur after six months of pregnancy and that do not meet the conditions provided for in article 30 of the Civil Code without legal effects. Parents may also grant their child a name.

1.2 Parents' experience

Pregnancy loss and neonatal death generate a varied, dynamic and highly individualized response in parents (Dias et al., 2017; Hutti, 2005). It is extremely difficult to predict the significance of a pregnancy loss or the death of a baby for any parent. Some parents may feel guilt and shame, others might feel relief and hopeful about the future, and others still may feel ambivalent about pregnancy and loss (Hutti et al., 2013; Hutti et al., 2017; Layne, 1990; Leon, 1992).

Parents' grief is the experience of parents that begins after pregnancy loss or neonatal death. It is a global and multifaceted phenomenon that is a concern for HCPs worldwide (Fenstermacher & Hupcey, 2013; Purandare et al., 2012; Abdel-Razeq & Al-Gamal, 2018). Grief is defined as the normal psychological process that occurs through the loss of a loved one's death. It is a universal, unique, and painful human emotional experience, which can be delimited in time, presents a predictably favourable evolution, and requires the need to adapt to the new situation (Barreto et al., 2012; Consonni & Petean, 2013; Koopmans et al., 2013).

Scientific research recognizes the special features of pregnancy losses or neonatal death, for the multiple losses that it entails for parents - the loss of a projected child, the loss of aspects of themselves, the loss of a stage of life, the loss of a dream and the loss of a creation (Dallay, 2013; López García de Madinabeitia, 2011). Despite the tragedy parents suffer, they are immersed in a disenfranchised grief, since it is a loss that cannot be openly acknowledged, expressed in public or supported by their social network (Doka, 1999).

An important antecedent surrounding pregnancy loss and neonatal death, which is constantly observed in the literature (Dallay, 2013; Fenstermacher & Hupcey, 2013; López García de Madinabeitia, 2011), is the dream of the expectation of parenthood, new life and future hopes. These are interrupted when the loss occurs. Parents can fight with the consequences derived from the loss such as: finding a sense of self, renegotiating the hopes and dreams of parents and maintaining the conjugal dyad through the complexities of pregnancy loss and neonatal death (McCreight, 2008).

Foetal death is often considered by researchers and the general population as *the loss of pregnancy* rather than the death of a baby. This causes *ambiguous* grief and some women to feel marginalized. Ambiguity can manifest itself through prolonged denial, indistinguishable limits, incessant search for information and emotional outbursts (Cacciatore, 2010; Cacciatore et al., 2008).

The depth and length of each parent’s grief varies and depends to some extent on many factors. In Table 5 some of these factors are included (Dallay, 2013; Fenstermacher & Hupcey, 2013; Worden, 2018):

Table 5 *Influential factors in parents' grief*

Influential factors in the grieving of parents	
Situational factors	Living children, the rearing of a surviving twin, recurrent perinatal losses, post-loss pregnancies and stressful life events
Internal factors	• **Attachment to the baby**: The presence of attachment increases emotional intensity after loss. • **Gender**: Men and women face loss differently. • **Personality**: Personality traits can modify or influence perinatal grief. For example, when there is a predisposition to shame, guilt, jealousy or envy.
External factors	• **Culture**: The perception of loss is influenced by culture, faith and tradition, which in turn will affect the response of parents. • **Social support**: Creating memories, encouraging parents to see and hold the baby, name the baby and celebrate a funeral, have been shown to positively influence the intensity of pain and the duration of perinatal grief. • **Myths surrounding the loss**: For instance, "it is easier to lose a child during pregnancy than later", "the pregnancy the more advanced it is, the harder it becomes", "it is better not to see the baby and be anesthetized during childbirth" , "It is better not to see the baby, since it can keep the traumatic image and not get rid of it", "it is better not to keep memories, turn the page as quickly as possible and focus on the future", "get pregnant again It will soon help you forget what happened".

Grief involves the risk of negative social, psychological and biological outcomes in the short and long term, particularly when it is sudden and traumatic as in pregnancy and neonatal losses. Parental grieving reactions after these losses, such as deep sadness, depressed mood, irritability, worry, anxiety and changes in diet and sleep patterns, resemble other grieving situations and are considered as a normal response (Krosch & Shakespeare-Finch, 2017; Tseng et al., 2017).

The symptoms of acute grief usually disappear over time and for most people the intensity is significantly reduced from 6 to 12 months after the loss. However, sometimes the recovery of pain or *the normalization of the psychosocial effects of perinatal death* may take 5 to 18 years (Cacciatore, 2010; Gravensteen et al., 2012; Koopmans et al., 2013; Purandare et al., 2012). There is no agreement in the existing literature about when parents' grief begins or ends (Fenstermacher & Hupcey, 2013).

Rando (1993) suggested that certain circumstances increase the likelihood of complicated grief such as: sudden death, the death of a baby or a child, the perception that death was avoidable, a markedly dependent relationship, concurrent mental health problems and a lack of social support during and after the loss. The pathological responses of grief include depression, disorder related to the post-traumatic stress disorder and complicated grief (Koopmans et al., 2013).

On the other hand, Worden (2018) establishes four complicated grieving reactions that include: chronic grief that is excessive in duration; delayed grief by suppression; exaggerated grief which has been aggravated by multiple factors such as marginalization, stigma or physiological trauma; and masked grief that results in somatic symptoms or alexithymia. The highest risk for parents is when the four criteria overlap. That is, grief lasts longer, father and/or mother does not have a safe place to express grief, the loss is socially stigmatized or invisibilized and the emotions are expressed through somatic ailments or self-destructive behaviours, such as social isolation, shame, eating disorders, or risk behaviours. Different studies have also shown that the experience of foetal death could affect the raising of subsequent children and cause tensions in the couple (Côte-Arsenault & Marshall, 2000; Frøen et al., 2011).

The pathological grief differs from the normal grief because of its duration and if parents' behaviour and daily activities are affected. Hughes & Riches (2003) identified two types of pathological grief: prolonged grief with absolutely no improvement in symptoms at 6 months after loss, and *absent* grief which may predispose to subsequent psychological problems. Risk factors associated with pathological grief include substance abuse, persistent thoughts of suicide, severe depression, a history of mental illness and the inability to perform daily activities.

Outward expressions of grief do not necessarily indicate what an individual parent is experiencing or what they need. These expressions may be influenced by factors and societal. There may also be some cultural, religious or spiritual expectations that affect how bereaved parents behave in public, how they organize funerals, the restrictions that they observe and/or the clothes they are expected to wear (Golan & Leichtentritt, 2016; Leichtentritt & Mahat-Shamir, 2017).

Social expectations regarding gender also influence expressions of grief between men and women. The social context encourages parents to maintain a façade of stoicism or a strong and protective role and does not allow men to express themselves emotionally. Consequently, men tend to cry less, to avoid talking about the loss and to express more anger (Due et al., 2017; Meaney et al., 2017).

1.3 Health Care Providers' experience

According to the literature, pregnancy losses and neonatal deaths are associated with a social stigma influenced by the social and cultural context (Brownlee & Oikonen, 2004; Dallay, 2013; Fenstermacher & Hupcey, 2013; Van & Meleis, 2003). Therefore, these losses are still considered taboo losses and are silenced and made invisible by social and health environments (Brierley-Jones et al., 2014; Flenady et al., 2016; Paudel et al., 2018). This silence and invisibility constitute a component which reinforces stigma, and, consequently, a critical obstacle to supporting bereaved parents (Heazell, 2016; Pollock et al., 2019). In addition, the cultural component, in many cases, represents an extra challenge for HCPs (Shorey et al., 2016). For instance, in Asian cultures, death is perceived as a forbidden conversational topic and a matter that is private to the family. Moreover, perinatal death is perceived as an infliction of punishment on the mother who has failed to see her childbearing responsibilities through (Moon Fai & Gordon Arthur, 2009).

In this context, a supportive and sensitive care provided by HCPs is important and necessary for the immediate and long-term well-being of parents (Ellis et al., 2016; Flenady et al., 2014). According to Fenstermacher & Hupcey (2013), there is a possibility that parents can maintain a healthy connection with their dead child and may even consider the experience of grieving as transformative, as long as they receive comprehensive support from HCPs, especially by the nursing staff. Nurses and midwives, due to the continuous contact with parents and their families, have been identified as the reference professionals to incorporate knowledge of the grieving process into clinical practice and lead grieving parents to a healthy resolution of the grief (Atienza-Carrasco et al., 2019; Camacho-Ávila et al., 2019; Ujda & Bendiksen, 2000).

Interdisciplinary teams that address the grief of perinatal death contribute to the improvement of somatic discomfort and to the relief of the its hostility. For example, the immediate care a woman receives during the delivery of a dead foetus has a significant effect on her emotional state up to 3 years after death. The benefits of these interactions are particularly noticeable in cases where women have low social support from friends and family (Mander, 2014).

The care of involuntary pregnancy losses has evolved from a model of denial and protection to open support. However, current guidance regarding care in pregnancy losses is inconsistent (Ellis et al., 2016). In practice, the emergency department is, frequently, the only opportunity for parents to receive formal support in miscarriages (Emond et al., 2019). In stillbirths, the guidelines mainly focus on medical management, while emotional support is relegated to the judgment of each healthcare professional (Ugwumadu, 2015). In addition, these recommendations only focus on specialized care and on the precise moment of the loss, but it is necessary to follow up after the loss, to assess individual needs, thus facilitating an optimal approach to ease the grieving process (Atienza-Carrasco et al., 2019).

On the other hand, sensitive and supportive care requires going beyond the medical cure and not considering these losses as a clinical problem (Ellis et al., 2016; Lee, 2012). Furthermore, care should be centred on parents, considering their social and cultural context and their needs (Flenady et al., 2014). For this, it is necessary that HCPs have knowledge and training of the current evidence of pregnancy and neonatal loss, the impact of losing a baby, and the diversity of experiences of parents. Training should also contemplate the common challenges in care and how to address them, psychological theories, and good communication principles (Bakhbakhi et al., 2017).

Communication has been identified as especially difficult and challenging for HCPs (Beaudoin & Ouellet, 2018; Martínez-Serrano et al., 2018; Willis, 2019). Therefore, communication skills training should focus on techniques for dealing with grief reactions, communicating the diagnosis of stillbirth, respectfully discussing the postmortem consent process, and the processes after discharge from hospital (Bakhbakhi et al., 2017).

For that, organizational involvement and clinical supervision are necessary for the adequate formation of HCPs and to ensure staff well-being and avoid staff burn out, after taking care of these situations of high emotional demand (Kenworthy & Kirkham, 2019; Worden, 2018).

In clinic, professionals find the care of bereaved parents stressful, challenging, and they may feel unprepared (Beaudoin & Ouellet, 2018; Hutti et al., 2016; Nash et al., 2018; Willis, 2019). Therefore, this support could be superficial and focused on medical tasks rather than caring of the whole person (Ellis et al., 2016). The challenging nature of this support may have a personal impact on nurses and midwives. Some reasons why it can be stressful and demanding to care for and support parents during a pregnancy loss or when a baby dies are (Hunter, 2007):

- The experiences of loss and grief of parents are intensely personal and unpredictable. Therefore, HCPs have to work with a great deal of uncertainty.
- The great influence that their actions and words have on parents could cause HCPs to be very anxious about inadvertently saying the wrong thing and causing additional distress.
- It could be particularly hard for HCPs to deal with parents' grief that cannot be alleviated and take a less active role, focusing on listening and giving parents time.
- On many occasions, they could deal simultaneously with their own emotional reactions, often without acknowledgment or support.
- HCPs may also feel that the death of a baby represents a professional failure. Some may blame themselves and fear complaints and litigation.
- Anger and hostility towards parents' HCPs could cause feelings of demoralization in contexts where HCPs are doing their best in difficult circumstances.
- Less experienced HCPs in caring for losses may be anxious about their ability to cope and experience shock, panic and fear and may not know what to do.
- Caring for parents experiencing childbearing losses may sometimes raise ethical issues for some HCPs.

- In working environments where HCPs work under great pressure and in stressful circumstances, they may feel frustrated and anxious if they do not have enough time to give the best possible care.

1.4 Theoretical perspectives

For the development of this research three methodological approaches have been used, which will be detailed below.

1.4.1 Multicultural Model of Coping after Pregnancy Loss and Motivational Theory of Coping

Multicultural Model of Coping after Pregnancy Loss (Fernández-Basanta et al., 2019; Van, 2012) and *Motivational Theory of Coping* (Skinner et al., 2003) have been used. Coping strategies are used by parents to reduce, manage, and live with the natural physical, mental, and emotional symptoms of grief (Puigarnau, 2008). Coping has been defined as a set of conscious or unconscious behaviours to deal with stressful life events.

Multicultural Model of Coping after Pregnancy Loss (Van, 2012, p.77) (Figure 3), subsequently expanded (Fernández-Basanta et al., 2019), postulates that connectedness is the central concept that facilitates coping after involuntary pregnancy losses and disconnectedness is the central concept that inhibits coping.

Connectedness, according to the Theory of Human Relatedness (Hagerty et al., 1993), refers to the personal and active involvement of a person with another person, object, group, or environment, but from the social environment of the person. This implication promotes a sense of comfort, well-being, and anxiety-reduction. This, therefore, excludes social support and nurse caring. The dimensions of connectedness are personal (self), interpersonal (others), and religious/spiritual, while ineffective coping with grief after pregnancy loss tended to occur in situations where women were disconnected from themselves or others.

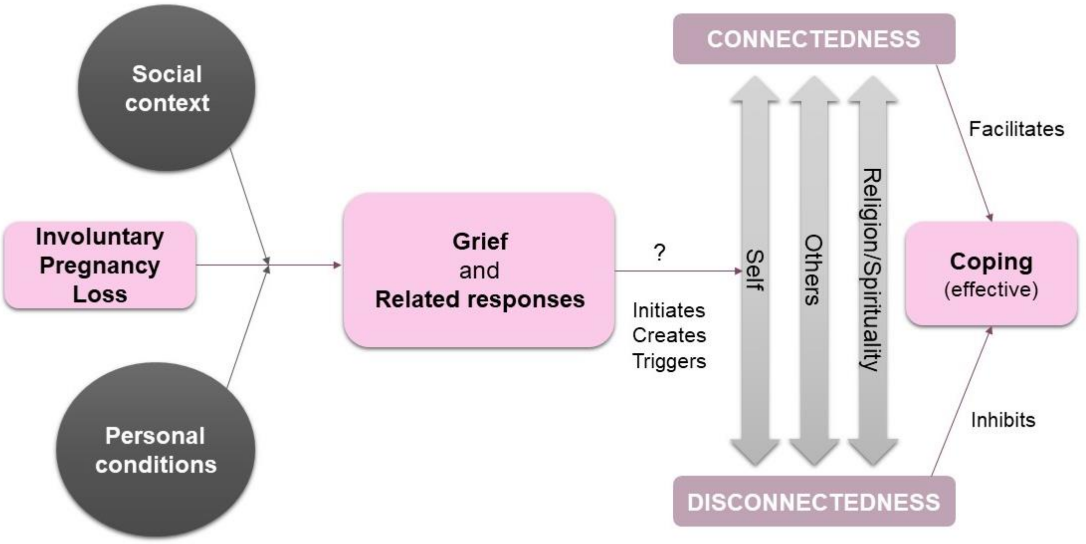

***Figure 3** Multicultural model of coping after pregnancy loss (Adapted from Van, 2012, p.78)*

Motivational Theory of Coping (Skinner et al., 2003) was used to fulfil our study aim and to deepen and provide an improved theoretical framework. This theory raises 12 families of higher order types of action, organized around three kinds of concerns. Each represents a class of concerns that humans can detect and they trigger organized patterns of biological behavior response or action trends:

- The first group of families is organized around challenges and threats to competition and, therefore, involves the evaluation of opportunities for (or threats of) control.

- The second set is organized around the challenges and threats to the relationship and involves evaluations of the availability (or absence) of trusted others.
- The third group of families they face is organized around the challenges and threats to autonomy and, therefore, involves the evaluation of opportunities for (and threats) to self-determined action.

Within each concern, four families are identified on the basis of (a) distinguishing forms of coping that are triggered by challenge versus threat assessments and (b) distinguishing between forms of coping that address the self *versus* the context. The result is 12 higher order coping families, organized into three sets of four and labeled using general action categories.

1.4.2 Caritative Caring Theory

Caritative Caring Theory (Eriksson, 1992, 1994, 1997, 2002; Eriksson et al., 2006; Lindström et al., 2006) has been used to understand the complexity and wholeness of the experience of nurses and midwives regarding the care provided on pregnancy losses.

Ontologically, the human being is conceived as an indivisible entity that includes body, soul and spirit. The human being has a unique vision of the world, as a result of individual experiences, and at the same time connected with the culture of the person. According to Eriksson (Eriksson, 1992, 1994, 1997, 2002; Eriksson et al., 2006; Lindström et al., 2006), caring maintains and enables health and well-being.

The purpose of caring is to alleviate suffering and promote health and life. The *ethos* of care includes *caritas*, love and charity, the respect of health professionals for the dignity of the person and a striving for a genuine communion and understanding of the unique human being. Therefore, caritative care is based on the relationship between the person who needs and hopes for care and the person who is caring, through a genuine communion and understanding for the unique human being.

Caring communion is understood as an act of human sharing in a caring relationship. Caring does not only imply performing professional nursing duties, but a motive. Professional caritative caring is a genuine mature attitude of responsibility, courage and wisdom. Caritative caring involves an encounter in which suffering and caring humans are participants in their own lived worlds of experiences and wishes.

Chapter 2: Aims

The general objectives of this thesis have been to know the coping of parents after a pregnancy or baby loss and to know the experiences of nurses and midwives in the care of involuntary pregnancy losses.

1. To know the experiences of **parents** in coping with pregnancy or perinatal loss.
   - **1.1 First study: Fernández-Basanta, S., Van, P., Coronado, C., Torres, M., & Movilla-Fernández, M. J. (2019). Coping after involuntary pregnancy loss: Perspectives of Spanish European women. OMEGA-Journal of Death and Dying, 0030222819852849.**
     - To identify the coping strategies of Spanish-European women following their pregnancy loss experiences.
   - **1.2 Second study: Fernández-Basanta, S., Coronado, C., & Movilla-Fernández, M. J. (2020). Multicultural coping experiences of parents following perinatal loss: A meta-ethnographic synthesis. Journal of Advanced Nursing, 76(1), 9-21.**
     - To synthesise the available body of qualitative work regarding how parents cope with perinatal loss.
2. To know the experiences of **midwives and nurses** in the care of pregnancy losses.

2.1 Third study: Fernández-Basanta, S., Movilla-Fernández, M. J., Coronado, C., Llorente-García, H., & Bondas, T. (2020). Involuntary Pregnancy Loss and Nursing Care: A Meta-Ethnography. International Journal of Environmental Research and Public Health, 17(5), 1486.

- To synthesise the available body of qualitative work regarding how midwives and nurses experience the care of pregnancy losses.

2.2 Fourth study: Primary healthcare midwives' experiences of caring for parents who have suffered an involuntary pregnancy loss: a phenomenological hermeneutic study

- To illuminate the experiences of primary healthcare midwives who care for parents who have suffered an involuntary pregnancy loss

Chapter 3: Compendium of publications

This section incorporates the results as publications, which constitute the body of the research carried out.

Findings will be presented according to the two central axes of the thesis.

First study - Coping after involuntary pregnancy loss: Perspectives of Spanish European women

Article

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Coping After Involuntary Pregnancy Loss: Perspectives of Spanish European Women

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Abstract

The purpose of this qualitative study was to discover the coping strategies used by Spanish (European) women to cope with a pregnancy loss. Sixteen women with miscarriages and stillbirths were interviewed. All of the women were Spanish European. The mean age of the women was 35 years, and most were university graduates, married, employed, and with living children. Audio-recorded interviews and field notes were transcribed and then subsequently coded and analyzed in individual or team sessions. Construction and confirmation of the categories and related themes derived from the data was a collaborative process. Two themes emerged regarding the coping strategies used by women: *talking* and *avoiding*. This study expands the theoretical model "Multicultural Model of Coping after Pregnancy Loss" and guides health providers regarding interventions used in practice.

Keywords

"perinatal grief," bereavement, coping, miscarriage, "qualitative research"

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Introduction

Grief is defined as the *normal* psychological process that occurs through the loss of a loved one's death. It is a universal, unique, and painful human emotional experience, which can be delimited in time, presents a predictably favorable evolution, and requires the need to adapt to the new situation (Barreto, de la Torre, & Pérez-Marín, 2012; Consonni & Petean, 2013; Koopmans, Wilson, Cacciatore, & Flenady, 2013). Some of the most common reactions present in perinatal grief, specifically, are deep sadness, depression, irritability, worry, anxiety, and alterations in eating and in sleeping patterns. The symptoms of acute grief usually diminish over time, but it has been reported that the normalization of the psychosocial effects of perinatal death takes between 5 and 18 years (Cacciatore, 2010; Flenady et al., 2014; Koopmans et al., 2013; Purandare et al., 2012).

Maternal bereavement is the experience of a mother that begins after the loss of a fetus due to miscarriage or stillbirth. It is a global and multifaceted phenomenon that is a concern for health-care providers (Fenstermacher & Hupcey, 2013; Purandare et al., 2012; Razeq & Al-Gamal, 2018).

Perinatal mortality has been reduced thanks to scientific advances and the quality of health care for pregnant women and newborns (Dallay, 2013; Koopmans et al., 2013). Despite this, worldwide between 20% and 30% of pregnancies end in miscarriage (Meaney, Corcoran, Spillane, & O'Donoghue, 2017), and the rate of fetal death was 18.4 per 1,000 of total births, representing 2.6 million fetal deaths annually in the world in 2015 (Lawn et al., 2016). In Spain, according to the latest data from the National Institute of Statistics, the perinatal mortality rate is 4.37 per 1,000 of the total births, and the late fetal mortality rate is 3.11 per 1,000 of the total births (Instituto Nacional de Estadística, 2018). However, the literature establishes the possibility that these ratios are underestimated (Flenady et al., 2014). This underreporting in Spain may be due to the fact that the data used are collected from the local civil registers, which are based on the voluntary declaration of the parents, and not on the data available to the hospitals (Suárez, López, Martínez, & Sánchez, 2008).

Globally, knowledge about this type of loss and care provided have evolved from nonrecognition to the provision of more humane care (Dallay, 2013). Despite this, pregnancy losses are still considered taboo losses and made invisible by the social and health environment, and parents perceive a lack of social and health support (Heazell, 2016). Consequently, these losses do not reach the relevance to influence political agendas. Invisibility of pregnancy loss is exacerbated in low-income countries, where poverty can contribute to complex situations for women in after pregnancy loss, while in high-income countries, the invisibility of pregnancy loss is not homogeneous and varies from one country to another (Frøen et al., 2011). In Spain, in the health providers' protocols of action, there is great variability in terms of interventions, and these are primarily aimed at clinical aspects (Pastor-Montero et al., 2011).

There is a lack of literature referring to the experiences of Spanish European women after pregnancy loss. One study reflected that women assertively sought individualized professional support to obtain assistance with managing their emotions and to talk about their loss experiences (Pastor-Montero, Vacas-Jaén, Rodríguez-Tirado, Marcías-Bezoya, & Pozo-Pérez, 2007).

In the literature (Cacciatore, Erlandsson, & Rådestad, 2013; Ryninks, Roberts-Collins, McKenzie-McHarg, & Horsch, 2014; Van, 2012; Van & Meleis, 2003; Yamazaki, 2010), strategies and coping behaviors in perinatal losses are described. But these belong to other cultures, which is a problem when it comes to transferring results to Spanish European women, because culture influences the construction of grief (Dallay, 2013; Fenstermacher & Hupcey, 2013; Van & Meleis, 2003). There are articles (Fenstermacher & Hupcey, 2013; Mander, 2014) that affirm that qualitative research is necessary to discover and describe the variations in the experience of perinatal grief through age groups, races, and cultures so that the concept of perinatal grief can be advanced and offer appropriate support.

Previous studies have shown that talking to loved ones about death contributes to the process of overcoming grief, while a lack of social support can prolong and worsen the grief response (Maguire et al., 2015). When grief is repressed or hidden behind a façade of strength or under patterns of work addiction, the sensations of pain, suffering, and emptiness due to the loss of the loved one would be numbed in this way (Hutti, Armstrong, Myers, & Hall, 2015; Yoffe, 2003). In the short or long term, this usually generates physical symptoms, psychosomatic illnesses, behavioral disorders, depression, or chronic grief, giving rise to pathological grief. The cultural factor influences the coping mechanisms used by individuals. While in North American cultures, there is a marked tendency to self-control and silent coping, in Spain, cultural frameworks allow for the expression of emotions (Yoffe, 2003).

This report expands the theoretical model "Multicultural Model of Coping after Pregnancy Loss" (Van, 2012, p.77). The model establishes connectedness as a facilitator of coping, while disconnectedness is the central concept that inhibits coping. This model consists of three dimensions of connectedness: personal (self), interpersonal (others), and religious/spiritual. Specifically, the interpersonal dimension (others) is widened because our data answer the questions of why and who. For all this, the aim of this study was to identify the coping strategies of Spanish European women following their pregnancy loss experiences. The results of this report are a component of a larger study in which coping after pregnancy loss was explored among women and their partners.

Implementation of the Study

This study was approved by the Ethics Committee (registration code 2015/232) and was developed within the current regulatory framework (Council of Europe, 1997; General Council of Nursing, 1999; Law 14/2007, of July 3, on biomedical research; Law 41/2002, of November 14, basic regulatory of the autonomy of the patient and rights and obligations in matters of information and clinical documentation; Organic Law 15/1999, of December 13, Protection of Personal Data; World Medical Association, 2013). The study participants were recruited by the collaboration of midwives and gynecologists of the Gynecology and Obstetrics Service of a major medical center located in northern Spain. They delivered an informational flyer to the parents after the loss, with which women gave their consent for the researcher to contact them by phone. During the first contact, the researcher and the women established appointments at times and locations convenient to the women. Eligibility criteria for the study included women who reported a recent experience of pregnancy loss (e.g., miscarriage, eugenics abortion, or fetal death) and assigned to a specific health-care area of northern Spain.

Informed consent was obtained from each participant before data collection. Before signing the consent, an additional information sheet was provided with content related to the study and their rights in the study. Participants were assured that they could stop the interview at any time and could skip any questions they did not want to answer. If interviewers perceived that a professional approach was necessary, they could contact the team of health professionals or recommend that the women request an appointment with a health professional to be seen. In all cases, the interviews were conducted at the first contact with the parents, at the request of the parents. Of the 16 interviews, 12 interviews were conducted with couples (male and female) and 4 with only women, although the results presented here are from the women, only. There was only one interview per participant. The average time between the loss and the interview was 1 month.

The individual interviews were conducted at the time and place chosen by the participants, usually their homes. The qualitative method used to collect data was grounded theory (Charmaz, 2006).

Using a semistructured interview format, the participants were asked about their experience of pregnancy loss. From their initial story, questions about the specific aspects, such as strategies and coping mechanisms, were explored. Some examples are as follows:

1. Have you used any coping mechanisms or strategies in this situation? Which ones?
2. What role did your family play at that time? What was the influence of your social environment?

The interviews were audio-recorded. After the completion of the interviews, the researcher wrote field notes. The interviews were transcribed by the researcher. The audio-recordings were destroyed using acceptable industry procedures.

Demographics

The mean age of the 16 participants was 35.18 years. The nationality of all the women was Spanish European, although one was from South America. The level of study of the participants was basic education ($n = 2$), medium professional training ($n = 3$), higher professional training ($n = 3$), and university studies ($n = 8$). Except one, all participants were married or partnered. Most (80%) were working at the time of their participation in the study. Their loss occurred as follows: first trimester ($n = 12$), second trimester ($n = 3$), or third trimester ($n = 1$). Regarding their reproductive history, $n = 8$ had previous children, $n = 3$ had previous losses, and $n = 3$ were included in a fertility program.

Data Analysis

The interviews were coded in individual and group sessions among the authors. Construction and confirmation of the categories and related themes were derived from the data and the field notes. Verbatim quotes were selected to illustrate the themes and the participants' perspectives. Preliminary results were presented to a group of registered nurses, who represented a variety of specialties, but predominately perinatal nursing. A group of practicing registered nurses, employed in mostly perinatal units in the United States, provided feedback to confirm our interpretation of the data and extend our understanding of the implications for education, research, and practice.

Results

The women of this study were open to participate and talk about their experiences. During the interview, they appeared comfortable, and, in many cases, they said the interview was therapeutic, and they expressed gratitude for having the opportunity to participate in the study. Some women cried when remembering their experiences; they were given the opportunity to stop the interview but declined and continued. Due to the short time since their loss (1 month), they described clinical aspects about their experience, perhaps in an effort to redirect from discussing more painful emotional issues.

From the analysis, two major themes were identified: talking and avoiding.

Talking

This theme focused on why and with whom the women used conversation as a coping strategy.These conversants were connected with the women on a personal level.

Participants talked most frequently with their husbands/partners, mothers, sisters, and other family members. They talked with these people because they wanted to be open and transparent with someone they could trust.

> Let's say, that we [my husband and I] spoke for 2 weeks about this topic, it was the only topic. (DP15, Involuntary Pregnancy Loss [IPL] 15 weeks, 38 years old)
>
> I say everything, he [my husband] listens to me. We have been together for 10 years, so we know each other very well [...] We support each other. (DP1, IPL 30 weeks, 31 years old)
>
> Yes, we [my husband and I] have discussed this many times, but without drama. For sure, without drama for our health. (DP13, IPL 7 weeks, 39 years old)
>
> But my mother, who saw him [the baby], would say to me, "Don't dwell on that because L [the baby] ... Remember him when he was in your womb and when you spoke to him and he responded, and when you had that bond." And then, that helped me and consoled me [...] "While I had him in my womb, I know that he was conscious of the love and the desire we had to have him." (DP1, IPL 30 weeks, 31 years old)
>
> My mother is helping me a lot, because she understands death in a different way. And she said, "I already know that it is a horrible experience. And hopefully I could die, if necessary, so that you would not have to experience all of this." [...] "Don't worry, because in the future you'll see this in a different [new] way." (DP1, IPL 30 weeks, 31 years old)
>
> I spoke much about this [the loss] with them [my sisters] [...] And I explained everything to them. (DP15, IPL 15 weeks, 38 years old)

Another group that stood out were people who had similar experiences, such as family members or close friends who had a pregnancy or fetal loss. The women highlighted that talking to others who had the same experience was beneficial for them.

> Two days after [the loss], we were with friends who just had the same experience. [...] So then, the first thing I told her was, "I thought of you, you know?" And we spoke [about our losses]. [...] It helped me to see the person who had the same experience and to feel supported by them. (DP2, IPL 7 weeks, 34 years old)
>
> [...] You see that they have gotten beyond it. They [women who experienced pregnancy loss] are coping by moving on and having children. (DP16, IPL 13 weeks, 31 years old)

> It's a relief to be able to talk with someone who had the same experience. (DP2, IPL 7 weeks, 34 years old)

Some would talk to coworkers, a more formal situation, because they did not want to pretend with their colleagues:

> I told coworkers because I was going to miss work and I wanted them to know [. . .] I had the need to talk about what happened so they could understand that I was missing work for an important reason. (DP20, IPL 6 weeks, 41 years old)

> I had to tell a work friend ... And it was a relief that someone knew about the loss. Because if not I would have to cover it up with excuses and lies. (DP13, IPL 7 weeks, 39 years old)

Avoiding

In the early stages of the loss, some women used avoidant coping regarding conversations, for various reasons. The most frequent reason for avoiding discussion of loss was due to their anticipation of negative and unsupportive responses from others.

> [I didn't talk about my loss because of things people would say to me such as ...] You're fine, you know that with your age the miscarriage rate is very high, what did you expect? Why are you ... Giving it so much [attention] ... that is just how it is. (DP9, IPL 8 weeks, 43 years old)

> I don't have the will to explain [the loss]. [. . .] It's not that not wanting to explain it is in the nature of my personality ... It's not acceptable to discuss these things. (DP9, IPL 8 weeks, 43 years old)

> [. . .] I made something up ... I told them I had bleeding due to a polyp ... It [the loss] would have been the talk of the funeral, "Look, 'Isabel' had a miscarriage." And then ... it would have been unnecessary whispering. (DP20, IPL 6 weeks, 41 years old)

> I don't like talking about ... I had a miscarriage ... Because I know that people may say, see a single mother by choice and now look what happened to her. (DP19, IPL 9 weeks, 37 years old)

Other reasons included the desire to protect oneself, as can be seen in the following quotes:

> We went to a spa, to see if we could disconnect, to find peace, to be together ... We did not even want to be with family [or talking family]. (DP15, IPL 15 weeks, 38 years old)

> The shock of meeting and them asking you how is your pregnancy going. Then, I felt my heart sank to my feet. I arrived home I just got in bed with my clothes on and did not want to talk, cook, or eat. (DP13, IPL 7 weeks, 39 years old)

> [. . .] But, I, for example, have not told my mother. And I still don't know why, but it may be for self-protection. (DP9, IPL 8 weeks, 43 years old)

The last reason for the use of avoidant coping was that they avoided the discomfort of retelling the story of the loss.

> I did not even pick up the phone. I did not want to talk to anyone ... It was remembering ... Everything ... with every person who called you ... (DP22, IPL 11 weeks, 35 years old)

> But I think that, right now, after these months, and after having gone through work of getting beyond it and packing it away ... It could reopen things that I think are already settled. (DP9, IPL 8 weeks, 43 years old)

Discussion

The analysis of this study with predominantly Spanish European women revealed that their coping strategies were guided by their preferences for communication. The women demonstrated divergent communication styles by either communicating or avoiding discussions.

The theoretical model "Multicultural Model of Coping after Pregnancy Loss," developed by studies with African American, Caucasian, and Asian American samples (Van, 2012), is expanded with our findings. The results of this study expanded and confirmed our understanding of the influence of connectedness or disconnected among interactions with self or others.

- *What* was discussed;
- With *whom* the communications occurred; and
- *Why* communication occurred or did not occur.

The time of data collection differs from one study to another. In this study, the mean time from the loss to the interview was 1 month, while in the study by Van (2012), the participants were interviewed in the final month of a subsequent pregnancy. Although evidence reflects the recency of the perinatal loss can influence women's responses related to talking or avoiding the loss (Flenady et al., 2014; Koopmans et al., 2013), the literature also reflects alternative perspectives. Specifically, talking and avoiding strategies have been used by women for more than a year in response to their perinatal losses (Carolan & Wright, 2017; Gopichandran, Subramaniam, & Kalsingh, 2018; Van, 2012). The capture of the sample at different moments of the experience of the phenomenon strengthens and expands the theoretical model.

On the other hand, our results revealed a cultural difference between both samples. The American samples used religion as a coping mechanism, while the Spanish group did not.

Talking

The benefit of informal support, provided by family, friends, and close people with similar experiences, is well documented in the research literature and coincides with our results (Gerber-Epstein, Leichtentritt, & Benyamini, 2009; Meaney et al., 2017), but we did find cultural differences. In investigations such as that of Allahdadian, Irajpour, Kazemi, and Kheirabadi (2015), cultural differences were visible in terms of the informal source of support. Their results, which were framed in the Arabic culture, highlighted that the role of the husband in this process was to be present, and the family and close friends were to perform daily activities and housekeeping and return to their normal lives. In our sample, women faced the loss of pregnancy, talking to their social environment, which included their husbands, family (mother and sisters), and close friends.

Our results do not coincide with those reported by Randolph, Hruby, and Sharif (2015). Their findings have shown that silence about losses is especially frequent in the workplace. This may be due to the idea that conversations about death are not normalized in the workplace and that the professional development of women can be affected by these conversations. In our results, women gave the news of the loss and talked about it with their coworkers. Being able to talk openly did not force them to pretend or try to distract from their experience.

The benefits of social support are widely reported in the literature as a healing element for women after pregnancy loss (Flenady et al., 2014; Koopmans et al., 2013; Sutan & Miskam, 2012). In addition, when the loss is recognized or publicly expressed, social support is usually greater (Randolph et al., 2015). In our results, we found that talking about loss is a relief for these women as they shared their experiences with others.

They felt accompanied in their loss, and this was especially visible in those who talked with other women about their experiences of pregnancy loss. Findings from this study support what has been reported by others. Talking to others who have gone through similar losses is helpful to women. Sharing these experiences helps them to normalize their feelings (Cacciatore & Bushfield, 2007).

Talking also validates their loss, especially with losses early in the pregnancy. Early losses lack tangible proof of the baby's existence that are present in later losses, such as physical changes in a woman's body that are socially perceptible, or memories recorded through photographs, footprints, or ultrasounds (Fernandez, Harris, & Leschied, 2011; Garrod & Pascal, 2019).

Avoiding

The avoidance behaviors of women were strongly influenced by cultural components. For instance, in Taiwanese society, these losses are taboo and represent failure to fulfill the reproductive tasks of mother, wife, and daughter-in-law. For this reason, Taiwanese women are alone during the loss (Tseng, Chen, & Wang, 2014). In the study of Gopichandran et al. (2018), Indian women faced a baby loss through isolation, returning to work, caring for their family's children, and having wishes for a viable new pregnancy, the support of family and friends, and religion. Isolating behaviors were due to guilt, pain, and shame because the women perceived a sense of stigma of failed womanhood. Our study was similar with respect to these avoidance behaviors due to the pain of reliving the experience it when they talked about it. But it is also due to other causes such as the desire to protect oneself and avoiding negative or nonbeneficial responses from others.

Avoidance behaviors may be because these women are not prepared to talk about their loss. According to the research literature (Dyregrov, Dyregrov, & Kristensen, 2016; Nazaré, Fonseca, & Canavarro, 2013), avoidant coping is associated either with adaptive or maladaptive responses that may be helpful following a loss and trauma. In our results, the mean time between loss and the interview was a month, and this could suggest an adaptive response in the grieving process because the presence of avoidance behaviors by parents is in the early stages of the grieving process.

Implications for Practice, Education, and Research

In practice, it is important that health providers acknowledge the perinatal loss and the individuality of this grief on the woman and her partner. Individuals cope with and build on the loss according to their situational factors (existence of previous children, previous pregnancy losses, the upbringing of a twin that survives), internal (personality, gender), and external (culture, social support; Dallay, 2013; Fenstermacher & Hupcey, 2013; Van & Meleis, 2003). This gives rise to the concept that the grief is externalized in a certain way and with a different duration between each one.

On the other hand, follow-up interventions must be carried out, to find out how the women are coping with the loss after leaving the hospital, because avoidance behaviors are frequent in the early stages of loss.

When educating health-care providers, grief must be included. It is important that health-care professionals, especially nurses, know about the grieving process and its symptoms. With this knowledge, health-care providers can give women educational resources to cope with a loss, helping women to understand that grief is a normal and healing process that occurs after a loss. In addition, this education could be extended to the close social environment of the women because these are the main support people. In our results, the feeling of *normality* and support was acquired by talking with other women with similar experiences. Finally, with this knowledge, the detection of pathological grief could be identified if it occurs.

Further research on men may also extend the work of Van (2012) on the coping mechanisms after the loss of a pregnancy. In this research, the coping mechanisms of Spanish European women, belonging to the Mediterranean cultural framework, have been collected. Research in other cultures, in different age groups and in different types of pregnancy loss, will broaden the knowledge of grief and, therefore, its proper management by health-care providers.

Conclusion

Spanish European bereaved women cope with the loss of pregnancy with two antagonistic strategies. They talk with their social circle (family, friends, and others with similar experiences) and with coworkers. They use this strategy because it is a relief for them, they normalize their feelings, others can empathize with them, they increase their social support system, they validate their loss, especially those early losses, and because they do not want to pretend. They use avoidant behaviors, mostly to anticipate negative responses and lacking support from others. They also use them as a mechanism of self-protection, avoiding the discomfort of retelling the story. This study guides health providers regarding interventions used in practice, which are based on recognizing the loss and the individuality of this processes of connecting with others and then structure and content of those connections.

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Second study - Multicultural coping experiences of parents following perinatal loss: A meta-ethnographic synthesis

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REVIEW PAPER

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Multicultural coping experiences of parents following perinatal loss: A meta-ethnographic synthesis

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Abstract

Aims: To synthesize research findings regarding the coping experiences of parents following perinatal loss.

Design: Noblit and Hare's interpretive meta-ethnography was followed.

Data Sources: A comprehensive systematic search of the published literature (2013–2018) was undertaken in five databases, complemented by supplementary searches.

Review Methods: Fourteen studies met the research objective and inclusion criteria.

Results: Five themes describe the coping strategies used by parents who experience perinatal loss. The themes were synthesized into the metaphor *Staying afloat in the storm*.

Conclusion: Parents use coping strategies to manage perinatal loss and the use of these strategies is conditioned by cultural, social, and individual factors. This study has implications for evidence-based practice by showing care needs and the importance of implementing emotional and patient-centred care interventions.

Impact: This meta-ethnography highlights the care needs of parents following perinatal loss, facilitating understanding of coping experiences. Increased knowledge about these experiences may contribute to the development and implementation of nursing and midwifery interventions that include emotional and patient-centred care.

KEYWORDS
coping, grief, literature review, meta-ethnography, midwives, nurses, perinatal death, qualitative research, systematic review

1 | INTRODUCTION

Parental bereavement is the experience of parents that begins following perinatal loss. The World Health Organization (2006) reports that the perinatal period ranges from 22 weeks of gestation to one week of independent life. However, this period is often extended in practice and in the literature (Fenstermacher & Hupcey, 2013; López García de Madinabeitia, 2011). In this meta-ethnography, perinatal loss is referred to as the loss of a foetus or baby due to a miscarriage, termination of pregnancy due to foetal anomalies (TFA), stillbirth, or neonatal death.

The available research recognizes the special features of perinatal bereavement, as it entails multiple losses for parents (Dallay, 2013). Despite the trauma of perinatal loss, individuals can still develop a healthy connection with the deceased child and it may even be a transformative grief experience if they receive comprehensive support from healthcare providers (HCPs), especially nursing staff (Cacciatore, 2010).

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1.1 | Background

Perinatal loss causes a set of painful emotional reactions to which grieving parents must respond. Short-term reactions include shock, anger, emptiness, helplessness, and loneliness; long-term reactions may include depression, anxiety, and post-traumatic stress disorder (PTSD) (Flenady et al., 2014; Koopmans, Wilson, Cacciatore, & Flenady, 2013). Some of these emotions are exacerbated in subsequent pregnancies following the loss (Côté-Arsenault & Marshall, 2000). Parents use coping strategies to reduce, manage, and live with the natural physical, mental, and emotional symptoms of grief (Puigarnau, 2008).

Perinatal mortality has been reduced by scientific advances and improved healthcare quality for pregnant women and new-borns (Dallay, 2013; Koopmans et al., 2013). Nevertheless, between 20%–30% of pregnancies end in miscarriage worldwide (Meaney, Corcoran, Spillane, & O'Donoghue, 2017). Furthermore, the rate of foetal death was 18.4‰ of all births, representing 2.6 million foetal deaths worldwide in 2015 (Lawn et al., 2016). However, the literature establishes the possibility that these statistics are underestimated due to the under-registration of deaths. The social undervaluation of these losses and the lack of support given to parents could explain this under-registration (Flenady et al., 2014; Frøen et al., 2011).

Despite the significant psychological impact on parents and the prevalence of these losses, HCPs find the care of bereaved parents stressful and challenging and feel unprepared to support these parents (Martinez-Serrano, Palmar-Santos, Solis-Munoz, Alvarez-Plaza, & Pedraz-Marcos, 2018). Instead, HCPs tend to address *clinical* care, while e*motional* care is often disregarded (Ellis et al., 2016; Lee, 2012). They receive little or no training in providing care in the context of these losses, making it difficult for HCPs to address the emotional sphere (Nuzum, Meaney, & O'Donoghue, 2014). What is clear from the available literature is that the provision of care to these families is crucial to prevent negative short- and long-term outcomes and that HCPs need training to manage the attention given to these parents. This is especially the case for nurses and midwives, who are the reference professionals for parents in pregnancy loss care (Ellis et al., 2016; Gold, 2007; Martinez-Serrano et al., 2018).

Cochrane Collaboration published a systematic review about support for parents and their families following perinatal death (Koopmans et al., 2013). Due to the high loss-to-follow-up rate, the three identified trials could not be analysed. As a result, the authors of the review recommended that other designs should be used to inform practice (Ellis et al., 2016; Koopmans et al., 2013). No previous publications have systematically analysed the available evidence on the coping experiences of both women and men following perinatal loss. This qualitative review provides a rich account of these coping experiences and a more in-depth understanding of this complex phenomenon. The findings of this meta-ethnography provide a basis of evidence for nursing and midwifery clinical practice.

2 | THE REVIEW

2.1 | Aims

This qualitative review aims to synthesize the available body of qualitative work regarding how parents cope with perinatal loss.

2.2 | Design

We conducted a systematic review of qualitative studies using meta-ethnography to synthesize the studies with an inductive and interpretive analysis (Noblit & Hare, 1988). The review has been written in accordance with the eMERGe reporting guidance (France et al., 2019). The research question used to guide the search strategy was as follows: How do parents cope with perinatal loss?

2.3 | Search methods

A comprehensive systematic search strategy was undertaken in the PubMed, Scopus, CINAHL, PsychINFO, and Web of Science databases in July 2018. This search was complemented with supplementary searches involving reference checking and searching for cited articles.

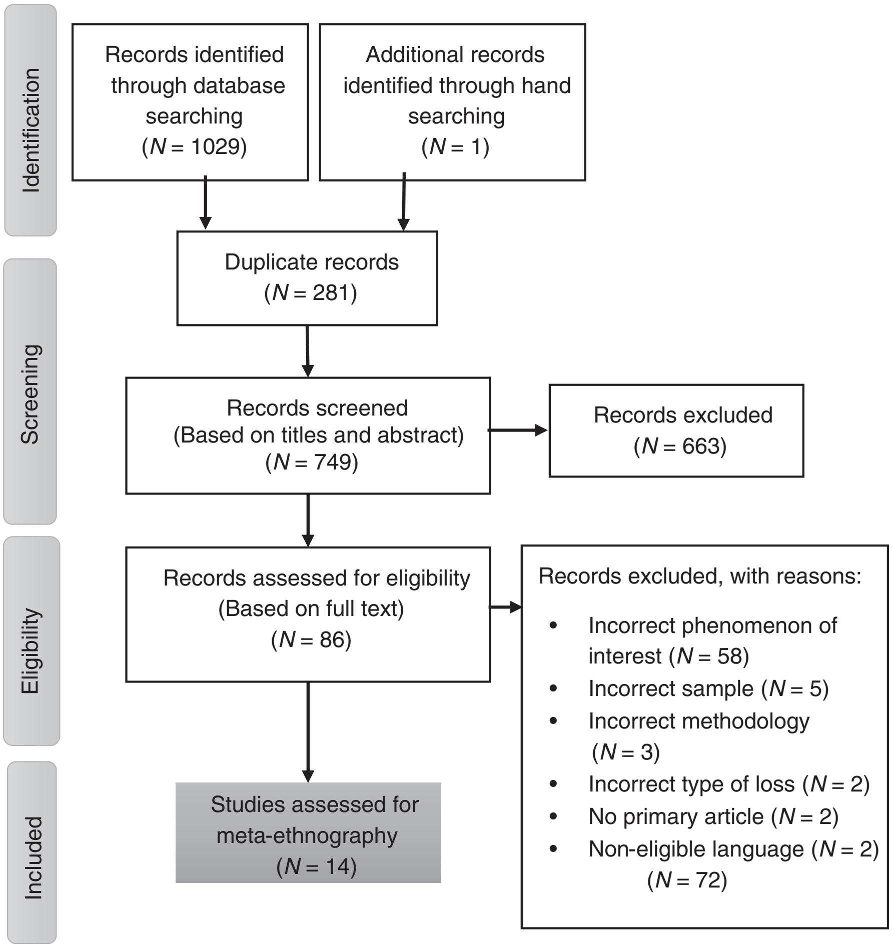
Search terms were developed from the research question using the SPIDER tool (File S1) (Cooke, Smith, & Booth, 2012). Medical Subject Headings, CINAHL descriptors and free terms were used as search terms. The Boolean operator "AND" was used to relate the search queries in SPIDER (terms in different columns). Truncations were employed to ensure a broad search. The limits selected in the databases were publication date (between 2013–2018) and language (English, Portuguese, and Spanish). We decided to set the start of the time range after the publication of the Cochrane systematic review (Koopmans et al., 2013).

Papers were included if they were original qualitative articles or mixed articles from which the qualitative results could be extracted published between 2013 and July 2018. They were focused on the experience of parents following perinatal loss. Inclusion was restricted to studies whose sample comprised mothers, fathers or parents and whose type of loss was miscarriage, TFA, foetal death, or neonatal loss. Grey literature, discussion or review papers and papers not in English, Portuguese, or Spanish were excluded.

2.4 | Search outcomes

Database searches yielded 1,029 records and supplementary searches provided one additional record. The selection process of the articles began with the elimination of 281 duplicate articles. The titles and abstracts of the retrieved papers (*N* = 749) were assessed against the inclusion and exclusion criteria. The full articles selected from the title and abstract screening (*N* = 86) were examined in relation to the inclusion and exclusion criteria. At this stage, 72 papers were excluded for not being relevant to the phenomenon of interest or because of the sample, methodology, type of loss, type of paper

FIGURE 1 PRISMA flowchart



or language. In both stages, the entire selection process was carried out individually by each author and in team sessions, the authors reached consensus. The final sample was 14 articles (Figure 1).

2.5 | Quality appraisal

Each primary study was appraised using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (QARI) (Joanna Briggs Institute, 2017) for evaluating qualitative research. Included articles were considered to have high quality with respect to their goals, designs, analyses, and results, providing useful knowledge on the topic (Table 1). The quality assessment was carried out in team sessions by all the authors.

2.6 | Data abstraction and synthesis

The interpretive meta-ethnographic method of Noblit and Hare (1988) was followed, which consists of seven steps: (1) getting started; (2) deciding what is relevant to the initial interest; (3) reading the studies; (4) determining how the studies are related; (5) translating the studies into one another; (6) synthesizing translations; and (7) expressing the synthesis. The studies were read independently by each author until all the authors were familiar with their contents (step 3). The primary articles were read and translated in alphabetical order by the surname of the principal author of the studies, ranking the first article as the richest in terms of data.

The main *first order* (participants' quotations) and *second order* (authors' interpretations) (Schütz, 1962) concepts were extracted across the full primary study by SFB and MJMF and recorded in a Microsoft Word table.

Using the constant comparison method (Strauss & Corbin, 1990) (step 4), different concepts were compared by SFB and MJMF in search of similarities and contrasts, which led to the formation of new concepts and the adoption of existing concepts. This was done by systematically and sequentially comparing concepts using the registered study characteristics (year, location, methodology, aim, size and type of sample, type of loss, data collection methods, and key findings) as context for the comparisons.

In step 5, SFB and MJMF organized the concepts in conceptual *piles* and then discussed and reorganized these *piles*. The juxtaposition of the first- and second-order constructions through reciprocal and refutational translations led to the development of *third-order constructions* (Schütz, 1962) by the authors (SFB and MJMF), which included a new understanding of the phenomenon. CC, independently audited the analytical coherence of the findings.

Finally, in step 6, all the authors independently developed a *storyline* of the phenomenon (Noblit, 2016). These overarching

TABLE 1 Quality assessment of included studies (Joanna Briggs Institute, 2017)

	Questions									
Article	1	2	3	4	5	6	7	8	9	10
Carolan and Wright (2017)	✓	✓	✓	✓	✓	✓	–	✓	✓	✓
Consonni and Petean (2013)	–	✓	✓	✓	✓	–	–	✓	✓	✓
Golan and Leichtentritt (2016)	✓	✓	✓	✓	✓	–	–	✓	✓	✓
Gopichandran et al. (2018)	✓	✓	✓	✓	✓	–	✓	✓	✓	✓
Kofod and Brinkmann (2017)	–	✓	✓	✓	✓	✓	–	✓	✓	✓
Lafarge et al. (2013)	–	✓	✓	✓	✓	–	✓	✓	✓	✓
Leichtentritt and Mahat-Shamir (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Leichtentritt and Weinberg-Kurnik (2016)	✓	✓	✓	✓	✓	✓	–	✓	✓	✓
Maguire et al. (2015)	–	✓	✓	✓	✓	–	–	✓	✓	✓
McGuinness (2015)	✓	✓	✓	✓	–	–	–	✓	✓	✓
Meaney et al. (2017)	✓	✓	✓	✓	✓	✓	–	✓	✓	✓
Nuzum et al. (2018)	✓	✓	✓	✓	✓	✓	–	✓	✓	✓
Pitt et al. (2016)	✓	✓	✓	✓	✓	✓	–	✓	✓	✓
Abdel-Razeq and Al-Gamal (2018)	✓	✓	✓	✓	✓	✓	–	✓	✓	✓

Abbreviations: ✓ Yes – Unclear ✗ No; Critical appraisal questions: (1) Is there congruity between the stated philosophical perspective and the research methodology? (2) Is there congruity between the research methodology and the research question or objectives? (3) Is there congruity between the research methodology and the methods used to collect data? (4) Is there congruity between the research methodology and the representation and analysis of data? (5) Is there congruity between the research methodology and the interpretation of results? (6) Is there a statement locating the researcher culturally or theoretically? (7) Is the influence of the researcher on the research, and vice-versa, addressed? (8) Are participants, and their voices, adequately represented? (9) Is the research ethical according to current criteria or, for recent studies, and is there evidence of Research Ethics Committee approval by an appropriate body? (10) Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

explanations were then merged, discussed, and used to generate hypotheses to produce the *line of argument* synthesis (Atkins et al., 2008; France et al., 2019).

The Confidence in the Evidence from Reviews of Qualitative research (CERQual) approach was used to show the degree of confidence in the review findings (Lewin et al., 2015). CERQual involves an assessment of the review findings in terms of four components: methodological limitations, coherence, relevance, and adequacy of data (File S2).

3 | RESULTS

An overview of the 14 included studies is given in Table 2. The sample sizes of the studies ranged from 8–59 participants. Research was primarily conducted in Israel, Ireland, the United States of America, India, Jordan, Brazil, the United Kingdom, Denmark, and Australia. Ten articles featured women; one article had men as participants and three studies used couples as participants. The most common type of loss in the studies was TFA, followed by stillbirth, neonatal death and miscarriage. Interpretive research designs were more common than descriptive designs. Interviews, both semi-structured and in-depth, were used to collect the data.

The analysis revealed the line of argument *Staying afloat in the storm*. This metaphor represents the coping experience of parents following perinatal loss. Once the loss occurs, an emotional storm is triggered that parents must weather. What they use to stay afloat symbolizes the coping strategies. These strategies may vary throughout their grieving journey. The five themes that emerged were searching for the meaning of the loss, connecting with the baby, talking about the experience, looking to the future, and avoidance (Table 3). The CERQual assessment showed low confidence in talking about the experience and looking to the future, since these strategies were present in few studies. Searching for the meaning of the loss, avoidance and connecting with the baby showed moderate confidence, meaning it is likely that they reasonably represent parents' coping experiences following perinatal loss (File S2). Below, the themes are presented accompanied by quotations extracted from the articles, indicating if the quotation is from a mother or father.

3.1 | Searching for the meaning of the loss

Mothers searched for the meaning of the loss to make sense of and gain control over the chaos that the loss generated rather than as a mechanism to satisfy or tolerate the pain (Carolan & Wright, 2017). When mothers did not obtain an objective response from the HCPs about the cause of the loss (Gopichandran, Subramaniam, & Kalsingh, 2018), some tried to make sense of their loss through religion (Consonni & Petean, 2013). The causes they found in religion oscillated between a benevolent divine purpose or divine punishment (Abdel-Razeq & Al-Gamal, 2018; Carolan & Wright, 2017; Consonni & Petean, 2013; Maguire et al., 2015). In Indian (Gopichandran et

TABLE 2 Paper characteristics

Authors (year) location	Methodology	Aim	Sample	Type of loss	Data collection methods	Key findings
Carolan and Wright (2017), USA	Phenomenology	To perceive and describe the experience of miscarriage of women of advanced maternal age	10 women	Miscarriage	Interview + Ecomap	Women experience miscarriage from a physical, emotional, temporal, and social context that includes intense loss and grief, having a sense of otherness, a continuous search for meaning, and feelings of regret and self-blame.
Consonni and Petean (2013), Brazil	Qualitative descriptive exploratory study	To investigate the grieving experiences of women who underwent TFA	10 women	TFA	Semi-structure interview	Mothers sought explanations and meanings for the loss, with religious responses and self-blame being very frequent. The mothers were and continued to be linked to their children; the TFA, although being a choice to minimize the pain of an inevitable loss, did not spare the women from experiences of great suffering.
Golan and Leichtentritt (2016), Israel	Phenomenology	To examine the meaning that women who experience SB ascribe to their loss in general and to the lost figure in particular.	10 women	SB	In-depth interviews	For women, the lost figure and the loss in general engender ambiguity both internally and externally, in the women's social environment.
Gopichandran et al. (2018), India	Qualitative research methods	To explore the social, emotional, and psychological impact of SB on women and their families in the Indian context.	8 women	SB	In-depth interviews	Women who experienced SB were frustrated when they could not find the cause and blamed various people in their lives. Women and their families perceived poor quality of services provided in the health system and reported that the HCPs were inconsiderate and insensitive. Coping mechanisms include: isolation, immersion in work, placing maternal love on other children, the anticipation of next pregnancy, and religiosity.
Kofod and Brinkmann (2017), Denmark	Qualitative study	To analyse how grieving the loss of an infant in contemporary Danish culture is experienced, interpreted, and enacted	13 couples	SB and neonatal death	In-depth semi-structured interviews	A normative ambivalence regarding the status of loss and the expression of mourning, built on the basis of cultural standards, is suggested. Grieving the loss of an infant requires a constant balancing in this ambivalent normative landscape.
Lafarge et al. (2013), UK	IPA	To examine the coping strategies women use both during and after a TFA procedure.	27 women	TFA	Qualitative interview	The coping strategies of women after TFA are: Remembering the baby, receiving and providing emotional support, avoidance behaviors and looking to the future. Women mostly used adaptive coping strategies but reported inadequacies in aftercare, which challenged their resources.
Leichtentritt and Mahat-Shamir (2017), Israel	Qualitative hermeneutic methodology	To reach an interpretive understanding of the continuing bond experience among mothers who underwent TFA.	28 women	TFA	In-depth interviews	The results highlight two themes: (a) strategies for relinquishing connection with the baby and (b) strategies for maintaining a postdeath relationship.
Leichtentritt and Weinberg-Kurnik (2016), Israel	Phenomenology	To examine the experience of Israeli fathers after TFA	17 Men	TFA	In-depth semi-structured interviews	The results indicate that men's experiences in this arena are socially constructed and limited by gender roles and expectations. The revealed themes address: (a) the lack of a socially constructed terminology; (b) the unclear definition of the feticide experience; (c) men's sense of obligation to protect themselves and others from the procedure and its ramifications, and (d) the policies and regulations used to exclude men from the feticide experience, and the strategies they use to exclude themselves.

(Continues)

TABLE 2 (Continued)

Authors (year) location	Methodology	Aim	Sample	Type of loss	Data collection methods	Key findings
Maguire et al. (2015), USA	Grounded theory	To assess how women define and experience grief over TFA and how this grief changes over time.	19 women	TFA	Three interviews at 1–3 weeks, 3 months, and 1 year	Themes that contributed to grief include self-blame for the diagnosis, guilt around the termination decision, social isolation related to discomfort with abortion, and grief triggered by reminders of pregnancy.
McGuinness (2015), Ireland	Focused-ethnography	This article discusses the findings from a qualitative research study carried out with mothers following late miscarriage, stillbirth, or neonatal death.	27 women	Late miscarriage, SB, and neonatal death	Face-to-face interviews	The findings describe that the immediate postnatal period for bereaved mothers holds memories that will last forever and may influence the grieving process. It highlights the importance of pregnancy to the majority of mothers and re-affirms the important role of a mother spending time with her baby involving husbands and partners and looking after other children. Normal grief stages were evident in the narratives of the bereaved mothers. It is important that mothering is acknowledged, supported, and validated following the loss of a baby
Meaney et al. (2017), Ireland	IPA	To gain detailed insight into their expectations of pregnancy and their experience of miscarriage diagnosis and management	10 women + 6 men	Miscarriage	Semi-structured interview	There are six superordinate themes in relation to the participant's experience of miscarriage: acknowledgement of miscarriage as a valid loss, misperceptions of miscarriage, the hospital environment, management of miscarriage, support and coping, reproductive history and implications for future pregnancies
Nuzum et al. (2018), Ireland	IPA	To explore the lived experiences and personal impact of stillbirth on bereaved parents	12 women + 5 men	SB	Semi-structured in-depth interviews	Stillbirth had a profound and enduring impact on bereaved parents. Four superordinate themes relating to the human impact of stillbirth emerged from the data: maintaining hope, importance of the personhood of the baby, protective care, and relationships (personal and professional). Bereaved parents recalled in vivid detail their experiences of care following diagnosis of stillbirth and their subsequent care. The time between diagnosis of a life-limiting anomaly or stillbirth and delivery is highlighted as important for parents as they find meaning in their loss.
Pitt et al. (2016), Australia	Thematic analysis	To provide an in-depth account of women's embodied experiences of prenatal diagnosis and TFA	59 women	TFA	In-depth interviews	Two key themes are presented below: Transitioning embodiment, and vulnerable bodies in comfortable spaces.
Abdel-Razeq and Al-Gamal (2018), Jordan	Phenomenology	To provide an in-depth and rich description of the living experience of the bereaved mothers after losing newborns and analyse how bereaved mothers reconstruct the meaning of losing a newborn	12 women	Neonatal death	Semi-structured interviews	Three main themes emerged from the analysis: longing and grieving, as natural emotional responses to the loss; adaptive work of coping, as the mothers internalized meanings to cope with their loss; and moving forward but with a scar, as the mothers moved on with their lives while they carried the unforgettable memories of the newborns" death experience.

Abbreviations: IPA, interpretative phenomenological analysis; SB, stillbirth; TFA, pregnancy termination for foetal abnormality; UK, United Kingdom; USA, United States of America.

TABLE 3 Metaphor, emerged themes and main stratified results

	"Staying afloat in the storm"				
	Searching for the meaning of the loss	**Talking about the experience**	**Looking to the future**	**Avoidance**	**Connecting with the baby**
Parents gender	♀	♀	♀	⚤	⚤
Type of loss	MS, TFA, SB, ND	MS, TFA, SB	TFA	MS, TFA, SB, ND	MS, TFA, SB, ND
Cultural context	USA, Brazil, India, Jordan	USA and India	UK	USA, Brazil, Israel, India, UK, Ireland, Jordan	Denmark, UK, Israel, Ireland, Australia
Key aspects	Sources: HCPs, religion, superstitions, blame (husband/family, HCPs and themselves) and medical reasons.	Talking with other causes: Know other cases of loss, establish social connections, reduce social isolation. Talking to their social circle is comforting and allows reciprocal support. Participating in support groups produces ambivalent feelings.	To allow to close stages of the grieving process; to search for positive aspects of the loss	How: Avoid contact with others and be distracted (with the company of their social circle, performing routine activities, returning to work, playing the role of mother with other children, taking care of others, changing their routine, and disconnecting from the baby). Why: To protect themselves, not to worry about their social environment and to avoid the reaction of others. Consequences of avoidance: Storing of emotions, tension in the couple, ignorance of the process and social isolation.	They use tokens and symbolic acts to establish a bond with the baby and to legitimize the loss. Tokens: a pregnancy diary, memory box, photographs. Symbolic acts: lighting a candle, writing a post, getting a tattoo, planting a tree, using the name of their baby with the next child, spending time with the baby, talking about the baby, visiting places of remembrance, and attending acts of remembrance.
Articles	Carolan and Wright (2017); Consonni and Petean (2013); Gopichandran et al. (2018); Maguire et al. (2015); Abdel-Razeq and Al-Gamal (2018)	Carolan and Wright (2017); Gopichandran et al. (2018); Maguire et al. (2015)	Lafarge et al. (2013)	Carolan and Wright (2017); Consonni and Petean (2013); Golan and Leichtentritt (2016); Gopichandran et al. (2018); Lafarge et al. (2013); Leichtentritt and Mahat-Shamir (2017); Leichtentritt and Weinberg-Kurnik (2016); Maguire et al. (2015); Nuzum et al. (2018); Pitt et al. (2016); Abdel-Razeq and Al-Gamal (2018)	Kofod and Brinkmann (2017); Lafarge et al. (2013); Leichtentritt and Mahat-Shamir (2017); McGuinness (2015); Meaney et al. (2017); Nuzum et al. (2018); Pitt et al. (2016)

Abbreviations: (♀), women and men; (⚤), women; MS, miscarriage; ND, neonatal death; SB, stillbirth; TFA, pregnancy termination for fetal abnormality; UK, United Kingdom; USA, United States of America.

al., 2018) and Arabic (Abdel-Razeq & Al-Gamal, 2018) cultures, some mothers took shelter in or renounced religion, depending on whether the answers provided by religion were comforting or not in their grieving process:

> After the surgery they told me that the baby had passed away before the surgery. So, that kind of helped because I didn't feel like we did it or the doctor did it… I felt, like, God did it and that was what He wanted.
>
> Mother (Maguire et al., 2015).

Other resources used were superstition and blaming the husband and family, HCPs and themselves (Gopichandran et al., 2018; Maguire et al., 2015). Contrarily, mothers with a high educational level looked for meaning in medical causes (Gopichandran et al., 2018; Maguire et al., 2015):

> We used to live in a haunted house previously. I got pregnant when I was living there. I think that is the reason for this baby's death. Mother (Gopichandran et al., 2018).

3.2 | Talking about the experience

When mothers shared their loss with others, they discovered cases of loss that they did not know of beforehand. They realized that they were not the only ones that had experienced this situation. Indeed, they established a social connection and felt relieved of the burden of social isolation (Maguire et al., 2015):

> […] [If you] start to tell people about what you experience [then] they would say, “Oh, yeah. I know. We had one baby before and we lost [it too].
>
> Mother (Maguire et al., 2015).

For mothers, talking with their close circle was comforting (Carolan & Wright, 2017; Gopichandran et al., 2018). Specifically, the contact of mothers with others with similar experiences facilitated reciprocal support and reduced isolation (Lafarge, Mitchell, & Fox, 2013; Maguire et al., 2015). As one mother said:

> My mother-in-law was a huge influence. She really helped me because she experienced a miscarriage; she suffered a loss farther along than I was […]. So, when it happened I was more comfortable talking to her.
>
> Mother (Carolan & Wright, 2017).

Some mothers participated in online support groups, which caused ambivalent feelings based on their mood when reading the comments; some joined face-to-face support groups, which allowed them to situate themselves in their own healing process, although in the long run, it was not helpful to participate in support groups, which included people who had experienced a variety of losses (Lafarge et al., 2013).

> Sometimes I found reading other people's accounts on the forum unhelpful as I felt guilty for not feeling as emotional or terrible as they did, but in time I was able to feel that this was positive, that I was coping and mentally strong.
>
> Mother (Lafarge et al., 2013).

3.3 | Looking to the future

In Lafarge et al. (2013), a tool that mothers used to cope with TFA was looking to the future. This strategy allowed mothers to achieve closure or move through the stages of the grieving process. For example, the funeral provided closure regarding the physical aspect of the loss. Looking to the future was also linked to searching for positive aspects in their experiences, such as by rationalizing, carrying out actions of good will and focusing on unresolved issues:

> As closure was provided through the funeral, postmortem, due date passing, the first birthday, now it is time to move on with our lives.
>
> Mother (Lafarge et al., 2013).

3.4 | Avoidance

In 11 papers, parents reported using avoidance strategies to deal with their loss and to protect themselves, since the pain of reliving the loss was avoided and blocked (Lafarge et al., 2013; Leichtentritt & Mahat-Shamir, 2017). Parents distracted their thoughts by mingling with their social circle, performing routine activities or changing their previous routine and returning to work (Abdel-Razeq & Al-Gamal, 2018; Consonni & Petean, 2013; Gopichandran et al., 2018; Lafarge et al., 2013). Specifically, mothers were distracted by playing the role of mother with other children (Gopichandran et al., 2018; Lafarge et al., 2013), whereas men took care of others (Leichtentritt & Weinberg-Kurnik, 2016):

> When you are busy caring for others… you also overlook yourself.
>
> Father (Leichtentritt & Weinberg-Kurnik, 2016).

Some parents did not talk about the loss and did not relate to their social environment because they wanted to avoid the reactions of others and did not want to worry their social circle with manifestations of sadness (Consonni & Petean, 2013; Gopichandran et al., 2018; Lafarge et al., 2013; Maguire et al., 2015; Pitt, McClaren, & Hodgson, 2016). They also did not go to medical consultations (Pitt et al., 2016):

> Women like me who have lost their babies are considered inauspicious. They (society) will talk badly if we even touch their normal babies. So, I do not go for any social functions.
>
> Mother (Gopichandran et al., 2018).

Culturally, some parents avoided expressing their grief due to the lack of social acceptance of these losses (Golan & Leichtentritt, 2016; Leichtentritt & Mahat-Shamir, 2017). In early losses, this avoidance was exacerbated, since expressions of mourning are prohibited in some social environments (Kofod & Brinkmann, 2017):

> People didn't want to hear… it's easier for everyone not knowing, not hearing… as if it just disappeared.
>
> Mother (Leichtentritt & Mahat-Shamir, 2017).

Some parents also used strategies to disconnect from the baby, such as denying the existence of the child, not keeping memories and blocking thoughts and feelings about the baby (Carolan & Wright, 2017; Lafarge et al., 2013; Leichtentritt & Mahat-Shamir, 2017; Pitt et al., 2016). Some mothers even questioned the biological or genetic connection between them and the baby (Leichtentritt & Mahat-Shamir, 2017):

> You convince yourself it is not really your genes… that genetics-wise you are okay. You make up stories which help you cope; you start believing them… that it's not yours.
>
> Mother (Leichtentritt & Mahat-Shamir, 2017).

The use of avoidance strategies led to the suppression of emotions and the emergence of tensions in the couple due to differences in coping between the sexes (Gopichandran et al., 2018; Lafarge et al., 2013; Nuzum, Meaney, & O'Donoghue, 2018). Attempts not to remember, see, talk, or experiment generated *ignorance* about certain aspects of the loss in parents. This meant that some of them later regretted not being present during the process (Leichtentritt & Mahat-Shamir, 2017):

> I think [partner] had a lot closer connection to him than I had, because I suppose I see my time with him as, when he was born to when he was buried… I remember thinking he's my son but he's not (very upset).
>
> Father (Nuzum et al., 2018).

Additionally, parents experienced social isolation both because of the use of this strategy and because of the taboo that surrounds these losses (Carolan & Wright, 2017; Lafarge et al., 2013; Meaney et al., 2017).

3.5 | Connecting with the baby

Parents used resources to establish a bond with their child, which allowed them to maintain a connection with their child and legitimize their loss, even though it was painful. This was especially important in early losses, since these are ambiguous losses that are socially invisible, unknown, and not acknowledged (Leichtentritt & Weinberg-Kurnik, 2016; Meaney et al., 2017):

> But the miscarriage itself, I'd say it was until then…and the whole discussion became a very public thing…it was only at that stage that I started to move on from it and that would have been five years, five years later and it was always something that would of upset me… it is hard to know what you are grieving for in a way because it is fleeting, you know the whole experience of being pregnant and then not being pregnant and thinking if I didn't remember this baby then who would.
>
> Father (Meaney et al., 2017).

Parents used tokens such as a pregnancy diary, especially in early losses where material memories were scarce, memory boxes and photographs (Kofod & Brinkmann, 2017; Lafarge et al., 2013; Leichtentritt & Mahat-Shamir, 2017; Pitt et al., 2016). Parents looked at these tokens privately, though in some cases, they shared them with their social environment so their baby would be socially acknowledged (Kofod & Brinkmann, 2017; Pitt et al., 2016). For example, Lafarge et al.'s (2013) study, conducted in the UK, showed that even for men, the process of making a memory box was therapeutic because the time parents put into making the box was time taken to remember the baby:

> My partner built a little box to put little mementos into. It took him many months to complete it as I think it was his time to think about the son he had lost.
>
> Mother (Lafarge et al., 2013).

Some parents performed rituals that connected them to the child. These symbolic acts involved lighting a candle, writing a post on a forum or doing something more permanent, like getting a tattoo or planting a tree (Lafarge et al., 2013; Leichtentritt & Mahat-Shamir, 2017; Nuzum et al., 2018). The name of the child also connected it to them, as in some cases the parents were able to use it with the next child (Leichtentritt & Mahat-Shamir, 2017; Nuzum et al., 2018). The performance of these rituals was culturally conditioned. In Jewish culture, parents could not enact public connection rituals, since mourning traditions are not accepted for early pregnancy losses (Leichtentritt & Mahat-Shamir, 2017):

> [I feel close to him in the graveyard] I just prefer it if there was no one else in the graveyard. I would definitely only feel it when I'm there on my own with him.
>
> Father (Nuzum et al., 2018).

Keeping the memory of the baby alive through talking about it in their social environment, visiting places of remembrance, and performing acts of remembrance provided mothers with closure and social acknowledgement of the baby (Lafarge et al., 2013; McGuinness, 2015). In advanced losses, spending time with the baby after birth favoured the existence and reinforcement of the bond (McGuinness, 2015; Nuzum et al., 2018):

> I wanted to take him home. I wanted as much time with him as we could… suppose we knew we wouldn't have long with him before we buried him.
>
> Father (Nuzum et al., 2018).

4 | DISCUSSION

The synthesis of the qualitative evidence revealed in-depth how parents cope with perinatal loss. From the 14 included papers, we identified the overarching metaphor *Staying afloat in the storm* based on five themes that show the coping strategies used by parents after these losses. This metaphor symbolizes the emotional storm that these losses represent to parents and how they cope using different strategies to stay afloat.

For this discussion, the Multicultural Model of Coping after Pregnancy Loss (MMCPL) (Van, 2012) and the Motivational Theory of Coping (MTC) (Skinner, Edge, Altman, & Sherwood, 2003) were found to be useful. We have merged these two theories with findings from different contexts and particularities. This has allowed us to present a deeper and more solid understanding of the coping experiences of parents following perinatal loss.

Van (2012) proposed the MMCPL, subsequently expanded (Fernández-Basanta, Van, Coronado, Torres, & Movilla-Fernández, 2019), which establishes connectedness as a facilitator of coping, while disconnectedness is the central concept that inhibits coping. Applied to our results, connectedness could be associated with the connectivity with the baby, the search for the meaning of the loss and talking about the experience, whereas disconnectedness could be associated with avoidance.

Connectedness captures the conditions that facilitate or constrain coping with grief and related responses after pregnancy loss. According to the model, women who connect with their social environment tend to cope with their grief more effectively than women who do not. Connectedness exists between them and the people they know and have a personal connection with (Van, 2012).

Although the MMCPL was designed based on the coping experiences of women after a pregnancy loss, it fits with our aim. To fulfil this aim and to deepen and provide an improved theoretical framework, we use the MTC (Skinner et al., 2003). In this model, searching for the meaning of the loss, talking about the experience and connecting with the baby are considered adaptive coping strategies, while avoidance stands out as a maladaptive strategy. The experiences of connectedness/confrontation and disconnectedness/avoidance are a back-and-forth process and are not mutually exclusive.

Grief is a universal human reaction to the loss of a loved one, but social and cultural contexts influence the way grief is manifested and the coping strategies used (Brownlee & Oikonen, 2004; Dallay, 2013; Fenstermacher & Hupcey, 2013; Van & Meleis, 2003). Perinatal losses are still considered taboo losses and are made invisible by social and health environments and some parents consequently perceive a lack of social and health support (France, Hunt, Ziebland, & Wyke, 2013; Heazell, 2016). Furthermore, the literature supports the existence of a *grief hierarchy* (Kofod & Brinkmann, 2017; Van & Meleis, 2003), where grief expressions are accepted depending on the type of loss. For instance, in early losses, suffering is less socially accepted and parents may be forced to constantly negotiate the importance of the loss and to perform actions that legitimize the existence of their pregnancy/baby (Kofod & Brinkmann, 2017; Leichtentritt & Weinberg-Kurnik, 2016; Meaney et al., 2017; Sawicka, 2016). Logsdon and Davis (2003) affirm that for social support to be considered useful, it must fulfil the expectations of the one receiving the support and should come from a person of trust. When these conditions are not in place, the person may leave their needs unfulfilled instead of receiving support from another source.

In some cultures, social context and religion establish that femininity is synonymous with motherhood, which means that when childlessness occurs, a woman is deprived of her gender identity and some mothers may experience social isolation (Gerber-Epstein, Leichtentritt, & Benyamini, 2009). However, religion can also have a protective effect for mothers, since it helps them make sense of the loss and cope with bereavement (Abdel-Razeq & Al-Gamal, 2018; Roberts & Lee, 2014). Our results show that when parents do not get answers that allow them to make sense of the loss, they may look to other resources, such as religion or superstition.

Looking to the future is a controversial strategy. In the MTC, it can be framed as an adaptive strategy, while in the MMCPL, it may belong to disconnectedness. Though this strategy represents a low-confidence finding, the controversy regarding it can be explained by the stage in the grieving process and the type of loss. The advanced stages in the grieving process, where the pain intensity is lower, may favour the emergence of strategies such as rationalization or the search for positive aspects of the loss (Dávalos et al., 2008). However, in TFA, the loss is *voluntary* and involves decision-making. This decision-making may involve visualizing and rationalizing death as an escape from suffering (Boyraz, Horne, & Waits, 2015).

The metaphor of *Staying afloat in the storm* symbolizes how parents cope with perinatal loss. Our findings showed that the five strategies are often conditioned by cultural, social, and individual factors, such as the taboo that surrounds these losses, the social expectations that condition grief expression, the lack of response from HCPs, the lack of social acknowledgment of the loss, the type of loss, and the stage in the grieving process. Giving emotional attention to these parents requires the provision of transcultural nursing care based on knowledge of the cultural context and background of the parents (Leininger, 1995). The provision of resources to prove the existence of the pregnancy/baby and of spaces where parents can express their grief is fundamental to legitimizing the loss (Martel & Ives-Baine, 2018; O'Leary & Warland, 2013). Therefore, care should contemplate an individual approach adapted to the needs of parents and not the creation of care protocols that generate barriers to the provision of comprehensive and individualized care. Nurses and midwives should lead out in the emotional care of parents experiencing perinatal loss by being the reference professional for parents (Capitulo, 2005), though the involvement of all HCPs is required. This study contributes to deepening the knowledge of the coping of parents following perinatal loss, which is important for developing nursing care in these situations. Furthermore, the MMCPL (Van, 2012) was confirmed and expanded, since our results develop in depth the factors that condition the use of coping strategies.

4.1 | Strengths and limitations

This study's strengths lie in its comprehensive search strategy. This strategy ensured that the review is based on studies conducted in geographical contexts with unique and defining characteristics and on various types of losses, providing a more complete vision of the phenomenon. In addition, the studies were evaluated using the QARI criteria (Joanna Briggs Institute, 2017) and the review findings were assessed with CERQual (Lewin et al., 2015), confirming their transparency and reliability. This process improves the trustworthiness and applicability of the results in the clinical setting, decision-making and future research.

One of the weaknesses of this review is related to the composition of the samples. According to the literature (Cacciatore, Erlandsson, & Rådestad, 2013) and the included studies, men are underrepresented. This makes it difficult to describe the male coping experience. Indeed, the profile of the informants in some of the studies was homogeneous, generating a limited view of the phenomenon. Another limitation refers to the generalization of the findings to countries outside western contexts. Taboos surrounding perinatal loss, social expectations regarding expressions of grief and the HCP-parent relationship can affect parents' coping experiences. In addition, meta-ethnography analysis can be challenging: even though the studies met the criteria to be included in this review, their objectives may not be in line with ours. Nevertheless, the meta-ethnography found both similarities and differences contributing to the refutational findings (i.e., religion).

The methodology used has been criticized for eliminating the original findings of the unique experience and extracting them from their context (Sandelowski, Barroso, & Voils, 2007). Despite this limitation, the goal of meta-ethnography is not to summarize or aggregate information but to synthesize studies through an inductive and interpretive analysis, taking into account the context of the studies (Bondas & Hall, 2007). The findings of this meta-ethnography are novel and offer a greater level of understanding of parents' coping experience following perinatal loss.

5 | CONCLUSION AND IMPLICATIONS

The findings revealed five coping strategies used by parents following perinatal loss. The overarching metaphor symbolizes the emotional storm that the loss represents and the strategies that parents use to stay afloat during it, influenced by cultural, social, and individual factors. Understanding these coping experiences may improve the knowledge of HCPs in the provision of care to these parents. This meta-ethnography can inform nurse and midwife evidence-based practice by showing the importance of coping knowledge and care needs in the context of perinatal loss and by promoting the design and implementation of emotional care strategies.

To expand knowledge of the experience of perinatal loss, in-depth research should approach samples that include men as participants. In addition, further research on informants with heterogeneous profiles will provide richer views of the phenomenon.

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CONFLICT OF INTEREST

The authors state that there is no conflict of interest.

AUTHOR CONTRIBUTIONS

S.F.-B., M.-J.M.-F.: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; S.F.-B., C.C., M.-J.M.-F.: Involved in drafting the manuscript or revising it critically for important intellectual content; S.F.-B., C.C., M.-J.M.-F.: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; S.F.-B., C.C., M.-J.M.-F.: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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Supporting Information

- Keywords and Boolean operators (see Appendix 1)
- CERQual Evidence Profile (see Appendix 2)
- eMERGe Reporting guideline (see Appendix 3)

Third study - Involuntary Pregnancy Loss and Nursing Care: A meta-ethnography

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Review

Involuntary Pregnancy Loss and Nursing Care: A Meta-Ethnography

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Abstract: Healthcare professionals find the care of parents following an involuntary pregnancy loss stressful and challenging. They also feel unprepared to support bereaved parents. The challenging nature of this support may have a personal impact on health professionals and the care provided to parents. The aim of this meta-ethnography is to synthesise nurses' and midwives' experiences of caring for parents following an involuntary pregnancy loss. A meta-ethnography of ten studies from five countries was carried out. GRADE CERQual was assessed to show the degree of confidence in the review findings. An overarching metaphor, *caring in darkness*, accompanied by five major themes provided interpretive explanations about the experiences of nurses and midwives in caring for involuntary pregnancy losses: (1) Forces that turn off the light, (2) strength to go into darkness, (3) avoiding stumbling, (4) groping in darkness, and (5) wounded after dealing with darkness. Nursing staff dealt with organizational difficulties, which encouraged task-focused care and avoidance of encounters and emotional connection with parents. However, nurses and midwives might go beyond in their care when they had competencies, support, and a strong value base, despite the personal cost involved.

Keywords: caring; meta-ethnography; meta-synthesis; midwives; miscarriage; nurses; perinatal loss; qualitative research; stillbirth

1. Introduction

Involuntary pregnancy loss is a relatively common occurrence. The exact prevalence of these losses is difficult to estimate. Previous research establishes that between 20–30% of pregnancies end in miscarriage worldwide. The precocity of the event or the intoxication of records with induced abortion rates could make it difficult to estimate miscarriages [1]. Regarding stillbirth, an estimated 2.6 million babies were stillborn worldwide in 2015 [2]. However, these statistics do not represent the totality of losses, since it is estimated that less than 5% of stillbirths have death records. Nevertheless, these numbers show that it is very likely that health professionals will encounter a significant number of families who have experienced a pregnancy loss in a current or previous pregnancy [3].

Involuntary pregnancy loss has been defined as the spontaneous demise of a pregnancy [4]. In this meta-ethnography, we included miscarriages and stillbirths. Miscarriage is an unplanned pregnancy loss before 20–24 completed weeks [5], and stillbirth is the death of a foetus that has reached a birth weight of 500 g, gestational age of 22 weeks, or crown-to-heel length of 25 cm [6].

1.1. Background

Pregnancy loss generates a varied, dynamic, and highly individualized response in parents [7,8]. Some parents may feel guilt and shame, others might feel relief and hopeful about the future, and others still may feel ambivalent about pregnancy and loss [9]. While there is a significant body of studies focused on the experience of heterosexual women who experience a pregnancy loss, the impact of miscarriage and stillbirth on male partners has been largely overlooked in academic research [10,11]. Emotional expressions are usually scarce and hushed, but the impact on their health is significant, especially if they do not have the opportunity to grieve openly [12].

Professional support for parents experiencing the involuntary pregnancy loss is needed, and nursing staff are those who accompany parents during pregnancy losses [13]. This care should go beyond medical cure and should be based on the conception of the person as an indivisible entity that includes body, soul, and spirit [14]. For these reasons, nurses and midwives are the reference professionals for parents [13].

In practice, professionals find the care of bereaved parents stressful and challenging. Therefore, this support could be superficial and focused on medical tasks rather than caring for the whole person [13]. The challenging nature of this support may have a personal impact on nurses and midwives. Health professionals may be required to set aside their own emotional responses and to focus on the tasks demanded by their work context and parents [15].

The care of involuntary pregnancy losses has evolved from a model of denial and protection to open support. Nevertheless, current care in pregnancy losses is inconsistent [13]. In miscarriages, the emergency department is, frequently, the only opportunity for parents to receive formal support [16]. In stillbirths, the guidelines mainly focus on medical management, while emotional support is relegated to the judgment of each healthcare professional [17]. Healthcare occurs mostly in hospital settings, and the requirements of this context influence the care parents receive [18].

1.2. Theoretical Perspective

Caritative Caring Theory [19] may serve to understand the complexity and wholeness of the experience of nurses and midwives regarding the care provided to pregnancy losses.

Ontologically, a human being is conceived as an indivisible entity that includes body, soul, and spirit. The human being has a unique vision of the world as a result of individual experiences and, at the same time, is connected with the culture of the person. According to Eriksson [20], caring maintains and enables health and well-being.

The purpose of caring is to alleviate suffering and to promote health and life. The ethos of care includes caritas, love and charity, the respect of health professionals for the dignity of the person, and a strive for genuine communion and understanding of the unique human being. Therefore, caritative care is based on the relationship between the person who needs and hopes for care and the person who is caring through a genuine communion and understanding for the unique human being [19].

Caring communion is understood as an act of human sharing in a caring relationship. Caring does not only imply performing professional nursing duties but a motive. Professional caritative caring is a genuine mature attitude of responsibility, courage, and wisdom. Caritative caring involves an encounter in which suffering and caring humans are participants in their own lived worlds of experiences and wishes [20].

Parents' experience following an involuntary pregnancy loss has been addressed in the literature [21], but studies are scarce and there is a lack of theory from the nursing and midwifery care perspective. The aim of this meta-ethnography is to synthesise nurses' and midwives' experiences of caring for parents following an involuntary pregnancy loss.

2. Materials and Methods

Meta-ethnography is a method that involves knowledge synthesis to enrich human discourse by translating individual qualitative studies into one another, reinterpreting and transforming findings [22]. This study follows the seven phases of synthesis described by Noblit and Hare (1988) [22]: (1) getting started, (2) deciding what is relevant to the initial interest, (3) reading the studies, (4) determining how the studies are related, (5) translating the studies into one another, (6) synthesising translations, and (7) expressing the synthesis. This review has been written in accordance with the eMERGe meta-ethnography reporting guidance [23] (Table A1).

2.1. Search Methods

A comprehensive systematic search strategy was undertaken in the PubMed, Scopus, CINAHL, PsychINFO, and Web of Science databases in August 2019. To maximize coverage and to improve reliability [24], back-and-forth tracking and manual searches were conducted on the International Journal of Nursing Studies, Midwifery, Birth, Women and Birth, and Sexual & Reproductive Healthcare. The search was performed with no time limitations. The search strategy was constructed according to the phenomenon of interest (involuntary pregnancy loss), the purpose of the study or evaluation (care experiences), the sample (midwives and nurses), and the type of research (qualitative research). In each, search terms and medical subject headings were included. These terms were combined using the Boolean operators OR, AND, and NOT. Truncations were also employed to ensure a broad search.

Titles, abstracts, and full texts of original qualitative or mixed articles were examined, and those considered suitable according to the research objective were included. Inclusion was restricted to studies in which the sample comprised nursing staff and in which the type of loss was miscarriages and stillbirths. Papers not in English, Portuguese, or Spanish were excluded. The elaboration of search strategies was carried out by the first author.

2.2. Search Outcomes

Database searches yielded 742 records. Supplementary searches did not provide any additional records. The selection process of the articles began with the elimination of 281 duplicate articles. The titles and abstracts of 517 retrieved papers were assessed against the inclusion and exclusion criteria. Thirty-five articles were read in full and examined in relation to the inclusion and exclusion criteria. At this stage, 25 papers were excluded for sample reasons, interest phenomenon, type of loss, methodology, and type of paper. In both stages, the entire selection process was executed by S.F.-B. and H.L.-G., and in team sessions with M.-J.M.-F. and C.C., the authors reached consensus. The final sample was 10 articles (Figure 1).

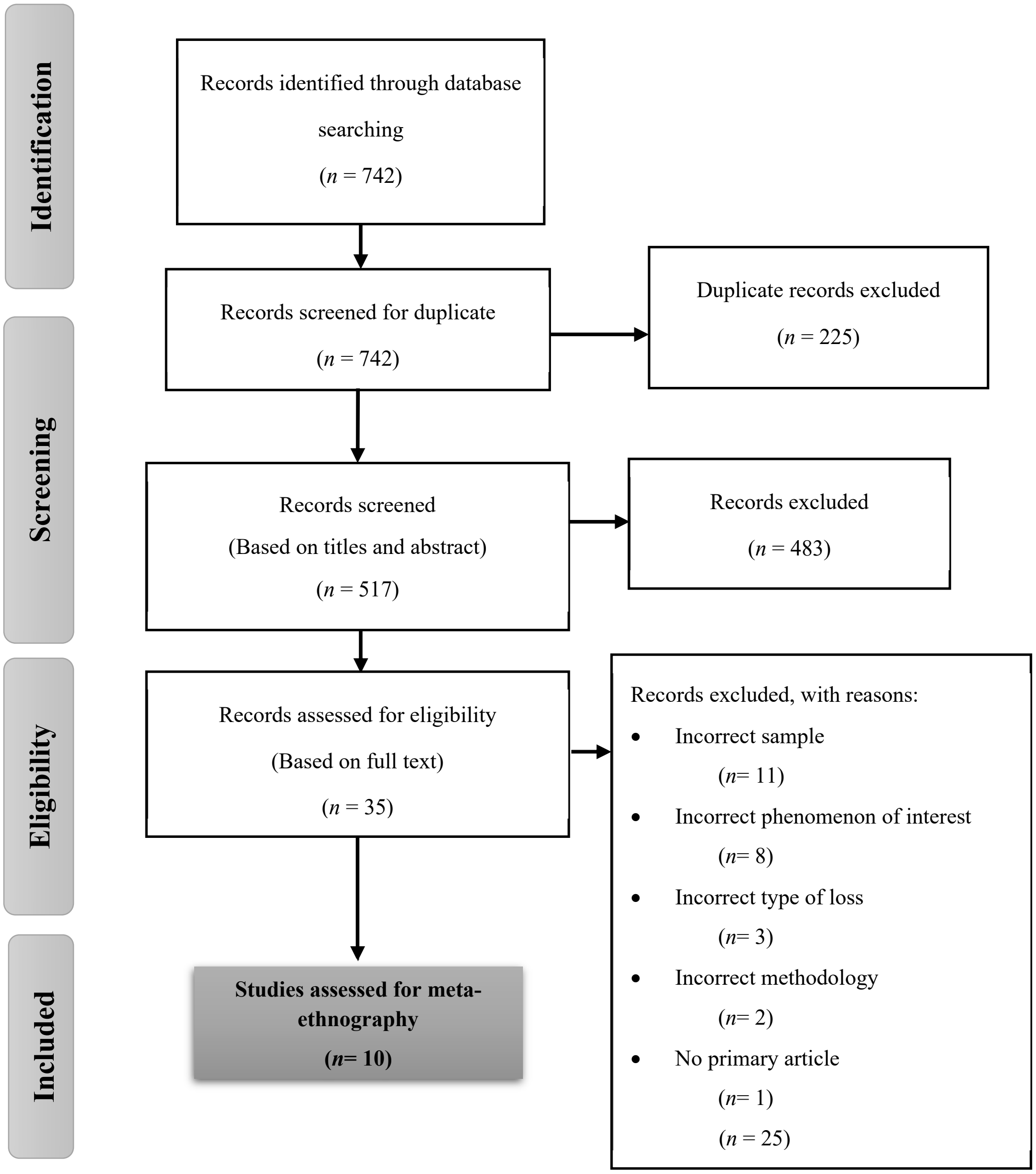

Figure 1. PRISMA flowchart.

2.3. *Quality Appraisal*

Each primary study was evaluated for quality using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (QARI) [25]. Included articles were considered to have high quality with regarding their goals, designs, analyses, and results, providing useful knowledge on the topic (Table 1). The quality assessment was performed in team sessions by S.F.-B., H.L.-G., and M.-J.M.-F.

Table 1. Quality assessment of included studies [25].

Article	Questions									
	1	2	3	4	5	6	7	8	9	10
Nallen (2006, 2007) † [26,27]	✓	✓	✓	✓	✓	✓	–	✓	✓	✓
Nash (2018) [28]	✓	✓	✓	✓	✓	✓	–	✓	✓	✓

Willis (2019) [29]	✗	✓	✓	✓	✓	✓	✗	✓	–	✓
McCreight (2005) [30]	✓	✓	✓	–	✓	✓	✗	✓	✓	✓
Beaudoin and Ouellet (2018) [31]	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓
Hutti (2016) [32]	–	✓	✓	✓	✓	✓	✓	✓	✓	✓
Roehrs et al. (2008) [33]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Martinez-Serrano et al. (2018) [34]	✓	✓	✓	✓	✓	✓	–	✓	✓	✓
Jones and Smythe (2015) [35]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Jonas-Simpson et al. (2010) [36]	✓	✓	✓	✓	✓	✓	–	✓	✓	✓

Abbreviations: ✓ yes – unclear ✗ no; critical appraisal questions: (1) Is there congruity between the stated philosophical perspective and the research methodology? (2) Is there congruity between the research methodology and the research question or objectives? (3) Is there congruity between the research methodology and the methods used to collect data? (4) Is there congruity between the research methodology and the representation and analysis of data? (5) Is there congruity between the research methodology and the interpretation of results? (6) Is there a statement locating the researcher culturally or theoretically? (7) Is the influence of the researcher on the research, and vice-versa, addressed? (8) Are participants and their voices adequately represented? (9) Is the research ethical according to current criteria, or for recent studies, is there evidence of ethical approval by an appropriate body? (10) Do the conclusions drawn in the research report flow from the analysis or interpretation of the data? [†] Two parts of the same study.

2.4. Data Extraction and Synthesis

Data extraction and synthesis was led by S.F.-B. Initial data extraction was carried out by S.F.-B. and subsequently discussed in team sessions. It involved the rereading of the included articles to describe each study’s aim, sample, method, type of loss, data collection methods, and key findings (Table 2) to provide context.

The primary articles were read and translated starting with the richest paper in terms of data [26,27] (step 3).

The first- and second-order [37] concepts were extracted across the full primary study by S.F.-B. and recorded in a Microsoft Word table. Using the constant comparison method (step 4), different concepts were compared by S.F.-B., T.B., and M.-J.M.-F. in search of similarities and contrasts, which led to the formation of new concepts and to the adoption of existing concepts. This was done by systematically and sequentially comparing concepts using the registered study characteristics (Table 2).

In step 5, the concepts were organized by S.F.-B. in conceptual piles and then the piles were discussed and reorganized by all the authors. It was determined that the studies met the criteria for reciprocal translation, so the first- and second-order constructions were placed, allowing the development of third-order constructions [37]. These new understandings were added to the reciprocal synthesis, building on the themes and metaphor (step 6). Five themes were developed in relation to preserving the studies’ key contents. All the authors agreed on the metaphoric themes and subthemes and on the overarching metaphor.

Table 2. Characteristics of included studies.

Authors (Year) Location	Methodology	Aim	Sample and Setting	Type of Loss	Data Collection Methods	Key Findings
Nallen (2006, 2007) Ireland [26,27]	Descriptive qualitative methodology	To explore midwives' views regarding the provision of bereavement support to parents affected by perinatal death	18 hospital midwives	Perinatal death	3 focus groups	The findings centred on 5 major themes which emerged from the data: role recognition, prerequisites to bereavement support, perceived barriers to bereavement support, coping strategies, and spiritual support.
Nash et al. (2018) Ireland [28]	Descriptive qualitative design	To explore the perceptions of midwives caring for women experiencing early pregnancy loss.	8 midwives *(maternity hospital)*	Early pregnancy loss *(<13 gestational week)*	Face-to-face semi-structured interviews	Themes identified were: "coping with the experience of early pregnancy loss", "compassionate care for women and midwives", and "what midwives found difficult".
Willis (2019) USA [29]	Descriptive qualitative methodology	To describe the experience of caring for women with a perinatal loss from the perspective of the nurse and to determine the extent to which the response to perinatal loss reflects a process.	9 labour and delivery nurses	Perinatal loss *(>20th gestational week to 1-month post birth)*	In-depth interviews	Several themes depicting nurses' experience were identified: struggling with emotions, carrying on in the moment, being present for the patient, expressing conflict, and taking care of self. A process was identified by nurses describing their response to perinatal loss. The process began with recognition of the loss and progressed through phases including the recognition of their emotional impact, connecting with the mother, dealing with emotions, acting professionally, preparing to return to work, and never forgetting the woman.
McCreight (2005) Ireland [30]	Not mentioned	To collaboratively explore with gynae nurses how they constructed meanings through their narratives in relation to the professionally defined but personally experienced events of pregnancy loss.	14 gynaecological nurses	Pregnancy loss	Semi-structured in-depth interviews	Emotion can be conceived of as a valid resource for professionals when integrated into a nurse's matrix of professional understandings. The study also demonstrates that value should be attached to emotional work which may not be fully visible, particularly for nurses working in gynaecological units. The emotional needs of nurses need to be fully acknowledged through recognition of the importance of managed emotion in the construction of professional knowledge.
Beaudoin and Ouellet (2018), Canada [31]	Fourth-generation constructivist evaluative method	To explore the factors influencing the practice of nurses with families experiencing perinatal loss in a secondary obstetric care centre in the Quebec region	7 obstetric nurses 3 managing nurses	Perinatal loss *(Death of a baby during the pregnancy (>20 gestational week) or a few days to a few weeks after childbirth)*	Semi-structured interviews	Five themes were identified: the quality of the relationship between the nurse and the bereaved family, the nurse's personal characteristics, the emotions felt by the nurse, work organization on the hospital unit, and the context in which nursing care is provided to families. These themes draw attention to the importance of building a solid relationship of trust with bereaved families in which honesty, empathy, human warmth, and listening have a central place.

Authors (Year) Location	Methodology	Aim	Sample and Setting	Type of Loss	Data Collection Methods	Key Findings
Hutti (2016) USA [32]	Not mentioned	To examine the experiences of, meaning for, and personal consequences for obstetric, emergency, and surgical nurses caring for women after foetal death and to determine how these nurses use Swanson's caring processes in providing such care.	28 obstetric, surgery, and emergency nurses	Foetal loss *(Included miscarriages (<20 gestational week) and stillbirths (from >20 gestational week to birth))*	Focus group	Swanson's caring processes were used as a way to describe the unified experiences of nurses who care for families after a perinatal loss. All nurses, regardless of specialty, used Swanson's caring processes, but they used them preferentially according to situational exigencies and level of rapport developed with each patient.
Roehrs et al. (2008) USA [33]	Descriptive qualitative methodology	To describe support needs and comfort level of labour nurses caring for families experiencing perinatal loss.	10 labour nurses	Perinatal loss *(between >20 gestational week and 7 days old)*	Online surveys and follow-up interviews	Nurses are generally comfortable but find it difficult to provide perinatal bereavement care. Strategies for coping include focusing on needed care, talking to nursing peers, and spending time with their own family members. Nurses take turns providing care depending on ''who is best able to handle it that day'' and prefer not to be assigned a labouring patient in addition to the grieving parents. Developing clinical expertise is necessary to gain the comfort level and the skills necessary to care for these vulnerable families. Orientation experiences and nursing staff debriefing would help.
Martinez-Serrano et al. (2018) Spain [34]	Hermeneutic-interpretative phenomenological approach	To explore the experiences of midwives regarding the attention given during labour in late foetal death.	17 hospital midwives and 1 primary health centre midwife	Late foetal death *(≥1000 g birth weight, ≥28* gestational week *and ≥35 cm body length)*	3 focus groups	Two main themes were identified: professionals for life not death and organizing the work without guidelines. Midwives felt that there is a lack of social awareness related to the possibility of antepartum death that keeps the mourning hidden and affects the midwives' practice during the late foetal death process. Midwives recognize difficulties in coping with a process that ends in death: organizations are not prepared for these events (not suitable rooms), and there is lack of training to cope with them and lack of continuity in the attention received by the parents when they are discharged.
Jones (2015) New Zeeland [35]	Hermeneutic interpretive phenomenology	To explore, understand, and appreciate the lived experience of midwives who have cared for parents whose baby has been stillborn.	5 self-employed midwives	Stillbirth *(the death of a baby before or during birth, from the 20 gestational week onwards, or weighing 400 grams or more at birth)*	Individual interviews	Two themes were identified. This paper focused on the theme "a pocketful of grief" which is made up of three subthemes: "shockwave", "self-protection", and "blameworthiness". The death of a baby is a significant event for the midwife providing care.
Jonas-Simpson	Exploratory qualitative	To explore their experience of caring for families whose babies	9 obstetrical nurses	Stillbirth *(>20 gestational week)*	In-depth face-to-face	Findings revealed that caring for bereaved families is a difficult yet meaningful experience valued by the nurses in this study.

Authors (Year) Location	**Methodology**	**Aim**	**Sample and Setting**	**Type of Loss**	**Data Collection Methods**	**Key Findings**
et al. (2010) Canada [36]	descriptive method	were born still or who died shortly after birth.			structured interview	Connecting and supporting bereaved families with their babies was identified as an essential part of practice. Understanding from colleagues as well as time and space for reflection were helpful. Nurses offered mothers anticipatory guidance and described thinking about the mothers, even years later.

Abbreviations: United States of America (USA).

The Confidence in the Evidence from Reviews of Qualitative research (CERQual) approach was used to show the degree of confidence in the review findings [38] (Table A2).

3. Results

The sample consisted of 10 qualitative primary articles. These studies were conducted in Ireland, the United States of America, Canada, Spain, and New Zealand; include a total of 129 nurses and midwives, predominantly in the hospital setting; and focused on stillbirth. Descriptive designs were more common than interpretive research designs. Semi-structured and in-depth interviews and focus groups were used to collect the data (Table 2).

A reciprocal synthesis, using the metaphor *caring in darkness* (Figure 2), provided interpretive explanations of the experiences of nurses and midwives in the care of involuntary pregnancy losses. This metaphor, accompanied by 5 themes, symbolizes the care experience of nurses and midwives in involuntary pregnancy losses. Unsupportive organizational culture, lack of preparation or knowledge, and an emotionally demanding care represented metaphorically by forces that turn off the light hindered the care. *Darkness* also represents the emotional state of parents following a pregnancy loss.

Going into darkness caused fear because healthcare professionals feel unprepared or unsupported, because they did not want to hurt parents even more, and because of the emotional implication involved. Despite that, having leader and peer support and guidance, previous experiences, and a strong value base encouraged nurses to care and to have the strength to go into darkness.

However, their motive to care may not be enough for many of them and they decided to avoid stumbling. Instead, the care provided was task-focused, in which encounters and emotional connections with parents were avoided. Those who went beyond the tasks tried to care in the best possible way despite the difficulties, groping in darkness. Wounded after dealing with darkness illustrates the consequences on nurses and midwives.

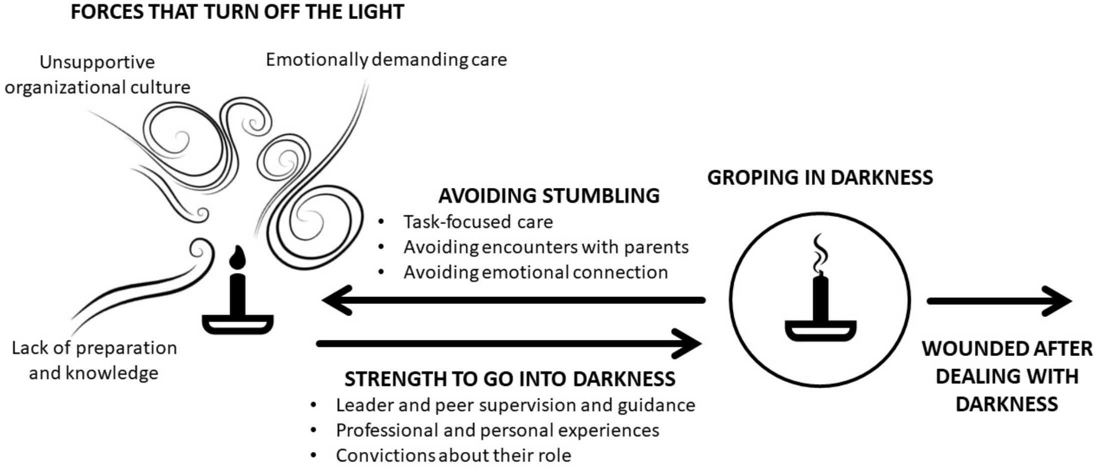

Figure 2. Caring in darkness.

The CERQual assessment showed high confidence in all the themes, meaning it is likely that they reasonably represent nurses and midwives' experiences in the care of involuntary pregnancy loss (Table A2).

3.1. *"Forces that Turn Off the Light"*

Unsupportive organizational culture, lack of knowledge and preparation, and emotionally demanding care were difficulties identified by nurses and midwives in the care of involuntary pregnancy losses. These were, metaphorically, forces that turned off the light and that left them in darkness.

3.1.1. Unsupportive Organizational Culture

Nurses and midwives found the health system unhelpful when it came to handling their own grief. This lack of backing was further exacerbated in early pregnancy losses [26–29]. A midwife referred to the abandonment of the health system as follows: *"Sometimes, you are left to deal with it on your own; especially, sometimes, it's on nights.... By the time you come back, sometimes, it just doesn't really emerge again."* Midwife [26,27].

Cost-efficiency policies may have contributed to nurses minimizing the emotional aspects of care to focus on physical aspects [30]. Beaudoin and Ouellet (2018) [31] reported that nurses sometimes had to carry out medical tasks that deprived parents of having moments of intimacy: *"Yes, (for) staying in the room with the parents, some are comfortable with that, but sometimes, they would rather be by themselves. I think that that can be harmful."*

The non-provision of whole care could also depend on the clinical setting where women were hospitalized. In the gynaecology service, mainly aimed at surgical pathologies, there was a tendency to marginalize the emotional aspects of work and to focus on the intervention treatment [30]: *"It made you come back to it, really think about what these women are going through, rather than just treating it as evacuation of uterus. We were a gynae unit on its own, and now, we're up here as a surgical on gynae unit. We have a few staff on the ward that would be surgically trained. They would have found it difficult at the beginning: some days you were busy and you didn't have time for people; they were just rushed in and rushed out again."* Nurse.

Nurses and midwives reported that the workload took time from talking and being with parents, complicating the establishment of a bond of trust with them [26,27,31]. Moreover, they could also be involved in the care of families with pregnancy loss while others simultaneously could not [26-28,32,33]. This situation required an emotional and behavioural adjustment with respect to listening, physical presence, and handling privacy and intimacy on the way from one room to another, which was hard for them [26–28,34]. *"The worst is having a labour patient at the same time, if you have a demise: being happy in one room and sad in another and you don't want to get the rooms wrong, and it is really hard."* Nurse [34]. Hutti et al. (2016) [32] reported that the development of that ability to adapt their emotional switches from care of the loss to another situation not so emotionally demanding depended on the idiosyncrasy of the services, being more difficult for delivery nurses due to such opposite emotions.

On the other hand, most services lacked exclusive spaces to take care of the loss. This situation favoured the contact of families with pregnancy losses with others who had not suffered any losses [28,31]. Furthermore, in early pregnancy losses, the lack of respectful places to leave the dead baby generated an emotional dilemma in nurses [30,31]. *"For my part, I would have liked... if there was a place for that instead of… going to weigh it in the same place as the placentas."* Nurse [31].

Administrative paperwork management, such as the baby name registration, autopsy, spiritual care provider, and emergency baptism, was also reported as a burden [31,33]. *"Some nurses don't mind taking care of patients with a loss; it's the paperwork that is so daunting!"* Nurse [33].

3.1.2. Lack of Preparation and Knowledge

Midwives and nurses reported a lack of preparation and knowledge regarding how to care for these parents, how to communicate with them, and how to behave besides a scarcity of tools to manage the emotional demands of parents and their own [26–35]. This caused them to feel insecure when caring [32].

"When I started working in the operating room, I was just put into a (perinatal loss) case, and I didn't know what to expect. I never really had any training on how to deal with the patient or with my own feelings. Unfortunately, sometimes, you are just thrown into things and you just learn." Nurse [32].

Some of them reported a lack of appropriate communication skills, and they found it difficult to know what, when, and how much to say; how to approach families; and how much to get involved [26–31,33–36]. *"My personal difficulty is this: what do you say to this woman? To me, everything seems banal."* [34].

A particularly controversial aspect was the lack of congruence regarding socially accepted behaviour with parents. This caused doubts about whether to show or contain their own emotions [26–31,33,35]. While some understood that emotional expression is a tool for establishing a bond of trust with the family, others felt that the emotional demonstration could further harm the parents, since the loss belonged to the parents [26,27,29–31,33,35].

Other situations that challenged nurses and midwives were communication with parents with recurring early losses, the inability to answer conclusively to parents' questions, the provision of information regarding practical aspects such as funeral arrangement, what happens next or who to contact, and the management of unexpected or unfamiliar behaviours or signs of exacerbated pain and suffering [26–28,31,32].

"They really don't recognize at all that they have had a baby, and they don't want anything to do with either the funeral arrangements or anything like that.... To accept that their way of dealing is also normal and natural for them, there can sometimes be a bit of conflict there." Midwife [26,27].

Unsupportive resources, training, or learning opportunities during the student stage and later as professionals were reported as caused by a lack of knowledge [28–31,33,34]. *"We have been taught a lot of techniques—a lot of theory—had a lot of practice of how to place such-and-such apparatus,... but nobody has taught us, or me personally during my career: nobody has taught me how to confront these cases and how I can help these people."* Midwife [34]. In the study of McCreight (2005) [30], carried out in the gynaecology service, some nurses noted that the contents of the training were incomplete by not meeting the emotional demands of the care.

Consequently, this led nurses and midwives to learn and care ad hoc, where their own personal or work experiences provided learning for the care of future losses [28,30,32]. Peer learning from experienced colleagues was also another resource [30], as a nurse reported: "*The training you get on the ward here is your own way of dealing with any type of bereavement. Plus, there are very experienced staff, and basically what you do is you learn from them, you take away parts of their way of dealing with it and adopt it for your own use; that's basically how the training is done, nothing formal as such."*

3.1.3. Emotionally Demanding Care

The majority of nurses and midwives experienced care as hard, difficult, and even a failure in the care process [29,32–34,36]. Some of them approached care from the weight of responsibility, in which their actions would have an impact on the well-being of parents [32,36]. *"It's scary to know that they're not going to forget anything that is said that day; so, be the right person at the right time for them. So, it's a huge responsibility, but it is a great honor."* Nurse [36]. Furthermore, some of them may feel unprepared to witness the emotional grief and suffering of parents and even the delivery [29,31,32].

"The first time I could see the parts of the baby. I was never really prepared for that. It was just shocking, and there was a moment after doing that case when I almost wanted to speak to a manager and say, 'I may not be able to do these types of cases.'" Nurse [32].

Apart from managing and dealing with parents' feelings, the care required emotional involvement on their behalf, as this midwife highlighted: *"The fact is it's hard for you, for you not as a midwife, as a person."* [34]. This deep and emotional implication had consequently a personal cost, especially when personal traumas were not overcome, when their beliefs and values were contrary, or depending on the relationship established with the parents and the story behind them, for instance, multiple pregnancy losses [26–32,34,36].

"It's very intense for the midwife looking after these people. There have been days when I've gone home and cried over different situations from here." Midwife [29].

3.2. "Strength to Go into Darkness"

Leader and peer support and guidance, having professional and personal experiences, and their convictions regarding their role were reported as motivating elements to deal with care in involuntary pregnancy losses. These created strengths to go into the darkness.

3.2.1. Leader and Peer Support and Guidance

Peer support provided security to care for involuntary pregnancy losses [31,32]. Moreover, a nurse from the Beaudoin and Ouellet (2018) [31] study underlined the key role that nursing leaders have: *"I think so, and that, I find that very brilliant: the respect that the assistants have toward their colleagues. The assistants are very much looking out for and listening to their gang."* Leader and peer supervision and guidance, and training were highly demanded by nurses and midwives, since the knowledge about how to care for the loss provided them with comfort, confidence, and reduction of concerns [26-28,30–34,36]. Even nonspecific training was considered beneficial [29].

3.2.2. Professional and Personal Experiences

They were considered as a source of learning and improvement in care [26-28,30,31,33]. Roehrs et al. (2008) [33] highlighted the enrichment of having those experiences in the student stage despite the hardness of the losses: *"[I had a] great orientation. I had 2 or 3 full-term losses in my orientation, and they were very difficult situations. I read a lot of info, talked with [others,] and reviewed reference books."* Nurse. Specifically, the nurse–parent bond was strengthened when nurses and midwives had personal experiences of loss or children, since these provided understanding and knowledge with which to empathize and feel safe [26-28,30,31,33]. *"I feel comfortable taking care of patients with early losses because that is where my personal experience lies. I find it more difficult to take care of patients with full-term demises."* Nurse [33].

3.2.3. Convictions about Care

Nurses and midwives recognized themselves as key in the provision of care and that they should be strong, supportive, and present for parents despite the personal cost involved [29,31,33,34], as a nurse reported: *"You don't want that feeling of having that pain and anguish for somebody because you do, but the patient needs care and you need to do it."* [29]. In addition, they considered themselves the ones providing compassion, understanding, and support [34,36]: *"Well, perhaps the midwife will be the one who has to attend this confinement… because it is supposed that we are the ones who are prepared and will be with and support them during this procedure."* Midwife [34].

On the other hand, the care of involuntary pregnancy losses was significant for them, since the care was both challenging and difficult besides meaningful [30–33,35,36]. The idea of making the loss bearable caused them to feel reward, gratitude, usefulness, and honour [33,36]: *"Well it's really—it's very difficult, but it's probably in some ways—it's more rewarding to help a family through a crisis like this,"* Nurse [36]

3.3. "Avoiding Stumbling"

To avoid stumbling in darkness, nurses and midwives did not go beyond, provided a task-focused care, and avoided encounters and emotional connections with parents.

3.3.1. Convictions about Care

Mainly, the care prioritized procedures over emotional aspects [31,32]. For instance, in early losses, the care becomes routine and the emotional aspect tends to disappear [28]: *"You're kind of saying the same things. It's very kind of routine, very much like a conveyer belt."* Midwife. Particularly, Hutti et al. (2016) [32] showed that surgery nurses were distressed when mothers woke up crying. They tried to control their crying by sedating them: *"She had had Versed. We like to give the Versed because it does help when they're crying. Some patients, even when they don't have a loss, they'll cry from the anaesthesia. So, we do give that."*

3.3.2. Avoiding Encounters with Parents

The lack of time due to high workload hindered establishing a bond of trust with parents, and therefore, care could have been superficial and without follow-up [26,27,31]. Moreover, Roehrs et al. (2008) [33] reported uncaring situations due to the impossibility of exclusive dedication to the loss:

"She had delivered in the bathroom. I felt bad that I was not in there with her when that happened, that I wasn't there even though I ran in the door as soon as she called." Nurse.

Delegating care to more experienced colleagues was another mechanism to avoid encounters with parents, as a midwife said: *"A baby comes back from autopsy, and everybody runs in every direction. They don't want to bath it or dress it or get it ready to put it in the little basket, and very often, the same one or two people are there."* Midwife [26,27].

3.3.3. Avoiding Emotional Connection

Nurses and midwives did not get emotionally involved with parents to avoid personal suffering and because they felt insecure and unprepared [28,31]. For example, some nurses put aside their feelings, others were able to depersonalize the baby to minimize the emotional burden of this loss, and even some of them had a feeling of rejection of care [26–29,31–35]. *"I think that sometimes I go in auto mode as I care for patients and don't realize the emotional toll until I go home."* Nurse [33].

3.4. "Groping in Darkness"

Nurses and midwives who went beyond the task-focused care did it in the best way they knew, which is represented by groping in darkness.

Midwives and nurses tried to provide care in the best possible way, despite the difficulties encountered [32,33,35], as this nurse reported: *"You have to just hope you made an experience OK for them, that you helped them in some way, because if you go home every day and think about all these people that have had horrible losses, you're not going to care for the next one effectively."* [32].

Care was based on the physical presence, on encouraging the expression of feelings of parents and normalizing the feelings of mothers, on comforting them physically and emotionally, and on the acknowledgement and memories created of the baby [26,27,29,31–34,36]. They also tried to individualize and adjust their care according to the situation, their relationships with patients, and the time available for care [32].

3.5. "Wounded after Dealing with Darkness"

The care of involuntary pregnancy losses caused a personal cost to nurses and midwives. This personal cost was the wounds caused by dealing with darkness.

On a personal level, nurses and midwives felt anxious, sad, grieved, anger, and inconsolable [28,29,31,32,36]. Sometimes, the feelings were so intense that they had an impact on their daily life [28,29], as this nurse expressed: *"I think more like exhaustion, like physical and mental exhaustion, is the best way to describe it: depressed. I could not sleep. I did not sleep well… hearing wailing, seeing the looks on their faces; you know, you just replay it over and over."* [29].

In situations of high emotional demand, such as the care of several losses in one day or the simultaneous care of a pregnancy loss and healthy pregnancy, nurses and midwives felt emotionally drained and could trigger burn out [26,27,29,30,32,36]. *"It's emotionally draining, not so much physically but emotionally. It's hard to be taking care of a patient with a stillbirth and then have to go into a patient's (room) who is delivering a live baby."* Nurse [32].

Midwives even felt guilty and responsible for the death of the baby despite the situation being beyond their control [26,27,35]: *"I felt that I had missed something and that I should have been able to make that baby come alive. I don't know why; it's just, I have live bubbies not dead ones. Why did it happen…? What did I do wrong...? What didn't I see happening...? Yeah... all those sorts of things. It was really raw emotions. I think you blame yourself for something like this, more than you think you do."* Midwife [35]. Frustration at the lack of institutional support and non-satisfaction of care expectations was also reported [26–29].

The management of these feelings; the high physical, mental, emotional, and spiritual needs of the parents; and their lack of training caused overwhelming feelings, and some of them could feel helpless and unqualified [29,31,32,35]. *"It's definitely overwhelming.… When I started my orientation, we had plenty of classes—a newborn class, a postpartum class—but there was never much talk about (perinatal loss)."* Nurse [29]. In the Roehrs et al. (2008) study [33], some nurses came to consider leaving the service because of the feeling of guilt and not feeling able to properly care for these parents: *"The fear of personal wrong doing or what part of this could be or is my fault make it difficult to come back to work after you have cared for the family in labor"*.

4. Discussion

From the analysis of the 10 qualitative primary articles emerged the metaphor *caring in darkness* (Figure 2). This metaphor represents the nurses' and midwives' experience in the care of involuntary pregnancy losses. Darkness represents both the suffering of parents and the challenges when caring for parents. They had to deal with an unsupportive organizational culture, lack of preparation or knowledge, and an emotionally demanding care, while they found motives to get into the parents' grief and suffering. The result of this confrontation was uncaring or was care based on lack of preparation and fear of hurting and on personal cost. This metaphor can be an incentive for action and could be useful for managers, leaders, and professionals, metaphorically providing candles that illuminate and guide nurses and midwives in the care of involuntary pregnancy losses.

Eriksson [19,20] states that the basic motive of caring is the caritas motive, where caritas is defined as altruistic love expressed in action. The readiness of nurses and midwives to share the parents' struggle of suffering is an essential aspect of caritative caring. In a context of scarcity of economic resources and marked masculine technological thinking, nurses and midwives may feel insecure when providing caritative care, for fear of being labelled as weak or unprofessional. From a clinical point of view, caritas in western health systems means going beyond a role. From the nurse, this requires competence, motivation, and moral integrity [39]. Our findings showed that, apart from competencies and support, it was ethos, or human value base, that motivated care in involuntary pregnancy losses.

Nurses confront human suffering on a daily basis and are expected to provide genuine care to alleviate people's distress rather than simple task-oriented responses [19]. Nurses and midwives are fundamental persons in the care of involuntary pregnancy losses and are better placed to build a genuine communion [14,19]. However, our results show that the care was mostly based on the performance of nursing tasks [28–32]. Nurses and midwives failed to establish a genuine communion with parents on many occasions.

A market mentality in health management systems may encourage the technical care and nonemotional involvement of nurses and midwives with parents [40]. This biomedical predominance is more pronounced in services such as gynaecology, emergencies, or surgery, where a wide variety of processes far from pregnancy losses are attended to. Therefore, the care could mainly address the accomplishment of medical tasks or may involve the medicalization of emotional aspects [30]. In this sense, Maturo (2012) [41] stated that the processes related to mental health are widely medicalized.

This context hinders the promotion of a caring culture and generates conflicts in health professionals, realizing that the interests of the administration are not equal to theirs. The Caritative Leadership theory [42] was created as a result of that and establishes that the entire caring culture and the leader are responsible for what is happening in the organization, especially in situations of noncaring, uncaring, nonchalance, and provocation. Leadership is understood as a powerful and fundamental tool in the delineation and maintenance of the ethical value base, direction, and content of nursing care in the complex demands of evidence-based, efficient, and cost-effective nursing care [43].

On the other hand, the majority of nurses see emotional engagement as a requirement of excellence in nursing practice [44]. The benefits of establishing a trust relationship with patients was reported in a recent meta-ethnography [45]. This relationship is a useful tool for personal communication sharing, which allows holistic nursing care, as it strengthens nurses' ability to recognize and respond properly to a variety of unvoiced needs. The development and maintenance of this trust relationship with parents implies work by nurses and midwives, which adds to the invisible and emotional labour that is generally not recognized in nursing [46].

According to Hochschild (1983) [47], emotional labour refers to a worker's endeavour to display emotions according to embedded social and cultural norms rather than what health professional actually feels. Emotional labour may be viewed as a western construction within Descartes' tradition of separating the rational mind from the emotional body [48]. However, caring implies feeling and feeling involves personal vulnerability [44]. Phillips (1996) [49] showed that emotional labour is denigrated by its association with femininity and that it occupies a second level with respect to cognitive or technical abilities.

Our results informed that difficulties in care encourage avoidance behaviours and that nurses and midwives experienced emotional exhaustion when they were emotionally involved with parents [26,27,29,32,36]. The fact that emotional labour is not recognized and is thus undervalued by the majority of healthcare organizations may contribute to understanding the empirical link between emotional labour, emotional exhaustion, and professional burnout [47]. In this sense, clinical supervision, understood as interprofessional support and as guidance and reflection, has been recognized by the literature as useful for improving professional growth and collegiality and for preventing burnout that risks the health of the nurse and nursing care [50].

4.1. Strengths and Limitations

The use of meta-synthesis has increased in the last decade. Meta-ethnography is a distinct, complex, and increasingly common and influential qualitative methodology in health and social care research [23]. Especially in nursing, qualitative syntheses are considered a useful method for examining participants' meanings, experiences, and perspectives, both deeply and broadly. Its employment is useful to identify research gaps; to inform the development of primary studies; and to provide evidence for the development, implementation, and evaluation of health interventions. This methodology involves a conceptual development that implies a fresh contribution to the literature, beyond the narrative and systematic literature reviews [51]. The elaboration of this meta-ethnography has followed the eMERGe reporting guidance [23]. The utilization of this guidance improves the transparency and completeness of the research process and, therefore, the quality of the meta-ethnography. This allows our results to contribute to the formation of robust evidence that serves as the basis for political and practical decision making.

On the other hand, a comprehensive search strategy has been carried out with the possibility of including articles in English, Spanish, and Portuguese, although no results were found in these last two languages. This search has been executed in two moments: an initial that was limited to the bibliography of the last ten years, and the definitive one without time limits. This has allowed a double check of the existing literature.

Another strength is that the studies were evaluated using the QARI criteria [25] and that the review findings were assessed with CERQual [38], confirming their transparency and reliability. This process improves the trustworthiness and applicability of the results in the clinical setting, decision-making, and future research.

Regarding the limitations, these are present in the composition of the sample. On the one hand, the cultural contexts of primary articles are located exclusively in western countries. On the other hand, the sample of the primary articles is almost exclusively feminine and mostly belonging to the hospital environment. However, nursing staff in primary care settings accompany these families after the loss and for a longer time, and in many cases, the bond created with the parents is stronger. New empirical research that addresses these limitations is needed.

4.2. Relevance to Clinical Practice

This meta-ethnography informs the body of knowledge in nursing science and enhances a change in clinical practice, since the results show the complexity of the care experience of nursing and midwifery in involuntary pregnancy losses.

Nurses and midwives require an organizational culture that is supportive for the development of a caring culture. At the formative level, the focus should be on the provision of whole care and on the establishment of genuine communion with parents. Therefore, training should be aimed at developing and strengthening skills that favour the connection with parents and at the provision of tools for managing the emotional demands of caring. Nursing leaders, due to their position among administration, nursing staff, and the proximity to care, are key to favouring the interconnection and the construction of bridges between them.

To expand knowledge of the care experience in involuntary pregnancy losses, further research focused on primary care midwives, who in many cases have the most lasting contact with parents, is required. Besides, it would be beneficial to know the personal experience of nurses and midwives in caring for these losses. This perspective would provide us with valuable information for practice and the education of future nursing professionals.

5. Conclusions

The overarching metaphor, caring in darkness, symbolises the experiences of nurses and midwives in the care of involuntary pregnancy losses. Darkness represents both the suffering of parents and the challenges when caring for parents. Nurses and midwives dealt with organizational difficulties, lack of knowledge, and with care that requires going beyond. This context encouraged task-focused care and avoidance of encounters and emotional connection with parents. Metaphorically, they avoided stumbling in the dark. However, some nurses and midwives went beyond in their care when they had competencies, support, and a strong value base despite the subsequent wounds involved in dealing with darkness. Those who went beyond the tasks tried to care in the best possible way, symbolized through the theme groping in darkness. Deepening the personal experience of nurses and midwives who care for pregnancy losses would complement our results and allow to have a complete overview of this experience. These results could improve knowledge in nursing science and could encourage change in clinical practice.

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Appendix A

Table A1. eMERGe reporting guideline [21].

	Criteria headings	Pages
Phase 1 Selecting meta-ethnography and getting started	**1. Rationale and context for the meta-ethnography** *Describe the gap in research or knowledge to be filled by the meta-ethnography and the wider context of the meta-ethnography*	1–2
	2. Aim(s) of the meta-ethnography *Describe the meta-ethnography aim(s)*	2
	3. Focus of the meta-ethnography *Describe the meta-ethnography review question(s) (or objectives)*	2
	4. Rationale for using meta-ethnography *Explain why meta-ethnography was considered the most appropriate qualitative synthesis methodology*	3, 8
Phase 2 Deciding what is relevant	**5. Search strategy** *Describe the rationale for the literature search strategy*	3
	6. Search processes *Describe how the literature searching was carried out and by whom*	3
	7. Selecting primary studies *Describe the process of study screening and selection, and who was involved*	3–4
	8. Outcome of study selection *Describe the results of study searches and screening*	3–4
Phase 3 Reading included studies	**9. Reading and data-extraction approach** *Describe the reading and data-extraction method and processes*	5
	10. Presenting characteristics of included studies *Describe characteristics of the included studies*	6–9
Phase 4 Determining how studies are related	**11. Process for determining how studies are related** *Describe the methods and processes for determining how the included studies are related:* *- Which aspects of studies were compared* *and* *- How the studies were compared*	5
	12. Outcome of relating studies *Describe how studies relate to each other*	5

Phase 5 **Translating studies into one another**	**13. Process of translating studies** *Describe the methods of translation:* • *Describe steps taken to preserve the context and meaning of the relationships between concepts within and across studies* • *Describe how the reciprocal and refutational translations were conducted* • *Describe how potential alternative interpretations or explanations were considered in the translations*	5
	14. Outcome of translation *Describe the interpretive findings of the translation*	10–15
Phase 6 **Synthesizing translations**	**15. Synthesis process** *Describe the methods used to develop overarching concepts (“synthesized translations”), and describe how potential alternative interpretations or explanations were considered in the synthesis*	5
	16. Outcome of synthesis process *Describe the new theory, conceptual framework, model, configuration, or interpretation of data developed from the synthesis*	10–15
Phase 7 **Expressing the synthesis**	**17. Summary of findings** *Summarize the main interpretive findings of the translation and synthesis, and compare them to existing literature*	15
	18. Strengths and limitations *Reflect on and describe the strengths and limitations of the synthesis:* - ***Methodological aspects:*** *for example, describe how the synthesis findings were influenced by the nature of the included studies and how the meta-ethnography was conducted*	17
	19. Recommendations and conclusions *Describe the implications of the synthesis*	18

Table A2. Confidence in the Evidence from Reviews of Qualitative research (CERQual) evidence profile.

Summary of Review Findings		**Studies Contributing to the Review Findings**	**Methodological Limitations**	**Coherence**	**Relevance**	**Adequacy of Data**	**Overall CERQual Assessment of Confidence**	**Explanation of Decision**
"Forces that turn off the light"	Unsupportive organizational culture	[26–34]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Minor concerns regarding relevance (One study included self-employed midwives as a sample)	No concerns about adequacy of data. There were rich data to support the finding across many studies.	Minor concerns	Very minor concerns regarding coherence; no concern about adequacy of data; and minor concerns regarding methodological limitations and relevance
	Lack of preparation and knowledge	[26–36]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	No concerns about adequacy of data. There were rich data to support the finding across all the studies.	Very minor concerns	Very minor concerns regarding coherence and relevance; no concern about adequacy of data; and minor concerns regarding methodological limitations

"Strengths to go into darkness"	Emotionally demanding care	[26–34,36]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Minor concerns as the data was rich	Minor concerns	Very minor concerns regarding relevance and coherence and minor concerns regarding methodological limitations and adequacy of data
	Leader and peer support and guidance	[26–28,30–34,36]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Moderate concerns as the data was partially rich	Minor concerns	Very minor concerns regarding coherence and relevance; moderate concern about adequacy of data; and minor concerns regarding methodological limitations
	Professional and personal experiences	[29–34,36]	Minor concerns regarding methodological limitations since	Very minor concerns regarding coherence	Very minor concerns regarding relevance (All	Moderate concerns as the data was partially rich	Minor concerns	Very minor concerns regarding coherence and relevance; moderate concern

			there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	(data very consistent within and across studies)	studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)			about adequacy of data; and minor concerns regarding methodological limitations
	Convictions about care	[29–34,36]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Minor concerns as the data was rich	Minor concerns	Minor concerns about methodological limitations and adequacy of data and very minor concern about coherence and relevance
“Avoiding stumbling”	Task-focused care	[28,31,32]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the	Very minor concerns regarding coherence (data very consistent within and	Very minor concerns regarding relevance (All studies included nurses and midwives as a	Moderate concerns as the data was partially rich	Minor concerns	Minor concerns about methodological limitations; moderate concerns regarding adequacy of data; and very minor concerns about relevance and coherence

		investigation, and vice versa	across studies)	sample, focused on pregnancy loss, and were relevant to the review)			
Avoiding encounters with parents	[26,27,31,33]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Moderate concerns regarding relevance (No studies include early pregnancy loss)	Moderate concerns as the data was partially rich	Moderate concerns	Minor concerns about methodological limitations; very minor concerns about coherence; and moderate concerns regarding adequacy of data and relevance
Avoiding emotional connection	[26-29,31–35]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Minor concerns regarding relevance (All studies included nurses and midwives as a sample, but early pregnancy loss was not included)	Minor concerns about adequacy of data. There were rich data to support the finding across all the studies.	Minor concerns	Very minor concerns about coherence and minor concerns about methodological limitations, relevance, and adequacy of data
“Groping in darkness”	[26,27,29–35]	Minor concerns regarding methodological	Very minor concerns regarding	Minor concerns regarding	Minor concerns about adequacy of	Minor concerns	Very minor concerns about coherence and minor concerns

		limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	coherence (data very consistent within and across studies)	relevance (All studies included nurses and midwives as a sample, but early pregnancy loss was not included)	data. There were rich data to support the finding across all the studies.		about methodological limitations, relevance, and adequacy of data
"Wounded after dealing with darkness"	[26–33,35,36]	Minor concerns regarding methodological limitations since there is lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Very minor concerns about adequacy of data. There were rich data to support the finding across many studies.	Very minor	Very minor concerns about coherence, relevance, and adequacy of data and minor concerns regarding methodological limitations

Definitions of levels of confidence from the CERQual evaluation [38]: High confidence: It is highly likely that the review finding is a reasonable representation of the phenomenon of interest. Moderate confidence: It is likely that the review finding is a reasonable representation of the phenomenon of interest. Low confidence: It is possible that the review finding is a reasonable representation of the phenomenon of interest. Very low confidence: It is not clear whether the review finding is a reasonable representation of the phenomenon of interest.

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Supporting Information

- Keywords and Boolean operators (see Appendix 4)

Fourth study - Primary healthcare midwives’ experiences of caring for parents who have suffered an involuntary pregnancy loss: a phenomenological hermeneutic study

Primary healthcare midwives' experiences of caring for parents who have suffered an involuntary pregnancy loss: a phenomenological hermeneutic study

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Conflict of interest

The authors state that there is no conflict of interest.

Ethical approval

The study obtained the approval of the Autonomous Committee of Research Ethics of Galicia (registration code 2015/232) and had the access permission by health area. All participants provided written informed consent to participate in the study.

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Objective: To illuminate the experiences of primary healthcare midwives who care for parents who have suffered an involuntary pregnancy loss.

Design: The phenomenological hermeneutic approach developed by Lindseth and Norberg was used to carry out face-to-face interviews.

Setting and participants: A purposive sample, consisting of 11 public primary healthcare midwives from a municipality in northern Spain, was selected. The participants’ ages ranged between 26 and 62 years, and they were all women.

Results: Four main themes were identified: (1) handling adversity, (2) finding a motive to get involved, (3) providing care from the rear, and (4) avoiding emotional connections with the parents. For the midwives, caring for parents who had suffered an involuntary pregnancy loss meant leaving their own comfort zone and handling adversity. The midwives either found reasons to go beyond the task, providing care based on their intuition, or they used emotional.

Conclusions: More knowledge and preparation in terms of communication skills and bereavement is crucial for midwives in order to meet the needs of parents who have suffered an involuntary pregnancy loss. A caring organizational culture and supportive leadership will facilitate care continuity between specialized and primary healthcare and promote the welfare of midwives.

Keywords

Caring, Midwifery, Miscarriage, Primary Healthcare, Qualitative Research, Stillbirth

Highlights

- This care involved midwives going beyond the task despite the personal costs.

- Lack of knowledge and support, and insecurity hindered the care provided.
- Caring was based on intuition.
- Midwives were sometimes unprepared to encounter the suffering of the parents.

Introduction

Involuntary pregnancy loss (IPL), including miscarriages and stillbirths, is a common occurrence, and, therefore, midwives have a high probability of encountering families who have experienced IPL in a current or previous pregnancy (Heazell et al., 2019). This loss can lead to a set of painful emotional reactions by the parents (Flenady et al., 2014). Previous research has focused mainly on the impact on women (Fernández-Basanta et al., 2019), whereas the experiences of men have been given little attention (McCreight, 2004).

The literature has highlighted the importance of the care provided by healthcare professionals in the management of these losses (Fernández-Basanta et al., 2020a). Midwives have a fundamental role in this care because of their frequent encounters with the parents (Ellis et al., 2016; Gold, 2007). However, knowledge, skills, and personal sacrifice are required in order to avoid delivering superficial and task-focused care (Ellis et al., 2016; Martínez-Serrano et al., 2018). Generally, recommendations are to provide care soon after the loss occurs, but follow-up has not been addressed in depth (Peters et al., 2016).

In the Spanish primary healthcare system, midwives are those who monitor a pregnancy and, in many cases, are the professionals who refer the patient to the hospital when they suspect a miscarriage or stillbirth has occurred. Therefore, these midwives function as the link between the parents and the healthcare system. They are also the professionals that accompany the parents throughout the subsequent process of loss. Although nurses' and midwives' experiences of caring for parents who have suffered an IPL have been synthesised previously in the literature, little research has been conducted on the primary healthcare midwife's perspective (Fernández-Basanta et al., 2020b). Currently, few guidelines exist for this health area; therefore, the care provided is based on each midwife's own professional judgement (López García de Madinabeitia, 2011).

Theoretical perspective

This study employed the caritative caring theory (Lindström et al., 2006) to gain a better understanding of the complexity and wholeness of the experiences of primary healthcare midwives in the care of IPLs.

Ontologically, the human being is conceived as an indivisible entity that includes body, soul, and spirit. The purpose of caring is to alleviate suffering and to promote health and life. The *ethos* of care includes caritas, love, and charity; the respect of health professionals for the dignity of the person; and a striving for a genuine communion and understanding of the unique human being. Therefore, caritative care is based on the relationship between the person who needs and hopes for care and the person who provides the care, through genuine communion and understanding of the uniqueness of the human being.

Aim

To illuminate the experiences of primary healthcare midwives who care for parents who have suffered an IPL.

Methods

Design

This qualitative study used a phenomenological hermeneutic design that was inspired by Ricoeur (1976) and developed by Lindseth and Norberg (2004). Lincoln and Guba (1985) proposed the following trustworthiness criteria for carrying out naturalistic inquiries: ‘credibility’, ‘transferability’, ‘dependability’, and ‘confirmability’. This study was carried out maintaining theoretical-epistemological adaptation and consistency. Credibility was ensured through the presentation of data according to the authors’ interpretations, along with the comments of the midwives. During the analysis, the researcher’s notes (collected after the interviews) were used, analysis was triangulated by all the authors, and results were sent to the midwives for validation. Transferability was facilitated through a description of the context and the participants. To enhance dependability, detailed descriptions of the study sample, data collection process, analysis and interpretation of the data, role of researchers, and study limitations are presented. Finally, confirmability was guaranteed by the researchers’ reflections on their own positions on the topic and an audit trail that detailed the process of data analysis and interpretation of the data.

None of the authors worked as a primary healthcare midwife, but one of us has professional experience working in a gynaecological hospital and primary healthcare encountering parents who has experienced IPLs. Analysis and interpretation of the data was triangulated by the authors to strengthen the interpretation by contesting and supplementing each other’s readings. Moreover, all authors were trained qualitative researchers who had experience working on the topic of IPL.

The authors' preunderstandings to be addressed during the study were that the care provided after an IPL should be focused on the human being as a whole and continue from the hospital to primary care and that the midwife is who has the competencies to provide care and follow up to parents who suffer IPLs.

Participants

Eleven midwives working in 10 primary healthcare centres in Spain, participated in the study. The number of potential participants from the 10 centres was 13. Two midwives did not participate (one due to family commitments and the other could not be reached). A purposive sample was performed, according to the study aim. In order to recruit participants, two authors (SFB and MJMF) attended the monthly meeting attended by all primary healthcare midwives. Details of the study were presented at the meeting and written information was given to the attendees. The inclusion criteria were being a primary healthcare midwife and having experience in providing care to parents who have suffered an IPL.

Data collection

Data were collected through face-to-face semi-structured interviews between February and April 2019 by SFB. Most of the interviews were conducted in the midwives' offices at the healthcare centres. Two were conducted at the Faculty of Nursing and Podiatry at the University of X. The interviews lasted 60 minutes on average. A guide based on a literature review and previous knowledge was used to conduct the interviews. All interviews commenced with the prompt 'Tell me about your experience of providing care for an IPL as a primary healthcare provider'. Further questions that encouraged narration were asked (table 1). A final open question was asked to gather relevant information not collected during the interview. Field notes collected after the interviews were integrated into the transcripts to enrich the data. The interviews were conducted in Spanish or Galician and were tape-recorded and transcribed (by SFB). Saturation was reached for 3 themes.

Table 1

Semi-structured interview script

Thematic field	**Questions**
Care provided for involuntary pregnancy losses	How do you act when an involuntary pregnancy loss occurs? How do you act with the father? What difficulties do you experience regarding the care?
Training	Do you think that in your professional career these losses are addressed in education or training? How useful is the current training in imparting the knowledge and skills necessary to provide care for and manage this situation?
Personal impact of involuntary pregnancy losses	How do you feel when you face these situations? What impact does the care of these losses have on you?
Coping strategies	How do you cope with caring for parents that have experienced an involuntary pregnancy loss?

Ethical considerations

Midwives were provided with verbal and written information on the study, and prior written informed consent was obtained from each participant. All midwives were informed about guaranteed confidentiality and the right to discontinue the interview at any time. The study obtained the approval of the Autonomous Committee of Research Ethics of Galicia (registration code 2015/232) and had the access permission by health area of X. The interviews were anonymized, and the audio recordings were destroyed after transcription.

Data analysis

The transcribed interviews were interpreted using a phenomenological hermeneutic method developed by Lindseth and Norberg (2004). The first step involved a naïve reading, in which three authors (SFB, CC, and MJMF) grasped the meaning as a whole and formulated a naïve understanding of the text. Next, a structural analysis was carried out by SFB. Any text relating to the experience of providing care to parents who have experienced IPLs was read through several times. Analytic questions were posed, and answers were searched for in the text. The text was divided into meaning units that were based on the aim of the study. The meaning units were condensed and abstracted to form preliminary subthemes and themes, which were compared with the naïve understanding for validation. The structural analysis was discussed in a dialectic movement between understanding and explanation until all the authors agreed. Finally, a comprehensive understanding was elaborated, based on the naïve understanding, structural analysis, study context, the researchers' preunderstandings, and theoretical perspectives. During this step, TB audited the analysis process and results.

The preunderstandings of the authors were discussed throughout the process in order to avoid bias in the interpretation of the data. These processes were recorded in notes. To support the data analysis, grids created for this purpose were used.

Results

All 11 midwives were Spanish and trained in Spain. They all had experience in specialized and primary healthcare. The age range was 26 to 62 years, and all were women. Table 2 presents their sociodemographic characteristics.

Table 2

Sociodemographic characteristics of the participants

Participant	Gender	Nationality	Age	Working experience
PCM1	Woman	Spanish	60	39 years
PCM2	Woman	Spanish	26	2 years
PCM3	Woman	Spanish	40	12 years
PCM4	Woman	Spanish	37	6 years
PCM5	Woman	Spanish	41	14 years
PCM6	Woman	Spanish	58	32 years
PCM7	Woman	Spanish	62	35 years
PCM8	Woman	Spanish	36	10 years
PCM9	Woman	Spanish	30	6 years
PCM10	Woman	Spanish	60	35 years
PCM11	Woman	Spanish	35	8 years

***Abbreviations**: PCM (Primary Care Midwife)

Four main themes were identified: ‘handling adversity’, ‘finding a motive to get involved’, ‘providing care from the rear’, and ‘avoiding emotional connections with the parents’.

Naïve understanding

Midwives reported that providing care to parents who have suffering an IPL involved leaving their own comfort zone and dealing with various forms of adversity, such as lack of training and knowledge, personal costs resulting from the provision of care, lack of organizational support, and lack of or little communication between specialised and primary healthcare providers. Under these circumstances, midwives had to look for reasons to go beyond task-focused care. The bond with the mother, coping strategies, a strong sense of professional responsibility, and having experienced the loss of a loved one were drivers. Care, therefore, meant that midwives got involved following their intuition, or that they avoided going beyond the provision of task-focused care because of their difficult encounters with the suffering parents.

Structural analysis

The structural analysis identified four themes of the lived experience of primary healthcare midwives who provide care to parents who have experienced an IPL (figure 1).

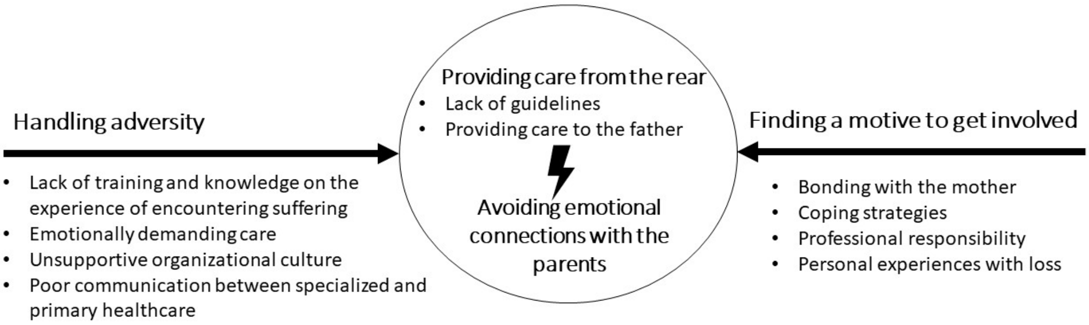

Fig.1 Themes and subthemes of the lived experience of primary healthcare midwives who provide care to parents who have experienced IPL

1. *Handling adversity*

Lack of training and knowledge on the experience of encountering suffering, emotionally demanding care, unsupportive organizational culture, and poor communication between specialized and primary healthcare were the difficulties that midwives had to deal with in the care of parents who have IPLs.

1.1 Lack of training and knowledge on the experience of encountering suffering

Midwives felt poorly prepared to care for the parents in the context of primary healthcare. Their training had not exposed them to these experiences, because their supervisors had wanted to protect them. Some commented that the lack of training reflects society's avoidance of topics related to death and suffering.

> *I think they don't train us, because my experience as a student was that they wouldn't let us face it. In my case, I wanted to face it and said yes, I was going to attend the stillbirth. But the midwife was who attended it, because 'you don't have to go through that as a student. (PCM9)*

The limited training available did not provide enough knowledge and skills to manage the emotional demands of this type of care. Moreover, the training did not address the care provided in primary healthcare and it did not include the experiences of women following IPLs.

> *We are not trained on how to deal with those losses. We don't know how we can help the woman. A lot of training is missing. That is, how to manage them* [the losses]*, and how to deal with them, and how to care for the couple. (PCM11)*

Midwives supplemented their lack of training with private training, peer learning, and the knowledge and skills acquired from their personal and professional experiences of loss. This allowed them to understand how the woman could feel and improved communication and empathy with the parents. However, private training meant that midwives had to be trained outside working hours, incurred travel costs, and may not have been able to fully participate in the private training due to the difficulties in balancing work and family life.

> *If you have experienced something ...* [personal experience provides you with] *some tools to face it. On your own, not because you had training (PCM5)*

As a result of lack of knowledge, midwives did not feel fully capable of leading in the provision of care and did not understand their role as the healthcare provider to the parents. Furthermore, at some point they experienced fear of failing in this role.

> *I would say listen and support them ... but we are not psychologists either. That is, to listen to them, yes, to understand them, of course, to be more open to everything they need in the next pregnancy, yes, but I don't know if we must do anything else. (PCM10)*

1.2 Emotionally demanding care

Caring for parents who have experienced an IPL entailed personal costs because of the emotional involvement with the parents. Being involved in this form of care was a challenge for midwives, because it forced them to leave their own comfort zone. Moreover, this care was in many ways the opposite of midwifery, which is the care of life. There could be questions of whether the care provided was adequate and the midwife may experience fear of legal repercussions in advanced losses. Nonetheless, some of them felt protected from legal reprisals, as primary healthcare providers. Metaphorically they feel that they are not in the front line of war, but in the rear.

> *I really like to listen, and I let them talk and I listen to them. But then that also makes you emotional. Then you have to know how to let go emotionally. (PCM4)*

It was especially difficult for them to manage their emotions after being exposed to those of the parents. In primary healthcare, the suspicion of IPL after not finding the heartbeat is emotionally devastating. In this context, the link between the midwife and the woman was closer before the IPL, especially in advanced losses. This original closeness entails higher personal costs because the woman is more able to express her discontent. For example, for one midwife, it was difficult to feel the mother's rejection: *But it was very painful. It was hard feeling her rejection (PCM7).*

1.3 Unsupportive organizational culture

Midwives found that the healthcare system did not provide them with resources for managing the emotional impact of their work with the parents. Although many of the midwives mentioned that the workload in healthcare centres is no excuse for not going beyond task-focused care, some midwives reported that the limited time for consultations sometimes prevented them from being more involved with the couple.

> *I believe that healthcare professionals should take care of ourselves—the care of the healthcare professional. If you do not do it on your own, the system also does not worry that this therapy will be performed. (PCM3)*

1.4 Poor communication between specialized and primary healthcare

Poor communication between specialized and primary care can cause a lack of continuity of care. For instance, on suspicion of a pregnancy loss, referred to the hospital for diagnosis, women may be sitting in waiting rooms with other pregnant women, despite warnings from the healthcare centre midwife.

> *That I call the hospital and say: 'I'm sending you a woman for whom I just can't find foetal monitoring'. I call the hospital so that when she arrives, she doesn't experience 'What are you here for?' and the woman has to say, 'Look, it's just that my child died.' (PCM7)*

During the validation phase of the results, one midwife suggested that this lack of communication is possibly due to structural deficiencies rather than a lack of communication between professionals.

Moreover, healthcare centres have the Connect 72 program, which is a program in which physicians and nurses automatically receive an alert for a telephone consultation within 72 hours after a patient is discharged. The system does not directly notify primary healthcare midwives, and although some cases are referred to midwives, not all are captured by them. Moreover, in early losses that did not require hospitalization, the system does not create the alert and the occurrence of a follow-up depends on whether the woman requests an appointment with the primary healthcare midwife. On the other hand, the call is made within 72 hours after discharge, which may be the time of greatest need for women.

2. *Finding a motive to get involved*

Despite the difficulties, midwives become more emotionally involved in the care when there is a strong bond with the mother, when they are better able to manage the involvement through coping strategies, when they feel a professional responsibility to care, and when they have also experienced a personal loss.

2.1 Bonding with the mother

The bond with the woman motivated midwives to go beyond task-focused care. This bond was created especially in primary healthcare. In many cases, women receive care from the same midwife during pregnancy, and a trusting relationship is built, in which women can express their feelings freely. This link was closer when losses were advanced, and therefore, the midwives’ involvement was easier.

> *If the IPL is in the third trimester, I think it is much easier for her to get in touch with you* [midwife], *to know that this is a place where she can be heard and so on. (PCM8)*

From the point of view of midwives, the primary healthcare setting allowed them to relate to the experiences of the women and use the feedback from the women to reflect on and to improve the care.

> *In a healthcare centre, you create a bond with them, that they share things with you that they don't tell you in the hospital. Then it is when you realize 'Well, yes a miscarriage affects them'. (PCM9)*

2.2 Coping strategies

The provision of care beyond medical tasks also depended on the coping tools of the midwives. Tools such as psychological therapy, which was used to enhance self-awareness of their feelings, helped them to understand the death in a way that allowed them to get more involved in the care. Many of the midwives understood IPLs as causes beyond them, as another possibility in life, or as unfavourable aspects of their work that could result in learning opportunities.

> *I personally went to therapy. I am very happy because I think it has helped me a lot to manage my issues, so as not be* [negatively] *affected by the issues of others. (PCM3)*

2.3 Professional responsibility

Although the provision of care was a challenge for midwives, and it entailed personal costs to get involved in the care, midwives felt it was their responsibility as professionals. Previous situations in which they received negative feedback from the woman, motivated them to go beyond task-focused care. On the other hand, this implication in the care was strongly influenced by the midwives' personalities.

> *For me* [the IPL] *is one hundred percent my responsibility. And it wouldn’t occur to me not to take care of her, even though it hurts. It hurts, but at the same time I want to take care of them. (PCM9)*

2.4 Personal experiences with loss

Finally, personal losses motivate midwives to get more involved in caring, because they understood the couple’s feelings and it was easier to empathize with them. One midwife reported the following: *As a result of having abortions, you get a little more involved in ... And you can understand a little better what the other person is feeling. (PCM5)*

3. Providing care from the rear

The care provide for these losses was based on the intuition of the midwives because of the lack of guidelines. Furthermore, the care of the father was an emerging concern in their narratives.

3.1 Lack of guidelines

Primary healthcare midwives do not have guidelines on providing care to parents who have experienced an IPL. Because of the lack of guidelines and knowledge, the care provided depends on the practices of each midwife and is based on their intuition. Furthermore, the healthcare follow-up of the woman is focused on her physical wellbeing, and consideration of other aspects depends on the requests of the woman.

> *So, it’s to improvise, listen, and communicate. And sometimes, even, being there and saying, ‘What do I do? What do I say?’ Because I don't know. (PCM2)*

The care is designed to allow the woman to express her experiences and feelings, listen to her, respect her time, resolve her doubts, and normalize her feelings.

3.2 Providing care to the father

One aspect that emerged from the midwives' narratives was the care provided to the partner. Midwives commented that the healthcare is mainly focused on mothers, because of the physical aspects. Some midwives reported that they did not know how to empathize with the father or how to deal with the fathers' feelings. Two possible reasons for this may be the weakness of the prior bond between the father and the midwife and the social pressure on the father to be strong and hermetic.

> *It is very difficult for men to open up, although I try to involve them. I don't know why, if it's because they don't have the confidence that women have with me or why. (PCM9)*

4. *Avoiding emotional connections with the parents*

Lack of knowledge and time, personal costs, high emotional demands of getting involved in the care, and lack of effective coping strategies could hinder midwives from going beyond task-focused care. Midwives may feel that they are incapable of encountering the suffering of these parents. Therefore, midwives may avoid encounters with the woman and partner and engage in superficial communication with them. They may also experience fear of getting involved.

> *I think what we are trying to do is cover this up a bit. As we say, to pass soon, and sometimes what we have is fear of entering... Maybe not knowing what to do with the answers that women can say. (PCM8)*

Discussion

This study focused on the meaning of lived experiences of primary healthcare midwives caring for parents who have suffered an IPL. For the midwives, this care involved handling adversity. Under these circumstances, they found motivation to go beyond task-focused care. In their provision of care the midwives followed their intuition or avoided encounters with the parents (figure 1).

Midwives may experience fear of being labelled unprofessional for providing *caritative* care or going beyond the medical task (Arman and Rehnsfeldt, 2006). Eriksson (2002) states that the basic motive of caring is the *caritas* motive, and, in the Western health systems, it means going beyond a role. Our findings showed *ethos*, or human value base, was what motivated midwives to get more involved in the care of these couples. This involvement is seen as a *gift* that the midwife gives the couples, as a result of a choice she makes because she wants to, not because she has to (Bolton, 2000). In this sense, the organizational culture could minimize the personal cost of this care by ensuring support for midwives and a caring culture, through training and the provision of spaces and time in which they can share their experiences and emotions.

According to the Caritative Caring Theory, genuine caring is provided to alleviate suffering and promote health and life (Lindström et al., 2006). Midwives are essential professionals in the genuine care of IPLs because they are best positioned to build strong ties with the parents. This situation is facilitated in the case of primary healthcare midwives, because a previous relationship was surely established (Ellis et al., 2016; Gold, 2007). However, taking care of these parents is a challenge for them (Beaudoin and Ouellet, 2018; Jones and Smythe, 2015).

Dealing with death causes anxiety in nursing staff, and adequate knowledge about dying care is needed (Zomorodi and Lynn, 2010). According to Begley (2003), structured support during clinical experiences and education about bereavement and communication should be included in the training of midwives. However, in Western societies, death, particularly IPLs, are taboo, and it means the antithesis of the expected in the midwifery discipline (Granero-Moya et al., 2016; Lang et al., 2011).

The social context also has influence on the experiences of male partners. The literature highlights a societal pressure on men to 'be strong' and the belief that 'men don't share' (O'Leary and Thorwick, 2006; Samuelsson et al., 2001). However, IPLs have been shown to have an impact on them, but the manifestations of these feelings may be different from those of women. Lack of knowledge by healthcare professionals regarding men's experiences may lead to helplessness and marginalization (Due et al., 2017; McCreight, 2004). However, our results showed that what midwives did not know was how to approach them. This may be due to the lack of a previous tie and to the fact that the encounters with the midwife were carried out as a couple and the man wanted to keep the façade of strength in front of the woman. According to Strandås and Bondas (2018), the development and maintenance of a trusting relationship with the parents, specifically with the men, requires work on the part of midwives. They should be supported by the healthcare organizations, which should facilitate the establishment of a couple-midwife relationship. Moreover, further research is needed to shed light on the experiences of men in these losses and to promote the establishment of a trusting relationship.

Guidelines often focus on specialized care that involves the acute moment of loss, but follow-up is hardly addressed (Koopmans et al., 2013; Peters et al., 2016). Our results, in line with the literature, showed that the care provided by midwives was based on their intuition or their personal and professional experiences (Hutti et al., 2016; McCreight, 2004; Nash et al., 2018).

Follow-up is hindered by poor communication between specialized and primary healthcare. In our results, this aspect was controversial, because although it emerged from the analysis of the interviews, in the validation phase, one of the midwives who previously reported this information, did not recognize the break between the two healthcare levels. This may be understood from the collaboration among professionals who are involved in the continuity of care. The involvement of other sectors is also necessary for continuity of care (Maarsingh et al., 2016). Various strategic collaboration plans have been carried out in our context, but they have not been successful in terms of continuity care (Guzmán-Fernández, 2011).

The literature highlights the important role of leaders in improving collaboration (Lemetti et al., 2015). According to Sjølie et al. (2020), first-line nursing managers are essential for improving the quality of care; they are able to change work practices, which leads to better outcomes for patients. However, in our context, the assistance units are physically far from the management ones (Guzmán-Fernández, 2011). It is necessary to have new forms of leadership and to professionalize management and strengthen competences and skills, including professionalism, leadership, decision-making, conflict management and problem-solving skills (Lemetti et al., 2015).

Our results highlighted the beneficial position of primary healthcare midwives in caring for these losses. The establishment of a previous emotional bond allowed the women to be more open and to share their experiences with the midwives. However, empathy and compassion may also entail additional emotional labour (McQueen, 2000). A market mentality and a predominant biomedical model can belittle the therapeutic value of that emotional involvement and promote the provision of task-focused care (McCreight, 2005; McQueen, 2000). This emotional demand can cause emotional exhaustion and professional burnout (Hunter and Smith, 2007; Huynh et al., 2008). In early losses, due to the high frequency in clinical practice, this exhaustion is often associated with the loss of the ability to provide compassionate care and a decrease in care quality (Houck, 2014).

Strengths and limitations

The face-to-face semi-structured interview was a useful tool in the data collection that allowed midwives to share their experiences freely and in detail. The different backgrounds of the research team enhanced the design and analysis phases of the study. Regarding the sample, this study provides the meaning of primary healthcare midwives' lived experiences, which offers a novel contribution not previously addressed in the body of knowledge. In addition, the sample was heterogeneous in relation to training and professional experience, which has enriched the knowledge of these experiences.

Results from this study can be transferred to other settings where midwives are present in primary healthcare. Moreover, the results may be beneficial for other professionals and disciplines with similar responsibilities to those performed by the midwives of this study.

Among the challenges of the study we highlight that the midwives were all women. According to them, being a woman might facilitate the establishment of a trusting bond with the mothers, with whom they felt comfortable to share their experience.

Conclusion

The findings of this study showed that in caring for parents who have experienced an IPL, primary healthcare midwives leave their comfort zone. They experience high emotional demands and lack of knowledge and must engage in support and communication with specialized healthcare. The absence of care guidelines and the lack of recognition of primary healthcare in care recommendations can cause midwives to avoid encountering parents' suffering. However, they go beyond task-focused care, providing care based on their intuition, when they find motivation to get more involved.

Education and training are required in order to prepare midwives for encounters with parents who have suffered an IPL. Leadership is also needed to facilitate care continuity through the improvement of communication between specialized and primary healthcare and the promotion of the welfare of midwives. This study fills a gap by elucidating the meaning of primary healthcare midwives' lived experiences, and can bring about change in clinical practice, by informing improvement efforts in the care of parents who suffer IPLs.

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Supporting Information

- Standards for Reporting Qualitative Research (SRQR) (see Appendix 5)

Chapter 4: General discussion

The aim of this doctoral thesis is to improve the care provided in these situations of loss, through the knowledge of the experiences of parents and nurses and midwives regarding pregnancy and baby losses. Although scientific advances have now contributed to reducing perinatal mortality, these losses remain a relatively common occurrence, especially early ones (Heazell et al., 2019).

Next, the discussion will be approached according to the two axes of the doctoral thesis.

4.1 Parents' experiences following a pregnancy and baby loss

Studies one (Fernández-Basanta et al., 2019) and two (Fernández-Basanta et al., 2020a) address the coping experience of parents after pregnancy and baby losses. Both studies reflected the process of connectedness and disconnectedness reported by Van (2012) in the Multicultural Model of Coping after Pregnancy Loss. Connectedness was associated with talking with their social environment, connecting with the baby and searching for the meaning of the loss. Through these strategies, parents were able to normalize their feelings, validate their loss, legitimize their child's existence and reduce social isolation. In addition, in environments that normalized these losses, parents could be transparent with their surroundings and feel relieved to share their experience.

The literature has also reported how helpful it is to talk to others, especially those who have gone through similar losses. Sharing these experiences helps them to normalize their feelings (Cacciatore & Bushfield, 2007). Feeling that they were not the only ones to whom this event happened was important to build their grief. For example, in early losses, talking helped validate their loss. These losses lacked tangible proof of the baby's existence that is present in later losses, such as physical changes in a woman's body that are socially perceptible, or memories recorded through photographs, footprints, or ultrasounds (Fernandez et al., 2011; Garrod & Pascal, 2019).

Connectedness was especially important and helpful in these losses, because they were still considered taboo losses and were made invisible by social and health environments and some parents consequently perceived a lack of social and health support (France et al., 2013; Heazell, 2016).

This context may lead to avoidance or disconnectedness behaviours. Our findings showed that the reasons to avoid connecting with the loss were due to a protective mechanism, either because reviving the loss caused them pain or to avoid the reaction of others. This could contribute to the emotions being stored, to marital tensions arising, to not wanting to know about the loss process or to be isolated. However, according to the stage in the grieving process this may be associated either with adaptive or maladaptive responses (Dyregrov et al., 2016; Nazaré et al., 2013). In the early stages, like the women in the first study (Fernández-Basanta et al., 2019), the mean time between loss and the interview was a month, and this could suggest an adaptive response in the grieving process because the presence of avoidance behaviours by parents appears in the early stages of the grieving process.

On the other hand, the Motivational Theory of Coping (Skinner et al., 2003) suggests that the experiences of connectedness/confrontation and disconnectedness/avoidance are a back-and-forth process and are not mutually exclusive. Our results hint that this back-and-forth process may be conditioned by taboo that surrounds these losses, the social expectations that condition grief expression, the lack of response from HCPs, the lack of social acknowledgment of the loss, the type of loss, and the stage in the grieving process.

The influence that culture and society have on grief and coping strategies has been supported by the bibliography (Brownlee & Oikonen, 2004; Dallay, 2013; Fenstermacher & Hupcey, 2013; Van & Meleis, 2003). For instance, the literature suggests the existence of a grief hierarchy (Kofod & Brinkmann, 2017; Van & Meleis, 2003), where grief expressions are accepted depending on the type of loss. For instance, in early losses, suffering is less socially accepted and parents may be forced to constantly negotiate the importance of the loss and to perform actions that legitimize the existence of their pregnancy/baby (Kofod & Brinkmann, 2017; Leichtentritt & Weinberg-Kurnik, 2016; Meaney et al., 2017; Sawicka, 2016). Logsdon & Davis (2003) affirm that for social support to be considered useful, it must fulfil the expectations of the one receiving the support and should come from a person of trust. When these conditions are not in place, the person may leave their needs unfulfilled instead of receiving support from another source.

Furthermore, in some cultures, social context and religion establish that femininity is synonymous with motherhood, which means that when childlessness occurs, a woman is deprived of her gender identity and some mothers may experience social isolation (Gerber-Epstein et al., 2009). However, religion can also have a protective effect for mothers, since it helps them make sense of the loss and cope with bereavement (Abdel-Razeq & Al-Gamal, 2018; Roberts & Lee, 2014). Our results (Fernández-Basanta et al., 2020a) show that when parents did not get answers that allow them to make sense of the loss, they looked to other resources, such as religion or superstition.

The influence of social expectations was also reported in men. Healthcare system and social circles did not recognize men as bereaved fathers, which results in the worsening of their psychological recovery (Leichtentritt & Weinberg-Kurnik, 2016; Obst & Due, 2019). This was due to the social belief that men should be caregivers, sources of strength and repress their emotions to keep the situation under control and be a comfort to the woman (Due et al., 2017).

Implications for practice and education

Giving emotional attention to the parents who have experienced pregnancy and baby loss requires the provision of transcultural nursing care based on knowledge of the cultural context and background of the parents (Leininger, 1995), and the provision of a whole care (Eriksson, 1992, 1994, 1997, 2002; Eriksson et al., 2006; Lindström et al., 2006). The provision of resources to prove the existence of the pregnancy/baby and of spaces where parents can express their grief is fundamental to legitimizing their loss (Martel & Ives-Baine, 2018; O'Leary & Warland, 2013).

It is important that HCPs acknowledge the pregnancy and baby loss and the individuality of this grief in both women and men. Individuals cope with and build the loss according to their situational factors, internal, and external (Dallay, 2013; Fenstermacher & Hupcey, 2013; Van & Meleis, 2003). Therefore, care should contemplate an individual approach adapted to the needs of parents and not the creation of care protocols that generate barriers to the provision of comprehensive and individualized care.

On the other hand, follow-up interventions must be carried out, to find out how women are coping with the loss after leaving the hospital, because avoidance behaviours are frequent in the early stages of loss.

Nurses and midwives should provide whole care, and because of their proximity to parents, they should be the reference professional for parents (Capitulo, 2005), although the involvement of all HCPs is required. For that, grief training is necessary. It is important that they know about the grieving process and its symptoms. With this knowledge, nurses and midwives can give women educational resources to cope with a loss, helping women to understand that grief is a normal and healing process that occurs after a loss. In addition, this education could be extended to the close social environment of the women because these are the main support people. In our results, the feeling of normality and support was acquired by talking with other women with similar experiences. Finally, with this knowledge, the detection of pathological grief could be identified if it occurs.

Strengths and limitations

Both studies offer insight into the coping experiences of women and men after a pregnancy and baby loss. These results, due to their heterogeneous character and based on previously developed models in other cultural contexts, demonstrate the transferability of the results. For example, the results of Fernández-Basanta et al. (2019) have contributed to expanding the theoretical model Multicultural Model of Coping after Pregnancy Loss (Van, 2012), by developing the concepts of connectedness or disconnected.

On the other hand, the comprehensive search strategy of Fernández-Basanta et al. (2020) ensured that the review was based on studies conducted in geographical contexts with unique and defining characteristics and on various types of losses, providing a more complete vision of the phenomenon.

The incorporation of involuntary pregnancy losses along with TOPFAs and neonatal deaths could be understood as a limitation. However, the bibliography supports the expansion of the concept (Fenstermacher & Hupcey, 2013; López García de Madinabeitia, 2011).

Regarding the masculine perspective, men are underrepresented in the literature (Cacciatore et al., 2013). This made it difficult to describe the male coping experience, as well as the generalization of the findings to countries outside western contexts.

Further research

Further research on men may also extend the work of Van (2012) on the coping mechanisms after the loss of a pregnancy. Research in other cultures, in different age groups and in different types of pregnancy loss, will broaden the knowledge of grief and, therefore, its proper management by HCPs.

4.2 Nurses and midwives' experiences in the care of involuntary pregnancy losses

Fernández- Basanta et al., (2020) together with study four show the care experiences of involuntary pregnancy losses of hospital midwives and nurses, and primary care midwives.

Eriksson (Eriksson, 1997, 2002; Lindström et al., 2006) states that basic motive of caring is the *caritas motive*, where *caritas* is defined as altruistic love expressed in action (Arman & Rehnsfeldt, 2006). The readiness of nurses and midwives to share the parents' struggle of suffering is an essential aspect of caritative caring (Arman & Rehnsfeldt, 2007). In a context of scarcity of economic resources and marked masculine technological thinking, nurses and midwives may feel insecure when providing *caritative* care, for fear of being labelled as weak or unprofessional (Arman & Rehnsfeldt, 2006; Nortvedt, 2001). From a clinical point of view, *caritas* in western health systems means going beyond a role. From the nurse this requires competence, motivation and moral integrity (Arman & Rehnsfeldt, 2006). Our findings (Fernández-Basanta et al., 2020b; study 4) showed that apart from competencies and support, it was *ethos*, or human value base, that motivated nurses and midwives to care for parents who have suffered an involuntary pregnancy loss.

Nurses confront human suffering on a daily basis and are expected to provide genuine caring to alleviate people’s distress rather than simple task-oriented responses (Eriksson, 1997, 2002; Huynh et al., 2008; Lindström et al., 2006). In the care of involuntary pregnancy losses, nurses and midwives are fundamental persons in that care and are better placed to build a genuine communion (Eriksson, 1997, 2002; Lindström et al., 2006; Nichols, 1984). This situation is especially facilitated in the case of primary healthcare midwives, as it is shown in study 4, since, in many cases, a previous relationship was previously established (Ellis et al., 2016; Gold, 2007). However, taking care of involuntary losses is a challenge for them (Fernández-Basanta, 2020b, and study 4).

According to our results (Fernández-Basanta et al., 2020b; study 4), care provided by nurses and midwives was based on their intuition or their personal and professional experiences. This is because guidelines do not address emotional care and, often, focus on specialized care that involves the acute moment of loss, but follow-up is hardly addressed (Koopmans et al., 2013; Peters et al., 2016). Furthermore, according to our results the care was mostly based on the performance of nursing tasks (Fernández-Basanta et al., 2020b; study 4). Nurses and midwives failed to establish a genuine communion with parents on many occasions.

This could be explained by the market mentality in health management systems, as it may encourage this technical care and non-emotional involvement of nurses and midwives with parents (Andipatin et al., 2019; Bolton, 2001; Hubbard et al., 2001; McQueen, 2000; Meerabeau, 1998). This biomedical predominance is more pronounced in services such as gynaecology, emergencies or surgery, where a wide variety of processes far from pregnancy losses are attended to. Therefore, the care could be mainly addressed to the accomplishment of medical tasks or may involve the medicalization of emotional aspects (Hutti et al., 2016, McCreight, 2005). In this sense, Maturo (2012) referred that the processes related to mental health are widely medicalized.

On the other hand, emotional engagement is seen as a requirement of excellence in nursing practice (Henderson, 2001). The benefits of establishing a trust relationship with patients was reported in a recent meta-ethnography (Strandås & Bondas, 2018). However, the development and maintenance of this trust relationship with parents implies work by nurses and midwives, which adds to the invisible and emotional labour that is generally not recognized in nursing (Smith, 1992).

According to Hochschild (1983), emotional labour refers to a worker’s endeavour to display emotions according to embedded social and cultural norms rather than what a health professional actually feels. Emotional labour may be viewed as a western construction within Descartes’ tradition of separating the rational mind from the emotional body (Huynh et al., 2008). However, caring implies feeling and feeling involves personal vulnerability (Henderson, 2001). Phillips (1996) showed that emotional labour is denigrated by its association with femininity and that it occupies a second level with respect to cognitive or technical abilities.

Our findings informed that difficulties in care encourage avoidance behaviours, and that nurses and midwives experienced emotional exhaustion when they were emotionally involved with parents (Fernández-Basanta et al. 2020b). The fact that emotional labour is not recognized - and is thus undervalued by the majority of healthcare organizations - may contribute to understanding the empirical link between emotional labour, emotional exhaustion and professional *burnout* (Hunter & Smith, 2007; Huynh et al., 2008). For instances, in early losses, due to the high frequency in clinical practice, this exhaustion is often associated with the loss of ability to provide compassionate care and a decrease in care quality (Houck, 2014).

In this sense, clinical supervision, understood as interprofessional support and guidance and reflection, has been recognized by the literature as useful for improving professional growth and collegiality, and preventing burnout that risks the health of the nurse and nursing care (Bondas, 2010).

Regarding follow-up, poor communication between specialized and primary healthcare could be difficult. Various strategic collaboration plans have been carried out in our context, but they have not been successful in terms of continuity care (Guzmán Fernández, 2011). In this sense, the Caritative Leadership theory (Bondas, 2003) establishes that the entire caring culture and the leader are responsible for what is happening in the organization, especially in situations of noncaring, uncaring, nonchalance, and provocation. Leadership is understood as a powerful and fundamental tool in the delineation and maintenance of the ethical value base, direction and content of nursing care in the complex demands of evidence-based, efficient and cost-effective nursing care (Bondas, 2009).

According to Sjølie et al. (2020), first-line nursing managers are essential for improving the quality of care by changing work practices in better outcomes for patients. However, in our context, as it has been shown in study 4, the assistance units are physically far from the management ones (Guzmán Fernández, 2011). Therefore, it is necessary to incorporate new forms of leadership and to professionalize management and strengthen competences and skills that include professionalism, leadership, decision-making, conflict management and problem-solving skills (Lemetti et al., 2015).

Finally, dealing with death needs adequate knowledge about dying care (Zomorodi & Lynn, 2010). According to Begley (2003), structured support during clinical experiences and education about bereavement and communication are necessary to be included in the training of midwives and nurses. However, in western societies, death - and particularly perinatal loss - is taboo and it means the antithesis of the expected in the midwifery discipline (Granero-Moya et al., 2016; Lang et al., 2011). For instance, our results (study 4) showed that midwives did not know how to approach the father. This may be due to the lack of a previous tie and to the fact that the encounters with the midwife were carried out as a couple and the man wanted to keep the façade of strength in front of the woman. The literature highlights that the lack of knowledge of HCPs regarding men's experiences may lead to helplessness and marginalization (Due et al., 2017; McCreight, 2004).

Implications for practice and education

Both studies inform the body of knowledge in nursing science and enhance a change in clinical practice, since the results show the complexity of the care experience of nursing and midwifery in involuntary pregnancy losses.

Nurses and midwives require an organizational culture that is supportive for the development of a caring culture. At the formative level, the focus should be on the provision of whole care and the establishment of genuine communion with parents. Therefore, training should be aimed at developing and strengthening skills that favour the connection with parents, and the provision of tools for managing the emotional demands of caring. Nursing leaders, due to their position among administration, nursing staff and the proximity to care, are key to favouring the interconnection and the construction of bridges between them.

Strengths and limitations

Our results show the experiences of nurses in caring for parents who have suffered an involuntary loss of pregnancy.

The use of a methodology such as meta-ethnography has been useful to identify research gaps; to inform the development of primary studies; and to provide evidence for the development, implementation, and evaluation of health interventions (Lachal et al., 2017; Tong et al., 2012). This methodology involves a conceptual development that implies a fresh contribution to the literature, beyond the narrative and systematic literature reviews (Britten et al., 2002). In addition, a comprehensive search strategy was carried out with the possibility of including articles in English, Spanish, and Portuguese, and, therefore, from different cultural contexts.

On the other hand, both studies were conducted according to guidelines that ensure the quality of the process. The elaboration of the meta-ethnography followed the eMERGe reporting guidance (France et al., 2019). The utilization of this guidance improves the transparency and completeness of reporting and facilitates that the review findings contribute to robust evidence. While study 4, was in line with the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

Regarding the sample, both studies provide the experiences of nurses and midwives of specialized care (Fernández-Basanta et al., 2020b) and primary care (study 4). The latter offers a novel contribution not previously addressed in the body of knowledge.

Regarding the limitations, the cultural contexts of primary articles are located exclusively in western countries. On the other hand, the sample of the primary articles is almost exclusively feminine.

Further research

To expand knowledge of the care experience in involuntary pregnancy losses, further research focused on other HCPs, who in many cases have the most lasting contact with parents, is required. Besides, it would be beneficial to know the personal experience of nurses and midwives in caring for these losses. This perspective would provide us with valuable information for practice and the education of future nursing professionals.

Chapter 5: Conclusion

1. Parental coping strategies following a pregnancy or baby loss were based experiences of connectedness/confrontation and disconnectedness/avoidance, exhibiting a back-and-forth process between them.
2. Connectedness/confrontation was associated with talking with their social environment, connecting with the baby and searching for the meaning of the loss.
3. Parents used strategies associated with connectedness/confrontation to normalize their feelings, not to pretend to their social environment, validate their loss, legitimize their child's existence and reduce social isolation.
4. Avoidance or disconnectedness behaviours were due to a protective mechanism, either because reviving the loss caused them pain or to avoid the reaction of others.
5. The use of coping strategies was conditioned by the taboo that surrounds these losses, the social expectations that condition grief expression, the lack of response from HCPs, the lack of social acknowledgment of the loss, the type of loss, and the stage in the grieving process.
6. Culture and society influenced grief and coping strategies.

7. Nurses and midwives dealt with organizational difficulties, lack of knowledge, and with care that required going beyond. This context encouraged task-focused care and avoidance of encounters and emotional connection with parents.
8. The care of involuntary pregnancy losses means for primary healthcare midwives leaving the comfort zone, due to the high emotional demand and lack of knowledge, support and communication with specialized healthcare.
9. The absence of care guidelines and the lack of recognition of primary healthcare in care recommendations could cause primary care midwives to avoid going beyond the provision of task-focused care because of their difficult encounters with grieving parents.
10. Some nurses and midwives went beyond in their care based on their intuition, when they had competencies, support, and a strong value base, despite the personal cost involved.

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Appendices

Appendix 1 - Keywords and Boolean operators

SPIDER tool	Data base	Search terms
Sample	**PubMed**	((((("Parents"[Mesh:exp]) OR “Nuclear Family” [mh]) OR “family” [tw]) OR “families” [tw]) OR "Women/psychology"[Mesh]) OR "Men/psychology"[Mesh]
	Scopus	(TITLE-ABS-KEY ("parents" OR "mother" OR "father" OR "Nuclear Family" OR "family" “women” OR "men"))
	CINAHL	TX: (MH "Women/PF") OR (MH "Men/PF") OR (MH "Parents+") OR (MH "Nuclear Family") OR (MH "Family/PF")
	PsichINFO	All fields: "parent$" OR "mother$" OR "father$" OR "nuclear famil*" OR "famil*" OR "women" OR "men"
	Web of Science	TS=(“Parent” OR “Father*” OR “Mother*” OR “Nuclear Family” OR famil* OR “women” OR “men”)
Phenomenon of **I**nterest	**PubMed**	(((((((((((((((("perinatal death"[MeSH Terms]) OR "perinatal loss" [tw]) OR "perinatal bereavement" [tw]) OR "Pregnancy Outcome"[Mesh]) OR "Fetal Death"[Mesh]) OR "Abortion, Spontaneous"[Mesh]) OR "Abortion, Eugenic"[Mesh]) OR "Stillbirth"[Mesh]) OR "Fetal Death"[Mesh]) OR "neonatal death" [tw]) OR "miscarriage" [tw]) OR "Abortion, Induced"[Mesh]) OR "pregnancy termination" [tw]) OR "Abortion, Therapeutic"[Mesh]) OR "fetal abnormality" [tw]) OR "fetal anomaly" [tw]) OR "perinatal grief" [tw])
	Scopus	(TITLE-ABS-KEY ("Perinatal Death" "perinatal loss" OR "perinatal bereavement" OR "Pregnancy Outcome" OR "fetal death" OR "Abortion, Spontaneous" OR "Abortion, Eugenic" OR "Stillbirth" OR "Fetal Death" OR "neonatal death" OR "miscarriage" OR "Abortion, Induced" OR "pregnancy termination" OR "Abortion, Therapeutic" OR "fetal abnormality" OR "fetal anomaly" OR "perinatal grief"))
	CINAHL	TX: (MH "Perinatal Death") OR ""perinatal loss"" OR "“perinatal bereavement”" OR (MH "Pregnancy Outcomes") OR "“Fetal Death”" OR (MH "Fetal Abnormalities") OR (MH "Abortion, Spontaneous") OR (MH "Abortion, Induced") OR ""Abortion, Eugenic"" OR ""Abortion, Therapeutic"" OR "“miscarriage”" OR "“neonatal death”" OR (MH "Pregnancy Termination Care (Iowa NIC)") OR "“pregnancy termination”" OR ""Stillbirth"" OR ""fetal anomaly"" OR "“perinatal grief”"
	PsichINFO	All fields: "perinatal death/" OR "perinatal loss" OR "perinatal bereavement" OR "Pregnancy Outcome" OR "fetal death/" OR "Abortion, Spontaneous" OR "Abortion, Eugenic" OR "Stillbirth/" OR "neonatal death/" OR "miscarriage/" OR "Abortion, Induced" OR "pregnancy termination" OR "Abortion, Therapeutic" OR "fetal abnormal*" OR "fetal anomal*" OR "perinatal grief"
	Web of Science	TS=(“perinatal death*” OR “perinatal loss” OR “perinatal bereavement” OR "Pregnancy Outcome" OR “fetal death” OR "Abortion, Spontaneous" OR "Abortion, Eugenic" OR “Stillbirth” OR “Fetal Death*” OR “neonatal death*” OR miscarriage* OR "Abortion, Induced" OR “pregnancy termination” OR "Abortion, Therapeutic" OR “fetal abnormality” OR “fetal anomaly” OR “perinatal grief”)
Design	**PubMed**	(((((((“phenomenology” [tw]) OR “grounded theory” [tw]) OR “ethnography” [tw]) OR “interview” [tw]) OR “interviews” [tw]) OR “focus group” [tw]) OR "Narration"[Mesh]) OR "narrative*" [tw]
	Scopus	(TITLE-ABS-KEY ("phenomenology" OR "grounded theory" OR "interview" "focus group" OR "Narration" OR "Narrative*"))
	CINAHL	TX: (MH "Interviews+") OR (MH "Focus Groups") OR (MH "Narratives")
	PsichINFO	All fields: "phenomenology" OR (“grounded theory”) OR (“ethnography ”) OR “interview$” OR (“focus group”) OR "Narration" OR "narrative$"
	Web of Science	TS=(phenomenology OR “grounded theory” OR ethnography OR “interview*” OR “focus group” OR "Narration" OR "Narrative*")
Evaluation	**PubMed**	((((((((((((((“experience”[tw]) OR “experiences”[tw]) OR “view” [tw]) OR “opinion” [tw]) OR “opinions” [tw]) OR “attitude” [tw]) OR “attitudes” [tw]) OR “perception” [tw]) OR “perceptions” [tw]) OR “beliefs” [tw]) OR “feelings” [tw]) OR "knowledge" [tw]) OR “needs” [tw]) OR "Adaptation, Psychological"[Mesh]) OR “coping” [tw]
	Scopus	(TITLE-ABS-KEY ("experience" OR "coping" OR "view" OR "opinion" OR "attitude" OR "perception" OR "beliefs" OR "feelings" OR "knowledge" OR "needs" OR "Adaptation, Psychological"))
	CINAHL	TX: "“experience”" OR (MH "Life Experiences") OR (MH "Coping+") OR "“view”" OR "“opinion”" OR (MH "Attitude") OR (MH "Perception") OR "“beliefs”" OR (MH "Feeling (NANDA)") OR (MH "Knowledge") OR "“needs”" OR (MH "Adaptation, Psychological")

	PsichINFO	All fields: "coping" OR "cope$" OR "feeling$" OR "knowledge$" OR "need$" OR "Adaptation, Psychological" OR "experience$" OR "view$" OR "opinion$" OR "attitude$" OR "attitude$" OR "belief$"
	Web of Science	TS=("experience*" OR “coping*” OR “view*” OR “opinion*” OR “attitude*” OR “perception*” OR “belief*” OR “feeling*” OR “knowledge*” OR “adaptation psychological” OR “needs”)
Relevance	**PubMed**	(("Qualitative Research"[Mesh]) OR "qualitative" [tw])
	Scopus	(TITLE-ABS-KEY ("Qualitative Research" OR "qualitative"))
	CINAHL	TX: (MH "Qualitative Studies+") OR "qualitative"
	PsichINFO	All fields: "Qualitative Research" OR "qualitative"
	Web of Science	TS=("Qualitative Research" OR qualitative)

Appendix 2 - CERQual Evidence Profile[a]

Summary of review findings	Studies contributing to the review findings	Methodological limitations	Coherence	Relevance	Adequacy of data	Overall CERQual assessment of confidence	Explanation of decision
1. Searching for the meaning of the loss: Mothers searched for the meaning of the loss to make sense and have control over the chaos that the loss generates. Their sources were health providers, religion, superstitions, blame (husband/family, HCPs and themselves) and medical reasons.	Carolan and Wright (2016); Consonni and Petean (2013); Gopichandran et al. (2018); Maguire et al. (2015); Abdel-Razeq and Al-Gamal (2018)	Moderate concerns regarding methodological limitations since reflexivity and cultural or theoretical position of the authors were unclear.	Very minor concerns regarding coherence (data very consistent within and across studies)	Minor concerns regarding relevance (studies do not represent all the cultural contexts)	Minor concerns regarding adequacy as the richness of data was generally good, but one study provided very little detail regarding the self-blaming of mothers.	Moderate confidence	Very minor concerns about coherence; minor concerns about relevance and adequacy; and moderate concerns about methodological limitations
2. Talking about the experience: When mothers talked about the experience with others they knew other cases of loss, established social connections and reduced social isolation. Especially with their social circle, talking was comforting and allowed reciprocal support. Participating in support groups produced ambivalent feelings.	Carolan and Wright (2016); Gopichandran et al. (2018); Maguire et al. (2015)	Moderate concerns regarding methodological limitations since reflexivity and cultural or theoretical position of the authors were unclear.	Minor concerns regarding coherence (data consistent within and across studies)	Moderate concerns regarding relevance (studies were setting in two countries and not focusing on neonatal death)	Serious concerns regarding adequacy as the data was thin and the quantity was limited	Low confidence	Minor concerns about coherence; moderate concerns about methodological limitations and relevance; and serious concerns about adequacy

3. Looking to the future: This strategy allowed mothers to search for positive aspects in their experiences, and to achieve closure or close stages in the grieving process.	Lafarge et al. (2013)	Minor concerns regarding methodological limitations due to a lack of clarity regarding the cultural or theoretical position of the authors and the philosophical perspective in the study design	Minor concerns regarding coherence (data are consistent)	Serious concerns regarding relevance (only one study was setting in one country and focusing on one type of loss)	Serious concerns regarding adequacy as the quantity of data was limited, with only one study	Low confidence	Minor concerns about methodological limitations and coherence; and serious concerns about relevance and adequacy
4. Avoidance: Parents avoided contact with others and were distracted to protect themselves, not to worry about their social environment and to avoid the reaction of others.	Carolan and Wright (2016); Consonni and Petean (2013); Golan and Leichtentritt (2016); Gopichandran et al. (2018); Lafarge et al. (2013); Leichtentritt and Mahat-Shamir (2017); Leichtentritt and Weinberg-Kurnik (2016); Maguire et al. (2015); Nuzum et al. (2018); Pitt et al. (2016); Abdel-Razeq and Al-Gamal (2018)	Moderate concerns regarding methodological limitations since reflexivity and cultural or theoretical position of the authors were unclear.	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance	Minor concerns about regarding adequacy: The studies contributing to this finding were rich and varied, but men were underrepresented	Moderate confidence	Very minor concerns about coherence and relevance; minor concerns about adequacy; and moderate concerns about methodological limitations
5. Connecting with the baby:	Kofod & Brinkmann (2017); Lafarge et al.	Moderate concerns	Minor concerns regarding	Minor concerns	Minor concerns about regarding	Moderate confidence	Minor concerns about coherence,

Parents used tokens and symbolic acts to establish a bond with the baby and to legitimize the loss.	(2013); Leichtentritt and Mahat-Shamir (2017); McGuinness (2015); Meaney et al. (2017); Nuzum et al. (2018); Pitt et al. (2016)	regarding methodological limitations since reflexivity of the authors were unclear	coherence (data consistent within and across studies)	regarding relevance (studies do not represent all the cultural contexts)	adequacy: The studies contributing to this finding were rich and varied, but men were underrepresented		relevance and adequacy; and moderate concerns about methodological limitations

*Definitions of levels of confidence from the CERQual evaluation (Lewin et al., 2015):

- **High confidence**: It is highly likely that the review finding is a reasonable representation of the phenomenon of interest.
- **Moderate confidence**: It is likely that the review finding is a reasonable representation of the phenomenon of interest.
- **Low confidence**: It is possible that the review finding is a reasonable representation of the phenomenon of interest.
- **Very low confidence**: It is not clear whether the review finding is a reasonable representation of the phenomenon of interest.

Appendix 3 - eMERGe Reporting guideline

		Pages
Phase 1 Selecting meta-ethnography and getting started	**1. Rationale and context for the meta-ethnography** *Describe the gap in research or knowledge to be filled by the meta-ethnography, and the wider context of the meta-ethnography*	2-5
	2. Aim(s) of the meta-ethnography *Describe the meta-ethnography aim(s)*	4
	3. Focus of the meta-ethnography *Describe the meta-ethnography review question(s) (or objectives)*	4
	4. Rationale for using meta-ethnography *Explain why meta-ethnography was considered the most appropriate qualitative synthesis methodology*	5; 30
Phase 2 Deciding what is relevant	**5. Search strategy** *Describe the rationale for the literature search strategy*	5-6
	6. Search processes *Describe how the literature searching was carried out and by whom*	6-7
	7. Selecting primary studies *Describe the process of study screening and selection, and who was involved*	6-7
	8. Outcome of study selection *Describe the results of study searches and screening*	6-7
Phase 3 Reading included studies	**9. Reading and data extraction approach** *Describe the reading and data extraction method and processes*	8-9
	10. Presenting characteristics of included studies *Describe characteristics of the included studies*	10-13

Phase 4 Determining how studies are related	**11. Process for determining how studies are related** *Describe the methods and processes for determining how the included studies are related:* *- Which aspects of studies were compared* *AND* *- How the studies were compared*	8-9
	12. Outcome of relating studies *Describe how studies relate to each other*	8-9
Phase 5 Translating studies into one another	**13. Process of translating studies** *Describe the methods of translation:* • *Describe steps taken to preserve the context and meaning of the relationships between concepts within and across studies* • *Describe how the reciprocal and refutational translations were conducted* • *Describe how potential alternative interpretations or explanations were considered in the translations*	8-9
	14. Outcome of translation *Describe the interpretive findings of the translation.*	14-27
Phase 6 Synthesizing translations	**15. Synthesis process** *Describe the methods used to develop overarching concepts ("synthesized translations") Describe how potential alternative interpretations or explanations were considered in the synthesis*	8-9
	16. Outcome of synthesis process *Describe the new theory, conceptual framework, model, configuration, or interpretation of data developed from the synthesis*	14-15
Phase 7 Expressing the synthesis	**17. Summary of findings** *Summarize the main interpretive findings of the translation and synthesis and compare them to existing literature*	27
	18. Strengths, and limitations	30-31

	Reflect on and describe the strengths and limitations of the synthesis: - ***Methodological aspects:*** *for example, describe how the synthesis findings were influenced by the nature of the included studies and how the meta-ethnography was conducted.*	
	19. Recommendations and conclusions *Describe the implications of the synthesis*	31-32

Appendix 4 - CERQual Evidence Profile[b]

Summary of review findings		**Studies contributing to the review findings**	**Methodological limitations**	**Coherence**	**Relevance**	**Adequacy of data**	**Overall CERQual assessment of confidence**	**Explanation of decision**
‘Forces that turn off the light’	Unsupportive organizational culture	(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Martínez-Serrano et al., 2018, McCreight, 2005, Nallen, 2006, 2007, Nash et al., 2018, Roehrs et al., 2008, Willis, 2019)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Minor concerns regarding relevance (One study included self-employed midwives as a sample)	No concerns about adequacy of data. There were rich data to support the finding across many studies.	Minor concerns	Very minor concerns regarding coherence; no concern about adequacy of data; and minor concerns regarding methodological limitations and relevance
	Lack of preparation and knowledge	(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Jonas-Simpson et al., 2010, Jones and Smythe, 2015, Martínez-Serrano et al., 2018, McCreight, 2005, Nallen, 2006, 2007, Nash et al., 2018, Roehrs et al., 2008, Willis, 2019)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	No concerns about adequacy of data. There were rich data to support the finding across all the studies.	Very minor concerns	Very minor concerns regarding coherence and relevance; no concern about adequacy of data; and minor concerns regarding methodological limitations
	Emotionally demanding care	(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Jonas-Simpson et al., 2010, Martínez-Serrano et al., 2018, McCreight, 2005, Nallen, 2006, 2007, Nash et al., 2018, Roehrs et al., 2008, Willis, 2019)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Minor concerns as the data was rich	Minor concerns	Very minor concerns regarding relevance and coherence; and minor concerns regarding methodological limitations and adequacy of data

	Leader and peer support and guidance	(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Jonas-Simpson et al., 2010, Martínez-Serrano et al., 2018, McCreight, 2005, Nallen, 2006, 2007, Nash et al., 2018, Roehrs et al., 2008)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Moderate concerns as the data was partially rich	Minor concerns	Very minor concerns regarding coherence and relevance; moderate concern about adequacy of data; and minor concerns regarding methodological limitations
‘Strengths to go into darkness’	Professional and personal experiences	(Beaudoin and Ouellet, 2018, McCreight, 2005, Nallen, 2006, 2007, Nash et al., 2018, Roehrs et al., 2008)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Moderate concerns as the data was partially rich	Minor concerns	Very minor concerns regarding coherence and relevance; moderate concern about adequacy of data; and minor concerns regarding methodological limitations
	Convictions about care	(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Jonas-Simpson et al., 2010, Martínez-Serrano et al., 2018, McCreight, 2005, Roehrs et al., 2008, Willis, 2019)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Minor concerns as the data was rich	Minor concerns	Minor concerns about methodological limitations and adequacy of data; very minor concern about coherence and relevance
‘Avoiding stumbling’	Task-focused care	(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Nash et al., 2018)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Moderate concerns as the data was partially rich	Minor concerns	Minor concerns about methodological limitations; moderate concerns regarding adequacy of data; and very minor concerns about relevance and coherence

	Avoiding encounters with parents	(Beaudoin and Ouellet, 2018, Nallen, 2006, 2007, Roehrs et al., 2008)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Moderate concerns regarding relevance (No studies include early pregnancy loss)	Moderate concerns as the data was partially rich	Moderate concerns	Minor concerns about methodological limitations; very minor concerns about coherence; and moderate concerns regarding adequacy of data and relevance
	Avoiding emotional connection	(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Jones and Smythe, 2015, Martínez-Serrano et al., 2018, Nallen, 2006, 2007, Nash et al., 2018, Roehrs et al., 2008, Willis, 2019)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Minor concerns regarding relevance (All studies included nurses and midwives as a sample, but early pregnancy loss was not included)	Minor concerns about adequacy of data. There were rich data to support the finding across all the studies.	Minor concerns	Very minor concerns about coherence; and minor concerns about methodological limitations, relevance and adequacy of data
‘Groping in darkness’		(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Jones and Smythe, 2015, Martínez-Serrano et al., 2018, McCreight, 2005, Nallen, 2006, 2007, Roehrs et al., 2008, Willis, 2019)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Minor concerns regarding relevance (All studies included nurses and midwives as a sample, but early pregnancy loss was not included)	Minor concerns about adequacy of data. There were rich data to support the finding across all the studies.	Minor concerns	Very minor concerns about coherence; and minor concerns about methodological limitations, relevance and adequacy of data
‘Wounded after dealing with darkness’		(Beaudoin and Ouellet, 2018, Hutti et al., 2016, Jonas-Simpson et al., 2010, Jones and Smythe, 2015, McCreight, 2005, Nallen, 2006, 2007, Nash et al., 2018, Roehrs et al., 2008, Willis, 2019)	Minor concerns regarding methodological limitations since lack of clarity regarding the influence of the researcher in the investigation, and vice versa	Very minor concerns regarding coherence (data very consistent within and across studies)	Very minor concerns regarding relevance (All studies included nurses and midwives as a sample, focused on pregnancy loss, and were relevant to the review)	Very minor concerns about adequacy of data. There were rich data to support the finding across many studies.	Very minor	Very minor concerns about coherence, relevance and adequacy of data; and minor concerns regarding methodological limitations

*Definitions of levels of confidence from the CERQual evaluation (Lewin et al., 2015):

- **High confidence**: It is highly likely that the review finding is a reasonable representation of the phenomenon of interest.
- **Moderate confidence**: It is likely that the review finding is a reasonable representation of the phenomenon of interest.
- **Low confidence**: It is possible that the review finding is a reasonable representation of the phenomenon of interest.
- **Very low confidence**: It is not clear whether the review finding is a reasonable representation of the phenomenon of interest.

Appendix 5 - Standards for Reporting Qualitative Research (SRQR)

Standards for Reporting Qualitative Research (SRQR)		
Topic		**Page (P.) or comment**
Title and abstract	Title	Yes
	Abstract	P. 1
Introduction	Problem formulation	P. 2
	Purpose or research question	P. 3
Methods	Qualitative approach and research paradigm	P.3
	Researcher characteristics and reflexivity	P.4
	Context	P. 4 and 7
	Sampling strategy	P. 5
	Ethical issues pertaining to human subjects	P. 6
	Data collection methods	P. 5
	Data collection instruments and technologies	P. 5
	Units of study	Table 2
	Data processing	P. 6
	Data analysis	P. 6-7
	Techniques to enhance trustworthiness	P. 3-4
Results/findings	Synthesis and interpretation	P. 7
	Links to empirical data	P. 8-14
Discussion	Integration with prior work, implications, transferability, and contribution(s) to the field	P. 15-18
	Limitations	P. 18
Others	Conflicts of interest	Title page
	Funding	Title page

Appendix 6 – Spanish summary

Introducción

La pérdida del embarazo -pérdidas involuntarias y terminaciones del embarazo debido a anomalías fetales- y la muerte neonatal generan una respuesta variada, dinámica y altamente individualizada en los padres. La investigación reconoce las características especiales de estas pérdidas, por las múltiples pérdidas que conlleva para los padres. Sin embargo, el estigma que rodea a estas pérdidas hace que se consideren pérdidas tabúes y que se silencien e invisibilicen en los entornos sociales y sanitarios.

El cuidado de los profesionales sanitarios, y en especial de enfermeras y matronas, es crucial para el bienestar a corto y largo plazo de los padres. No obstante, los profesionales sanitarios informan lo poco preparado que se encuentran y de lo estresante y exigente que resulta el cuidado de estas pérdidas. Diversas dificultades a la hora de cuidar generan que a menudo este cuidado sea superficial y basado en la realización de técnicas.

Perspectivas teóricas

Para el desarrollo de esta investigación se han utilizado tres enfoques metodológicos, que se detallarán a continuación.

Los padres utilizan estrategias de afrontamiento para reducir, manejar y vivir con los síntomas naturales físicos, mentales y emocionales del dolor (Puigarnau, 2008). El afrontamiento se ha definido como un conjunto de comportamientos conscientes o inconscientes para lidiar con eventos estresantes de la vida.

El *Modelo Multicultural de Afrontamiento después de la Pérdida del Embarazo* (Van, 2012, p.77), posteriormente expandido (Fernández-Basanta et al., 2019), postula que la conexión es el concepto central que facilita el manejo después de la pérdida involuntaria del embarazo, y la desconexión es el concepto central que inhibe el afrontamiento.

La *Teoría de la Motivación de Afrontamiento* (Skinner et al., 2003) se utilizó para cumplir con nuestro objetivo de estudio y para profundizar y proporcionar un marco teórico mejorado. Esta teoría plantea 12 familias de tipos de acción de orden superior, organizadas en torno a tres tipos de preocupaciones. Cada uno representa una clase de preocupaciones que los humanos pueden detectar y desencadenan patrones organizados de respuesta de comportamiento biológico o tendencias de acción.

Finalmente, también se ha empleado la *Teoría del Cuidado Caritativo* (Eriksson, 1992, 1994, 1997, 2002; Eriksson et al., 2006; Lindström et al., 2006). Esta teoría supone que el cuidado es el núcleo de la enfermería. El cuidado caritativo implica un encuentro de cuidado entre el ser humano que sufre y el cuidador que se basa en sus propias experiencias y deseos.

Ontológicamente, el ser humano se concibe como una entidad indivisible que incluye cuerpo, alma y espíritu. El espíritu de cuidado incluye caritas, amor y caridad; el respeto de los profesionales de la salud por la dignidad de la persona; y un esfuerzo por una comunión genuina y la comprensión del ser humano único. El c*aritas* representa el amor incondicional que constituye el motivo del cuidado. Por lo tanto, el cuidado caritativo se basa en la relación entre la persona que necesita y espera atención y la persona que brinda el cuidado, a través de la comunión genuina y la comprensión de la singularidad del ser humano.

Objetivos

Los objetivos generales de esta tesis han sido conocer el afrontamiento de los padres después de un embarazo o pérdida del bebé y conocer las experiencias de enfermeras y matronas en el cuidado de las pérdidas involuntarias del embarazo.

1. Conocer las experiencias de afrontamiento de los padres que han sufrido la pérdida de un embarazo o pérdida del embarazo o perinatal.
    1.1 Primer estudio: **Fernández-Basanta, S., Van, P., Coronado, C., Torres, M., & Movilla-Fernández, M. J. (2019). Coping after involuntary pregnancy loss: Perspectives of Spanish European women. OMEGA-Journal of Death and Dying, 0030222819852849**.
        - Identificar las estrategias de afrontamiento de las mujeres españolas después de sus experiencias de pérdida de embarazo

    1.2 Segundo estudio: **Fernández-Basanta, S., Coronado, C., & Movilla-Fernández, M. J. (2020). Multicultural coping experiences of parents following perinatal loss: A meta-**

ethnographic synthesis. Journal of Advanced Nursing, 76(1), 9-21.

- Sintetizar el cuerpo de conocimiento cualitativo disponible sobre cómo los padres afrontan la pérdida perinatal.

2. Conocer las experiencias de matronas y enfermeras en el cuidado de la pérdida de embarazos.

   2.1 Tercer estudio: **Fernández-Basanta, S., Movilla-Fernández, M. J., Coronado, C., Llorente-García, H., & Bondas, T. (2020). Involuntary Pregnancy Loss and Nursing Care: A Meta-Ethnography. International Journal of Environmental Research and Public Health, 17(5), 1486**.

   - Sintetizar el cuerpo de conocimiento cualitativo disponible sobre cómo las matronas y las enfermeras experimentan el cuidado de las pérdidas de embarazos.

   2.2 Cuarto estudio: **Primary healthcare midwives' experiences of caring for parents who have suffered an involuntary pregnancy loss: a phenomenological hermeneutic study** (bajo revision)

   - Iluminar las experiencias de las matronas de atención primaria de la salud que cuidan a los padres que han sufrido una pérdida involuntaria del embarazo.

Metodología

Esta tesis doctoral está compuesta de 4 estudios de investigación cualitativa, de los cuales un estudio empírico y una meta-etnografía fueron desarrollados para cada objetivo. [Para la visualización de las referencias, tablas y figuras ver capítulo 3: Compendio de publicaciones]

Objetivo 1, estudio 1: Fernández-Basanta, S., Van, P., Coronado, C., Torres, M., & Movilla-Fernández, M. J. (2019). Coping after involuntary pregnancy loss: Perspectives of Spanish European women. OMEGA-Journal of Death and Dying, 0030222819852849.

Este estudio fue aprobado por el Comité de Ética (código de registro 2015/232) y se desarrolló dentro del marco regulatorio actual del Consejo de Europa 1997; Consejo General de Enfermería, 1999; Ley 41/2002, de 14 de noviembre, de regulación básica de la autonomía del paciente y los derechos y obligaciones en materia de información y documentación clínica; Ley 14/2007, de 3 de julio, de investigación biomédica; Ley Orgánica 15/1999, de 13 de diciembre, de Protección de Datos Personales; Asociación Médica Mundial 2013). Las participantes del estudio fueron reclutadas por la colaboración de matronas y ginecólogas del Servicio de Ginecología y Obstetricia de un importante centro médico ubicado en el norte de España. Entregaron una hoja informativa sobre el estudio a los padres después de la pérdida del embarazo, en el que las madres proporcionaban sus datos de contacto para que la investigadora pudiese contactar con ellas. En el primer contacto, la investigadora y las madres establecieron citas en horarios y lugares convenientes para las madres. Los criterios de elegibilidad para el estudio incluyeron mujeres que informaron una experiencia reciente de pérdida de embarazo (por ejemplo, aborto involuntario, aborto eugenésico o muerte fetal), y fueron asignadas al Área de Salud específica del norte de España.

Se obtuvo el consentimiento informado de cada participante antes de la recopilación de datos. Antes de firmar el consentimiento, se proporcionó una hoja de información adicional con contenido relacionado con el estudio y sus derechos en el mismo. Se aseguró a las participantes que podrían detener la entrevista en cualquier momento y que podrían omitir cualquier pregunta que no quisieran responder. En todos los casos, las entrevistas se realizaron en el primer contacto con los padres, a solicitud de los padres. De las 16 entrevistas, 12 se realizaron en parejas (hombres y mujeres) y 4 solo con mujeres, aunque los resultados presentados aquí son solo de mujeres. Solo hubo una entrevista por participante. El tiempo promedio entre la pérdida y la entrevista fue de un mes.

Las entrevistas individuales se realizaron en el momento y lugar elegido por los participantes, generalmente en sus hogares. El método cualitativo utilizado para recopilar datos fue la teoría fundamentada (Charmaz, 2006).

Utilizando un formato de entrevista semiestructurada, se preguntó a los participantes sobre su experiencia de pérdida de embarazo. Desde su historia inicial, se exploraron preguntas sobre aspectos específicos, como estrategias y mecanismos de afrontamiento.

Las entrevistas fueron grabadas en audio. Después de completar las entrevistas, la investigadora escribió notas de campo. Las entrevistas fueron transcritas por la investigadora. Las grabaciones de audio fueron destruidas utilizando procedimientos industriales aceptables.

Demografía

La edad media de las 16 participantes fue de 35,18 años. La nacionalidad de todas las mujeres era española europea, aunque una era de América del Sur. El nivel de estudio de los participantes fue: educación básica (n = 2), formación profesional media (n = 3), formación profesional superior (n = 3) y estudios universitarios (n = 8). Excepto una, todos los participantes estaban casadas o en pareja. La mayoría (80%) estaban trabajando en el momento de su participación en el estudio. Su pérdida ocurrió de la siguiente manera: primer trimestre (n = 12), segundo trimestre (n = 3) o tercer trimestre (n = 1). Con respecto a su historial reproductivo: n = 8 tuvo hijos anteriores, n = 3 tuvo pérdidas previas y n = 3 se incluyeron en un programa de fertilidad.

Análisis de los datos

Las entrevistas fueron codificadas en sesiones individuales y grupales entre los autores. La construcción y confirmación de las categorías y temas relacionados se derivaron de los datos y las notas de campo. Se seleccionaron citas literales para ilustrar los temas y las perspectivas de los participantes. Los resultados preliminares se presentaron a un grupo de enfermeras registradas, que representaban una variedad de especialidades, pero predominantemente enfermería perinatal. Un grupo de enfermeras registradas en ejercicio, empleadas, en su mayoría, en unidades perinatales en Estados Unidos, proporcionaron comentarios para confirmar nuestra interpretación de los datos y ampliar nuestra comprensión de las implicaciones para la educación, la investigación y la práctica.

Objetivo 1, estudio 2: Fernández-Basanta, S., Coronado, C., & Movilla-Fernández, M. J. (2020). Multicultural coping experiences of parents following perinatal loss: A meta-ethnographic synthesis. Journal of Advanced Nursing, 76(1), 9-21.

Se llevó a cabo una revisión sistemática de estudios cualitativos utilizando la meta-etnografía para sintetizar los estudios con un análisis inductivo e interpretativo (Noblit y Hare, 1988). La revisión ha sido escrita de acuerdo con la guía eMERGe (France et al., 2019). La pregunta de investigación utilizada para guiar la estrategia de búsqueda fue la siguiente: ¿Cómo afrontan los padres la pérdida perinatal?

Métodos de búsqueda

En julio de 2018 se llevó a cabo una estrategia integral de búsqueda sistemática en las bases de datos PubMed, Scopus, CINAHL, PsychINFO y Web of Science. Esta búsqueda se complementó con búsquedas complementarias que incluían la verificación de referencias y la búsqueda de artículos citados.

Los términos de búsqueda se desarrollaron a partir de la pregunta de investigación utilizando la herramienta SPIDER (Cooke, Smith y Booth, 2012). Se utilizaron títulos de temas médicos (MeSH), descriptores CINAHL y palabras libres como términos de búsqueda. El operador booleano "AND" se utilizó para relacionar las consultas de búsqueda dentro de SPIDER (términos en diferentes columnas). Se emplearon truncamientos para garantizar una búsqueda amplia. Los límites seleccionados en las bases de datos fueron la fecha de publicación (entre 2013 y 2018) y el idioma (inglés, portugués y español). Decidimos establecer el inicio del rango de tiempo después de la publicación de la revisión sistemática Cochrane (Koopmans et al., 2013).

Los documentos se incluyeron si eran artículos cualitativos originales o artículos mixtos de los que se podían extraer los resultados cualitativos publicados entre 2013 y julio de 2018. Se centraron en la experiencia de los padres después de la pérdida perinatal. La inclusión se restringió a los estudios cuya muestra comprendía madres, padres o padres y cuyo tipo de pérdida fue aborto espontáneo, aborto eugenésico, muerte fetal o pérdida neonatal. Se excluyeron la literatura gris, los documentos de discusión o revisión y los artículos que no estaban en inglés, portugués o español.

Resultados de búsqueda

Las búsquedas en las bases de datos arrojaron 1029 registros y las búsquedas complementarias proporcionaron un registro adicional. El proceso de selección de los artículos comenzó con la eliminación de 281 artículos duplicados. Los títulos y resúmenes de los documentos recuperados (N = 749) se evaluaron con los criterios de inclusión y exclusión. Se examinaron los artículos completos seleccionados del título y la selección de resúmenes (N = 86) en relación con los criterios de inclusión y exclusión. En esta etapa, se excluyeron 72 artículos por no ser relevantes para el fenómeno de interés o por la muestra, metodología, tipo de pérdida, tipo de papel o idioma. En ambas etapas, todo el proceso de selección se llevó a cabo individualmente por cada autora y en sesiones de equipo, las autoras llegaron a un consenso. La muestra final fue de 14 artículos.

Valoración de calidad

Cada estudio primario se evaluó utilizando el Instrumento de Evaluación y Evaluación Cualitativa (QARI) del Instituto Joanna Briggs (JBI, 2017) para evaluar la investigación cualitativa. Se consideró que los artículos incluidos tenían una alta calidad con respecto a sus objetivos, diseños, análisis y resultados, proporcionando un conocimiento útil sobre el tema. La evaluación de calidad fue realizada en sesiones de equipo por todas las autoras.

Abstracción y síntesis de datos

Se siguió el método interpretativo meta-etnográfico de Noblit y Hare (1988), que consta de 7 pasos: 1) comenzar; 2) decidir qué es relevante para el interés inicial; 3) leer los estudios; 4) determinar cómo se relacionan los estudios; 5) traducir los estudios entre sí; 6) sintetizar traducciones; y 7) expresar la síntesis. Los estudios fueron leídos de forma independiente por cada autora hasta que todas las autoras estuvieran familiarizadas con su contenido (paso 3). Los artículos principales fueron leídos en orden alfabético por el apellido del autor principal de los estudios, clasificando el primer artículo como el más rico en términos de datos.

Los conceptos principales de primer orden (citas de los participantes) y de segundo orden (interpretaciones de los autores) (Schütz, 1962) fueron extraídos a través del estudio primario completo por SFB y MJMF y registrados en una tabla de Microsoft Word. Utilizando el método de comparación constante (Strauss y Corbin, 1990) (paso 4), SFB y MJMF compararon diferentes conceptos en busca de similitudes y contrastes, lo que condujo a la formación de nuevos conceptos y la adopción de conceptos existentes. Esto se realizó mediante la comparación sistemática y secuencial de conceptos utilizando las características registradas del estudio (año, ubicación, metodología, objetivo, tamaño y tipo de muestra, tipo de pérdida, métodos de recolección de datos y hallazgos clave) como contexto para las comparaciones.

En el paso 5, SFB y MJMF organizaron los conceptos en pilas conceptuales y luego discutieron y reorganizaron estas pilas. La yuxtaposición de las construcciones de primer y segundo orden a través de traducciones recíprocas y refutacionales condujo al desarrollo de construcciones de tercer orden (Schütz, 1962) por las autoras (SFB y MJMF), que incluyeron una nueva comprensión del fenómeno. CC, auditó independientemente la coherencia analítica de los hallazgos

Finalmente, en el paso 6, todas las autoras desarrollaron independientemente una historia del fenómeno (Noblit, 2016). Estas explicaciones generales se fusionaron, discutieron y utilizaron para generar hipótesis para producir la síntesis de la línea de argumentación (Atkins et al., 2008; France et al., 2019).

El enfoque Confianza en la evidencia de las revisiones de la investigación cualitativa (CERQual) se utilizó para mostrar el grado de confianza en los resultados de la revisión (Lewin et al., 2015).

Objetivo 2, estudio 3: Fernández-Basanta, S., Movilla-Fernández, M. J., Coronado, C., Llorente-García, H., & Bondas, T. (2020). Involuntary Pregnancy Loss and Nursing Care: A Meta-Ethnography. International Journal of Environmental Research and Public Health, 17(5), 1486.

Este estudio sigue las siete fases de síntesis descritas por Noblit y Hare (1988). Esta revisión se ha escrito de acuerdo con la guía de informes de metaetnografía eMERGe (France et al., 2019).

Métodos de búsqueda

En agosto de 2019, se llevó a cabo una estrategia de búsqueda sistemática integral en las bases de datos PubMed, Scopus, CINAHL, PsychINFO y Web of Science. Para maximizar la cobertura y mejorar la confiabilidad, se realizaron seguimientos y búsquedas manuales en nternational Journal of Nursing Studies, Midwifery, Birth, Women and Birth, Sexual and Reproductive Healthcare. La búsqueda se realizó sin limitaciones de tiempo. La estrategia de búsqueda se construyó de acuerdo con el fenómeno de interés (pérdida involuntaria del embarazo), el propósito del estudio o evaluación (experiencias de atención), la muestra (matronas y enfermeras) y el tipo de investigación (investigación cualitativa). En cada uno de ellos, se incluyeron términos de búsqueda y encabezados de temas médicos. Estos términos se combinaron utilizando los operadores booleanos OR, AND y NOT. Los truncamientos también se emplearon para garantizar una búsqueda amplia.

Se examinaron títulos, resúmenes y textos completos de artículos cualitativos o mixtos originales, y se incluyeron aquellos considerados adecuados de acuerdo con el objetivo de la investigación. La inclusión se restringió a estudios cuya muestra comprendía personal de enfermería y cuyo tipo de pérdida fuese aborto espontáneo y muerte fetal. Se excluyeron trabajos que no estaban en inglés, portugués o español. La elaboración de estrategias de búsqueda fue realizada por SFB.

Resultados de búsqueda

Las búsquedas en la base de datos arrojaron 742 registros. Las búsquedas complementarias no proporcionaron ningún registro adicional. El proceso de selección de los artículos comenzó con la eliminación de 281 artículos duplicados. Los títulos y resúmenes de 517 documentos recuperados se evaluaron con los criterios de inclusión y exclusión. Treinta y cinco artículos fueron leídos en su totalidad y examinados en relación con los criterios de inclusión y exclusión. En esta etapa, se excluyeron 25 artículos por razones de muestra, fenómeno de interés, tipo de pérdida, metodología y tipo de documento. En ambas etapas, SFB y HLLG ejecutaron todo el proceso de selección, y en sesiones de equipo con MJMF y CC, los autores llegaron a un consenso. La muestra final fue de 10 artículos.

Valoración de calidad

Se evaluó la calidad de cada estudio primario utilizando el Instrumento de Evaluación y Evaluación Cualitativa (QARI) del Instituto Joanna Briggs (JBI, 2017). Se consideró que los artículos incluidos tenían una alta calidad con respecto a sus objetivos, diseños, análisis y resultados, proporcionando un conocimiento útil sobre el tema. La evaluación de calidad se realizó en sesiones de equipo por SFB, HLLG y MJMF.

Extracción y síntesis de datos

La extracción y síntesis de datos fue dirigida por SFB. SFB llevó a cabo la extracción de datos inicial y posteriormente se discutió en sesiones de equipo. Implicó la relectura de los artículos incluidos para describir el objetivo, la muestra, el método, el tipo de pérdida, los métodos de recopilación de datos y los hallazgos clave de cada estudio, para proporcionar un contexto.

Los artículos principales se leyeron comenzando con el artículo más rico en términos de datos (paso 3). Los conceptos de primer y segundo orden (Schütz, 1962) fueron extraídos a través del estudio primario completo por SFB y registrados en una tabla de Microsoft Word. Utilizando el método de comparación constante (paso 4), SFB, TB y MJMF compararon diferentes conceptos en busca de similitudes y contrastes, lo que condujo a la formación de nuevos conceptos y la adopción de conceptos existentes. Esto se realizó mediante la comparación sistemática y secuencial de conceptos utilizando las características de estudio registradas.

En el paso 5, los conceptos fueron organizados por SFB en pilas conceptuales y luego las pilas fueron discutidas y reorganizadas por todas las autoras. Se determinó que los estudios cumplían los criterios para la traducción recíproca, por lo que se colocaron las construcciones de primer y segundo orden, lo que permitió el desarrollo de construcciones de tercer orden (Schütz, 1962). Estas nuevas comprensiones se agregaron a la síntesis recíproca, basándose en los temas y la metáfora (paso 6). Se desarrollaron cinco temas en relación con la preservación de los contenidos clave de los estudios. Todas las autoras estuvieron de acuerdo en los temas y subtemas y la metáfora general.

El enfoque Confianza en la evidencia de las revisiones de la investigación cualitativa (CERQual) se utilizó para mostrar el grado de confianza en los resultados de la revisión (CERQual).

Objetivo 2, estudio 4: Primary healthcare midwives’ experiences of caring for parents who have suffered an involuntary pregnancy loss: a phenomenological hermeneutic study (bajo revision)

Este estudio cualitativo utilizó un diseño hermenéutico fenomenológico inspirado en Ricoeur (1976) y desarrollado por Lindseth y Norberg (2004).

Lincoln y Guba (1985) propusieron los siguientes criterios de confiabilidad para llevar a cabo investigaciones naturalistas: "credibilidad", "confirmabilidad", "transferibilidad" y "confiabilidad". Este estudio se realizó manteniendo la adaptación y consistencia teórico-epistemológica. La credibilidad se garantizó mediante la presentación de datos de acuerdo con las interpretaciones de las autoras, junto con los comentarios de las matronas. Durante el análisis, se utilizaron las notas del investigador (recopiladas después de las entrevistas), el análisis fue triangulado por todas las autoras, y los resultados fueron ofrecidos a las matronas la posibilidad de reconocimiento y comentarios. Además, las reflexiones de las investigadoras sobre sus propias posiciones sobre el tema y una pista de auditoría que detalla el proceso de análisis de datos e interpretación de los datos garantizaron la confirmabilidad. La transferibilidad se facilitó mediante una descripción del contexto y los participantes. Para mejorar la fiabilidad, se presentan descripciones detalladas de la muestra del estudio, el proceso de recopilación de datos, el análisis y la interpretación de los datos, el papel de las investigadoras y las limitaciones del estudio.

El análisis y la interpretación de los datos fueron triangulados por las autoras para fortalecer la interpretación impugnando y complementando las lecturas de cada una. Todas las autoras fueron investigadoras cualitativas capacitadas que tenían experiencia trabajando en el tema de las pérdidas involuntarias del embarazo. Además, una de las autoras tiene experiencia profesional trabajando en un hospital ginecológico y en atención primaria de salud.

Las interpretaciones previas de las autoras que se abordaron durante el estudio fueron que la atención brindada después de una pérdida involuntaria del embarazo debe centrarse en el ser humano en su conjunto y continuar desde el hospital hasta la atención primaria y que la matrona es quien tiene las competencias para brindar atención y seguimiento a los padres que sufren una pérdida involuntaria del embarazo.

Participantes

Once matronas que trabajan en 10 centros de atención primaria en España participaron voluntariamente en el estudio. El número de participantes potenciales de los 10 centros fue de 13. Dos matronas no participaron (una debido a compromisos familiares y la otra no pudo ser contactada). Se realizó una muestra intencional, de acuerdo con el objetivo del estudio. Para reclutar participantes, dos autoras (SFB y MJMF) asistieron a la reunión mensual a la que asistieron todas las matronas de atención primaria. Los detalles del estudio se presentaron en la reunión y se proporcionó información escrita a los asistentes. Los criterios de inclusión fueron ser una matrona de atención primaria y tener experiencia en el cuidado de padres que han sufrido una pérdida involuntaria del embarazo.

Recopilación de datos

SFB recopiló datos a través de entrevistas narrativas entre febrero y abril de 2019. Los participantes pudieron elegir el lugar para la entrevista. La mayoría de las entrevistas se realizaron en las consultas de las matronas en los centros de salud. Dos se llevaron a cabo en la Facultad de Enfermería y Podología de la Universidad de X. Las entrevistas duraron un promedio de 60 minutos. Se utilizó una guía basada en una revisión de la literatura y conocimientos previos para realizar las entrevistas. Todas las entrevistas comenzaron con el mensaje "Cuénteme sobre su experiencia de cuidado de las pérdidas involuntarias del embarazo como matrona de atención primaria". Se utilizó una ruta de preguntas con temas principales basados en la investigación de la literatura y el conocimiento previo. Se hicieron preguntas adicionales que alentaron una narración adicional. Las notas de campo recopiladas después de las entrevistas se integraron en las transcripciones para enriquecer los datos. Las entrevistas se realizaron en español o gallego y fueron grabadas y transcritas por SFB. Se alcanzó la suficiencia de datos para permitir la iluminación del fenómeno.

Consideraciones éticas

Se proporcionó a las matronas información verbal y escrita sobre el estudio, y se obtuvo el consentimiento informado previo por escrito de cada participante. Se informó a todas las matronas sobre la confidencialidad garantizada, la participación voluntaria y el derecho a suspender la entrevista en cualquier momento. El estudio obtuvo la aprobación del Comité Autónomo de Ética de Investigación de Galicia (código de registro 2015/232) y tuvo el permiso de acceso por área de salud de X. Las entrevistas fueron anonimizadas y las grabaciones de audio fueron destruidas después de la transcripción.

Análisis de los datos

Las entrevistas transcritas se interpretaron utilizando un método hermenéutico fenomenológico desarrollado por Lindseth y Norberg (2004). El primer paso implicó una lectura ingenua, en la que tres autores (SFB, CC y MJMF) captaron el significado en su conjunto y formularon una comprensión ingenua del texto. A continuación, SFB realizó un análisis estructural. Cualquier texto relacionado con la experiencia de brindar atención a padres que han experimentado una pérdida involuntaria del embarazo se leyó varias veces. Se plantearon preguntas analíticas y se buscaron respuestas en el texto. El texto se dividió en unidades de significado que se basaron en el objetivo del estudio. Las unidades de significado se condensaron y resumieron para formar subtemas y temas preliminares, que se compararon con la comprensión ingenua para la validación. El análisis estructural se discutió en un movimiento dialéctico entre comprensión y explicación hasta que todas las autoras estuvieran de acuerdo. Finalmente, se elaboró una comprensión integral, basada en la comprensión ingenua, el análisis estructural, el contexto de estudio, los entendimientos previos de las investigadoras y las perspectivas teóricas. Durante este paso, TB auditó el proceso de análisis y los resultados.

Las interpretaciones previas de los autores se discutieron durante todo el proceso para evitar distorsiones en la interpretación de los datos. Estos procesos se registraron en notas. Para apoyar el análisis de datos, se utilizaron cuadrículas creadas para este propósito.

Resultados

A continuación, se presentan los principales resultados de cada artículo [Para la visualización de las referencias y citas textuales ver capítulo 3: Compendio de publicaciones]

Objetivo 1, estudio 1: Fernández-Basanta, S., Van, P., Coronado, C., Torres, M., & Movilla-Fernández, M. J. (2019). Coping after involuntary pregnancy loss: Perspectives of Spanish European women. OMEGA-Journal of Death and Dying, 0030222819852849.

Las mujeres de este estudio estaban abiertas a participar y hablar sobre sus experiencias. Durante la entrevista, parecían cómodas y, en muchos casos, dijeron que la entrevista fue terapéutica y expresaron su gratitud por tener la oportunidad de participar en el estudio. Algunas mujeres lloraron al recordar sus experiencias; se les dio la oportunidad de detener la entrevista, pero decidieron continuar. Debido al poco tiempo transcurrido desde su pérdida (un mes), describieron aspectos clínicos sobre su experiencia, tal vez en un esfuerzo por redirigir la discusión de temas emocionales más dolorosos.

A partir del análisis, se identificaron dos temas principales: hablar y evitar.

Hablar

Este tema se centró en por qué y con quién las mujeres usaron la conversación como estrategia de afrontamiento. Estos conversadores estaban conectados con las mujeres a nivel personal. Los participantes hablaron con mayor frecuencia con sus maridos/parejas, madres, hermanas y otros miembros de la familia. Hablaron con estas personas porque querían ser abiertas y transparentes con alguien en quien pudieran confiar.

Otro grupo que se destacó fueron las personas que tuvieron experiencias similares, como miembros de la familia o amigos cercanos que tuvieron un embarazo o pérdida fetal. Las mujeres destacaron que hablar con otras personas que tuvieron la misma experiencia fue beneficioso para ellas.

Algunos hablaron también con compañeros/as de trabajo, una situación más formal, porque no querían fingir delante de ellos.

Evitar

En las primeras etapas de la pérdida, algunas mujeres utilizaron la capacidad de afrontamiento evasivo con respecto a las conversaciones, por varias razones. La razón más frecuente para evitar la discusión de la pérdida se debió a su anticipación de respuestas negativas y sin apoyo de los demás. Otras razones incluyen el deseo de protegerse. La última razón para el uso de afrontamiento evitativo fue que evitaron la incomodidad de volver a contar la historia de la pérdida.

Objetivo 1, estudio 2: Fernández‐Basanta, S., Coronado, C., & Movilla‐Fernández, M. J. (2020). Multicultural coping experiences of parents following perinatal loss: A meta‐ethnographic synthesis. Journal of Advanced Nursing, 76(1), 9-21.

El análisis reveló la línea de argumento *Mantenerse a flote en la tormenta*. Esta metáfora representa la experiencia de afrontamiento de los padres después de la pérdida perinatal. Una vez que ocurre la pérdida, se desencadena una tormenta emocional que los padres deben superar. Lo que usan para mantenerse a flote simboliza las estrategias de afrontamiento. Estas estrategias pueden variar a lo largo de su viaje de duelo. Los 5 temas que surgieron fueron buscar el significado de la pérdida, mantenerse conectado con el bebé, hablar sobre la experiencia, mirar hacia el futuro y evitar.

La evaluación CERQual mostró poca confianza al hablar sobre la experiencia y mirar hacia el futuro, ya que estas estrategias estuvieron presentes en pocos estudios. La búsqueda del significado de la pérdida, la evitación y la conexión con el bebé mostraron una confianza moderada, lo que significa que es probable que representen razonablemente las experiencias de afrontamiento de los padres después de la pérdida perinatal.

1. Buscando el significado de la pérdida

Las madres buscaron el significado de la pérdida para tener sentido y ganar control sobre el caos que la pérdida generaba, en lugar de como un mecanismo para satisfacer o tolerar el dolor. Cuando las madres no obtuvieron una respuesta objetiva de los profesionales sanitarios acerca de la causa de la pérdida, algunas trataron de dar sentido a su pérdida a través de la religión. Las causas que encontraron en la religión oscilaron entre un propósito divino benevolente o un castigo divino. En las culturas india y árabe, algunas madres se refugiaron o renunciaron a la religión, dependiendo de si las respuestas proporcionadas por la religión fueron reconfortantes o no en su proceso de duelo.

Otros recursos utilizados fueron la superstición y culpar al marido y la familia, a los profesionales sanitarios y a ellas mismas. Por el contrario, las madres con un alto nivel educativo buscaron significado en causas médicas.

2. Hablando de la experiencia

Cuando las madres compartieron su pérdida con otras personas, descubrieron casos de pérdida que no conocían de antemano. Se dieron cuenta de que no eran las únicas que habían experimentado esta situación. De hecho, establecieron una conexión social y se sintieron aliviadas de la carga de aislamiento social. Para las madres, hablar con su círculo cercano fue reconfortante. Específicamente, el contacto de las madres con otras personas con experiencias similares facilitó el apoyo recíproco y redujo el aislamiento social.

Algunas madres participaron en grupos de apoyo online, que causaron sentimientos ambivalentes en función de su estado de ánimo al leer los comentarios; algunos se unieron a grupos de apoyo presenciales, lo que les permitió ubicarse en su propio proceso de curación, aunque a la larga, no fue útil participar en grupos de apoyo, ya que incluían personas que habían experimentado una variedad de pérdidas.

3. Mirar hacia el futuro

Una herramienta que las madres usaban para hacer frente a los abortos eugenésicos era mirar hacia el futuro. Esta estrategia permitió a las madres lograr el cierre o pasar por las etapas del proceso de duelo. Por ejemplo, el funeral proporcionó el cierre con respecto al aspecto físico de la pérdida. Mirar hacia el futuro también estaba vinculado a la búsqueda de aspectos positivos en sus experiencias, como racionalizar, llevar a cabo acciones de buena voluntad y centrarse en cuestiones no resueltas.

4. Evitar

Los padres informaron que usaron estrategias de evitación para lidiar con su pérdida y para protegerse, ya que se evitó y bloqueó el dolor de revivir la pérdida. Los padres distrajeron sus pensamientos mezclándose con su círculo social, realizando actividades rutinarias o cambiando su rutina anterior y volviendo al trabajo. Específicamente, las madres se distrajeron jugando el papel de madre con otros niños, mientras que los hombres se ocuparon de los demás.

Algunos padres no hablaron sobre la pérdida y no se relacionaron con su entorno social porque querían evitar las reacciones de los demás y no querían preocupar a su círculo social con manifestaciones de tristeza. Tampoco asistieron a consultas médicas.

Culturalmente, algunos padres evitaron expresar su dolor debido a la falta de aceptación social de estas pérdidas. En las pérdidas tempranas, esta evitación se exacerbó, ya que las expresiones de duelo están prohibidas en algunos entornos sociales.

Algunos padres también usaron estrategias para desconectarse del bebé, como negar la existencia del niño, no guardar recuerdos y bloquear los pensamientos y sentimientos sobre el bebé. Algunas madres incluso cuestionaron la conexión biológica o genética entre ellas y el bebé.

El uso de estrategias de evitación condujo a la supresión de las emociones y al surgimiento de tensiones dentro de la pareja debido a las diferencias en el enfrentamiento entre los sexos. Los intentos de no recordar, ver, hablar o experimentar generaron ignorancia sobre ciertos aspectos de la pérdida en los padres. Esto significó que algunos de ellos lamentaron no estar presentes durante el proceso.

Además, los padres experimentaron aislamiento social tanto por el uso de esta estrategia como por el tabú que rodea estas pérdidas.

5. Conectando con el bebé

Los padres utilizaron recursos para establecer un vínculo con su hijo, lo que les permitió mantener una conexión con su hijo y legitimar su pérdida, aunque fue doloroso. Esto fue especialmente importante en las pérdidas tempranas, ya que estas son pérdidas ambiguas que son socialmente invisibles, desconocidas y no reconocidas.

Los padres usaron recuerdos como un diario de embarazo, especialmente en pérdidas tempranas donde los recuerdos materiales eran escasos, cajas de recuerdos y fotografías. Los padres miraron estos recuerdos de forma privada, aunque en algunos casos las compartieron con su entorno social para que su bebé fuera reconocido socialmente. Por ejemplo, un estudio mostró que incluso para los hombres, el proceso de hacer una caja de recuerdos fue terapéutico, porque el tiempo que los padres dedicaron a hacer la caja fue tiempo para recordar al bebé.

Algunos padres realizaron rituales que los conectaron con el niño. Estos actos simbólicos implicaron encender una vela, escribir una publicación en un foro o hacer algo más permanente, como hacerse un tatuaje o plantar un árbol. El nombre del niño también lo conectó con ellos, ya que en algunos casos los padres pudieron usarlo con el próximo niño. La realización de estos rituales estaba condicionada culturalmente. En la cultura judía, los padres no podían realizar rituales de conexión pública, ya que no se aceptan las tradiciones de duelo por la pérdida temprana del embarazo.

Mantener vivo el recuerdo del bebé al hablar sobre ello en su entorno social, visitar lugares de recuerdo y realizar actos de recuerdo proporcionó a las madres el cierre y el reconocimiento social del bebé. En las pérdidas avanzadas, pasar tiempo con el bebé después del nacimiento favoreció la existencia y el refuerzo del vínculo.

Objetivo 2, estudio 3: Fernández-Basanta, S., Movilla-Fernández, M. J., Coronado, C., Llorente-García, H., & Bondas, T. (2020). Involuntary Pregnancy Loss and Nursing Care: A Meta-Ethnography. International Journal of Environmental Research and Public Health, 17(5), 1486.

Una síntesis recíproca, utilizando la metáfora *Cuidar en la oscuridad*, proporcionó explicaciones interpretativas de las experiencias de enfermeras y matronas en el cuidado de pérdidas involuntarias de embarazos. Esta metáfora, acompañada de 5 temas, simboliza la experiencia de cuidado de enfermeras y matronas en pérdidas involuntarias de embarazo. La cultura organizacional no solidaria, la falta de preparación o conocimiento y una atención emocional exigente, representada metafóricamente por *fuerzas que apagan la luz*, obstaculizaron el cuidado. La oscuridad también representa el estado emocional de los padres después de una pérdida de embarazo.

Entrar en la oscuridad causó miedo, porque las profesionales de la salud se sintieron sin preparación o sin apoyo, no querían dañar a los padres aún más, y debido a la implicación emocional que suponía involucrarse. A pesar de eso, contar con el apoyo y la orientación de líderes y pares, experiencias previas y una sólida base de valores alentó a las enfermeras a cuidar, la *fuerza para adentrarse en la oscuridad*.

Sin embargo, su motivo de cuidado puede no ser suficiente para muchas de ellas y decidieron evitar *tropezar*. Por eso, la atención prestada se centró en las tareas, en donde se evitaron encuentros y conexiones emocionales con los padres. Las que fueron más allá de las tareas trataron de cuidar de la mejor manera posible a pesar de las dificultades, *a tientas en la oscuridad*. *Lesionadas después de lidiar con la oscuridad* ilustra las consecuencias para las enfermeras y las matronas.

La evaluación CERQual mostró una gran confianza en todos los temas, lo que significa que es probable que representen razonablemente las experiencias de enfermeras y matronas en el cuidado de la pérdida involuntaria del embarazo.

1. "Fuerzas que apagan la luz"

La cultura organizacional no solidaria, la falta de conocimiento y preparación y el cuidado emocional exigente fueron dificultades identificadas por las enfermeras y las matronas en el cuidado de las pérdidas involuntarias del embarazo. Estas fueron, metafóricamente, f*uerzas que apagaron la luz dejándolas en la oscuridad*.

1.1 Cultura organizacional no solidaria

Las enfermeras y las matronas encontraron que el sistema sanitario no era útil cuando se trataba de manejar su propio dolor. Esta falta de respaldo se exacerbó aún más en las pérdidas de embarazo temprano.

Las políticas de rentabilidad pueden haber contribuido a que las enfermeras minimicen los aspectos emocionales del cuidado para centrarse en los aspectos físicos.

La no provisión de atención integral también podría depender del entorno clínico donde las mujeres fueron hospitalizadas. En el servicio de ginecología, dirigido principalmente a patologías quirúrgicas, había una tendencia a marginar los aspectos emocionales del trabajo y a centrarse en el tratamiento de intervención.

Las enfermeras y las matronas informaron que la carga de trabajo robó tiempo de hablar y estar con los padres, lo que complica el establecimiento de un vínculo de confianza con ellos. Además, también podrían participar en la atención de familias con pérdida de embarazo y otras que no lo hicieron simultáneamente. Esta situación requirió un ajuste emocional y conductual con respecto a la escucha, la presencia física, el manejo de la privacidad y la intimidad, en el camino de una habitación a otra, lo que fue difícil para ellos. El desarrollo de esa capacidad de adaptar sus interrupciones emocionales desde el cuidado de la pérdida a otra situación no tan emocionalmente exigente dependía de la idiosincrasia de los servicios, siendo más difícil para las enfermeras de paritorio, debido a tales emociones opuestas.

Por otro lado, la mayoría de los servicios carecían de espacios exclusivos para atender la pérdida. Esta situación favoreció el contacto de las familias con pérdidas de embarazo con otras que no habían sufrido ninguna pérdida. Además, en las pérdidas tempranas del embarazo, la falta de lugares respetuosos para dejar al bebé fallecido generó un dilema emocional en las enfermeras.

La gestión administrativa del papeleo, como el registro del nombre del bebé, la autopsia, la provisión de atención espiritual y el bautismo de emergencia, también se informó como una carga.

1.2 Falta de preparación y conocimiento

Las matronas y las enfermeras informaron una falta de preparación y conocimiento sobre cómo cuidar a estos padres, cómo comunicarse con ellos y cómo comportarse, además de la escasez de herramientas para manejar las demandas emocionales de los padres y de los suyos. Esto hizo que se sintieran inseguros cuando se preocupaban. Algunas de ellas informaron de la falta de habilidades de comunicación apropiadas y les resultó difícil saber qué, cuándo y cuánto decir, cómo acercarse a las familias y cuánto involucrarse.

Un aspecto particularmente controvertido fue la falta de congruencia con respecto al comportamiento socialmente aceptado con los padres. Esto causó dudas sobre si mostrar o contener sus propias emociones. Mientras que algunos entendieron la expresión emocional como una herramienta para establecer un vínculo de confianza con la familia, otros sintieron que la demostración emocional podría dañar aún más a los padres, ya que la pérdida pertenecía a los padres. Otras situaciones que desafiaron a las enfermeras y matronas fueron la comunicación con los padres con pérdidas tempranas recurrentes, la incapacidad de responder de manera concluyente a las preguntas de los padres, la provisión de información sobre aspectos prácticos como los arreglos funerarios, lo que sucede a continuación o con quién comunicarse, y el manejo de comportamientos inesperados o desconocidos o signos de dolor y sufrimiento exacerbados.

Los recursos que no facilitan apoyo, la falta de capacitación o de oportunidades de aprendizaje durante la etapa estudiantil, y luego como profesionales, se informaron como una causa de falta de conocimiento. En consecuencia, esto llevó a las enfermeras y las matronas a aprender y cuidar *ad hoc*, donde sus propias experiencias personales o laborales les proporcionaron aprendizaje para el cuidado de pérdidas futuras. El aprendizaje entre colegas experimentados también fue otro recurso.

1.3 Cuidado emocionalmente exigente

La mayoría de las enfermeras y matronas experimentaron la atención como algo difícil, difícil e incluso un fracaso en el proceso de atención. Algunos de ellos se enfocaron en la atención desde el peso de la responsabilidad, en el cual sus acciones tendrían un impacto en el bienestar de los padres. Además, algunos de ellas pueden sentirse poco preparadas para presenciar el dolor emocional y el sufrimiento de los padres, e incluso el parto.

Además de manejar y lidiar con los sentimientos de los padres, el cuidado requirió la participación emocional por su parte. En consecuencia, esta implicación profunda y emocional tuvo un coste personal, especialmente cuando no se superaron traumas personales, cuando sus creencias y valores eran contrarios, o dependiendo de la relación establecida con los padres y la historia detrás de ellos, por ejemplo, múltiples pérdidas de embarazo.

2. "Fuerza para adentrarse en la oscuridad"

El apoyo y la orientación de líderes y colegas, los cuales tienen experiencias profesionales y personales, y sus convicciones con respecto a su rol se informaron como elementos motivadores para tratar la atención en pérdidas involuntarias de embarazo.

2.1 Apoyo y orientación de líderes y pares

El apoyo de colegas proporcionó seguridad para atender las pérdidas involuntarias de embarazos. La supervisión y orientación de líderes y pares, y la capacitación fueron muy demandadas por las enfermeras y matronas, ya que el conocimiento sobre cómo cuidar la pérdida les proporcionó comodidad, confianza y reducción de preocupaciones. Incluso el entrenamiento no específico se consideró beneficioso.

2.2 Experiencias personales y profesionales

Fueron considerados como una fuente de aprendizaje y mejora en la atención. Específicamente, el vínculo entre padres y enfermeras se fortaleció cuando las enfermeras y las matronas tuvieron experiencias personales de pérdidas, ya que estas proporcionaron comprensión y conocimiento para empatizar y sentirse seguros

2.3 Convicciones sobre el cuidado

Las enfermeras y las matronas se reconocieron a sí mismas como clave en la provisión de cuidado, y que deberían mostrarse fuertes, solidarias y presentes para los padres, a pesar del coste personal de involucrarse. Además, se consideraban a sí mismas como las que brindaban compasión, comprensión y apoyo.

Por otro lado, el cuidado de las pérdidas involuntarias del embarazo fue significativo para ellas, ya que el cuidado fue desafiante y difícil además de significativo. La idea de hacer que la pérdida fuese soportable les causó sentimientos de recompensa, gratitud, utilidad y honor.

3. "Evitar tropezar"

Para evitar tropezar en la oscuridad, las enfermeras y las matronas no fueron más allá y brindaron atención centrada en las tareas y evitaron encuentros y conexiones emocionales con los padres.

3.1 Cuidado enfocado en tareas

Principalmente, la atención priorizó los procedimientos sobre los aspectos emocionales. Por ejemplo, en pérdidas tempranas, la atención se convierte en rutina y el aspecto emocional tiende a desaparecer. En particular, las enfermeras de cirugía ginecológica estaban angustiadas cuando las madres se despertaban llorando. Intentaron controlar su llanto administrándole sedantes.

3.2 Evitar encuentros con padres

La falta de tiempo debido a la alta carga de trabajo obstaculizó el establecimiento de un vínculo de confianza con los padres y, por lo tanto, la atención podría haber sido superficial y sin seguimiento.

Delegar la atención a compañeras más experimentadas fue un mecanismo para evitar encuentros con los padres.

3.3 Evitar la conexión emocional

Las enfermeras y las matronas no se involucraron emocionalmente con los padres para evitar el sufrimiento personal y porque se sentían inseguras y sin preparación. Por ejemplo, algunas enfermeras dejaron de lado sus sentimientos, otras pudieron despersonalizar al bebé para minimizar la carga emocional de esta pérdida, e incluso algunas de ellas tuvieron un sentimiento de rechazo a la atención.

4. "A tientas en la oscuridad"

Las enfermeras y matronas que fueron más allá del cuidado centrado en tareas, lo hicieron de la mejor manera que sabían, lo que se representa a tientas en la oscuridad.

Las matronas y las enfermeras trataron de brindar atención de la mejor manera posible, a pesar de las dificultades encontradas. El cuidado se basó en la presencia física, en fomentar la expresión de los sentimientos de los padres y normalizar los sentimientos de las madres, consolarlas física y emocionalmente, y en el reconocimiento y los recuerdos creados del bebé. También trataron de individualizar y ajustar su atención de acuerdo con la situación, sus relaciones con los pacientes y el tiempo disponible para la atención.

5. "Heridas después de lidiar con la oscuridad"

El cuidado de las pérdidas involuntarias del embarazo supuso un coste personal a las enfermeras y matronas. Este coste personal fueron las heridas causadas por lidiar con la oscuridad.

A nivel personal, las enfermeras y las matronas se sintieron ansiosas, tristes, afligidas, enojadas e inconsolables. A veces, los sentimientos eran tan intensos que tenían un impacto en su vida diaria. En situaciones de alta demanda emocional, como el cuidado de varias pérdidas en un día o el cuidado simultáneo de una pérdida de embarazo y un embarazo saludable, las enfermeras y las matronas se sintieron agotadas emocionalmente y pudieron desarrollar agotamiento. Las matronas incluso se sintieron culpables y responsables de la muerte del bebé, a pesar de que la situación estaba fuera de su control. La frustración por la falta de apoyo institucional y la no satisfacción de las expectativas de cuidado también se informó.

El manejo de estos sentimientos, las altas necesidades físicas, mentales, emocionales y espirituales de los padres, y su falta de formación causaron sentimientos abrumadores, y algunos de ellas pudieron sentirse desamparadas y poco cualificadas. Incluso, algunas enfermeras consideraron abandonar el servicio debido al sentimiento de culpa y la incapacidad de cuidar adecuadamente a estos padres.

Objetivo 2, estudio 4: Primary healthcare midwives' experiences of caring for parents who have suffered an involuntary pregnancy loss: a phenomenological hermeneutic study (bajo revision)

Se identificaron cuatro temas principales: "manejando la adversidad", "encontrar un motivo para involucrarse", "cuidado desde la retaguardia" y "evitar conexiones emocionales con los padres".

Comprensión ingenua

Las matronas informaron que brindar atención a los padres que sufren una pérdida involuntaria del embarazo implicaba abandonar su propia zona de confort y enfrentar diversas formas de adversidad, como la falta de formación y conocimiento, el coste personal resultante de la prestación de cuidado, la falta de apoyo organizacional y la falta de o poca comunicación entre profesionales sanitarios de atención especializada y primaria. En estas circunstancias, las matronas tuvieron que buscar razones para ir más allá de la atención centrada en tareas. El vínculo con la madre, las estrategias de afrontamiento, un fuerte sentido de responsabilidad profesional y haber experimentado la pérdida de un ser querido fueron los impulsores. La atención, por lo tanto, significaba que las matronas se involucraron siguiendo su intuición, o que evitaban ir más allá de la provisión de atención centrada en tareas debido a la dureza de los encuentros con los padres que sufren.

Análisis estructural

El análisis estructural identificó cuatro temas de la experiencia vivida de las matronas de atención primaria de salud que brindan atención a los padres que han experimentado una pérdida involuntaria del embarazo.

1. Manejando la adversidad

La falta de formación y conocimiento sobre cómo abordar el sufrimiento, la atención emocionalmente exigente, la cultura organizacional poco solidaria y mala comunicación entre la atención médica especializada y atención primaria fueron las dificultades que tuvieron que enfrentar las matronas para el cuidado de los padres sufrieron una pérdida involuntaria del embarazo.

1.1 Falta de capacitación y conocimiento sobre la experiencia de encontrar sufrimiento

Las matronas se sintieron mal preparadas para cuidar a los padres en el contexto de la atención primaria de salud. Su formación no los había expuesto a estas experiencias, porque sus supervisores habían querido protegerlas. Algunas comentaron que la falta de formación refleja la evitación de la sociedad de temas relacionados con la muerte y el sufrimiento.

La formación limitada disponible no proporcionó suficientes conocimientos y habilidades para manejar las demandas emocionales de este tipo de cuidado. Además, la capacitación no abordó la atención brindada en atención primaria de salud y no incluyó las experiencias de las mujeres después de las pérdidas involuntarias del embarazo.

Las matronas complementaron su falta de formación con formación privada, aprendizaje entre compañeras y el conocimiento y las habilidades adquiridas de sus experiencias de pérdida personales y profesionales. Esto les permitió comprender cómo se podía sentir la mujer y mejorar la comunicación y la empatía con los padres.

Como resultado de la falta de conocimiento, las matronas no se sentían completamente capaces de liderar la prestación de cuidado y no entendían su rol como profesional sanitario para los padres. Además, en algún momento experimentaron temor a fallar en su rol.

1.2 Cuidado emocionalmente exigente

Cuidar a los padres que han experimentado una pérdida involuntaria del embarazo conlleva un coste personal debido a la participación emocional con los padres. Estar involucrada en esta forma de cuidado fue un desafío para las matronas, ya que las obligó a abandonar su propia zona de confort. Además, este cuidado era, en muchos sentidos, lo opuesto a su profesión, que es el cuidado de la vida. Pudieron existir dudas sobre si la atención brindada fue adecuada y las matronas pudieron experimentar temor a repercusiones legales en pérdidas avanzadas. No obstante, algunas de ellas se sintieron protegidas de represalias legales, como profesionales sanitarios de atención primaria. Metafóricamente sienten que no están en primera línea de guerra, sino en la retaguardia.

Fue especialmente difícil para ellas manejar sus emociones después de estar expuestos a las de los padres. En la atención primaria, la sospecha de una pérdida involuntaria del embarazo después de no encontrado el latido del corazón es emocionalmente devastadora. Esta situación era peor si el vínculo entre la matrona y la mujer era más sólido antes de la pérdida del embarazo, por ejemplo, en pérdidas avanzadas. Esta cercanía original implica mayores costes personales porque la mujer se siente más capaz de expresar su descontento.

1.3 Cultura organizacional no solidaria

Las matronas reflejaron que el sistema sanitario no les proporcionaba recursos para manejar el impacto emocional de su trabajo con los padres. Aunque muchas de las matronas mencionaron que la carga de trabajo en los centros de salud no es una excusa para no ir más allá del cuidado centrado en tareas, algunas informaron que el tiempo limitado para las consultas a veces les impedía involucrarse más con estas parejas.

1.4 Mala comunicación entre la atención médica especializada y primaria

La mala comunicación entre atención especializada y atención primaria pudo causar una falta de continuidad de la atención. Por ejemplo, ante la sospecha de una pérdida de embarazo, remitida al hospital para su diagnóstico, las mujeres pueden estar sentadas en salas de espera con otras mujeres embarazadas, a pesar de las advertencias de la matrona del centro de salud. Cuando se presentaron los resultados a las participantes, una matrona sugirió que esta falta de comunicación posiblemente se deba a deficiencias estructurales en lugar de una falta de comunicación entre profesionales.

Además, los centros de salud tienen el programa Conecta 72, que es un programa en el que médicos y enfermeras reciben automáticamente una alerta para una consulta telefónica dentro de las 72 horas posteriores al alta de un paciente. El sistema no notifica directamente a las matronas de atención primaria, y aunque algunos casos son referidos a las matronas, no todos los casos son capturados por ellas. Además, en las pérdidas tempranas que no requirieron hospitalización, el sistema no crea la alerta y, por tanto, el seguimiento depende de si la mujer solicita una cita con la matrona de atención primaria. Por otro lado, la llamada se realiza dentro de las 72 horas posteriores al alta, que puede ser el momento de mayor necesidad para las mujeres.

2. Encontrar un motivo para involucrarse

A pesar de las dificultades, las matronas se involucran más emocionalmente en el cuidado cuando existe un fuerte vínculo con la madre, cuando están en mejores condiciones para manejar la participación a través de estrategias de afrontamiento, cuando sienten la responsabilidad profesional de cuidar y cuando también han experimentado una pérdida personal.

2.1 Vinculación con la madre

El vínculo con la mujer motivó a las matronas a ir más allá de la atención centrada en las tareas. Este vínculo fue creado especialmente en atención primaria. En muchos casos, las mujeres reciben atención de la misma matrona durante el embarazo, y se construye una relación de confianza, en la cual las mujeres pueden expresar sus sentimientos libremente. Este vínculo fue más arraigado cuanto más tardías fueran las pérdidas.

Desde el punto de vista de las matronas, el entorno de atención primaria les permitió relacionarse con las experiencias de las mujeres y utilizar los comentarios de las mujeres para reflexionar y mejorar la atención.

2.2 Estrategias de afrontamiento

La provisión de atención más allá de las tareas médicas también dependía de las herramientas de afrontamiento de las matronas. Herramientas como la terapia psicológica, que se utilizó para aumentar la autoconciencia de sus sentimientos, les ayudó a comprender la muerte de una manera que les permitió involucrarse más en la atención. Muchas de las matronas entendieron las pérdidas del embarazo como causas más allá de ellas, como otra posibilidad en la vida o como aspectos desfavorables de su trabajo que podrían resultar en oportunidades de aprendizaje.

2.2 Responsabilidad profesional

Aunque el cuidado fue un desafío para las matronas, y conllevó costes personales involucrarse en la atención, las matronas sintieron que era su responsabilidad como profesionales. Las situaciones anteriores en las que recibieron comentarios negativos de la mujer, los motivaron a ir más allá de la atención centrada en las tareas. Por otro lado, esta implicación en la atención estuvo fuertemente influenciada por las personalidades de las matronas.

2.3 Experiencias personales con pérdida

Finalmente, las pérdidas personales motivaron a las matronas a involucrarse más en el cuidado, porque entendieron los sentimientos de la pareja y fue más fácil empatizar con ellas.

3. Cuidado desde la retaguardia

El cuidado de estas pérdidas se basó en la intuición de las matronas debido a la falta de guías de práctica clínica. Además, el cuidado del padre era una preocupación emergente en sus narraciones.

3.1 Falta de guías de práctica clínica

Las matronas de atención primaria de la salud no tienen guías de práctica clínica para brindar atención a los padres que han experimentado una pérdida involuntaria del embarazo. Debido a la falta de estas guías y de conocimientos, la atención brindada depende de las prácticas de cada matrona y se basa en su intuición. Además, el seguimiento sanitario de la mujer se centra en su bienestar físico, y la consideración de otros aspectos depende de las solicitudes de la mujer.

El cuidado está diseñado para permitirle a la mujer expresar sus experiencias y sentimientos, escucharla, respetar su tiempo, resolver sus dudas y normalizar sus sentimientos.

3.2 Cuidar al padre

Un aspecto que surgió de las narrativas de las matronas fue la atención brindada a la pareja de la mujer. Las matronas comentaron que la atención sanitaria se centra principalmente en las madres, debido a los aspectos físicos. Algunas matronas informaron que no sabían cómo empatizar con el padre o cómo lidiar con los sentimientos de los padres. Dos posibles razones para esto pueden ser la debilidad del vínculo previo entre el padre y la matrona, y la presión social sobre el padre para que sea fuerte y hermético.

4. Evitar las conexiones emocionales con los padres

La falta de conocimiento y tiempo, el coste personal, las altas demandas emocionales de involucrarse en el cuidado y la falta de estrategias de afrontamiento efectivas podrían impedir que las matronas vayan más allá del cuidado centrado en tareas. Las matronas pudieron sentir que son incapaces de lidiar con el sufrimiento de estos padres. Por lo tanto, las matronas pudieron evitar encuentros con la mujer y la pareja y entablar una comunicación superficial con ellos. También pudieron experimentar miedo a involucrarse.

Discusión

La discusión se abordará de acuerdo con los dos ejes de la tesis doctoral.

Experiencias de los padres después de un embarazo y pérdida del bebé

Los estudios uno (Fernández-Basanta et al., 2019) y dos (Fernández-Basanta et al., 2020a) abordan la experiencia de afrontamiento de los padres después del embarazo y la pérdida del bebé. Ambos estudios reflejaron el proceso de conexión y desconexión informado por Van (2012) en el *Modelo Multicultural de Afrontamiento después de la Pérdida del Embarazo*. La conexión se asoció con hablar con su entorno social, mantenerse conectado con el bebé y buscar el significado de la pérdida. A través de estas estrategias, los padres pudieron normalizar sus sentimientos, validar su pérdida, legitimar la existencia de sus hijos y reducir el aislamiento social. Además, en entornos que normalizaron estas pérdidas, los padres podrían ser transparentes con su entorno y sentirse aliviados de compartir su experiencia.

La literatura también ha informado lo útil que es hablar con otros, especialmente con aquellos que han sufrido pérdidas similares. Compartir estas experiencias les ayuda a normalizar sus sentimientos (Cacciatore y Bushfield, 2007). Sentir que no eran los únicos a quienes les sucedió este evento fue importante para construir su dolor. Por ejemplo, en pérdidas tempranas, hablar ayudó a validar su pérdida. Estas pérdidas carecían de pruebas tangibles de la existencia del bebé que está presente en pérdidas posteriores, como cambios físicos en el cuerpo de una mujer que son socialmente perceptibles, o recuerdos grabados a través de fotografías, huellas o ultrasonidos (Fernández et al., 2011; Garrod y Pascal, 2019).

La conexión fue especialmente importante y útil en estas pérdidas, porque todavía se consideraban pérdidas tabúes y eran invisibles por los entornos sociales y de salud y, en consecuencia, algunos padres percibieron la falta de apoyo social y de salud (France et al., 2013; Heazell, 2016).

Este contexto puede conducir a conductas de evitación o desconexión. Nuestros hallazgos mostraron que las razones para evitar conectarse con la pérdida se debieron a un mecanismo de protección, ya sea porque revivir la pérdida les causó dolor o para evitar la reacción de otros. Esto podría contribuir al almacenamiento de emociones, al surgimiento de tensiones matrimoniales, a no querer saber sobre el proceso de pérdida o a aislarse. Sin embargo, según la etapa del proceso de duelo, esto puede estar asociado con respuestas adaptativas o desadaptativas (Dyregrov et al., 2016; Nazaré et al., 2013). En las primeras etapas, como las mujeres del primer estudio (Fernández-Basanta et al., 2019), el tiempo medio entre la pérdida y la entrevista fue de un mes, y esto podría sugerir una respuesta adaptativa en el proceso de duelo debido a que las conductas de evitación de los padres aparecen en las primeras etapas del proceso de duelo.

Por otro lado, la *Teoría de la Motivación de Afrontamiento* (Skinner et al., 2003) sugiere que las experiencias de conexión/confrontación y desconexión/evitación son un proceso de ida y vuelta y no son mutuamente excluyentes. Nuestros resultados sugieren que este proceso de ida y vuelta puede estar condicionado por el tabú que rodea estas pérdidas, las expectativas sociales que condicionan la expresión del duelo, la falta de respuesta de los profesionales sanitarios, la falta de reconocimiento social de la pérdida, el tipo de pérdida, y la etapa en el proceso de duelo.

La influencia que la cultura y la sociedad tienen sobre el duelo y las estrategias de afrontamiento ha sido respaldada por la bibliografía (Brownlee y Oikonen, 2004; Dallay, 2013; Fenstermacher y Hupcey, 2013; Van y Meleis, 2003). Por ejemplo, la literatura sugiere la existencia de una jerarquía de duelo (Kofod y Brinkmann, 2017; Van y Meleis, 2003), donde las expresiones de duelo se aceptan según el tipo de pérdida. En las pérdidas tempranas, el sufrimiento es menos aceptado socialmente y los padres pueden verse obligados a negociar constantemente la importancia de la pérdida y a realizar acciones que legitimen la existencia de su embarazo/bebé (Kofod y Brinkmann, 2017; Leichtentritt y Weinberg-Kurnik , 2016; Meaney et al., 2017; Sawicka, 2016). Logsdon y Davis (2003) afirman que para que el apoyo social se considere útil, debe cumplir con las expectativas de quien recibe el apoyo y debe provenir de una persona de confianza. Cuando estas condiciones no están establecidas, la persona puede dejar sus necesidades sin satisfacer en lugar de recibir apoyo de otra fuente.

Además, en algunas culturas, el contexto social y la religión establecen que la feminidad es sinónimo de maternidad, lo que significa que cuando se produce la falta de hijos, una mujer se ve privada de su identidad de género y algunas madres pueden experimentar aislamiento social (Gerber-Epstein et al., 2009). Sin embargo, la religión también puede tener un efecto protector para las madres, ya que les ayuda a dar sentido a la pérdida y hacer frente a la pérdida (Abdel - Razeq y Al-Gamal, 2018; Roberts y Lee, 2014). Nuestros resultados (Fernández - Basanta et al., 2020a) muestran que cuando los padres no obtuvieron respuestas que les permitieran dar sentido a la pérdida, buscaron otros recursos, como la religión o la superstición.

La influencia de las expectativas sociales también se informó en los hombres. El sistema sanitario y los círculos sociales no reconocieron a los hombres como padres desconsolados, lo que resulta en un empeoramiento de su recuperación psicológica (Leichtentritt y Weinberg-Kurnik, 2016; Obst y Due, 2019). Esto se debió a la creencia social de que los hombres deberían ser cuidadores, fuentes de fortaleza y reprimir sus emociones para mantener la situación bajo control y ser un consuelo para la mujer (Due et al., 2017).

Implicaciones para la práctica y la educación

Prestar atención emocional a los padres que han experimentado un embarazo y la pérdida del bebé requiere la provisión de atención de enfermería transcultural basada en el conocimiento del contexto cultural y los antecedentes de los padres (Leininger, 1995), y la provisión de una atención integral (Eriksson, 1992, 1994, 1997, 2002; Eriksson et al., 2006; Lindström et al., 2006). La provisión de recursos para probar la existencia del embarazo/bebé y de espacios donde los padres pueden expresar su dolor es fundamental para legitimar su pérdida (Martel e Ives-Baine, 2018; O'Leary y Warland, 2013).

Es importante que los profesionales sanitarios reconozcan el embarazo y la pérdida del bebé y la individualidad de este dolor tanto en mujeres como en hombres. Las personas enfrentan y acumulan la pérdida de acuerdo con sus factores situacionales, internos y externos (Dallay, 2013; Fenstermacher y Hupcey, 2013; Van y Meleis, 2003). Por lo tanto, la atención debe contemplar un enfoque individual adaptado a las necesidades de los padres y no la creación de protocolos de atención que generen barreras para la provisión de atención integral e individualizada.

Por otro lado, las intervenciones de seguimiento deben llevarse a cabo, para descubrir cómo las mujeres están lidiando con la pérdida después de salir del hospital, porque los comportamientos de evitación son frecuentes en las primeras etapas de la pérdida.

Las enfermeras y las matronas deben brindar atención integral y, debido a su proximidad con los padres, deben ser el profesional de referencia para los padres (Capitulo, 2005), aunque se requiere la participación de todos los profesionales sanitarios. Para eso, la formación en duelo es necesaria. Es importante que sepan sobre el proceso de duelo y sus síntomas. Con este conocimiento, las enfermeras y las matronas pueden brindar a las mujeres recursos educativos para hacer frente a una pérdida, ayudando a las mujeres a comprender que el dolor es un proceso normal y de curación que ocurre después de una pérdida. Además, esta educación podría extenderse al entorno social cercano de las mujeres porque estas son las principales personas de apoyo. En nuestros resultados, la sensación de normalidad y apoyo se adquirió al hablar con otras mujeres con experiencias similares. Finalmente, con este conocimiento, la detección del duelo patológico podría identificarse si ocurre.

Fortalezas y limitaciones

Estos resultados, debido a su carácter heterogéneo y basados en modelos previamente desarrollados en otros contextos culturales, demuestran la transferibilidad de los resultados. Por ejemplo, los resultados de Fernández-Basanta et al. (2019) han contribuido a expandir el modelo teórico *Modelo Multicultural de Afrontamiento después de la Pérdida del Embarazo* (Van, 2012), al desarrollar los conceptos de conexión o desconexión.

Por otro lado, la estrategia de búsqueda integral de Fernández-Basanta et al. (2020) aseguraron que la revisión se basó en estudios realizados en contextos geográficos con características únicas y definitorias y en varios tipos de pérdidas, proporcionando una visión más completa del fenómeno.

La incorporación de pérdidas involuntarias de embarazo junto con interrupciones del embarazo debido a anomalías fetales y muertes neonatales podría entenderse como una limitación. Sin embargo, la bibliografía apoya la expansión del concepto (Fenstermacher & Hupcey, 2013; López García de Madinabeitia, 2011).

Con respecto a la perspectiva masculina, los hombres están poco representados en la literatura (Cacciatore et al., 2013). Esto dificultó la descripción de la experiencia de afrontamiento masculina, así como la generalización de los hallazgos a países fuera de los contextos occidentales.

Futuras líneas de investigación

La investigación adicional sobre los hombres también puede extender el trabajo de Van (2012) sobre los mecanismos de afrontamiento después de la pérdida de un embarazo. La investigación en otras culturas, en diferentes grupos de edad y en diferentes tipos de pérdida de embarazo, ampliará el conocimiento del duelo y, por lo tanto, su manejo adecuado por parte de los profesionales sanitarios.

Experiencias de enfermeras y matronas en el cuidado de pérdidas involuntarias de embarazos

Fernández-Basanta et al. (2020) junto con el estudio cuatro muestran las experiencias de atención de pérdidas involuntarias de embarazos de matronas y enfermeras de hospitales, y matronas de atención primaria.

Eriksson (Eriksson, 1997, 2002; Lindström et al., 2006) afirma que el motivo básico del cuidado es el *caritas*, donde se define como el amor altruista expresado en acción (Arman y Rehnsfeldt, 2006). La preparación de las enfermeras y las matronas para compartir la lucha de sufrimiento de los padres es un aspecto esencial del cuidado caritativo (Arman y Rehnsfeldt, 2007). En un contexto de escasez de recursos económicos y un marcado pensamiento tecnológico masculino, las enfermeras y las matronas pueden sentirse inseguras cuando brindan atención caritativa, por temor a ser etiquetadas como débiles o poco profesionales (Arman y Rehnsfeldt, 2006; Nortvedt, 2001). Desde un punto de vista clínico, el *caritas* en los sistemas de salud occidentales significa ir más allá de un rol. De la enfermera esto requiere competencia, motivación e integridad moral (Arman y Rehnsfeldt, 2006). Nuestros hallazgos (Fernández-Basanta et al., 2020b; estudio 4) mostraron que, aparte de las competencias y el apoyo, fue el *ethos*, o la base de valor humano, lo que motivó a las enfermeras y matronas a cuidar a los padres que han sufrido una pérdida involuntaria del embarazo.

Las enfermeras confrontan el sufrimiento humano a diario y se espera que brinden un cuidado genuino para aliviar la angustia de las personas en lugar de respuestas simples orientadas a tareas (Eriksson, 1997, 2002; Huynh et al., 2008; Lindström et al., 2006). En el cuidado de la pérdida involuntaria del embarazo, las enfermeras y las matronas son personas fundamentales en ese cuidado y están en mejores condiciones para construir una comunión genuina con ellos (Eriksson, 1997, 2002; Lindström et al., 2006; Nichols, 1984). Esta situación se ve especialmente facilitada en el caso de las matronas de atención primaria de salud, como se muestra en el estudio 4, ya que, en muchos casos, se estableció una relación previa (Ellis et al., 2016; Gold, 2007). Sin embargo, atender las pérdidas involuntarias es un desafío para ellas (Fernández-Basanta, 2020b, y estudio 4).

Según nuestros resultados (Fernández-Basanta et al., 2020b; estudio 4), la atención brindada por enfermeras y matronas se basó en su intuición o en sus experiencias personales y profesionales. Esto se debe a que las guías de práctica clínica no abordan la atención emocional y, a menudo, se centran en la atención especializada que involucra el momento agudo de pérdida, pero el seguimiento apenas se aborda (Koopmans et al., 2013; Peters et al., 2016). Además, según nuestros resultados, la atención se basó principalmente en el desempeño de las tareas de enfermería (Fernández-Basanta et al., 2020b; estudio 4). Las enfermeras y las matronas no lograron establecer una comunión genuina con los padres en muchas ocasiones.

Esto podría explicarse por la mentalidad del mercado en los sistemas de gestión de la salud, ya que puede fomentar esta atención técnica y la participación no emocional de las enfermeras y matronas con los padres (Andipatin et al., 2019; Bolton, 2001; Hubbard et al., 2001; McQueen, 2000; Meerabeau, 1998). Este predominio biomédico es más pronunciado en servicios como ginecología, emergencias o cirugía, donde se atiende a una amplia variedad de procesos lejanos a la pérdida del embarazo. Por lo tanto, la atención podría dirigirse principalmente a la realización de tareas médicas o puede implicar la medicalización de los aspectos emocionales (Hutti et al., 2016, McCreight, 2005). En este sentido, Maturo (2012) refirió que los procesos relacionados con la salud mental están ampliamente medicalizados.

Por otro lado, el compromiso emocional es visto como un requisito de excelencia en la práctica de enfermería (Henderson, 2001). Los beneficios de establecer una relación de confianza con los pacientes se informaron en una meta-etnografía reciente (Strandås y Bondas, 2018). Sin embargo, el desarrollo y mantenimiento de esta relación de confianza con los padres implica un esfuerzo a enfermeras y matrona, lo que se suma al trabajo invisible y emocional que generalmente no se reconoce en enfermería (Smith, 1992).

Según Hochschild (1983), el trabajo emocional se refiere al esfuerzo de un/a trabajador/a de mostrar emociones de acuerdo con normas sociales y culturales integradas, en lugar de lo que realmente siente esa persona. El trabajo emocional puede verse como una construcción occidental, dentro de la tradición de Descartes de separar la mente racional del cuerpo emocional (Huynh et al., 2008). Sin embargo, el cuidado implica sentimiento y el sentimiento implica vulnerabilidad personal (Henderson, 2001). Phillips (1996) demostró que el trabajo emocional es denigrado por su asociación con la feminidad y que ocupa un segundo nivel con respecto a las habilidades cognitivas o técnicas.

Nuestros hallazgos informaron que las dificultades en la atención favorecen las conductas de evitación, y que las enfermeras y las matronas experimentaron agotamiento emocional cuando se involucraron emocionalmente con los padres (Fernández-Basanta et al. 2020b). El hecho de que el trabajo emocional no sea reconocido, y por lo tanto esté infravalorado por la mayoría de las organizaciones de atención médica, puede contribuir a comprender el vínculo empírico entre el trabajo emocional, el agotamiento emocional y el agotamiento profesional (Hunter & Smith, 2007; Huynh et al., 2008). Por ejemplo, en las pérdidas tempranas, debido a la alta frecuencia en la práctica clínica, este agotamiento a menudo se asocia con la pérdida de la capacidad de proporcionar atención compasiva y una disminución en la calidad de la atención (Houck, 2014).

En este sentido, la supervisión clínica, entendida como apoyo interprofesional y orientación y reflexión, ha sido reconocida por la literatura como útil para mejorar el crecimiento profesional y la colegialidad, y prevenir el agotamiento que pone en riesgo la salud de la enfermera y la atención de enfermería (Bondas, 2010).

Con respecto al seguimiento, la mala comunicación entre la atención médica especializada y primaria podría ser difícil. Se han llevado a cabo varios planes de colaboración estratégica en el contexto español, pero no han tenido éxito en términos de atención de continuidad (Guzmán Fernández, 2011). En este sentido, la *Teoría del Liderazgo Caritativo* (Bondas, 2003) establece que toda la cultura solidaria y el líder son responsables de lo que sucede en la organización, especialmente en situaciones de indiferencia. El liderazgo se entiende como una herramienta poderosa y fundamental en la delineación y mantenimiento de la base del valor ético, la dirección y el contenido del cuidado de enfermería en las complejas demandas de la atención de enfermería basada en laevidencia, eficiencia y coste-efectividad (Bondas, 2009).

De acuerdo con Sjølie et al. (2020), los supervisores/as de enfermería de primera línea son esenciales para mejorar la calidad de la atención al cambiar las prácticas laborales en mejores resultados para los pacientes. Sin embargo, en nuestro contexto, como se ha demostrado en el estudio 4, las unidades de asistencia están físicamente lejos de las gerenciales (Guzmán Fernández, 2011). Por lo tanto, es necesario incorporar nuevas formas de liderazgo y profesionalizar la gestión, y fortalecer las competencias y habilidades que incluyen profesionalismo, liderazgo, toma de decisiones, manejo de conflictos y habilidades para resolver problemas (Lemetti et al., 2015).

Finalmente, lidiar con la muerte necesita un conocimiento adecuado sobre el cuidado de la muerte (Zomorodi y Lynn, 2010). Según Begley (2003), es necesario incluir el apoyo estructurado durante las experiencias clínicas y la educación sobre el duelo y la comunicación en la capacitación de matronas y enfermeras. Sin embargo, en las sociedades occidentales, la muerte, y particularmente la pérdida perinatal, es tabú y significa la antítesis de lo esperado en la disciplina de la matronería (Granero-Moya et al., 2016; Lang et al., 2011). Por ejemplo, nuestros resultados (estudio 4) mostraron que las matronas no sabían cómo acercarse al padre. Esto puede deberse a la falta de un vínculo previo y al hecho de que los encuentros con la matrona se llevaron a cabo en pareja y el hombre quería mantener la fachada de fuerza frente a la mujer. La literatura destaca que la falta de conocimiento de los profesionales sanitarios sobre las experiencias de los hombres puede conducir a la impotencia y la marginación (Due et al., 2017; McCreight, 2004).

Implicaciones para la práctica y la educación.

Ambos estudios informan al cuerpo de conocimiento en ciencias de enfermería y promueven un cambio en la práctica clínica, ya que los resultados muestran la complejidad de la experiencia del cuidado de enfermería y matronería en pérdidas involuntarias de embarazo.

Las enfermeras y las matronas requieren una cultura organizacional que apoye el desarrollo de una cultura solidaria. En el nivel formativo, el enfoque debe estar en la provisión de cuidados integrales y el establecimiento de una comunión genuina con los padres. Por lo tanto, la formación debe estar dirigida a desarrollar y fortalecer habilidades que favorezcan la conexión con los padres y la provisión de herramientas para manejar las demandas emocionales del cuidado. Los líderes de enfermería, debido a su posición entre la administración, el personal de enfermería y la proximidad a la atención, son clave para favorecer la interconexión y la construcción de puentes entre ellos.

Fortalezas y limitaciones

El uso de una metodología como la meta-etnografía ha sido útil para identificar brechas en la investigación; informar el desarrollo de estudios primarios, y para proporcionar evidencia para el desarrollo, implementación y evaluación de intervenciones de salud (Lachal et al., 2017; Tong et al., 2012). Esta metodología implica un desarrollo conceptual que implica una nueva contribución a la literatura, más allá de las revisiones narrativas y sistemáticas de la literatura (Britten et al., 2002). Además, se llevó a cabo una estrategia de búsqueda integral con la posibilidad de incluir artículos en inglés, español y portugués y, por lo tanto, de diferentes contextos culturales.

Por otro lado, ambos estudios se realizaron de acuerdo con pautas que aseguran la calidad del proceso. La elaboración de la meta-etnografía siguió la guía de informes eMERGe (France et al., 2019). La utilización de esta guía mejora la transparencia y la integridad de los informes y facilita que los hallazgos de la revisión contribuyan a evidencia sólida. Mientras que el estudio 4, estuvo en línea con los *Standards for Reporting Qualitative Research* (SRQR) (O'Brien et al., 2014).

Con respecto a la muestra, ambos estudios proporcionan las experiencias de enfermeras y matronas de atención especializada (Fernández-Basanta et al., 2020b) y atención primaria (estudio 4). Este último ofrece una contribución novedosa, no abordada previamente en la literatura.

En cuanto a las limitaciones, los contextos culturales de los artículos primarios se ubican exclusivamente en países occidentales. Por otro lado, la muestra de los artículos primarios es casi exclusivamente femenina.

Futuras líneas de investigación

Para ampliar el conocimiento de la experiencia de cuidado en pérdidas involuntarias de embarazos, se requiere más investigación centrada en otros profesionales de la salud, que en muchos casos tienen el contacto más duradero con los padres. Además, sería beneficioso conocer la experiencia personal de enfermeras y matronas en el cuidado de estas pérdidas. Esta perspectiva nos proporcionaría información valiosa para la práctica y la educación de futuros profesionales de enfermería.

Conclusiones

1. Las estrategias de afrontamiento de los padres después de un embarazo o pérdida del bebé se basaron en experiencias de

conexión/confrontación y desconexión/evitación, exhibiendo un proceso de ida y vuelta entre ellas.

2. La conexión/confrontación se asoció con hablar con su entorno social, mantenerse conectado con el bebé y buscar el significado de la pérdida.
3. Los padres utilizaron estrategias asociadas con la conexión/confrontación para normalizar sus sentimientos, no mentir a su entorno social, validar su pérdida, legitimar la existencia de sus hijos y reducir el aislamiento social.
4. Las conductas de evitación o desconexión se debieron a un mecanismo de protección, ya sea porque revivir la pérdida les causó dolor o para evitar la reacción de los demás.
5. El uso de estrategias de afrontamiento estuvo condicionado por el tabú que rodea a estas pérdidas, las expectativas sociales que condicionan la expresión del duelo, la falta de respuesta de los profesionales sanitarios, la falta de reconocimiento social de la pérdida, el tipo de pérdida y la etapa en la que se encuentra en el proceso de duelo.
6. La cultura y la sociedad influyeron en el dolor y en las estrategias de afrontamiento.
7. Las enfermeras y las matronas lidiaron con dificultades organizativas, falta de conocimiento y con un cuidado que requería ir más allá de la tarea. Este contexto fomentó la atención centrada en las tareas y la evitación de encuentros y conexión emocional con los padres.
8. El cuidado de las pérdidas involuntarias del embarazo implicó que las matronas de atención primaria tuvieran que abandonar la zona de confort, debido a la alta demanda emocional que exigía el cuidado y a la

falta de conocimiento, apoyo y comunicación con la atención especializada.

9. La ausencia de guías o protocolos de atención y la falta de reconocimiento de la atención primaria de salud en las recomendaciones de cuidado podrían haber hecho que las matronas de atención primaria evitasen ir más allá de la provisión de cuidado centrada en tareas debido a la dificultad de los encuentros con padres en duelo.
10. Algunas enfermeras y matronas fueron más allá en el cuidado, en cuál fue basado en su intuición, cuando tenían competencias, apoyo y unos valores de base sólidos, a pesar del coste personal que suponía involucrarse.